

**Annotated Bibliography:
Improving Communication in Oncology**

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Introduction

We created this annotated bibliography to support the development of educational programs to help physicians communicate more effectively with people diagnosed with cancer. We searched Medline, PsycLit, and Cancer computerized databases for articles published primarily since 1990. Our aim was to identify empiric research, literature reviews, and literature-based opinion pieces that clarified important aspects of communication at the transition from cure or control of cancer, to control of symptoms. Thus the bibliography is not meant to reflect the entire clinician-patient communication literature, either generally or for people with cancer. We also recognized that the transition is in some ways an artifact of the medical profession not addressing “cure” and “care” equally, in the context of a longitudinal relationship. Despite this ideal, and for a variety of reasons, physicians and patients still experience this transition as a major shift in the goals and nature of treatment, and in the physician-patient relationship.

We identified and annotated 375 articles for this project. This bibliography includes the ones that make the greatest contribution to understanding the transition. The articles are organized into the following categories:

- I Physician-patient communication
 - A) Communication skills training
 - B) Physician-patient relationship
 - C) Giving information
 - D) Empathy and support
 - E) Shared decision-making

- II Oncologist stress and burnout

- III Communication at the end of life: Quality of life

- IV Hope and spirituality

I. PATIENT-PHYSICIAN COMMUNICATION

A. Communication skills training

Baile WF, Kudelka AP, Beale EA, et al. Communication skills training in oncology: Description and preliminary outcomes of workshops on breaking bad news and managing patient reactions to illness. *Cancer*. 1999;in press.

Objective: To increase oncologists' confidence in breaking bad news and managing stressful patient encounters.

Design: Two half-day workshops.

Setting: University of Texas MD Anderson Cancer Center

Subjects: Twenty-seven oncology faculty of which fifteen attended the bad news workshop and twelve the "problem situation" workshop.

Interventions: One workshop focused on breaking bad news and the other on dealing with "problem situations." The five-hour workshops combined a didactic presentation with experiential role-plays to enhance communication skills. The participants met as a large group for the didactic portion and in small groups with trained facilitators for the role-plays.

Measures: Self-efficacy measures were administered before and after the workshops. Additionally, participants were mