

References: Advance Directives

REF ID: 4319

Level IV: Non-experimental study

Topic 3: Assessment

Ahronheim, J. C., Mulvihill, M., Sieger, C., Park, P., & Fries, B. E. (2001). State practice variations in the use of tube feeding for nursing home residents with severe cognitive impairment. *Journal of the American Geriatrics Society*, 49(2), 148-152.

Journal Article, Research, Tables/Charts

OBJECTIVE: To describe the differences in prevalence of tube feeding among states and to examine possible factors that could explain practice patterns. **DESIGN:** Analysis of random samples from an interstate data bank comprised of the Minimum Data Set (MDS), a standardized, federally mandated assessment instrument for nursing home residents. **SETTING:** Nursing homes in four states participating in a federal demonstration project of case mix payment plus five others with existing MDS data systems. **PARTICIPANTS:** Individuals 65 years of age and older (N = 57,029), who had very severe cognitive impairment, including total dependence in eating, and who resided in nursing homes during 1994, the most recent year for which uniform data were available. **MEASUREMENTS:** State-by-state differences in prevalence of tube feeding, controlling for demographic and clinical variables. **RESULTS:** The prevalence of tube feeding ranged from 7.5% in Maine to 40.1% in Mississippi. Each state had a significantly elevated prevalence of tube feeding compared with Maine, with odds ratios (ORs) ranging from 1.50 to 5.83, $P < .001$. Specific directives not to provide tube feeding (OR 0.41, $P < .001$), and white race (OR 0.45, $P < .001$) were strongly and negatively associated with tube feeding. **CONCLUSIONS:** Wide regional variations exist in the use of tube feeding of nursing home residents with equivalent impairments. Sociodemographic factors could be important, but more study is needed to determine whether physician characteristics, such as race, attitudes, or knowledge, have an impact and to clarify medical standards for the use of tube feeding in this population.

REF ID: 5432

Level V: Case report

Topic 3: Assessment

Allen, R. S., & Shuster, J. L. J. (2002; 2002). The role of proxies in treatment decisions: Evaluating functional capacity to consent to end-of-life treatments within a family context. *Behavioral Sciences & the Law*, 20(3), 235-252.

Journal; Peer Reviewed Journal

Psychology as a profession has entered the arena of palliative and hospice care later in the process than other health care professions. Through the use of Familial Advance Planning Evaluations, however, psychologists can assist individuals and families in facing end-of-life transitions in important ways. Hospice and palliative care philosophy treats the patient and family as the unit of care. End-of-life decision-making is therefore a family matter as well as a normative developmental transition. Yet, little is known about the decision-making process. This paper reviews the literature regarding informed consent, advance care planning, and proxy decision-making and outlines a theoretical model for familial decision-making. Previous models of end-of-life capacity evaluations and family assessments are presented and serve as the basis for a comprehensive assessment of familial decision-making at the end of life. Functional capacity evaluations of individuals at the end of life regarding decisions about life-sustaining medical treatments enable both the individual patient and one identified proxy from his or her family to discuss important issues families may (PsycINFO Database Record (c) 2006 APA, all rights reserved)

REF ID: 5431

Level V: Case report

Topic 6: Comprehensive

Atkinson, J. M., Garner, H. C., Patrick, H., & Stuart, S. (2003; 2003). Issues in the development of

advance directives in mental health care. *Journal of Mental Health, 12(5), 463-474.*

Journal; Peer Reviewed Journal

Background: Interest in advance directives in mental health care is growing internationally. There is no clear universal agreement as to what such an advance directive is or how it should function. Aim: To describe the range of issues embodied in the development of advance directives in mental health care. Method: The literature on advance directives is examined to highlight the pros and cons of different versions of advance directive. Results: Themes emerged around issues of terminology, competency and consent, the legal status of advance directives independent or collaborative directives and their content. Opinions vary between a unilateral legally enforceable instrument to a care plan agreed between patient and clinician. Conclusion: There is immediate appeal in a liberal democracy that values individual freedom and autonomy in giving weight to advance directives in mental health care. They do not, however, solve all the problems of enforced treatment and early access to treatment. They also raise new issues and highlight persistent problems. (PsycINFO Database Record (c) 2006 APA, all rights reserved) (journal abstract)

REF ID: 4236

Level II: Individual experimental study

Topic 3: Assessment

Beach, M. C., & Morrison, R. S. (2002). The effect of do-not-resuscitate orders on physician decision-making.[see comment]. *Journal of the American Geriatrics Society, 50(12), 2057-2061.*

Clinical Trial. Journal Article. Randomized Controlled Trial

The effect of do-not-resuscitate (DNR) orders on physicians' decisions to provide life-prolonging treatments other than cardiopulmonary resuscitation (CPR) for patients near the end of life was explored using a cross-sectional mailed survey. Each survey presented three patient scenarios followed by 10 treatment decisions. Participants were residents and attending physicians who were randomly assigned surveys in which all patient scenarios included or did not include a DNR order. Response to three case scenarios when a DNR order was present or absent were measured. Response from 241 of 463 physicians (52%) was received. Physicians agreed or strongly agreed to initiate fewer interventions when a DNR order was present versus absent (4.2 vs 5.0 ($P = .008$) in the first scenario; 6.5 vs 7.1 ($P = .004$) in the second scenario; and 5.7 vs 6.2 ($P = .037$) in the third scenario). In all three scenarios, patients with DNR orders were significantly less likely to be transferred to an intensive care unit, to be intubated, or to receive CPR. In some scenarios, the presence of a DNR order was associated with a decreased willingness to draw blood cultures (91% vs 98%, $P = .038$), central line placement (68% vs 80%, $P = .030$), or blood transfusion (75% vs 87%, $P = .015$). The presence of a DNR order may affect physicians' willingness to order a variety of treatments not related to CPR. Patients with DNR orders may choose to forgo other life-prolonging treatments, but physicians should elicit additional information about patients' treatment goals to inform these decisions.

REF ID: 4241

Level II: Individual experimental study

Topic 3: Assessment

Beck, A., Brown, J., Boles, M., & Barrett, P. (2002). Completion of advance directives by older health maintenance organization members: The role of attitudes and beliefs regarding life-sustaining treatment. *Journal of the American Geriatrics Society, 50(2), 300-306.*

Clinical Trial. Journal Article. Randomized Controlled Trial

OBJECTIVES: This study examined whether older health maintenance organization (HMO) members' attitudes and beliefs regarding life-sustaining treatment were associated with their completion of advance directives (ADs). DESIGN: A mailed survey of 1,247 subjects, aged 75 and older, participating in a randomized trial comparing two educational interventions designed to increase AD completion: mailed written materials versus written materials plus a videotape. AD completion was documented by medical record review. SETTING: The initial trial took place in October 1994 at a large group-model HMO in the Denver metropolitan area. The survey was mailed to participants 3 months after the trial.

PARTICIPANTS: All HMO members aged 75 and older who received medical care at one of the medical offices (n = 1247) were mailed the survey. Participants were the 735 members who returned the survey. **MEASUREMENTS:** AD completers were compared with noncompleters on survey items pertaining to attitudes and beliefs regarding life-sustaining treatment. **RESULTS:** Of survey respondents, AD completers (n = 313) differed from noncompleters (n = 422) in their agreement with the following attitudinal/belief statements: (1) Putting my wishes for life-sustaining treatment in writing is too binding (completers = 12, noncompleters = 35); (2) I prefer that my family decide what kind of medical care is best for me if I should become unable to communicate my wishes (completers = 69, noncompleters = 88); and (3) My physician clearly understands my wishes for life-sustaining treatment (completers = 76, noncompleters = 43; all values, P < .0001). **CONCLUSIONS:** Completers were more likely to believe that their physicians understood their wishes and less likely to think that ADs are too binding. More noncompleters wanted their family to decide, even though an AD would increase their families' ability to do so. AD completion rates might increase if they were characterized as a way to preserve flexibility in a complex medical system, help families reach amicable decisions on behalf of their loved ones, and increase patients' confidence that their physician understands their wishes for life-sustaining treatment.

REF ID: 5213

Level VI: Opinion

Topic 4.1: Management-General

Beghe, C. (2000). An advance directive programme in nursing homes reduced health services use without affecting patient satisfaction... commentary on molloy DW, guyatt GH, russo R et al. systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. JAMA 2000 mar 15;283:1437-44. Evidence-Based Nursing, 3(4), 125.

Journal Article, Abstract, Commentary

comment on ref id: 5214

QUESTION: Does systematic implementation of an advance directive programme in nursing homes affect patient and family satisfaction and reduce healthcare costs? **Design:** Randomised {allocation concealed}*, blinded {residents}*, controlled trial with 18 months of follow up. **Setting:** 6 nursing homes in Ontario, Canada, each with > 100 residents. **Patients:** 1292 nursing home residents. **Intervention:** 6 nursing homes were matched in pairs on key characteristics and randomised 1 home per pair to either an advance directive programme (3 intervention homes, 636 patients) or to continue with usual policies of advance directives (3 control homes, 656 patients). The intervention homes used an advance directive programme called Let Me Decide (LMD), which consisted of healthcare choices related to life threatening illness, cardiac arrest, and nutrition. The LMD advance directive programme involved educating hospital and nursing home staff, residents, and families about advance directives. Trained nurses classified residents as being mentally competent or incompetent. Competent residents and family members of incompetent residents had the choice of completing the LMD advance directive. **Main outcome measures:** Resident and family self reported satisfaction with health care received and involvement in decision making, deaths, and healthcare services use. All costs were reported in Canadian dollars. **Main results:** In the intervention homes, 527 of 636 residents (83%) agreed to participate, and 444 of these (70%) completed advance directives. In the control homes, 606 of 656 residents (92%) agreed to participate, and 374 of these (57%) completed advance directives. Per resident, intervention homes had lower mean number of admission to hospital (0.27 v 0.48, p=0.001), fewer hospital days (2.61 v 5.86, p=0.01), lower hospital costs (CN\$1772 v \$3869, p=0.003), and lower total healthcare costs (CN\$3490 v \$5239, p=0.013) than control homes. No differences existed between residents from intervention and control homes for satisfaction with health care or rate of death. **Conclusion:** Systematic implementation of an advance directive programme in nursing homes reduced healthcare services use and costs without affecting patient satisfaction or mortality. *Information

provided by author. [Original article accession number: 2000044809 (clinical trial, research, tables/charts)]

REF ID: 4290

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ChambersEvans, J., & Carnevale, F. A. (2005). Dawning of awareness: The experience of surrogate decision making at the end of life. *Journal of Clinical Ethics*, 16(1), 28-45.

Journal Article, Research, Tables/Charts

abstract not available

REF ID: 4224

Level III: Quasi-experimental study

Topic 4.1: Management-General

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life.[see comment]. *Journal of Clinical Oncology*, 23(24), 5520-5525.

Journal Article. Multicenter Study

PURPOSE: This study examined a novel intervention, dignity therapy, designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member. The objective of this study was to establish the feasibility of dignity therapy and determine its impact on various measures of psychosocial and existential distress. **PATIENTS AND METHODS:** Terminally ill inpatients and those receiving home-based palliative care services in Winnipeg, Canada, and Perth, Australia, were asked to complete pre- and post-intervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality; and a post-intervention satisfaction survey. **RESULTS:** Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family. Post-intervention measures of suffering showed significant improvement ($P = .023$) and reduced depressive symptoms ($P = .05$). Finding dignity therapy helpful to their family correlated with life feeling more meaningful ($r = 0.480$; $P = .000$) and having a sense of purpose ($r = 0.562$; $P = .000$), accompanied by a lessened sense of suffering ($r = 0.327$; $P = .001$) and increased will to live ($r = 0.387$; $P = .000$). **CONCLUSION:** Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

REF ID: 5210

QM: Quality Measures

Topic 5: Evaluation/Follow-up

Clarke, E. B., Curtis, J. R., Luce, J. M., Levy, M., Danis, M., & Nelson, J. et al. (2003). Quality indicators for end-of-life care in the intensive care unit.[see comment]. *Critical Care Medicine*, 31(9), 2255-2262.

Journal Article

OBJECTIVE: The primary goal of this study was to address the documented deficiencies in end-of-life care (EOLC) in intensive care unit settings by identifying key EOLC domains and related quality indicators for use in the intensive care unit through a consensus process. A second goal was to propose specific clinician and organizational behaviors and interventions that might be used to improve these EOLC quality indicators. **PARTICIPANTS:** Participants were the 36 members of the Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup and 15 nurse-physician teams from 15 intensive care units affiliated with the work group members. Fourteen adult medical, surgical, and mixed intensive care units from 13 states and the District of Columbia in the United States and one mixed intensive care unit in Canada were represented. **METHODS:** An in-depth literature review was

conducted to identify articles that assessed the domains of quality of EOLC in the intensive care unit and general health care. Consensus regarding the key EOLC domains in the intensive care unit and quality performance indicators within each domain was established based on the review of the literature and an iterative process involving the authors and members of the RWJF Critical Care End-of-Life Peer Workgroup. Specific clinician and organizational behaviors and interventions to address the proposed EOLC quality indicators within the domains were identified through a collaborative process with the nurse-physician teams in 15 intensive care units. MEASUREMENTS AND MAIN RESULTS: Seven EOLC domains were identified for use in the intensive care unit: a) patient- and family-centered decision making; b) communication; c) continuity of care; d) emotional and practical support; e) symptom management and comfort care; f) spiritual support; and g) emotional and organizational support for intensive care unit clinicians. Fifty-three EOLC quality indicators within the seven domains were proposed. More than 100 examples of clinician and organizational behaviors and interventions that could address the EOLC quality indicators in the intensive care unit setting were identified. CONCLUSIONS: These EOLC domains and the associated quality indicators, developed through a consensus process, provide clinicians and researchers with a framework for understanding quality of EOLC in the intensive care unit. Once validated, these indicators might be used to improve the quality of EOLC by serving as the components of an internal or external audit evaluating EOLC continuous quality improvement efforts in intensive care unit settings.

REF ID: 4317

Level IV: Non-experimental study

Topic 3: Assessment

CohenMansfield, J. (2002). Development of a framework to encourage addressing advance directives when resources are limited. *Journal of Aging and Health, 14(1), 24-41.*

Journal Article, Algorithm, Research, Tables/Charts

Objectives: Advance directives are used to increase autonomy in decisions regarding care when a person lacks the ability to communicate such wishes. Based on studies showing internal consistency in individuals' preferences, this study demonstrates a new method for identifying a list of questions that may best predict patient preferences. Method: Participants were 71 residents of a large nursing home and 97 hospital patients. All were administered the Preferences for Life-Sustaining Treatment Questionnaire. Advance directives sequence models were developed using conditional probabilities concerning preferences for utilization of specific treatment options, given prior responses to different treatment options. Results: Models resulted in more than 90% accuracy of treatment preferences for both samples and eliminated two thirds to three quarters of questions asked. Conclusions: Although the specific models need validation using larger samples, they demonstrate a method that facilitates transfer of information concerning treatment preferences if future incapacitation occurs.

REF ID: 4287

Level V: Case report

Topic 3: Assessment

Cook, D., Rocker, G., Marshall, J., Griffith, L., McDonald, E., & Guyatt, G. et al. (2006). Levels of care in the intensive care unit: A research program. *American Journal of Critical Care, 15(3), 269-279.*

Journal Article, Research, Tables/Charts

A multidisciplinary research program on levels of care was conducted in 15 adult intensive care units in North America, Europe, and Australia. The program addressed advance directives for cardiopulmonary resuscitation, provision of advanced life support, and clinicians' discomfort with evolving treatment plans. The results indicated that the factors that determined the establishment of directives for advance life support differed from the factors that informed a decision to limit or withdraw support after admission to an intensive care unit. In addition, clinicians' prognoses were imprecise and often an underestimation of the probability of short-term survival. Finally, some degree of discomfort was common in care providers in the intensive care unit, most often because they thought interventions were

excessive and not compatible with an acceptable future quality of life. The provision of advanced life support mandates explicit decision making about how life-support measures should be used.

REF ID: 4245

Level IV: Non-experimental study

Topic 3: Assessment

Cook, D. J., Guyatt, G., Rocker, G., Sjokvist, P., Weaver, B., & Dodek, P. et al. (2001).

Cardiopulmonary resuscitation directives on admission to intensive-care unit: An international observational study.[see comment]. *Lancet*, 358(9297), 1941-1945.

Journal Article. Multicenter Study

BACKGROUND: Resuscitation directives should be a sign of patient's preference. Our objective was to ascertain prevalence, predictors, and procurement pattern of cardiopulmonary resuscitation directives within 24 h of admission to the intensive-care unit (ICU). **METHODS:** We enrolled 2916 patients aged 18 years and older from 15 ICUs in four countries, and recorded whether, when, and by whom their cardiopulmonary resuscitation directives were established. By polychotomous logistic regression we identified factors associated with a resuscitate or do-not-resuscitate directive. **FINDINGS:** Of 2916 patients, 318 (11%; 95% CI 9.8-12.1) had an explicit resuscitation directive. In 159 (50%; 44.4-55.6) patients, the directive was do-not-resuscitate. Directives were established by residents for 145 (46%; 40.0-51.3) patients. Age strongly predicted do-not-resuscitate directives: for 50-64, 65-74, and 75 years and older, odds ratios were 3.4 (95% CI 1.6-7.3), 4.4 (2.2-9.2), and 8.8 (4.4-17.8), respectively. APACHE II scores greater than 20 predicted resuscitate and do-not-resuscitate directives in a similar way. An explicit directive was likely for patients admitted at night (odds ratio 1.4 [1.0-1.9] and 1.6 [1.2-2.3] for resuscitate and do-not-resuscitate, respectively) and during weekends (1.9 [1.3-2.7] and 2.2 [1.5-3.2], respectively). Inability to make a decision raised the likelihood of a do-not-resuscitate (3.7 [2.6-5.4]) than a resuscitate (1.7 [1.2-2.3]) directive (p=0.0005). Within Canada and the USA, cities differed strikingly, as did centres within cities. **INTERPRETATION:** Cardiopulmonary resuscitation directives established within 24 h of admission to ICU are uncommon. As well as clinical factors, timing and location of admission might determine rate and nature of resuscitation directives.

REF ID: 4251

Level II: Individual experimental study

Topic 3: Assessment

Coppola, K. M., Ditto, P. H., Danks, J. H., & Smucker, W. D. (2001). Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Archives of Internal Medicine*, 161(3), 431-440.

Clinical Trial. Journal Article. Randomized Controlled Trial

BACKGROUND: Past research has documented that primary care physicians and family members are often inaccurate when making substituted judgments for patients without advance directives (ADs). This study compared the accuracy of substituted judgments made by primary care physicians, hospital-based physicians, and family surrogates on behalf of elderly outpatients and examined the effectiveness of ADs in improving the accuracy of these judgments. **PARTICIPANTS AND METHODS:** Participants were 24 primary care physicians of 82 elderly outpatients, 17 emergency and critical care physicians who had no prior experience with the patients, and a baseline comparison group of family surrogates. The primary outcome was accuracy of physicians' predictions of patients' preferences for 4 life-sustaining treatments in 9 hypothetical illness scenarios. Physicians made substituted judgments after being provided with no patient AD, patient's value-based AD, or patient's scenario-based AD. **RESULTS:** Family surrogates' judgments were more accurate than physicians'. Hospital-based physicians making predictions without ADs had the lowest accuracy. Primary care physicians' accuracy was not improved by either AD. Accuracy and confidence in predictions of hospital-based physicians was significantly improved for some scenarios using a scenario-based AD. **CONCLUSIONS:** Although ADs do not improve the accuracy of substituted judgments for primary care physicians or family surrogates, they increase the accuracy of hospital-based physicians. Primary care physicians are

withdrawing from hospital-based care in growing numbers, and emergency medicine and critical care specialists most often are involved in decisions about whether to begin life-sustaining treatments. If ADs can help these physicians better understand patients' preferences, patient autonomy more likely will be preserved when patients become incapacitated.

REF ID: 4315

Level IV: Non-experimental study

Topic 3: Assessment

Costello, J. (2002). Do not resuscitate orders and older patients: Findings from an ethnographic study of hospital wards for older people. *Journal of Advanced Nursing*, 39(5), 491-499.

Journal Article, Practice Guidelines, Research

Background and aim. This paper reports on the findings from an ethnographic study involving three wards in two hospitals in the Northwest of England and focuses on the controversial issue of Do Not Resuscitate (DNR) orders. The study aimed to explore the way in which terminal care was provided to older patients and examined the way in which DNR orders were a socially constructed part of the practices of both nurses and doctors. Method. An ethnographic approach was adopted that used participant observation and semi-structured interviews with nurses and doctors. A purposive sample of 28 qualified nurses and five medical staff were interviewed. The decision-making process of DNR orders became the focus of the interview questions. Findings. The findings reveal that DNR decision-making was largely socially constructed from the interactions of hospital staff. Patients were not asked their preference and were excluded from any decision-making about Cardiopulmonary Resuscitation (CPR) or DNR orders. Two major findings emerge. First, DNR orders and the non-use of CPR could be seen as a form of medical beneficence, resulting from the often described paternalistic attitudes of hospital doctors. Second, there was a clear indication that DNR orders and the non-use of CPR for certain patients was based on improving the quality of patients' lives. Conclusion. The study raises issues about the quality of care received by frail older patients whom the nurses felt would not survive a futile medical procedure. The conclusion considers the need for hospitals to formulate and implement CPR policies, particularly in the prevailing climate in which patients are encouraged to become active participants in their own health care.

REF ID: 4288

Level I: Systematic Reviews

Topic 3: Assessment

Cox, C. L., Cole, E., Reynolds, T., Wandrag, M., Breckenridge, S., & Dingle, M. (2006). Implications of cultural diversity in do not attempt resuscitation (DNAR) decision-making. *Journal of Multicultural Nursing & Health*, 12(1), 20-28.

Journal Article, Research, Systematic Review

OBJECTIVE(S): To consider the implications of Black and Minority ethnic (BME) people's cultural diversity on the DNAR decision-making process and to make recommendations for ethically sound practice within the health care team. METHOD(S): The project involved a critical exposition of the literature involving the hallmarks of a systematic review. RESULT(S): Findings from the review indicate that the involvement of the patient and/or family may not always be apparent and advance directives, which are generally accepted in Western Civilization, hold little or no relevance within the BME population. There are important cultural differences regarding advance care planning and end-of-life decision-making. CONCLUSION(S): Research has demonstrated that people's values and beliefs in association with their culture will influence their views about decision-making. Culture furnishes the beliefs and values of a given population; gives individuals a sense of identity; self-worth and belonging and also provides the rules for people's behavior. Therefore, culture, values and ethnicity will influence black and minority ethnic (BME) people and family member views about Do Not Attempt Resuscitation.

REF ID: 4239

Level IV: Non-experimental study

Topic 3: Assessment

Curtis, J. R., Engelberg, R. A., Wenrich, M. D., Nielsen, E. L., Shannon, S. E., & Treece, P. D. et al. (2002). Studying communication about end-of-life care during the ICU family conference: Development of a framework.[see comment]. *Journal of Critical Care, 17(3), 147-160.*

Journal Article. Multicenter Study

PURPOSE: Family-clinician communication in the intensive care unit (ICU) about withholding and withdrawing life support occurs frequently, yet few data exist to guide clinicians in its conduct. The purpose of this study was to develop an understanding of the way this communication is currently conducted. **METHODS:** We identified family conferences in the ICUs of 4 Seattle-area hospitals. Conferences were eligible if the physician leading the conference believed that discussion about withholding or withdrawing life support or the delivery of bad news was likely to occur and if all conference participants consented to participate. Fifty conferences were audiotaped, transcribed, and analyzed by using the principles of grounded theory. **RESULTS:** We developed 2 frameworks for describing and understanding this communication. The first framework describes communication content, including introductions, information exchange, discussions of the future, and closings. The second framework describes communication styles and support provided to families and other clinicians and includes a variety of techniques such as active listening, acknowledging informational complexity and emotional difficulty of the situation, and supporting family decision making. These frameworks identify what physicians discuss, how they present and respond to issues, and how they support families during these conferences. **CONCLUSIONS:** This article describes a qualitative methodology to understand clinician-family communication during the ICU family conference concerning end-of-life care and provides a frame of reference that may help guide clinicians who conduct these conferences. We also identify strategies clinicians use to improve communication and enhance the support provided. Further analyses and studies are needed to identify whether this framework or these strategies can improve family understanding or satisfaction or improve the quality care in the ICU. Copyright 2002, Elsevier Science (USA). All rights reserved.

REF ID: 4326

Level V: Case report

Topic 3: Assessment

Dendaas, N., Pellino, T. A., Roberts, K. F., & Cleary, J. (2001). Responding to SUPPORT: An academic medical center examines its end-of-life care practices... study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of Pain and Symptom Management, 21(2), 121-128.*

Journal Article, Forms, Research, Tables/Charts

The purpose of this exploratory study was to examine the end-of-life (EOL) care rendered to patients and families within a large midwestern academic medical center during a recent one-year period. An investigator-developed audit tool was used to review the final hospitalization records of 100 patients. Data were collected regarding demographic variables, final hospitalization, medical diagnoses and histories, and documented end-of-life care. Major findings included a majority of deaths occurring within medical services on critical care units, a frequent short length of stay, a majority of Do Not Resuscitate or Withdrawal of Support orders being written 1-3 days prior to death, an unstable health status prior to admission, and presence of at least one significant chronic illness in the past medical history. Findings are being used to address EOL care related issues within the institution.

REF ID: 4299

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Topic 3: Assessment

Dexter, P. R., Wolinsky, F. D., Gramelspacher, G. P., Eckert, G. J., & Tierney, W. M. (2003). Opportunities for advance directives to influence acute medical care. *Journal of Clinical Ethics, 14(3), 173-182.*

Journal Article, Research, Tables/Charts

abstract not available

REF ID: 4252

Level II: Individual experimental study

Topic 4.1: Management-General

Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., & Dresser, R. et al. (2001). Advance directives as acts of communication: A randomized controlled trial. *Archives of Internal Medicine, 161*(3), 421-430.

Clinical Trial. Journal Article. Randomized Controlled Trial

BACKGROUND: Instructional advance directives are widely advocated as a means of preserving patient self-determination at the end of life based on the assumption that they improve surrogates' understanding of patients' life-sustaining treatment wishes. However, no research has examined whether instructional directives are effective in improving the accuracy of surrogate decisions. **PARTICIPANTS AND METHODS:** A total of 401 outpatients aged 65 years or older and their self-designated surrogate decision makers (62% spouses, 29% children) were randomized to 1 of 5 experimental conditions. In the control condition, surrogates predicted patients' preferences for 4 life-sustaining medical treatments in 9 illness scenarios without the benefit of a patient-completed advance directive. Accuracy in this condition was compared with that in 4 intervention conditions in which surrogates made predictions after reviewing either a scenario-based or a value-based directive completed by the patient and either discussing or not discussing the contents of the directive with the patient. Perceived benefits of advance directive completion were also measured. **RESULTS:** None of the interventions produced significant improvements in the accuracy of surrogate substituted judgment in any illness scenario or for any medical treatment. Discussion interventions improved perceived surrogate understanding and comfort for patient-surrogate pairs in which the patient had not completed an advance directive prior to study participation. **CONCLUSIONS:** Our results challenge current policy and law advocating instructional advance directives as a means of honoring specific patient wishes at the end of life. Future research should explore other methods of improving surrogate decision making and consider the value of other outcomes in evaluating the effectiveness of advance care planning.

REF ID: 4311

Level V: Case report

Topic 3: Assessment

Doorenbos, A. Z., & Nies. (2003). The use of advance directives in a population of asian indian hindus. *Journal of Transcultural Nursing, 14*(1), 17-24.

Journal Article, Research, Tables/Charts

Advance directives are a way to communicate the kind of care that people desire at the end of life. Recent research shows that ethnic minorities have been found to complete advance directives significantly less often than Caucasians, and no information was available regarding advance directives in the Asian Indian population. To address this shortcoming, this descriptive exploratory design sampled a community sample of 45 Asian Indian Hindus. Being female and having an individualistic decision-making style were significantly positively correlated with advance directive completion. Having strong religious affiliation and a family decisionmaking style were significantly negatively correlated with advance directive completion. The results of this study provide needed information regarding the Asian Indian population and how Hinduism affects advance directives.

REF ID: 4320

Level V: Case report

Topic 3: Assessment

Douglas, R., & Brown, H. N. (2002). Patients' attitudes toward advance directives. *Journal of Nursing Scholarship, 34*(1), 61-65.

Journal Article, Research, Tables/Charts

PURPOSE: To explore hospitalized patients' attitudes toward advance directives, their reasons for

completing or not completing advance directive forms, and demographic differences between patients who did and did not complete advance directive forms. DESIGN AND METHOD: The convenience sample comprised 30 hospitalized patients in North Carolina. Participants were interviewed using an adapted advance directive attitude survey (ADAS), and were asked five general questions about advance directives. Validity and reliability were established on the adapted tool. FINDINGS: The overwhelming majority of participants had received information on advance directives and they were moderately positive about them. The majority who had completed advance directives were Caucasian, female, over age 65, had less than a high school education, and perceived their health as poor. Most believed that an advance directive would ensure they received the treatment they desired at the end of life. CONCLUSIONS: Patients' attitudes alone did not determine who will and will not complete advance directives. Most participants who completed advance directives had specific reasons for doing so. Nurses have responsibility for discussing advance directives with patients, families, and physicians to ensure adequate education about the completion of advance directives.

REF ID: 3346

Level III: Quasi-experimental study

Topic 5: Evaluation/Follow-up

Engelberg RA, Patrick DL, & Curtis, J. R. (2005). Correspondence between patients' preferences and surrogates' understandings for dying and death. *Journal of Pain and Symptom Management*, 30(6), 498-509.

Controlled Clinical Trial; Journal Article; MEDLINE

We examined the agreement between hospice patients' preferences for desired experiences during the last week of life and their surrogates' understandings of those preferences (n=92 pairs). Analyses included percent agreement, intraclass correlation coefficients, and Bland-Altman plots. Demographic characteristics and communication measures associated with better agreement were identified using t-tests and analysis of variance. The median number of items on which patients and family members agreed was 14 of 30 (interquartile range, IQR 10, 16). Preferences with good agreement included both observable and non-observable experiences. Patients who reported having had conversations about treatment preferences and who reported that their surrogates knew their preferences reported higher agreement. Surrogates display a better understanding of what is important to patients at the end of life if they have had discussions about patient preferences. These discussions may enable surrogates and clinicians to more accurately follow patient preferences.

REF ID: 2347

Level I: RCT

Topic 4.1: Management-General

Engelhardt, J. B., McClive-Reed, K. P., Toseland, R. W., Smith, T. L., Larson, D. G., & Tobin, D. R. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: A randomized trial. *American Journal of Managed Care (AM J MANAGE CARE)*, 12(2), 93-100.

journal article; clinical trial; research; tables/charts

Objective: To evaluate the Advanced Illness Coordinated Care Program (AICCP), delivered by allied health personnel to improve care for patients coping with advanced illness and in need of preparation for end-of-life (EOL) care.; Study Design: Clinical trial involving 275 patients and 143 surrogates in 6 settings who were randomly assigned to the AICCP or usual care (UC).; Methods: The AICCP participants met with a care coordinator for assistance with provider communication, care coordination, and support. The AICCP was evaluated for effects on satisfaction with care, advance planning, consistency of care with patient preferences, and healthcare costs.; Results: The AICCP increased patient satisfaction with care and communication (P = .03), and AICCP surrogates reported fewer problems with provider support (P = .03). More AICCP than UC participants completed an advance directive (AD) (69.4% vs 48.4%; P = .006), and the AICCP group completed more ADs per participant (P = .01). Median time to AD documentation was 46 days for AICCP and 238 days for UC (P = .02).

There was no difference in survival (AICCP 43% vs UC 42%). Six-month costs were lower with AICCP than with UC (\$12 123 vs \$16 295); however, the difference did not reach statistical significance.; Conclusions: The AICCP improved satisfaction with care and helped patients develop and revise more ADs, sooner, without affecting mortality. This program may be delivered in a range of managed care, fee-for-service, and group-model settings.

REF ID: 4301

Level V: Case report

Topic 3: Assessment;

Gallo, J. J., Straton, J. B., Klag, M. J., Meoni, L. A., Sulmasy, D. P., & Wang, N. et al. (2003). Life-sustaining treatments: What do physicians want and do they express their wishes to others? *Journal of the American Geriatrics Society, 51(7), 961-969.*

Journal Article, Questionnaire/Scale, Research, Tables/Charts

OBJECTIVES: To assess whether older physicians have discussed their preferences for medical care at the end of life with their physicians, whether they have established an advance directive, and what life-sustaining treatment they wish in the event of incapacity to make these decisions for themselves. **DESIGN:** Mailed survey to a cohort of physicians. **SETTING:** Physicians who were medical students at the Johns Hopkins University in graduating classes from 1946 to 1964. **PARTICIPANTS:** Physicians who completed the advance directive questionnaire (mean age 68). **MEASUREMENTS:** Questionnaires were sent out to known surviving physicians of the Precursors Study, an on-going study that began in 1946, asking physicians about their preferences for life-sustaining treatments. **RESULTS:** Of 999 physicians who were sent the survey, 765 (77%) responded. Forty-six percent of the physicians felt that their own doctors were unaware of their treatment preferences or were not sure, and of these respondents, 59% had no intention of discussing their wishes with their doctors within the next year. In contrast, 89% thought their families were probably or definitely aware of their preferences. Sixty-four percent reported that they had established an advance directive. Compared with physicians without advance directives, physicians who established an advance directive were more likely to believe that their doctors (odds ratio (OR) = 3.42, 95% confidence interval (CI) = 2.49-4.69) or family members (OR = 9.58, 95% CI = 5.33-17.23) were aware of their preferences for end-of-life care and were more likely to refuse treatments than those without advance directives. **CONCLUSION:** This survey of physicians calls attention to the gap between preferences for medical care at the end of life and expressing wishes to others through discussion and advance directives, even among physicians.

REF ID: 5209

QM: Quality Measures

Topic 5: Evaluation/Follow-up

Gohmann, S. F., & Head, B. (2001). Hospice benchmarking: One state's initiative to analyze and improve hospice care. *Journal of Hospice and Palliative Nursing, 3(2), 41-50.*

Journal Article, Research, Tables/Charts

PURPOSE. To detail one state's experience in determining appropriate hospice indicators, collecting data from hospice member organizations, analyzing the data, sharing best practices, and implementing improvement efforts. **DATA SOURCES.** Benchmarking data for participants in the Kentucky Benchmarking Program. **CONCLUSIONS.** Benchmarking offers organizations the opportunity to compare important indicators, develop criteria for selfevaluation, and initiate related improvement efforts. **IMPLICATIONS FOR PRACTICE.** Benchmarking is important to hospice and palliative nursing because it provides the necessary comparative data to justify performance improvement and the development of practice standards. Search terms: Benchmarking, best practices, data analysis, performance/quality improvement

REF ID: 5428

Level V: Case report

Topic 4.1: Management-General

Gorman, T. E., Ahern, S. P., Wiseman, J., & Skrobik, Y. (2005; 2005). Residents' end-of-life

decision making with adult hospitalized patients: A review of the literature. *Academic Medicine*, 80(7), 622-633.

Journal; Peer Reviewed Journal

Purpose: The authors performed a structured literature review to understand residents' experiences with end-of-life (EOL) decision making with adult hospitalized patients, specifically regarding decisions to withhold or withdraw advanced life-support measures. Method: An Ovid-based strategy was used to search Medline, ERIC, PsychINFO, and CINHALL databases for articles published between 1966 and February 2005, combining the domains of "resuscitation orders," "decision making," and "internship and residency." All quantitative and qualitative studies examining residents' EOL decision making with adult hospitalized patients were included. The authors developed and applied a scoring system for relevance and quality, performed data abstraction and quality assessment independently and in duplicate, then met to collate findings and identify factors in residents' EOL decision making. Results: The searches yielded 884 articles, of which 26 were included. Variable methodologies precluded meta-analysis. In these studies, residents felt unprepared to handle patient EOL decision making, although exposure to EOL discussions helped them gain confidence. Residents' attitudes, skills, and knowledge were key determinants of whether EOL decisions were addressed. Many misinterpreted the terms "DNR" and "futility." Residents' understanding of the patient EOL decision-making process could be extremely variable, and their do-not-resuscitate discussions suboptimal. Residents' lived practice experience of the patient EOL decision-making process was often at odds with what they were taught in formal curricula. Conclusions: Educational strategies aimed at changing residents' knowledge, skills and attitude should address the hidden curriculum for the patient EOL decision-making process that is part of the experienced culture of every day practice. Future studies of this experienced culture would inform specific educational interventions. (PsycINFO Database Record (c) 2006 APA, all rights reserved) (journal abstract)

REF ID: 4300

Level V: Case report

Topic 3: Assessment:

Greiner, K. A., Perera, S., & Ahluwalia, J. S. (2003). Hospice usage by minorities in the last year of life: Results from the national mortality followback survey. *Journal of the American Geriatrics Society*, 51(7), 970-978.

Journal Article, Research, Tables/Charts

OBJECTIVES: To examine racial/ethnic variations in rates of hospice use in a national cohort and to identify individual characteristics associated with hospice use. **DESIGN:** Secondary analysis of the 1993 National Mortality Followback Survey (NMFS), a nationally obtained sample using death certificates and interviews with relatives (proxy respondents) to provide mortality, social, and economic data and information about healthcare utilization in the last year of life for 23,000 deceased individuals. **SETTING:** Hospice care. **PARTICIPANTS:** Individuals aged 15 and older who died in 1993. Subjects were included in this analysis if they died of nontraumatic causes (N = 11,291). **MEASUREMENTS:** Hospice use was dichotomized by proxy responses indicating use or nonuse of home or inpatient hospice services. The percentage of individuals using hospice services in the last year of life was calculated. **RESULTS:** Unadjusted bivariate results found that African Americans were less likely to use hospice than whites (odds ratio (OR) = 0.59; P <.001) and that those without a living will (LW) (OR = 0.23; P <.001) and without a cancer diagnosis (OR = 0.28; P <.001) were less likely to use hospice. The negative relationship between African Americans and hospice use was unaffected when controlled for sex, education, marital status, existence of a LW, income, and access to health care. Logistic models revealed that presence of a LW diminished the negative relationship between African Americans and hospice use, but the latter remained significant (OR = 0.83; P =.033). A subanalysis of subjects aged 55 and older showed a significant interaction between access to care and race/ethnicity with respect to hospice use (P =.044). Inclusion of income in this multivariable logistic model attenuated the relationship between African-American race/ethnicity and hospice use (OR = 0.77), and the difference

between whites and African Americans became only marginally statistically significant ($P = .060$).
CONCLUSION: In the 1993 NMFS, hospice use was negatively associated with African-American race/ethnicity independent of income and access to healthcare. The relationship is not independent of age, insurance type, or history of stroke. For subjects aged 55 and older, access to healthcare may be an important confounder of the negative relationship between African-American race/ethnicity and hospice use. Consistent with previous studies, this analysis found that African Americans were less likely to use LWs than whites. The reduced importance of African-American race/ethnicity on hospice use with the inclusion of presence of a LW in logistic models suggests that similar cultural processes may shape differences between African Americans and whites in advance care planning and hospice use.

REF ID: 4228

Level II: Individual experimental study

Topic 4.1: Management-General

Gutheil, I. A., & Heyman, J. C. (2005). Communication between older people and their health care agents: Results of an intervention. *Health & Social Work, 30*(2), 107-116.

Clinical Trial. Journal Article. Randomized Controlled Trial

This study examined an intervention to help high-functioning community-dwelling older people communicate their wishes for care at the end of life with someone they would trust to make health care decisions for them if necessary. Groups consisted of dyads of older people and their potential or designated health care agents randomly assigned to the intervention (STEP program) or control group. STEP participants received three group sessions with educational and support components. For individual participants, there was a statistically significant difference between groups on knowledge of the health care proxy form and the roles and responsibilities of the agent. For the dyads of older people and their agents, there was a significantly higher mean communication score for the STEP participants than for the control group. The findings demonstrate that it is possible to affect advance communication about wishes at the end of life through a group intervention.

REF ID: 4235

Level V: Case report

Topic 3: Assessment

Guyatt, G., Cook, D., Weaver, B., Rocker, G., Dodek, P., & Sjokvist, P. et al. (2003). Influence of perceived functional and employment status on cardiopulmonary resuscitation directives.[see comment]. *Journal of Critical Care, 18*(3), 133-141.

Journal Article. Multicenter Study

BACKGROUND: Perceptions about functional and employment status before admission to the intensive care unit (ICU) may influence how patients and clinicians make decisions about cardiopulmonary resuscitation. OBJECTIVE: To examine the relationship between cardiopulmonary resuscitation directives established within 24 hours of admission to the ICU and clinical perceptions of premorbid functional and employment status. DESIGN: Prospective observational study in 15 university-affiliated centers in Canada, the United States, Australia, and Sweden. Patients: A total of 1,008 ICU patients aged 18 years or older expected to stay in the ICU at least 72 hours. Measurements: By using multinomial logistic regression, we examined the relationship between functional status and employment status perceived by the ICU team 1 month before ICU admission (the independent variables) and resuscitation status (the dependent variable). Each patient had either an explicit resuscitation directive (to resuscitate or not to resuscitate), or an implicit resuscitation directive to resuscitate. RESULTS: On average, patients were 61.7 years (± 17.4 y) old with an Acute Physiology and Chronic Health Evaluation (APACHE) II score of 21.5 (± 8.7); 846 (83.9%) were ventilated mechanically within 48 hours and 345 (34.2%) died in the ICU. Most patients (793, 78.7%) had no explicit resuscitation directive; 98 (9.7%) had an explicit plan to resuscitate, whereas 117 (11.6%) had an explicit plan of do-not-resuscitate. Of 1,008 patients, 98 (9.7%) were severely functionally limited, 217 (21.5%) were somewhat limited, 628 (62.3%) were totally independent, and 65 (6.4%) had unknown functional status 1 month before ICU admission. Severe functional status impairment was

associated moderately with an explicit plan to resuscitate (odds ratio, 2.2 relative to no explicit directive) and associated strongly with an explicit do-not-resuscitate plan (odds ratio, 6.2 relative to no explicit directive, P value on the difference =.011). This relationship was not influenced by age, sex, APACHE II score, medical or surgical status, admission diagnosis, employment status, or city. However, severe functional status was associated strongly and significantly with an explicit do-not-resuscitate directive among those who could not participate in decision making (odds ratio, 8.2; 95% confidence interval, 4.5-15.0), and more weakly associated in those who could participate (odds ratio, 1.7; 95% confidence interval, 0.3-8.6). Being unemployed was associated with an increased odds of an explicit resuscitation directive versus no explicit directive (odds ratio, 5.5; 95% confidence interval, 2.2-13.4). **CONCLUSIONS:** Functional status impairment perceived by the ICU team is associated clearly with do-not-resuscitate directives in patients unable to participate in decision making. However, the association appears much weaker in patients able to participate in decision making. Patients' perceived employment status also may influence resuscitation decisions. Our results emphasize the challenges of ensuring that crucial resuscitation decisions are not affected adversely by patients' inability to participate in decisions, and by their functional and employment status.

REF ID: 4297

Level III: Quasi-experimental study

Topic 3: Assessment;

Haydar, Z. R., Lowe, A. J., Kahveci, K. L., Weatherford, W., & Finucane, T. (2004). Differences in end-of-life preferences between congestive heart failure and dementia in a medical house calls program. *Journal of the American Geriatrics Society*, 52(5), 736-740.

Journal Article, Research, Tables/Charts

OBJECTIVES: To compare end-of-life preferences in elderly individuals with dementia and congestive heart failure (CHF). **DESIGN:** Retrospective case-control study. **SETTING:** Geriatrician-led interdisciplinary house-call program using an electronic medical record. **PARTICIPANTS:** Homebound individuals who died while under the care of the house-call program from October 1996 to April 2001. **MEASUREMENTS:** Medical records review for demographics, functional status, advance medical planning, hospice use, and place of death. **RESULTS:** Of 172 patients who died in the program, 29 had CHF, 79 had dementia, 34 had both, and 30 had neither. Patients with CHF were younger (82.6 vs 87.0, P=.011) and less functionally dependent (activities of daily living score 9.1 vs 11.5, P=.001). Time from enrollment to death was not significantly different (mean \pm standard deviation=444 \pm 375 days for CHF vs 325 \pm 330 days for dementia, P=.113). A do-not-resuscitate (DNR) directive was given in 62% of patients with CHF and 91% with dementia (P<.001). Advance medical planning discussions were not significantly different (2.10 in CHF vs 1.65 in dementia, P=.100). More patients with CHF participated in their advance medical planning than those with dementia (86% vs 17%, P<.001). Hospice was used in 24% of CHF and 61% of dementia cases (P<.001). Finally, 45% of patients with CHF and 18% of patients with dementia died in the acute hospital (P=.006). Multivariate analysis showed that the fact that more patients with CHF were involved in their medical planning was not significant in predicting end-of-life preferences. Alternatively, Caucasian ethnicity was an independent predictor of having a documented DNR and death outside of the acute hospital. **CONCLUSION:** In the months before death, patients with CHF were more likely to have care plans directed at disease modification and treatment, whereas dementia patients were more likely to have care plans that focused on symptom relief and anticipation of dying. Several factors may contribute to this difference.

REF ID: 4244

Level II: Individual experimental study

Topic 4.1: Management-General

Heffner, J. E., & Barbieri, C. (2001-Dec). Effects of advance care education in cardiovascular rehabilitation programs: A prospective randomized study. *Journal of Cardiopulmonary Rehabilitation*, 21(6), 387-391.

Clinical Trial. Journal Article. Multicenter Study. Randomized Controlled Trial

PURPOSE: To determine the effect of advance care education provided to patients enrolled in cardiovascular rehabilitation (CVR) programs and assess patients' acceptance of the educational program. **METHODS:** In a multicenter, prospective, randomized study, the authors administered two questionnaires 6 months apart to 284 patients enrolled in 14 CVR programs in 11 states. An educational group (99 subjects) participated in educational programs related to advance care planning and received advance directive forms after completing the first questionnaires; 185 subjects served as controls. Primary outcomes were completion of patient-physician discussions of end-of-life issues and patient confidence that their end-of-life wishes were understood by their physicians. Secondary outcomes were completion of formal advance directives and patient acceptance of the educational program. **RESULTS:** Both the educational and control groups demonstrated a larger proportion of patients at the end of the study, compared with the amount at the beginning of the study, who had completed living wills, durable powers of attorney for healthcare, and discussions with their physicians about advance directives and life support care. These outcomes were not observed more commonly after the educational intervention. Neither groups gained confidence, however, that their physicians understood their end-of-life wishes. Only 8.6% of patients had a negative response to the educational program. **CONCLUSIONS:** Advance care education is well received by patients enrolled in CVR programs. Enrollment in CVR promotes advance care planning to a small but measurable degree CVR rehabilitation programs appear to be acceptable sites for advance care planning but further research is needed to develop effective educational interventions.

REF ID: 3396

Level II: Individual experimental study

Topic 4.1: Management-General

Heiman H, Bates DW, Fairchild D, Shaykevich S, & Lehmann, L. S. (2004). Improving completion of advance directives in the primary care setting: A randomized controlled trial. *The American Journal of Medicine*, 117(5), 318-324.

Clinical Trial; Journal Article; Multicenter Study; Randomized Controlled Trial; Core Clinical (AIM); MEDLINE

BACKGROUND: Since 1991, hospitals have asked patients whether they have advance directives, but few patients complete these documents. We assessed two simple interventions to improve completion of advance directives among elderly or chronically ill outpatients. **METHODS:** We conducted a cluster randomized controlled trial involving 1079 patients from five general medicine clinics that were affiliated with an academic medical center. Patients were either > or =70 years of age or > or =50 years old with a chronic illness. The study comprised three arms: physician reminders recommending documentation of advance directives, physician reminders plus mailing advance directives to patients together with educational literature, or neither intervention (control). The main outcome measure was completion of an advance directive. **RESULTS:** After 28 weeks, 1.5% (5/332) of patients in the physician reminder group, 14% (38/277) in the physician reminder plus patient mailing group, and 1.8% (5/286) in the control group had completed advance directives. In multivariate analyses, patients in the physician reminder plus patient mailing group were much more likely than controls to have completed advance directives (odds ratio [OR] = 5.9; 95% confidence interval [CI]: 1.5 to 22), whereas patients in the physician reminder-only group were no more likely than controls to have completed advance directives (OR = 0.88; 95% CI: 0.21 to 3.7). **CONCLUSION:** Mailing health care proxy and living will forms and literature to patients before an appointment at which their physicians received a reminder about advance directives yielded a small but significant improvement in completion of these documents. A physician reminder alone did not have an effect.

REF ID: 4296

Level V: Case report

Topic 3: Assessment;

Hickman, S. E., Tolle, S. W., BrummelSmith, K., & Carley, M. M. (2004). Use of the physician orders for life-sustaining treatment program in oregon nursing facilities: Beyond resuscitation

status. *Journal of the American Geriatrics Society*, 52(9), 1424-1429.

Journal Article, Forms, Research, Tables/Charts

OBJECTIVES: Program was designed to communicate resident/surrogate treatment preferences in the form of medical orders. To assess statewide nursing facility use of the Physician Orders for Life-Sustaining Treatment (POLST) and to identify the patterns of orders documented on residents' POLST forms. **DESIGN:** Telephone survey; on-site POLST form review. **SETTING:** Oregon nursing facilities. **PARTICIPANTS:** One hundred forty-six nursing facilities in the telephone survey; 356 nursing facility residents aged 65 and older at seven nursing facilities in the POLST form review. **MEASUREMENTS:** A telephone survey; onsite POLST form reviews. **RESULTS:** In the telephone survey, 71% of facilities reported using the POLST program for at least half of their residents. In the POLST form review, do-not-resuscitate (DNR) orders were present on 88% of POLST forms. On forms indicating DNR, 77% reflected preferences for more than the lowest level of treatment in at least one other category. On POLST forms indicating orders to resuscitate, 47% reflected preferences for less than the highest level of treatment in at least one other category. The oldest old (> or = 85, n=167) were more likely than the young old (65-74, n=48) to have orders to limit resuscitation, medical treatment, and artificial nutrition and hydration. **CONCLUSION:** The POLST program is widely used in Oregon nursing facilities. A majority of individuals with DNR orders requested some other form of life-extending treatment, and advanced age was associated with orders to limit treatments.

REF ID: 4294

Level IV: Non-experimental study

Topic 4.1: Management-General

Jezewski, Brown, J. K., Wu, Y. B., Meeker, Feng, J., & Bu, X. (2005). Oncology nurses' knowledge, attitudes, and experiences regarding advance directives. *Oncology Nursing Forum*, 32(2), 319-327.

Journal Article, Research, Tables/Charts

PURPOSE/OBJECTIVES: To determine oncology nurses' knowledge of, attitudes toward, and experiences with advance directives (ADs). **DESIGN:** Descriptive, correlation survey. **SAMPLE:** Usable responses from 794 (21% return) of 3,840 randomly selected members of the Oncology Nursing Society. The typical respondent was female, Caucasian, married or living as married, middle-aged, and Christian. **METHODS:** A mailed survey using the Knowledge, Attitudinal, and Experiential Survey on Advance Directives instrument. **MAIN RESEARCH VARIABLES:** Knowledge, attitudes, experiences, confidence, and ADs. **FINDINGS:** Overall, oncology nurses were most knowledgeable about ADs in general (70% correct) and less knowledgeable about the Patient Self-Determination Act (51% correct) and their state laws (53% correct). The mean total knowledge score based on the three subscales was 17.4 out of a possible 30, or 58% correct. The nurses' experience with ADs was measured using a five-item subscale with a mean score of 4 (SD = 1.11). They were less confident in their ability to assist patients with completing ADs. Respondent attitudes reflected an advocacy role in end-of-life decisions. Attitude items were reviewed individually. Respondents strongly agreed (97%) with the statement that patients should receive sufficient medication to relieve pain even though it may hasten death, which reflects the emphasis in oncology on adequate pain management at the end of life. **CONCLUSIONS:** Nurses' knowledge scores were low. Nurses in the study were not highly confident in their ability to assist patients with ADs. Demographic variables generally did not influence knowledge, confidence, or experience scores. **IMPLICATIONS FOR NURSING:** More education related to ADs is needed and could be administered through in-service classes or continuing education. Nurses' responses indicated that they need more time to assist patients with completing ADs. This is difficult in the current practice environment but must be recognized as critically important.

REF ID: 3354

Level V: Case report

Topic 4.1: Management-General

Kwak J, & Haley, W. E. (2005). Current research findings on end-of-life decision making among

racially or ethnically diverse groups. *The Gerontologist*, 45(5), 634-641.

Journal Article; Review; MEDLINE

PURPOSE: We reviewed the research literature on racial or ethnic diversity and end-of-life decision making in order to identify key findings and provide recommendations for future research. **DESIGN AND METHODS:** We identified 33 empirical studies in which race or ethnicity was investigated as either a variable predicting treatment preferences or choices, where racial or ethnic groups were compared in their end-of-life decisions, or where the end-of-life decision making of a single minority group was studied in depth. We conducted a narrative review and identified four topical domains of study: advance directives; life support; disclosure and communication of diagnosis, prognosis, and preferences; and designation of primary decision makers. **RESULTS:** Non-White racial or ethnic groups generally lacked knowledge of advance directives and were less likely than Whites to support advance directives. African Americans were consistently found to prefer the use of life support; Asians and Hispanics were more likely to prefer family-centered decision making than other racial or ethnic groups. Variations within groups existed and were related to cultural values, demographic characteristics, level of acculturation, and knowledge of end-of-life treatment options. Common methodological limitations of these studies were lack of theoretical framework, use of cross-sectional designs, convenience samples, and self-developed measurement scales. **IMPLICATIONS:** Although the studies are limited by methodological concerns, identified differences in end-of-life decision-making preference and practice suggest that clinical care and policy should recognize the variety of values and preferences found among diverse racial or ethnic groups. Future research priorities are described to better inform clinicians and policy makers about ways to allow for more culturally sensitive approaches to end-of-life care.

REF ID: 4291

Level V: Case report

Topic 3: Assessment; Topic 3: Assessment

Lamberg, J. L., Person, C. J., Kiely, D. K., & Mitchell, S. L. (2005). Decisions to hospitalize nursing home residents dying with advanced dementia. *Journal of the American Geriatrics Society*, 53(8), 1396-1401.

Journal Article, Research, Tables/Charts

OBJECTIVES: To describe the prevalence of, timing of, and factors associated with decisions not to hospitalize nursing home residents with advanced dementia who were dying. **DESIGN:** Retrospective cohort study. **SETTING:** Six hundred seventy five-bed nursing facility in Boston. **PARTICIPANTS:** Two hundred forty residents in a teaching nursing home who died between January 2001 and December 2003 with advanced dementia. **MEASUREMENTS:** The prevalence and timing of do-not-hospitalize (DNH) orders were determined from the medical record. Data describing demographic characteristics, health conditions, advance care planning, sentinel events, and health services usage during the last 6 months of life were examined. Factors associated with having a DNH order were identified. **RESULTS:** At the time of death, 83.8% of subjects had a DNH order. The prevalence of DNH orders was 50.0% and 34.4%, 30 and 180 days before death, respectively. Hospital transfers were common during the last 6 months of life (24.6%). Factors independently associated with having a DNH order before death included surrogate decision-maker was not the subject's child (adjusted odds ratio (AOR)=4.39, 95% confidence interval (CI)=1.52-12.66), eating problems (AOR=4.17, 95% CI=1.52-11.47), aged 92 and older (AOR=2.78, 95% CI=1.29-5.96), and length of stay 2 years or longer (AOR=2.34, 95% CI=1.11-4.93). **CONCLUSION:** For most institutionalized persons with advanced dementia, a decision to forgo hospitalization is not made until death is imminent. Thus, hospital transfers are common near the end of life. The finding that DNH orders are associated with patient and surrogate factors can help clinicians identify cases in which decisions to forgo hospitalizations may be facilitated.

REF ID: 5211

Level VI: Opinion

Topic 4.1: Management-General

Lever, J. A. (2005). 5 themes described the views of older people on advance care statements and

their role in end of life care. *Evidence-Based Nursing*, 8(2), 64.

Journal Article, Abstract, Commentary

comment on: REF ID: 5212

Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life: the views of older people about advance care statements. *SOC SCI MED* 2004 Jul; 59(1): 57-68 (

What are the views of older people on advance care statements and their role in end of life care and treatment decisions? DESIGN Qualitative study. SETTING Sheffield, UK. PARTICIPANTS 32 older people (72% women; 27 were 60-80 years of age) who were recruited from 6 diverse community groups representing older people in Sheffield, UK. METHODS 8 focus group discussions were held with participants to explore beliefs and understandings, risks and benefits, and preferences of older people regarding "life prolonging" and "basic care" technologies in end of life management. A slide show describing a man with early Alzheimer's disease and his plans for end of life care was used to prompt discussion. The discussions were transcribed verbatim and analysed for major themes. MAIN FINDINGS Advance statements can aid personal integrity and help families of older people. Although advance care statements were a new idea to most participants, they identified several positive attributes of such statements. Participants recognised that advance care statements have the potential to enhance choice and autonomy about issues of care and treatment before onset of cognitive impairment. Several participants also stated that advance statements would be a good way to avoid extra stress during serious illness because important decisions about care and treatment that may be urgently needed will have already been considered and agreed upon. Advance statements were also reported to have the potential to relieve families of the "burden" of decision making. Advance statements and euthanasia. Some participants expressed concern that completing an advance statement might be interpreted as a request for euthanasia. The term "pulling the plug" was used to describe the type of clinical actions they thought would result from adherence to an advance care statement. Such concerns and doubts about the meaning of euthanasia and how it differed from permissible forms of non-treatment were identified in relation to all types of care and treatment innovation addressed in the focus groups. Concerns about future applicability of advance care statements. Most participants envisaged problems in making decisions for a future situation that was difficult to imagine. Underpinning this was the notion that life is precious, even in the face of grave illness and advanced old age. Participants recognised difficulties associated with anticipating their requirements during a final illness and getting the timing of advanced care planning right. Participants perceived a risk of leaving it "too late." Worries and difficulties in thinking about and discussing death and dying. Although some participants indicated that they had thought about their own dying and death at length, for others found that dying was not easy to contemplate. Most participants thought that family members would be able to refuse or give consent for particular types of treatment on their behalf. As a result, some did not feel the need to think about making an advance statement. However, participants also spoke of difficulties in discussing end of life care with their families. The need to build trusting relationships with clinicians. Initially, advance care statements were seen by some participants as a safeguard against physicians "playing God." However, some recognised that in certain situations (eg, sudden illness), physicians needed to make decisions on their behalf, often "snap" decisions without time to consult family or previous statements of wishes. This recognition was linked to an awareness that when dying, a person may no longer wish to adhere to the stipulations of an advance statement. Participants recognised the paradox of wanting control and autonomy but also wanting to be cared for at a time of vulnerability. CONCLUSION Older people perceived that advance care statements have the potential to aid personal integrity and help their families during terminal care and treatment decisions, but they also identified several barriers to their completion.

REF ID: 4229

Level V: Case report

Topic 3: Assessment; Topic 3: Assessment

Levy, C. R., Ely, E. W., Payne, K., Engelberg, R. A., Patrick, D. L., & Curtis, J. R. (2005). Quality

of dying and death in two medical ICUs: Perceptions of family and clinicians. *Chest*, 127(5), 1775-1783.

Journal Article. Multicenter Study

OBJECTIVE: We compared perceptions of the quality of dying and death in the ICU across nurses, resident physicians, attending physicians, and family members. The aim was to obtain a surrogate assessment of the quality of the dying process and examine differences in the perceptions of different types of raters. **DESIGN:** Cross-sectional survey of family members and ICU clinicians conducted following the death of enrolled patients. **SETTING:** Two medical ICUs at academic tertiary care medical centers. **PATIENTS:** Patients dying in the ICU (n = 68). **MEASUREMENTS AND RESULTS:** The previously validated Quality of Dying and Death (QODD) instrument was modified for use in the ICU. Within 48 h of the time of death, the nurse, resident, and attending physician caring for the patient were asked to complete the QODD. One month following the death, a designated family member was contacted and the QODD was administered on the telephone. Family members and attending physicians gave the most favorable ratings of death, while nurses and residents provided less favorable ratings. Significant differences between these groups were notable ($p < 0.01$) on items related to patient autonomy: maintaining dignity, being touched by loved ones, and the overall quality of death. **CONCLUSIONS:** The perception of dying and death in the ICU varies considerably between nurses, attending physicians, resident physicians, and family members. Further studies are needed to explain these differences and determine the utility of the ICU QODD instrument for assessing and improving the quality of end-of-life care in the ICU.

REF ID: 4232

Level IV: Non-experimental study

Topic 3: Assessment;

Levy, M., Tanios, M. A., Nelson, D., Short, K., Senechia, A., & Vespia, J. et al. (2004). Outcomes of patients with do-not-intubate orders treated with noninvasive ventilation.[see comment]. *Critical Care Medicine*, 32(10), 2002-2007.

Clinical Trial. Journal Article. Multicenter Study

OBJECTIVE: To determine whether diagnosis and bedside observations predict outcomes of patients who have declined intubation but accept noninvasive positive pressure ventilation (NPPV) to treat their respiratory failure. **DESIGN:** Prospective multiple-center cohort trial. **SETTING:** Two teaching hospitals and two community-based hospitals in southeastern New England from January through October 1999. **PATIENTS:** All patients receiving NPPV for acute respiratory failure were screened and enrolled if they had a written do-not-intubate (DNI) order. **INTERVENTIONS:** Patients were begun on NPPV with mean inspiratory and expiratory pressures of 13.4 +/- 0.3 and 5.0 +/- 1 cm H₂O, respectively. Respiratory therapists recorded demographic information, blood gases, and ventilator type and settings, and they made bedside assessments of cough strength, presence of airway secretions, awake state, and agitation. Patients were followed until discharge for duration of NPPV, survival status, and disposition. **MEASUREMENTS AND MAIN RESULTS:** Of 1,211 screened patients, 114 had a DNI status and were enrolled into the study. Of these, 49 (43%) survived to discharge. Age, gender, location in a community vs. teaching hospital, and initial pH and PaO₂ did not affect survival, but a higher baseline PaCO₂ was associated with a favorable odds ratios for survival to discharge. Diagnosis was an important determinant of survival, with congestive heart failure patients having significantly better survival rates than those with chronic obstructive pulmonary disease, cancer, pneumonia, or other diagnoses. A stronger cough and being awake were also associated with increased probability of survival. **CONCLUSION:** Patients with respiratory failure and a DNI status have a high overall mortality rate when treated with NPPV, but those with diagnoses such as congestive heart failure or chronic obstructive pulmonary disease, who have a strong cough, or who are awake have better prognoses. These data should be useful when counseling DNI patients and their families on use of NPPV.

REF ID: 4230**Level V: Case report****Topic 5: Evaluation/Follow-up**

Marco, C. A., Buderer, N., & Thum, S. D. (2005-Feb). End-of-life care: Perspectives of family members of deceased patients. *American Journal of Hospice & Palliative Care*, 22(1), 26-31.

Journal Article. Multicenter Study

This study was undertaken to determine the opinions of family members of deceased patients regarding end-of-life care. This multisite cross-sectional survey was administered to 969 volunteer participants during 1997 to 2000. Eligible participants included immediate family members of deceased patients at five local institutions in a regional health system. Among 969 respondents, most (84.4 percent) indicated that the care for their family member was excellent. Reasons cited for satisfaction included overall care (40.2 percent), staff effort (23.2 percent), and communication (16.4 percent). Reasons cited for dissatisfaction included perceived incompetence (9.7 percent), perceived uncaring attitude (8.4 percent), and perceived understaffing (3.7 percent). Respondents were more satisfied with communication from nursing staff (88 percent) than physicians' communication (78 percent, $p < 0.001$, Bowker's test). Respondents indicated higher overall satisfaction with nursing (90 percent) and pastoral care (87 percent), than with physician care (81 percent, $p < 0.001$ and $p = 0.006$, Bowker's test). A unique survey instrument can be used to measure family perceptions and opinions regarding end-of-life care.

REF ID: 4242**Level IV: Non-experimental study****Topic 3: Assessment**

Marrie, T. J., Fine, M. J., Kapoor, W. N., Coley, C. M., Singer, D. E., & Obrosky, D. S. (2002). Community-acquired pneumonia and do not resuscitate orders. *Journal of the American Geriatrics Society*, 50(2), 290-299.

Journal Article. Multicenter Study

OBJECTIVES: From a cohort of patients with community-acquired pneumonia (CAP) who required admission to hospital, to describe the subset of patients having a do not resuscitate (DNR) order and to compare them with those who did not have such an order. **DESIGN:** Retrospective subset analysis of data from the pneumonia patient outcomes research team study. **SETTING:** Three hospitals in the United States and one in Canada. **PARTICIPANTS:** Hospitalized patients aged 18 and older with CAP. **MEASUREMENTS:** Sociodemographic features, severity of illness, antibiotic therapy, length of stay, mortality, admission to special care units, and mortality attributable to pneumonia. **RESULTS:** The 199 (14.9) of 1,339 inpatients with CAP who had a DNR order written within 24 hours of admission and an additional 96 (7.2) patients who had such an order written later were compared with the 1,044 who never had a DNR order. The 199 patients with an initial DNR and 96 later DNR were older (median age 81 and 78 vs 65 years, respectively; $P < .001$), more likely to be white (92.5 and 90.6 vs 84.8; $P = .007$), and more likely to have come from a nursing home or chronic care facility (53.8 and 31.3 vs 4.5; $P < .001$). The two DNR groups received more antibiotics for a longer time than the never DNR patients. The DNR patients had longer lengths of stay than the never DNR patients (medians 9 and 12 vs 7 days). There were 89 in-hospital deaths among the 1,339 patients, but only 11 of these were among patients who did not have a DNR order during the first 30 days (sensitivity, specificity, and positive and negative predictive values of a DNR order for in-hospital mortality were 87.6, 82.6, 26.4, and 98.9, respectively). The 90-day mortality rates were 43.2 for the initial DNR group, 61.5 in the later DNR group, and 4.7 for the never DNR group ($P < .001$). Pneumonia-attributable mortality accounted for most of the in-hospital deaths but did not differ by DNR status. Only 31.7 of the initial DNR patients and 24.0 of the later DNR patients were discharged home, versus 82.6 of the other patients ($P < .001$). In a multivariate analysis, the following were predictive of initial DNR: age, nursing home care, active cancer, dementia, neuromuscular disorders, altered mental status, low systolic blood pressure, tachypnea, abnormal hematocrit, abnormal blood urea nitrogen, and absence of alcohol or intravenous drug abuse. In similar analyses of DNR at any time, additional predictors included aspiration, low white blood count, chronic

pulmonary disease, cerebrovascular disease, and congestive heart failure. CONCLUSION: Most in-hospital pneumonia deaths occur in patients who have a DNR order. DNR orders written within 24 hours of admission primarily reflect comorbid status, whereas DNR orders written later during hospitalization reflect the futility of care plus comorbidity.

REF ID: 4307

Level V: Case report

Topic 4.1: Management-General

McDonald, D. D., Deloge, J., Joslin, N., Petow, W. A., Severson, J. S., & Votino, R. et al. (2003). Communicating end-of-life preferences... including commentary by saunders JM and wilson D with author response. *Western Journal of Nursing Research*, 25(6), 652-675.

Journal Article, Commentary, Research, Response, Tables/Charts

The purpose of this survey was to explore how adults communicate their end-of-life preferences. Face-to-face interviews were conducted with 119 community-dwelling adults who had previously engaged in conversations about their end-of-life preferences. Factors that made it easier to initiate the discussion included having personal experience with illness or death (24.4%), being straightforward (24.4%), or having someone else facilitate the discussion (11.8%). Most described vague end-of-life preferences such as not wanting any machines (41.2%) or heroics (34.5%). Although 22.7% reported using a living will to make their preferences clear, only 5.9% mentioned repeating or reinforcing their preferences. In all, 21% had discussed their end-of-life preferences with their physicians. These findings show discussions about end-of-life preferences frequently lack the clarity and detail needed by significant others and health care providers to honor the preferences. Routine dialogue with health care providers and significant others about end-of-life preferences might provide greater clarity and comfort.

REF ID: 4318

Level V: Case report

Topic 4.1: Management-General

Middlewood, S., Gardner, G., & Gardner, A. (2001). Dying in hospital: Medical failure or natural outcome? *Journal of Pain and Symptom Management*, 22(6), 1035-1041.

Journal Article, Research, Tables/Charts

The purpose of this study was to describe patterns of medical and nursing practice in the care of patients dying of oncological and hematological malignancies in the acute care setting in Australia. A tool validated in a similar American study was used to study the medical records of 100 consecutive patients who died of oncological or hematological malignancies before August 1999 at The Canberra Hospital in the Australian Capital Territory. The three major indicators of patterns of end-of-life care were documentation of Do Not Resuscitate (DNR) orders, evidence that the patient was considered dying, and the presence of a palliative care intention. Findings were that 88 patients were documented DNR, 63 patients' records suggested that the patient was dying, and 74 patients had evidence of a palliative care plan. Forty-six patients were documented DNR 2 days or less prior to death and, of these, 12 were documented the day of death. Similar patterns emerged for days between considered dying and death, and between palliative care goals and death. Sixty patients had active treatment in progress at the time of death. The late implementation of end-of-life management plans and the lack of consistency within these plans suggested that patients were subjected to medical interventions and investigations up to the time of death. Implications for palliative care teams include the need to educate health care staff and to plan and implement policy regarding the management of dying patients in the acute care setting. Although the health care system in Australia has cultural differences when compared to the American context, this research suggests that the treatment imperative to prolong life is similar to that found in American-based studies. Copyright (C) 2001 by the United States Cancer Pain Relief Committee

REF ID: 4223

Level V: Case report

Topic 2: Prevention

Miura, Y., Asai, A., Matsushima, M., Nagata, S., Onishi, M., & Shimbo, T. et al. (2006). Families'

and physicians' predictions of dialysis patients' preferences regarding life-sustaining treatments in Japan. *American Journal of Kidney Diseases*, 47(1), 122-130.

Journal Article, Multicenter Study

BACKGROUND: Substituted judgment traditionally has been used often for patient care in Japan regardless of the patient's competency. It has been believed that patient preferences are understood intuitively by family and caregivers. However, there are no data to support this assumption.

METHODS: A questionnaire survey was administered to 450 dialysis patients in 15 hospitals to determine their preferences for cardiopulmonary resuscitation (CPR) and dialysis therapy under various circumstances. Simultaneously, we asked family members and physicians of these patients about patient preferences to evaluate their ability to predict what their patients would want. The accuracy of families' and physicians' judgments was assessed by means of kappa coefficient. **RESULTS:** Three hundred ninety-eight pairs, consisting of a patient, 1 of his or her family members, and the physician in charge, participated from 15 hospitals in Japan, with a response rate of 88%. Sixty-eight percent of family members correctly predicted patients' current preferences for CPR, 67% predicted patients' preferences for dialysis when they were severely demented, and 69% predicted patients' preferences for dialysis when they had terminal cancer. Corresponding figures for physicians were 60%, 68%, and 66%. When using kappa coefficient analysis, those results indicated that neither family members nor physicians more accurately predicted their patients' wishes about life-sustaining treatments than expected by chance alone. (All kappa coefficients <0.4.) **CONCLUSION:** Our study suggests that patients who want to spend their end-of-life period as they want should leave better advance directives.

REF ID: 5214

Level II: Individual experimental study

Topic 4.1: Management-General

Molloy, D. W., Guyatt, G. H., Russo, R., Goeree, R., O'Brien, B. J., & Bedard, M. et al. (2000). Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. *JAMA: Journal of the American Medical Association*, 283(11), 1437-1444.

Journal Article, Clinical Trial, Research, Tables/Charts

critiqued in REF ID: 5213, EB Nursing **CONTEXT:** Although advance directives are commonly used in the community, little is known about the effects of their systematic implementation. **OBJECTIVES:** To examine the effect of systematically implementing an advance directive in nursing homes on patient and family satisfaction with involvement in decision making and on health care costs. **DESIGN:** Randomized controlled trial conducted June 1, 1994, to August 31, 1998. **SETTING AND PARTICIPANTS:** A total of 1292 residents in 6 Ontario nursing homes with more than 100 residents each. **INTERVENTION:** The Let Me Decide advance directive program included educating staff in local hospitals and nursing homes, residents, and families about advance directives and offering competent residents or next-of-kin of mentally incompetent residents an advance directive that provided a range of health care choices for life-threatening illness, cardiac arrest, and nutrition. The 6 nursing homes were pair-matched on key characteristics, and 1 home per pair was randomized to take part in the program. Control nursing homes continued with prior policies concerning advance directives. **MAIN OUTCOME MEASURES:** Residents' and families' satisfaction with health care and health care services utilization over 18 months, compared between intervention and control nursing homes. **RESULTS:** Of 527 participating residents in intervention nursing homes, 49% of competent residents and 78% of families of incompetent residents completed advance directives. Satisfaction was not significantly different in intervention and control nursing homes. The mean difference (scale, 1-7) between intervention and control homes was -0.16 (95% confidence interval [CI], -0.41 to 0.10) for competent residents and 0.07 (95% CI, -0.08 to 0.23) for families of incompetent residents. Intervention nursing homes reported fewer hospitalizations per resident (mean, 0.27 vs 0.48; $P = .001$) and less resource use (average total cost per patient, Can \$3490 vs Can \$5239; $P = .01$) than control nursing homes. Proportion of deaths in intervention (24%) and control (28%) nursing homes were similar ($P = .20$). **CONCLUSION:** Our data suggest that systematic implementation of a program to increase use of

advance directives reduces health care services utilization without affecting satisfaction or mortality. PMID: 10732933 [PubMed - indexed for MEDLINE]

REF ID: 3378

Level II: Individual experimental study

Topic 4.1: Management-General

Morrison RS, Chichin E, Carter J, Burack O, Lantz M, & Meier, D. E. (2005). The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *Journal of the American Geriatrics Society*, 53(2), 290-294.

Clinical Trial; Journal Article; Randomized Controlled Trial; Bioethics; MEDLINE

OBJECTIVES: To assess the effect of a multicomponent advance care planning intervention directed at nursing home social workers on identification and documentation of preferences for medical treatments and on patient outcomes. **DESIGN:** Controlled clinical trial. **SETTING:** New York City nursing home. **PARTICIPANTS:** One hundred thirty-nine newly admitted long-term care residents. **INTERVENTION:** Nursing home social workers were randomized to the intervention or control groups. The intervention consisted of baseline education in advance care planning that incorporated small-group workshops and role play/practice sessions for intervention social workers; structured advance care planning discussions with residents and their proxies at admission, after any change in clinical status, and at yearly intervals; formal structured review of residents' goals of care at preexisting regular team meetings; "flagging" of advance directives on nursing home charts; and feedback to individual healthcare providers of the congruence of care they provided and the preferences specified in the advance care planning process. Control social workers received an educational training session on New York State law regarding advance directives but no additional training or interventions. Subjects were enrolled from January 9, 2001 through May 25, 2003 and followed for 6 months after enrollment. **MEASUREMENTS:** Nursing home chart documentation of advance directives (healthcare proxies, living wills) and do-not-resuscitate orders; preferences for artificial nutrition and hydration, intravenous antibiotics, and hospitalization; and concordance of treatments received with documented preferences were compared for residents assigned to intervention and control social workers. **RESULTS:** Intervention residents were significantly more likely than residents in the control group to have their preferences regarding cardiopulmonary resuscitation (40% vs 20%, $P=.005$), artificial nutrition and hydration (47% vs 9%, $P<.01$), intravenous antibiotics (44% vs 9%, $P<.01$), and hospitalization (49% vs 16%, $P<.01$) documented in the nursing home chart. Control residents were significantly more likely than intervention residents to receive treatments discordant with their prior stated wishes. Two of 49 (5%) intervention residents received a treatment in conflict with their prior stated wishes (one hospitalization, one episode of intravenous antibiotics), compared with 17 of 96 (18%) control patients ($P=.04$). **CONCLUSION:** This generalizable intervention directed at nursing home social workers significantly improved the documentation and identification of patients' wishes regarding common life-sustaining treatments and resulted in a higher concordance between patients' prior stated wishes and treatments received.

REF ID: 4247

Level V: Case report

Topic 4.1: Management-General

Moss, A. H., Hozayen, O., King, K., Holley, J. L., & Schmidt, R. J. (2001). Attitudes of patients toward cardiopulmonary resuscitation in the dialysis unit.[see comment]. *American Journal of Kidney Diseases*, 38(4), 847-852.

Journal Article. Multicenter Study

Some dialysis units have a policy of performing cardiopulmonary resuscitation (CPR) on all patients who experience cardiac arrest while undergoing dialysis. However, to perform CPR on patients who do not want it is contrary to ethics and the law. We interviewed hemodialysis patients in 12 units in Missouri, New York, and West Virginia to learn their attitudes about CPR. Four hundred sixty-nine of 830 patients (57%) agreed to be interviewed. Eighty-seven percent of patients wanted to undergo CPR if cardiac arrest were to occur while undergoing dialysis. Patients who had seen CPR on television were

more likely to report that they knew what CPR was (94% versus 68%; $P < 0.001$) and to want CPR (88% versus 78%; $P = 0.033$). Thirteen percent of patients did not want CPR if cardiac arrest were to occur while undergoing dialysis. Compared with patients who wanted CPR, those who did not were older (69 versus 59 years; $P = 0.026$), had more comorbid conditions (2.0 versus 1.5 comorbid conditions; $P = 0.016$), and were more likely to have a living will (61% versus 43%; $P = 0.01$), be widowed (36% versus 20%; $P = 0.026$), and live in a nursing home (9% versus 3%; $P = 0.017$). Blacks were significantly more likely to want CPR than whites (adjusted odds ratio, 6.56; 95% confidence interval, 2.57 to 22.27). Only 20 of 58 patients (35%) who did not want CPR were certain they had a do-not-resuscitate order in their dialysis chart. Ninety-two percent of patients who wanted CPR agreed that patients who did not want CPR should have their wishes respected by the dialysis unit. We conclude that most dialysis patients want to undergo CPR, but also want other patients' preferences not to be resuscitated to be respected. Dialysis units need to do a better job of identifying patients who prefer not to be resuscitated and respecting their wishes in the event of cardiac arrest while undergoing dialysis. Most importantly, nephrologists and dialysis unit staff need to educate dialysis patients about the poor outcomes with CPR so that dialysis patients' decisions about CPR are informed.

REF ID: 5208

QM: Quality Measures

Topic 5: Evaluation/Follow-up

Nerenz, D. R. (2001). Capacities and limitations of information systems as data sources on quality of care at the end of life. *Journal of Pain and Symptom Management*, 22(3), 773-783.

Journal Article

Assessing quality of care at the end of life involves measurements in several domains—use of evidence-based guidelines, patient and family satisfaction, quality of life, and incidence of adverse events, among others. There are several different data sources from which to calculate quality measures. Each data source has a balance of strengths and weaknesses, and not all data sources are available in all possible settings of care. This paper describes how various data sources can be used to obtain the key data elements required for quality of care measures, as well as the challenges to linking data elements across sites and levels of care. There are some important quality domains (e.g., interpersonal and spiritual aspects of care) that are very difficult to assess using readily available data; primary data collection through interview and survey methods will be required to assess quality in these areas.

REF ID: 4325

Level VI: Opinion

Topic 4.1: Management-General

O'Keeffe, S. (2001). Development and implementation of resuscitation guidelines: A personal experience. *Age and Ageing*, 30(1), 19-25.

Journal Article, Practice Guidelines, Research, Tables/Charts

OBJECTIVES: to develop and implement guidelines on the appropriate use of cardiopulmonary resuscitation, which would ensure patient involvement in decision-making about cardiopulmonary resuscitation whenever possible but without offering illusory choices where resuscitation was unlikely to succeed. **DESIGN:** quantitative guidelines were developed after a review of the literature on survival after cardiopulmonary resuscitation. Patients were classified according to their estimated likelihood of survival to discharge after resuscitation: 10%, group C. Qualitative guidelines were developed after consideration of the legal and ethical principles of cardiopulmonary resuscitation. It was decided to inform competent patients in group A that cardiopulmonary resuscitation would be inappropriate, and to seek the preferences of competent patients in group B. The operation of the guidelines was examined in patients aged 65 years or more admitted under a single consultant in an acute community hospital. **RESULTS:** 147 patients were studied: 39 in group A, 26 in group B and 82 in group C. Of 36 patients in groups A and B judged competent, cardiopulmonary resuscitation discussions were only undertaken in 17, usually because acute distress or anxiety precluded effective communication. Of the 23 patients or family members from whom cardiopulmonary resuscitation preferences were sought, four opted for full

cardiopulmonary resuscitation and six for limited cardiopulmonary resuscitation (usually witnessed-arrest only and no ventilation). **CONCLUSION:** it is difficult to involve acutely ill elderly patients in cardiopulmonary resuscitation decision-making. Limited cardiopulmonary resuscitation is a useful option for patients, relatives and doctors.

REF ID: 4295

Level I: Systematic Reviews

Topic 4.1: Management-General

Patel, R. V., Sinuff, T., & Cook, D. J. (2004). Influencing advance directive completion rates in non-terminally ill patients: A systematic review. *Journal of Critical Care, 19(1), 1-9.*

Journal Article, Research, Systematic Review, Tables/Charts

PURPOSE: To conduct a systematic review of educational advance care planning interventions directed at patients without terminal illness to determine their influence on the completion rate of advance directives (AD). **MATERIALS AND METHODS:** We searched MEDLINE; Cochrane Library, and reference lists of all pertinent retrieved articles for randomized trials (RCTs), restricted to English language and adults > or =18 years. Two investigators independently and in duplicate determined trial eligibility. We included published RCTs evaluating an educational intervention comprised of at least one of; written, audio, or video materials, or direct counseling, and if an outcome included AD completion rate. **RESULTS:** Nine RCTs (N=3,206) were included. Overall, methodologic quality and reporting transparency were poor. The median composite quality score was 5 (range, 0-10). The odds ratios for AD completion rates ranged from 0.41 to 106.0 across the trials (test of heterogeneity $P < .001$). The summary odds ratio for these educational interventions was 3.71 (95% C.I. 1.46, 9.40). Trials with greater methodologic rigor and reporting transparency produced a more conservative estimate of effect, 2.42 [0.96, 6.10] versus 28.69 [5.08, 162.06] for less rigorous and poorly reported trials ($P = .013$). **CONCLUSIONS:** Advance directive completion rates documenting patient preferences for end-of-life care may be increased by simple patient-directed educational interventions. Copyright (C) 2004 by Elsevier Science (USA).

REF ID: 4292

Level IV: Non-experimental study

Topic 4.1: Management-General

Paton, C., & Esop, R. (2005). Patients' perceptions of their involvement in decision making about antipsychotic drug choice as outlined in the NICE guidance on the use of atypical antipsychotics in schizophrenia. *Journal of Mental Health, 14(3), 305-310.*

Journal Article, Research, Tables/Charts

Introduction: The NICE technology appraisal for atypical antipsychotics in patients with schizophrenia recommends that prescribers and patients should make the choice of antipsychotic drug jointly. In order to make an informed choice, patients must feel that they have been given sufficient information. The aim of this study was to survey patients' perceptions of the information they had been given about their medication and whether they felt that they had been given a choice with respect to the medication they received. **Methods:** We approached 100 outpatients with a known diagnosis of schizophrenia who attended one of three clinics in Oxleas NHS trust. Questions were asked about the information they had received about their medication and whether they felt that they had been given a choice. Patient demographic details were also collected. **Results:** Eighty-four patients consented to be interviewed. Fifty-four (64%) were happy with the medication prescribed for them but 47 (56%) felt that they had not received enough information about their medication. Twenty (24%) of these patients were not concerned as they felt happy to trust their doctor. There was a trend towards patients prescribed typical antipsychotics being more likely to have unmet information needs ($p = .062$). Those prescribed atypicals were more likely to have participated in agreeing a relapse plan ($p = .016$). Information needs varied widely. **Discussion:** Patients perceive the information they receive about antipsychotic drugs as being suboptimal. Without information, true informed choice is impossible. It is difficult to see how the information needs of all patients can be met without patients and carers taking a more active role in

questioning prescribers. Written copies of standard questions could be made available as prompts to facilitate this process.

REF ID: 3371

Level II: Individual experimental study

Topic 4.1: Management-General

Pearlman RA, Starks H, Cain KC, & Cole, W. G. (2005). Improvements in advance care planning in the veterans affairs system: Results of a multifaceted intervention. *Archives of Internal Medicine*, 165(6), 667-674.

Clinical Trial; Journal Article; Randomized Controlled Trial; Core Clinical (AIM); MEDLINE

BACKGROUND: Advance care planning (ACP) aims to guide health care in the event of decisional incapacity. Interventions to promote ACP have had limited effectiveness. We conducted an educational and motivational intervention in Department of Veterans Affairs outpatient clinics to increase ACP use and proxy and health care provider understanding of patients' preferences and values. **METHODS:** We recruited 23 providers and up to 14 of each of their patients; the patients were randomized to the control or intervention group. Eligibility criteria included a preexisting relationship with the provider, age 55 years or older, chronic health condition(s), and no recorded advance directive. The intervention group (n = 119) received an ACP workbook, motivational counseling by social workers, and cues to providers to discuss ACP. The control group (n = 129) received an advance directive booklet. **RESULTS:** The intervention patients reported more ACP discussions with their providers (64% vs 38%; P<.001). Living wills were filed in the medical record twice as often in the intervention group (48% vs 23%; P<.001). Provider-patient dyads in the intervention group had higher agreement scores than the control group for treatment preferences, values, and personal beliefs (58% vs 48%, 57% vs 46%, and 61% vs 47%, respectively; P<.01 for all comparisons). The agreement scores for the proxy-patient dyads did not differ between groups for treatment preferences and values, but were higher in the intervention than the control group for personal beliefs (67% vs 56%). **CONCLUSION:** This intervention demonstrates mixed results and highlights the ongoing challenges of helping health care providers and potential proxy decision makers represent patient preferences and values.

REF ID: 4243

Level IV: Non-experimental study

Topic 3: Assessment

Perkins, H. S., Geppert, C. M., Gonzales, A., Cortez, J. D., & Hazuda, H. P. (2002). Cross-cultural similarities and differences in attitudes about advance care planning. *Journal of General Internal Medicine*, 17(1), 48-57.

Journal Article. Multicenter Study

OBJECTIVE: Culture may have an important impact on a patient's decision whether to perform advance care planning. But the cultural attitudes influencing such decisions are poorly defined. This hypothesis-generating study begins to characterize those attitudes in 3 American ethnic cultures. **DESIGN:** Structured, open-ended interviews with blinded content analysis. **SETTING:** Two general medicine wards in San Antonio, Texas. **PATIENTS:** Purposive sampling of 26 Mexican-American, 18 Euro-American, and 14 African-American inpatients. **MEASUREMENTS AND MAIN RESULTS:** The 3 groups shared some views, potentially reflecting elements of an American core culture. For example, majorities of all groups believed "the patient deserves a say in treatment," and "advance directives (ADs) improve the chances a patient's wishes will be followed." But the groups differed on other themes, likely reflecting specific ethnic cultures. For example, most Mexican Americans believed "the health system controls treatment," trusted the system "to serve patients well," believed ADs "help staff know or implement a patient's wishes," and wanted "to die when treatment is futile." Few Euro Americans believed "the system controls treatment," but most trusted the system "to serve patients well," had particular wishes about life support, other care, and acceptable outcomes, and believed ADs "help staff know or implement a patient's wishes." Most African Americans believed "the health system controls treatment," few trusted the system "to serve patients well," and most believed they should "wait

until very sick to express treatment wishes." CONCLUSION: While grounded in values that may compose part of American core culture, advance care planning may need tailoring to a patient's specific ethnic views.

REF ID: 4227

Level II: Individual experimental study

Topic 3: Assessment

Perry, E., Swartz, J., Brown, S., Smith, D., Kelly, G., & Swartz, R. (2005). Peer mentoring: A culturally sensitive approach to end-of-life planning for long-term dialysis patients. *American Journal of Kidney Diseases*, 46(1), 111-119.

Clinical Trial. Journal Article. Multicenter Study. Randomized Controlled Trial

BACKGROUND: This study is designed to explore the impact of peer mentoring on end-of-life decision making. **METHODS:** A controlled randomized intervention study with 203 patients from 21 dialysis centers across Michigan explored the impact of peer mentors, dialysis patients trained to help other patients, on end-of-life planning. **RESULTS:** Communicating information on advance directives (ADs) through peer mentoring significantly influenced the completion of ADs overall compared with distributing standard printed material or no specific designed intervention. However, the influence was most prominent among African Americans, not only increasing actual completion of ADs ($P < 0.001$) and comfort discussing ADs ($P < 0.01$), but also improving subjective well-being ($P < 0.05$) and anxiety ($P < 0.05$) during the study period. These effects of peer mentoring did not appear among white patients, although printed material on ADs decreased reported suicidal ideation ($P < 0.05$). **CONCLUSION:** These results suggest the importance of addressing specific cultural factors in the process of AD education. Common practice assumes that printed materials are effective in educating patients about health care and decision making. However, peer mentoring, a relationship-centered person-to-person approach, may be more effective in some cultural groups because it partakes of oral, rather than written, traditions. Acknowledging cultural differences and tailoring our approach could be powerful in enhancing trust and participation and decreasing potential disparities in health care outcomes.

REF ID: 4256

Level V: Case report

Topic 3: Assessment

Puchalski, C. M., Zhong, Z., Jacobs, M. M., Fox, E., Lynn, J., & Harrold, J. et al. (2000). Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP. study to understand prognoses and preferences for outcomes and risks of treatment. hospitalized elderly longitudinal project. *Journal of the American Geriatrics Society*, 48(5 Suppl), S84-90.

Journal Article. Multicenter Study

OBJECTIVE: To determine the extent to which older or seriously ill inpatients would prefer to have their family and physician make resuscitation decisions for them rather than having their own stated preferences followed if they were unable to decide themselves. **DESIGN:** Analysis of existing data from the Hospitalized Elderly Longitudinal Project (HELP) and the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). **SETTING:** Five teaching hospitals in the United States. **PARTICIPANTS:** 2203 seriously ill adult inpatients (SUPPORT) and 1226 older inpatients (HELP) who expressed preferences about resuscitation and about advance decision-making. **MEASURES:** We used a logistic regression model to determine which factors predicted preferences for family and physician decision-making. **RESULTS:** Of the 513 HELP patients in this analysis, 363 (70.8%) would prefer to have their family and physician make resuscitation decisions for them whereas 29.2% would prefer to have their own stated preferences followed if they were to lose decision-making capacity. Of the 646 SUPPORT patients, 504 (78.0%) would prefer to have their family and physician decide and 22.0% would prefer to have their advance preferences followed. Independent predictors of preference for family and physician decision-making included not wanting to be resuscitated and having a surrogate decision-maker. **CONCLUSIONS:** Most inpatients who are older or have serious illnesses

would not want their stated resuscitation preferences followed if they were to lose decision-making capacity. Most patients in both groups would prefer that their family and physician make resuscitation decisions for them. These results underscore the need to understand resuscitation preferences within a broader context of patient values.

REF ID: 4305

Level V: Case report

Topic 2: Prevention

Rosnick, C. B., & Reynolds, S. L. (2003). Thinking ahead: Factors associated with executing advance directives. *Journal of Aging and Health, 15(2), 409-429.*

Journal Article, Equations & Formulas, Research, Tables/Charts

This article examines why older adults do or do not execute advance directives. **METHODS.** Secondary data analysis was conducted on data from the Charlotte County (Florida) Healthy Aging Study, on 451 adults who were relatively healthy and affluent. Exploratory logistic regressions were conducted on the probability that respondents had executed advance directives. **RESULTS.** Findings indicated that increasing age and higher income were the most consistent indicators of having executed an advance directive. Also, individuals reporting taking more prescription medications were more likely to have all the advance directives, except the durable power of attorney for health care. Reporting more negative life events was predictive of having executed the durable power of attorney for health care. **DISCUSSION.** These findings suggest that in addition to awareness of advance directives, demographic, health, and situational factors may affect the willingness of older adults to execute advance directives. Further research should examine other, more representative, samples to confirm these findings.

REF ID: 4253

Level V: Case report

Topic 2: Prevention

Roter, D. L., Larson, S., Fischer, G. S., Arnold, R. M., & Tulsky, J. A. (2000-25). Experts practice what they preach: A descriptive study of best and normative practices in end-of-life discussions. *Archives of Internal Medicine, 160(22), 3477-3485.*

Journal Article. Multicenter Study

BACKGROUND: Advance directives (ADs) are widely regarded as the best available mechanism to ensure that patients' wishes about medical treatment at the end of life are respected. However, observational studies suggest that these discussions often fail to meet their stated goals. **OBJECTIVES:** To explore best practices by describing what physicians who are considered expert in the area of end-of-life bioethics or medical communication do when discussing ADs with their patients and to explore the ways in which best practices of the expert group might differ in content or style from normative practice derived from primary care physicians' discussions of ADs with their patients collected as part of an earlier study. **DESIGN:** Nonexperimental, descriptive study of audiotaped discussions. **SETTING:** Outpatient primary care practices in the United States. **PARTICIPANTS:** Eighteen internists who have published articles in the areas of bioethics or communication and 48 of their patients. Fifty-six academic internists and 56 of their established patients in 5 practice sites in 2 locations-Durham, NC, and Pittsburgh, Pa. Eligible patients were at least 65 years old or suffered from serious medical illness and had not previously discussed ADs with their physician. Expert clinicians had discretion regarding patient selection, while the internists chose patients according to a predetermined protocol. **MEASUREMENTS:** Coders applied the Roter Interaction Analysis System (RIAS) to audiotapes of the medical visits to describe communication dynamics. In addition, the audiotapes were scored on 21 items reflecting physician performance in specific skills related to AD discussions. **RESULTS:** Experts spent close to twice as much time (14.7 vs 8.1 minutes, $P < .001$) and were less verbally dominant ($P < .05$) than other physicians during AD discussions. When length of visit was controlled statistically, the expert physicians gave less information about treatment procedures and biomedical issues ($P < .05$) and asked fewer related questions ($P < .05$) but tended toward more psychosocial and lifestyle discussion and

questions. Experts engaged in more partnership building ($P<.05$) with their patients. Patients of the expert physicians engaged in more psychosocial and lifestyle discussion ($P<.001$), and more positive talk ($P<.05$) than patients of community physicians. Expert physicians scored higher on the 21 items reflecting AD-specific skills ($P<.001$). CONCLUSIONS: Best practices as reflected in the performance of expert physicians reflect differences in measures of communication style and in specific AD-related proficiencies. Physician training in ADs must be broad enough to include both of these domains. *Arch Intern Med.* 2000;160:3477-3485.

REF ID: 4255

Level IV: Non-experimental study

Topic 1: Risks

Roth, K., Lynn, J., Zhong, Z., Borum, M., & Dawson, N. V. (2000). Dying with end stage liver disease with cirrhosis: Insights from SUPPORT. study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of the American Geriatrics Society*, 48(5 Suppl), S122-30.

Journal Article. Multicenter Study

OBJECTIVES: To understand patterns of care and end-of-life preferences for patients dying with end stage liver disease with cirrhosis (ESLDC). METHODS: Data were collected during the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), a prospective cohort study of seriously ill hospitalized adults at five teaching hospitals in the United States, and included all patients enrolled in SUPPORT with ESLDC. RESULTS: Of 575 patients with ESLDC, 166 died during index hospitalization, and 168 died in the following year. The majority were male (65%) and white (80%); the median age was 52 years. Most rated their quality of life as poor or fair, and multiple comorbidities were common. Most spent their last few days completely disabled. Families often reported loss of most income and the need to leave work or other activities in order to care for patients. Pain was at least moderately severe most of the time in one-third of patients. End-of-life preferences were not associated with survival. Most patients (66.8%) preferred CPR, but DNR orders and orders against ventilator use increased near death. CONCLUSIONS: Patients with liver disease were young, likely to be male, and often had low incomes. The high burden of pain was comparable to that reported for patients with lung and colon cancer. Persons dying with liver disease may benefit from increased attention to relief of symptoms, improved home care, and advanced care planning.

RS, M., E, C., J, C., O, B., M, L., & DE, M. (2005). The effect of a social work intervention to enhance advance care planning documentation in the nursing home. *Journal of the american geriatrics society*. (pp. 290-294)

REF ID: 4322

Level I: Systematic Reviews

Topic 6: Comprehensive

Rutledge, D. N., Bookbinder, M., Donaldson, N. E., & Pravikoff, D. S. (2001). End-of-life care series. part III. learnings beyond the SUPPORT and HELP studies. *Online Journal of Clinical Innovations*, 4(6), 1-60.

Journal Article, Care Plan, Research, Systematic Review, Tables/Charts, Website

Following publication of reports of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) and the Hospitalized Elderly Longitudinal Project (HELP), interest among consumers and healthcare professionals in end-of-life care has grown steadily. Optimal end-of-life care integrates palliative care principles with more traditional models of care. Ideally, palliative care is available to patients in various healthcare settings to ensure early referral when a serious illness makes death a probability. This review synthesizes findings from research following the SUPPORT and HELP studies and addresses among other topics, patient preferences for care, outcomes, advance directives, and policy issues. It also includes implications for care.

REF ID: 4323

Level I: Systematic Reviews

Topic 6: Comprehensive

Rutledge, D. N., Donaldson, N. E., & Pravikoff, D. S. (2001). End-of-life care series. part II. end-of-life care for hospitalized adults in america -- learnings from the SUPPORT and HELP studies. *Online Journal of Clinical Innovations*, 4(5), 1-57.

Journal Article, Research, Systematic Review, Tables/Charts

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) examined over 9,000 seriously ill hospitalized patients in the United States, tracing their hospital experiences and following the course of their illnesses for six months. Its companion study, the Hospitalized Elderly Longitudinal Project (HELP), collected similar data on patient preferences, decision making, and outcomes among persons over the age of 80. Key findings from these studies pertained to communication issues, potential overtreatment and utilization of excessive resources, and potential undertreatment of symptoms such as pain, dyspnea, or confusion. This manuscript reviews published findings from selected SUPPORT and HELP reports and describes their implications for nursing practice.

REF ID: 4240

Level II: Individual experimental study

Topic 2: Prevention

Schwartz, C. E., Wheeler, H. B., Hammes, B., Basque, N., Edmunds, J., & Reed, G. et al. (2002). Early intervention in planning end-of-life care with ambulatory geriatric patients: Results of a pilot trial. *Archives of Internal Medicine*, 162(14), 1611-1618.

Clinical Trial. Evaluation Studies. Journal Article. Randomized Controlled Trial

BACKGROUND: A large discrepancy exists between the wishes of dying patients and their actual end-of-life care. However, retrospective clinical experience suggests that early advance care planning (ACP) can markedly reduce this discrepancy. This article describes a randomized trial to evaluate the short-term clinical utility of early ACP. We also assessed the feasibility of performing a larger prospective study to document long-term outcomes. **METHODS:** Ambulatory geriatric patients (N = 61) were randomized to either a control group, which received only a Massachusetts Health Care Proxy form to complete, or an intervention group, in which each patient and health care agent discussed ACP with a trained nurse facilitator. The benefits and burdens of life-sustaining treatments were discussed, and patient goals and preferences for these treatments were documented. **RESULTS:** Two-month follow-up revealed that the intervention achieved higher congruence between agents and patients in their understanding of patients' end-of-life care preferences, with 76% (19/25) in complete agreement vs 55% (12/22) of the controls (effect size [ES] = -0.43). There was also a greater increase in patient knowledge about ACP in the intervention group (ES = 0.22). Intervention patients became less willing to undergo life-sustaining treatments for a new serious medical problem (ES = -0.25), more willing to undergo such treatments for an incurable progressive disease (ES = 0.24), and less willing to tolerate poor health states (ES = -0.78). Practical insights were gained about how to conduct a larger study more effectively. **CONCLUSION:** A facilitated discussion about end-of-life care between patients and their health care agents helps define and document the patient's wishes for both patient and agent.

REF ID: 5212

Level V: Case report

Topic 4.1: Management-General

Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. H., & Clark, D. (2004). Planning for the end of life: The views of older people about advance care statements. *Social Science & Medicine*, 59(1), 57-68.

Journal Article, Research

CRITIQUED IN REF ID: 5211, EB NURSING

Advance statements about medical care have been heralded by some as a solution to the problem of end of life decision making for people not able to participate in discussions about their care. Since death is now most likely to occur at the end of a long life, it is important to understand the views and values which older people express in relation to these. This paper reports on a study which used focus groups to explore older people's views about advance statements and the role these might play in end of life care decisions. Participants were 32 older people or their representatives who belonged to six diverse community groups in Sheffield, UK. Advance statements were understood primarily in terms of their potential to aid personal integrity and to help the families of older people by reducing the perceived 'burden' of their decision making. However, concerns were expressed about the perceived link between advance care statements and euthanasia, their future applicability, and the possibility that preferences for care may change. Participants also reported worries and difficulties related to thinking about and discussing death and dying. Trust between doctor and patient, built up over time, was perceived to be important in creating an environment in which the communication necessary to underpin advance care planning could take place. Lastly, participants did not perceive that during dying they would be ready necessarily to adhere to an advance statement and 'disengage' from their lives. We conclude that, rather than emphasising the completion of advance statements, it may be preferable to conceptualise advance care planning as a process of discussion and review between clinicians, patients and families.

REF ID: 5429

Level V: Case report

Topic 1: Risks

Shulman, K. I., Cohen, C. A., & Hull, I. (2005; 2005). Psychiatric issues in retrospective challenges of testamentary capacity. *International Journal of Geriatric Psychiatry, 20*(1), 63-69.

Journal; Peer Reviewed Journal

Background: Challenges to Wills on the basis of lack of testamentary capacity are likely to increase due to a combination of economic factors, high prevalence of mental disorders in old age and the complexity of many modern families. Geriatric psychiatrists and other experts will be asked to provide expert assessment of the testamentary capacity of individuals whose Wills are being challenged retrospectively. The traditional criteria described in the Banks vs Goodfellow case have been held as the standard for testamentary capacity. However, these criteria may not be comprehensive enough for the coming generation of expert assessors. Method: The literature and selected international case law relevant to testamentary capacity were reviewed. Particular focus is placed on the conceptual and empirical approaches to the assessment of complex capacities that may inform the development of specific legal standards. In addition, 25 consecutive medico-legal reports on retrospective testamentary capacity were analyzed according to co-morbid medical and psychiatric disorders as well as psychosocial and behavioural variables. Illustrative case vignettes are included. Results: The typical profile for retrospective challenges to testamentary capacity included a radical change from a previous Will (72%), where undue influence was alleged (56%), in a testator with no biological children (52%), who executed the Will less than a year prior to death (48%). Co-morbid conditions were dementia (40%), alcohol abuse (28%) and other neurological/ psychiatric conditions (28%). Conclusions: While Banks vs Goodfellow continues to provide a sound basis for assessing testamentary (task-specific) capacity, the complexity and subtlety of the issues reflected in these cases highlight the need to go beyond the traditional criteria and assess situation-specific factors. Expert assessors need to determine whether the testator appreciated the consequences of executing or changing a Will, especially when there has been a radical change in the context of a complex or conflictual family environment. Empirical studies addressing the cognitive functions relevant to testamentary capacity and the development of legal standards based on a competency construct may also help to inform retrospective capacity assessments. (PsycINFO Database Record (c) 2006 APA, all rights reserved) (journal abstract)

REF ID: 4231

Level V: Case report

Topic 1: Risks

Sinuff, T., Cook, D. J., Rocker, G. M., Griffith, L. E., Walter, S. D., & Fisher, M. M. et al. (2004). DNR directives are established early in mechanically ventilated intensive care unit patients. *Canadian Journal of Anaesthesia*, 51(10), 1034-1041.

Journal Article. Multicenter Study

PURPOSE: Setting treatment goals in the intensive care unit (ICU) often involves resuscitation decisions. Our objective was to study the rate of establishing do-not-resuscitate (DNR) directives, determinants, and outcomes of those directives for mechanically ventilated patients. **METHODS:** In a multicentre observational study, we included consecutive adults with no DNR directives within 24 hr of ICU admission who were mechanically ventilated for at least 48 hr. We identified the rate with which DNR directives were established, and factors associated with these directives. **RESULTS:** Among 765 patients, DNR directives were established for 231 (30.2%) patients; 143 (62.1%) of these were established within the first week. Factors independently associated with a DNR directive were: patient age [$>$ or $=$ 75 yr (hazard ratio [HR] 2.3, 95% confidence interval 1.5-3.4), 65 to 74 yr (HR 1.8, 1.2-2.7), 50 to 64 yr (HR 1.4, 1.0-2.2) relative to 90%]; and physician perception of patient preference to limit life support (no advanced life support [(HR 5.8, 3.6-9.4) or partial advanced life support (HR 3.2, 2.2-4.6) compared to full measures]. **CONCLUSION:** One third of mechanically ventilated patients had DNR directives established early during their ICU stay after the first 24 hr of admission. The strongest predictors of DNR directives were physician prediction of low probability of survival, physician perception of patient preference to limit life support, organ dysfunction, medical diagnosis and age.

REF ID: 3356

Level II: Individual experimental study

Topic 4.1: Management-General

Song MK, Kirchhoff KT, Douglas J, Ward S, & Hammes, B. (2005). A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. *Medical Care*, 43(10), 1049-1053.

Clinical Trial; Journal Article; Randomized Controlled Trial; Health Administration; MEDLINE

BACKGROUND: Although many healthcare providers and researchers consider it necessary to assist patients with end-stage chronic illnesses to plan for the end of life, they tend to avoid discussing end-of-life issues with patients before major surgery. Consequently, surgical patients and their families generally have insufficient knowledge to make plans in case of life-threatening complications. **OBJECTIVE:** The objective of this study was to evaluate short-term effects of Patient-Centered Advance Care Planning (PC-ACP). **DESIGN AND SUBJECTS:** Thirty-two dyads of patients undergoing cardiac surgery and their surrogates were randomly assigned to receive either the PC-ACP intervention (PC-ACP) or usual care. **MEASURES:** Measures studied were patient-surrogate congruence regarding goals for future medical care, patient and surrogate knowledge of advance care planning and anxiety, and patient decisional conflict. Congruence and anxiety were measured before and after the intervention. Decisional conflict and knowledge of advance care planning were measured after the intervention. **RESULTS:** Compared with the control group, PC-ACP significantly improved patient-surrogate congruence (Delta=1.27, $P<0.01$) and reduced patients' decisional conflict (Delta=-0.77, $P<0.05$). Anxiety change (pre/post) did not differ between treatment and control groups. No difference in knowledge of advance care planning was found between the 2 groups. **CONCLUSIONS:** The PC-ACP can be an effective approach to advance care planning. Its specificity and relevance to patients' actual medical conditions (as exemplified by its plans for potential complications related to cardiac surgery) can lead to greater patient-surrogate congruence without increasing decisional conflict and anxiety.

REF ID: 5430

Level V: Case report

Topic 4.1: Management-General

Srebnik, D. (2004; 2004). Benefits of psychiatric advance directives: Can we realize their potential? [references]. *Journal of Forensic Psychology Practice*, 4(4), 71-82.

Journal; Peer Reviewed Journal

Psychiatric advance directives (PADs) document mental health treatment preferences in advance of periods of incapacity. While many have recognized the potential benefits of PADs to recipients of mental health services and service systems, empirical evidence to support or refute the benefits of PADs is lacking. This article reviews the extant literature and presents data from an ongoing study of PADs within three broad categories of PAD benefits: increasing choice and autonomy, promoting treatment involvement and dialogue, and improving crisis mental health treatment. The article concludes that when PADs are used during crises, clients feel more empowered and positive about their treatment, family and clinician communication is enhanced and burden is reduced, treatment is provided more rapidly and in a manner consistent with preferences, and escalation of symptoms and associated hospitalization is often averted. However, assuring that clinicians are aware of and access the documents during crises are major challenges to their use. Higher volumes of completed PADs, specific legislation about PADs, and especially leadership and values consistent with client choice and recovery may help increase the likelihood that PADs will be accessed and used. (PsycINFO Database Record (c) 2006 APA, all rights reserved) (journal abstract)

REF ID: 4238

Level IV: Non-experimental study

Topic 4.1: Management-General

Sulmasy, D. P., & McIlvane, J. M. (2002). Patients' ratings of quality and satisfaction with care at the end of life. *Archives of Internal Medicine*, 162(18), 2098-2104.

Journal Article. Multicenter Study

OBJECTIVE: To elicit ratings of quality and satisfaction with care from medical inpatients, especially those near the end of life. **METHODS:** We conducted a cross-sectional survey of 84 seriously ill medical inpatients at 2 academic medical centers. Forty-five had do-not-resuscitate orders. Patients were interviewed using a valid and reliable instrument, the Quality of End-of-Life Care and Satisfaction With Treatment scale (scored from 1.0-5.0) and standard measures of symptoms, anxiety, depression, and delirium. **RESULTS:** Mean patient ratings of quality of care were higher regarding physicians than nurses (4.39 vs 4.24; $P = .01$). Mean patient ratings of satisfaction with physicians were also higher, but not significantly (4.53 vs 4.43; $P = .32$). In analysis of variance models, patient ratings of physician quality were lowest for patients with do-not-resuscitate orders who were treated by a house-staff service compared with other patients ($P = .01$). These patients were also least satisfied with their physicians ($P = .03$). Nondepressed patients with private attending physicians rated nursing quality the highest ($P = .16$). These patients also reported the highest satisfaction with nurses ($P = .002$). Quality and satisfaction were not related to severity of illness, and pain was only weakly associated with satisfaction with physicians. **CONCLUSIONS:** Patients with do-not-resuscitate orders who were treated by a house-staff service gave the lowest ratings of physician quality and satisfaction. Only private patients who were not depressed were highly satisfied with their nursing care. Further study is required to better understand these findings and whether they are amenable to quality improvement.

REF ID: 4222

Level III: Quasi-experimental study

Topic 4.1: Management-General

Tang, S. T., Liu, T. W., Lai, M. S., Liu, L. N., & Chen, C. H. (2005). Concordance of preferences for end-of-life care between terminally ill cancer patients and their family caregivers in taiwan. *Journal of Pain & Symptom Management*, 30(6), 510-518.

Clinical Trial. Journal Article. Multicenter Study

There is a dearth of information in the literature about the concordance of preferences for end-of-life care between terminally ill patients and their family surrogates outside the Western countries. The purpose of this study was to examine the extent of concordance in preferences for end-of-life care goals and life-sustaining treatments between Taiwanese terminally ill cancer patients and their primary family caregivers. A total of 617 dyads of patients-family caregivers across 21 hospitals throughout Taiwan

were surveyed. Overall agreements on the goals for end-of-life care and preferences for initiating life-sustaining treatments ranged from 62.4% to 96.9% (average: 71.0%). Kappa values for the extent of concordance ranged from 0.13 to 0.46 (average: 0.29), indicating poor to moderate consistency in personal preferences. Family caregivers had a significantly more aggressive attitude toward each examined life-sustaining treatment for their ill family members than the patients' own stated preferences. In societies, such as in Asian countries, where physicians' respect for patient autonomy is frequently subordinate to the power of family, disagreements between a patient and family about end-of-life care may result in the patient's preferences being overridden at the end of life. To effect real change and to gain increased agreement on preferences for end-of-life care, an open dialogue between patients and their primary family caregivers should become standard.

REF ID: 4248

Level IV: Non-experimental study

Topic 4.1: Management-General

The, A. M., Hak, T., Koeter, G., & van der Wal, G. (2001). Collusion in doctor-patient communication about imminent death: An ethnographic study. *Western Journal of Medicine*, 174(4), 247-253.

Case Reports. Duplicate Publication. Journal Article. Multicenter Study

OBJECTIVE: To discover and explore the factors that result in the "false optimism about recovery" observed in patients with small cell lung cancer. **DESIGN:** A qualitative observational (ethnographic) study in 2 stages over 4 years. **SETTING:** Lung diseases ward and outpatient clinic in a university hospital in the Netherlands. **PARTICIPANTS:** 35 patients with small cell lung cancer. **RESULTS:** False optimism about recovery usually developed during the first course of chemotherapy and was most prevalent when the cancer could no longer be seen on x-ray films. This optimism tended to vanish when the tumor recurred, but it could develop again, though to a lesser extent, during further courses of chemotherapy. Patients gradually found out the facts about their poor prognosis, partly by their physical deterioration and partly through contact with fellow patients in a more advanced stage of the illness who were dying. False optimism about recovery was the result of an association between physicians' activism and patients' adherence to the treatment calendar and to the "recovery plot," which allowed them to avoid acknowledging explicitly what they should and could know. The physician did and did not want to pronounce a "death sentence," and the patient did and did not want to hear it. **CONCLUSION:** Solutions to the problem of collusion between physician and patient require an active, patient-oriented approach by the physician. Perhaps solutions have to be found outside the physician-patient relationship itself--for example, by involving "treatment brokers."

REF ID: 4237

Level IV: Non-experimental study

Topic 4.1: Management-General

The, A. M., Pasman, R., Onwuteaka-Philipsen, B., Ribbe, M., & van der Wal, G. (2002). Withholding the artificial administration of fluids and food from elderly patients with dementia: Ethnographic study.[see comment]. *BMJ*, 325(7376), 1326.

Journal Article. Multicenter Study

OBJECTIVE: To clarify the practice of withholding the artificial administration of fluids and food from elderly patients with dementia in nursing homes. **DESIGN:** Qualitative, ethnographic study in two phases. **SETTING:** 10 wards in two nursing homes in the Netherlands. **PARTICIPANTS:** 35 patients with dementia, eight doctors, 43 nurses, and 32 families. **RESULTS:** The clinical course of dementia was considered normal and was rarely reason to begin the artificial administration of fluids and food in advanced disease. Fluids and food seemed to be given mainly when there was an acute illness or a condition that needed medical treatment and which required hydration to be effective. The medical condition of the patient, the wishes of the family, and the interpretations of the patients' quality of life by their care providers were considered more important than living wills and policy agreements. **CONCLUSIONS:** Doctors' decisions about withholding the artificial administration of fluids and food

from elderly patients with dementia are influenced more by the clinical course of the illness, the presumed quality of life of the patient, and the patient's medical condition than they are by advanced planning of care. In an attempt to understand the wishes of the patient doctors try to create the broadest possible basis for the decision making process and its outcome, mainly by involving the family.

REF ID: 4250

Level II: Individual experimental study

Topic 3: Assessment

Tierney, W. M., Dexter, P. R., Gramelspacher, G. P., Perkins, A. J., Zhou, X. H., & Wolinsky, F. D. (2001). The effect of discussions about advance directives on patients' satisfaction with primary care.[see comment]. *Journal of General Internal Medicine, 16*(1), 32-40.

Clinical Trial. Journal Article. Randomized Controlled Trial

BACKGROUND: Discussions of end-of-life care should be held prior to acute, disabling events. Many barriers to having such discussions during primary care exist. These barriers include time constraints, communication difficulties, and perhaps physicians' anxiety that patients might react negatively to such discussions. **OBJECTIVE:** To assess the impact of discussions of advance directives on patients' satisfaction with their primary care physicians and outpatient visits. **DESIGN:** Prospective cohort study of patients enrolled in a randomized, controlled trial of the use of computers to remind primary care physicians to discuss advance directives with their elderly, chronically ill patients. **SETTING:** Academic primary care general internal medicine practice affiliated with an urban teaching hospital.

PARTICIPANTS: Six hundred eighty-six patients who were at least 75 years old, or at least 50 years old with serious underlying disease, and their 87 primary care physicians (57 residents, 30 faculty general internists) participated in the study. **MEASUREMENTS AND MAIN RESULTS:** We assessed patients' satisfaction with their primary care physicians and visits via interviews held in the waiting room after completed visits. Controlling for satisfaction at enrollment and physician, patient, and visit factors, discussing advance directives was associated with greater satisfaction with the physician ($P = .052$). At follow-up, the strongest predictor of satisfaction with the primary care visit was having previously discussed advance directives with that physician ($P = .004$), with a trend towards greater visit satisfaction when discussions were held during that visit ($P = .069$). The percentage of patients scoring a visit as "excellent" increased from 34% for visits without prior advance directive discussions to 51% for visits with such discussions ($P = .003$). **CONCLUSIONS:** Elderly patients with chronic illnesses were more satisfied with their primary care physicians and outpatient visits when advanced directives were discussed. The improvement in visit satisfaction was substantial and persistent. This should encourage physicians to initiate such discussions to overcome communication barriers might result in reduced patient satisfaction levels.

REF ID: 4298

Level V: Case report

Topic 4.1: Management-General

Tilden, V. P., Tolle, S. W., Drach, L. L., & Perrin, N. A. (2004). Out-of-hospital death: Advance care planning, decedent symptoms, and caregiver burden. *Journal of the American Geriatrics Society, 52*(4), 532-539.

Journal Article, Research, Tables/Charts

OBJECTIVES: To examine the end-of-life experiences of elderly decedents dying out of the hospital and their family caregivers in a state in which the vast majority of Medicare deaths occur in community settings. **DESIGN:** Telephone survey of family caregivers 2 to 5 months after decedents' deaths. **SETTING:** Statewide (Oregon) random sample of death certificates. **PARTICIPANTS:** One thousand one hundred eighty-nine family caregivers of decedents aged 65 and older who died of natural deaths in community settings between 2000 and 2002. **MEASUREMENTS:** A 69-item telephone questionnaire with single-item indicators and embedded scales that indexed advance directives, use of life-sustaining treatments, hospice enrollment, decedent symptom experience and perceived distress, family financial hardship, out-of-pocket expenses, and caregiver strain. **RESULTS:** Most decedents had advance

directives (78.3%) and were enrolled in hospice (62.4%). Although perceived decedent symptom distress was low overall, certain symptoms (e.g., pain, dyspnea, constipation) were distressing for approximately half of decedents experiencing them. Financial hardship, out-of-pocket expenses, and caregiver strain were frequently reported. American Indian race and younger age were associated with decedent symptom distress. Greater perceived decedent symptom distress, hospice enrollment, more caregiver involvement, and more financial burden were associated with greater caregiver strain. CONCLUSION: Despite high rates of advance directives and hospice enrollment, perceived symptom distress was high for a subset of decedents, and caregiver strain was common. As location of death increasingly shifts nationwide from hospital to community, unmet decedent and family needs require new clinical skills and healthcare policies.

REF ID: 3342

Level III: Quasi-experimental study

Topic 3: Assessment

True G, Phipps EJ, Braitman LE, Harralson T, Harris D, & Tester, W. (2005). Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine*, 30(2), 174-179.

Clinical Trial; Journal Article; MEDLINE

BACKGROUND: Although studies have reported ethnic differences in approaches to end of life, the role of spiritual beliefs is less well understood. PURPOSE: This study investigated differences between African American and White patients with cancer in their use of spirituality to cope with their cancer and examined the role of spiritual coping in preferences at end-of-life. METHODS: The authors analyzed data from interviews with 68 African American and White patients with an advanced stage of lung or colon cancer between December 1999 and June 2001. RESULTS: Similar high percentages of African American and White patients reported being "moderately to very spiritual" and "moderately to very religious." African American patients were more likely to report using spirituality to cope with their cancer as compared to their White counterparts ($p = .002$). Patients who reported belief in divine intervention were less likely to have a living will ($p = .007$). Belief in divine intervention, turning to higher power for strength, support and guidance, and using spirituality to cope with cancer were associated with preference for cardiopulmonary resuscitation, mechanical ventilation, and hospitalization in a near-death scenario. CONCLUSIONS: It was found that patients with cancer who used spiritual coping to a greater extent were less likely to have a living will and more likely to desire life-sustaining measures. If efforts aimed at improving end-of-life care are to be successful, they must take into account the complex interplay of ethnicity and spirituality as they shape patients' views and preferences around end of life.

REF ID: 4221

Level IV: Non-experimental study

Topic 6: Comprehensive

van Delden, J. J., Lofmark, R., Deliens, L., Bosshard, G., Norup, M., & Cecioni, R. et al. (2006). Do-not-resuscitate decisions in six European countries.[see comment]. *Critical Care Medicine*, 34(6), 1686-1690.

Journal Article. Multicenter Study

OBJECTIVE: To study and compare the incidence and main background characteristics of do-not-resuscitate (DNR) decision making in six European countries. DESIGN: Retrospective. SETTING: We studied DNR decisions simultaneously in Belgium (Flanders), Denmark, Italy (four regions), the Netherlands, Sweden, and Switzerland (German-speaking part). In each country, random samples of death certificates were drawn from death registries to which all deaths are reported. The deaths occurred between June 2001 and February 2002. PARTICIPANTS: Reporting physicians received a mailed questionnaire about the medical decision making that had preceded death. The response percentage was 75% for the Netherlands, 67% for Switzerland, 62% for Denmark, 61% for Sweden, 59% for Belgium,

and 44% for Italy. The total number of deaths studied was 20,480. INTERVENTIONS: None. MEASUREMENTS AND MAIN RESULTS: Measurements were frequency of DNR decisions, both individual and institutional, and patient involvement. Before death, an individual DNR decision was made in about 50-60% of all nonsudden deaths (Switzerland 73%, Italy 16%). The frequency of institutional decisions was highest in Sweden (22%) and Italy (17%) and lowest in Belgium (5%). DNR decisions are discussed with competent patients in 10-84% of cases. In the Netherlands patient involvement rose from 53% in 1990 to 84% in 2001. In case of incompetent patients, physicians bypassed relatives in 5-37% of cases. CONCLUSIONS: Except in Italy, DNR decisions are a common phenomenon in these six countries. Most of these decisions are individual, but institutional decisions occur frequently as well. In most countries, the involvement of patients in DNR decision making can be improved.

REF ID: 4249

Level IV: Non-experimental study

Topic 3: Assessment

van Walraven, C., Forster, A. J., Parish, D. C., Dane, F. C., Chandra, K. M., & Durham, M. D. et al. (2001). Validation of a clinical decision aid to discontinue in-hospital cardiac arrest resuscitations.[see comment]. *JAMA*, 285(12), 1602-1606.

Journal Article. Validation Studies

CONTEXT: Most patients undergoing in-hospital cardiac resuscitation do not survive to hospital discharge. In a previous study, we developed a clinical decision aid for identifying all patients undergoing resuscitation who survived to hospital discharge. OBJECTIVE: To validate our previously derived clinical decision aid. DESIGN, SETTING, AND PARTICIPANTS: Data from a large registry of in-hospital resuscitations at a community teaching hospital in Georgia were analyzed to determine whether patients would be predicted to survive to hospital discharge (ie, whether their arrest was witnessed or their initial cardiac rhythm was either ventricular tachycardia or ventricular fibrillation or they regained a pulse during the first 10 minutes of chest compressions). Data from 2181 in-hospital cardiac resuscitation attempts in 1987-1996 involving 1884 pulseless patients were analyzed. MAIN OUTCOME MEASURE: Comparison of predictions based on the decision aid with whether patients were actually discharged alive from the hospital. RESULTS: For 327 resuscitations (15.0%), the patient survived to hospital discharge. For 324 of these resuscitations, the patients were predicted to survive to hospital discharge (sensitivity = 99.1%, 95% confidence interval, 97.1%-99.8%). In 269 resuscitations, patients did not satisfy the decision aid and were predicted to have no chance of being discharged from the hospital. Only 3 of these patients (1.1%) were discharged from the hospital (negative predictive value = 98.9%), none of whom were able to live independently following discharge from the hospital. CONCLUSION: This decision aid can be used to help physicians identify patients who are extremely unlikely to benefit from continued resuscitative efforts.

REF ID: 4312

Level IV: Non-experimental study

Topic 3: Assessment

Verbeek, P. R., Vermeulen, M. J., Ali, F. H., Messenger, D. W., Summers, J., & Morrison, L. J. (2002). Derivation of a termination-of-resuscitation guideline for emergency medical technicians using automated external defibrillators. *Academic Emergency Medicine*, 9(7), 671-678.

Journal Article, Research, Tables/Charts

OBJECTIVES: To determine the association between characteristics of cardiac arrest and survival to hospital discharge following failed resuscitation by defibrillation-trained emergency medical technicians (EMT-Ds), and to propose an out-of-hospital termination-of-resuscitation (TOR) guideline for EMT-Ds. METHODS: A 22-month retrospective review of 700 out-of-hospital primary cardiac arrest patients in a large emergency medical services (EMS) system who received exclusively EMT-D care. RESULTS: Seven hundred primary cardiac arrest patients were identified. Follow-up was obtained in 662 cases (94.6%). Of these, 36 (5.4%) achieved a return of spontaneous circulation (ROSC) prior to transport.

Among the 626 patients who failed to achieve ROSC at any time, two (0.3%) survived to discharge. Multivariate analysis showed that ROSC at any time had the strongest association with survival [odds ratio (OR) 45.5; 95% confidence interval (95% CI) = 8.5 to 243.7]. A shock prior to transport (OR 6.9; 95% CI = 1.2 to 40.3) and cardiac arrest witnessed by EMS personnel (OR 4.4; 95% CI = 1.0 to 18.5) were also independently associated with survival. These variables were incorporated into a TOR guideline. The guideline was 100% sensitive (95% CI = 99.1 to 100) in identifying survivors and had 100% negative predictive value (95% CI = 75.3 to 100) for identifying nonsurvivors of out-of-hospital cardiac arrest in the study population. CONCLUSIONS: In this EMS system, cardiac arrest patients may be considered for out-of-hospital TOR following EMT-D resuscitation attempts when there has been no ROSC, no shock has been given, and the arrest was not witnessed by EMS personnel. These guidelines require prospective validation.

REF ID: 5207

QM: Quality Measures

Topic 5: Evaluation/Follow-up

Wenger, N. S., & Rosenfeld, K. (2001). Quality indicators for end-of-life care in vulnerable elders. *Annals of Internal Medicine*, 135(8 part 2), 677-685.

Journal Article

ABSTRACT NOT AVAILABLE

REF ID: 5433

Level V: Case report

Topic 4.1: Management-General

Werth, J. L. J., & Blevins, D. (2002; 2002). Public policy and end-of-life care. *American Behavioral Scientist*, 46(3), 401-417.

Journal; Peer Reviewed Journal

End-of-life public policy has the potential to affect everyone. The purpose of this article is to provide an overview of recent significant policy activity. The authors begin by reviewing the Medicare and Medicaid hospice benefit and the Patient Self-Determination Act, highlighting state-level developments, and noting significant court cases. They then discuss common concerns with Medicare, advance directives, hospice, and pain management, proposing remedies for the concerns. The article ends with recommendations for advocacy by behavioral and social science professionals. (PsycINFO Database Record (c) 2006 APA, all rights reserved)

REF ID: 4233

Level III: Quasi-experimental study

Topic 4.1: Management-General

Wissow, L. S., Belote, A., Kramer, W., Compton-Phillips, A., Kritzler, R., & Weiner, J. P. (2004). Promoting advance directives among elderly primary care patients. *Journal of General Internal Medicine*, 19(9), 944-951.

Clinical Trial. Journal Article. Multicenter Study

OBJECTIVE: To determine efficient ways of promoting advance directives among heterogeneous populations of elderly ambulatory patients. DESIGN: One-year quasi-experimental trial. SETTING: Five suburban and urban health centers in one region of a large managed care organization. One additional suburban center served as a control site. PARTICIPANTS: Individuals ages 65 and older (N=2,120) who were continuously enrolled and had a health maintenance visit with their primary care provider during the study year. INTERVENTION: Physician education (oral and written) and physician and patient prompts to discuss advance directives. MAIN RESULTS: Sixty-six (7.8%) of patients at the intervention centers completed new advance directives, versus 9 of 1,277 (<1%) at the comparison center (P <.001). Patients 75 and older were twice as likely (odds ratio [OR], 2.0; 95% confidence limits [CL], 1.2 to 3.3) as those 65 to 74 to file a new advance directive, and the odds were twice as great (OR, 2.6; 95% CL, 1.4 to 4.6) at centers serving communities with median household income over the state median. Gender, recent hospitalization, emergency room visits, and number of chronic conditions were

not related to making new directives nor was predominant ethnicity of the center community (African-American versus white). Adjusted for these factors, the intervention resulted in a 20-fold increase (95% CL, 10.4 to 47.8) in the odds of creating a new advance directive. Doctors reported barriers of time and unwillingness to press discussions with patients. CONCLUSIONS: A replicable intervention largely targeting doctors achieved a modest increase in advance directives among elderly ambulatory patients. Future interventions may need to target lower-income patients, "younger" elderly, and more specifically address doctors' attitudes and comfort discussing advance directives.

REF ID: 4303

Level IV: Non-experimental study

Topic 4.1: Management-General

Young, A. J., OforiBoateng, T., Rodriguez, K. L., & Plowman, J. L. (2003). Meaning and agency in discussing end-of-life care: A study of elderly veterans' values and interpretations. *Qualitative Health Research, 13*(8), 1039-1062.

Journal Article, Research, Tables/Charts

The authors of this exploratory study used textual analysis of transcribed interviews to examine the mental constructs that individuals form around advance care terminology and to learn how elderly veterans conceptualize the language used in the Veterans Administration advance directive. They found that respondents often negotiated meaning by drawing on rigid schemas, specific mental constructs already in place: The Lord's Will, Machine Talk, Being a Burden, and Being Productive. The authors also examined the transcripts for agency. In addition to assigning external agency for end-of-life care decisions, respondents often expressed a complex interaction of "self" and "other" agency. These results challenge us to develop communication methods that allow patients to claim agency and participate fully in decisions regarding their health care, especially at the end of life.

REF ID: 4225

Level V: Case report

Topic 3: Assessment

Zingmond, D. S., & Wenger, N. S. (2005-22). Regional and institutional variation in the initiation of early do-not-resuscitate orders. *Archives of Internal Medicine, 165*(15), 1705-1712.

Journal Article. Multicenter Study

BACKGROUND: Do-not-resuscitate (DNR) orders are an important step in decision making about aggressiveness of care for patients in hospitals. The use of DNR orders is known to vary with patient characteristics, but few studies have investigated the role of hospital factors or of regional variation. We examined these influences on the use of early DNR orders (written or =80 years). In multivariate analyses, the odds of having early DNR orders written were significantly lower in for-profit (vs private nonprofit) hospitals, higher in the smallest (vs the largest) hospitals, and lower in academic (vs nonacademic) hospitals. Standardized rates of DNR order use varied 10-fold across counties. The highest rates were among patients from rural areas. However, variation in use did not correspond well to county population, hospital bed availability, or population density. CONCLUSIONS: Hospital characteristics appear to be associated with the use of DNR orders, even after accounting for differences in patient characteristics. This association reflects institutional culture, technological bent, and physician practice patterns. If these factors do not match patient preferences, then improvements in care are needed.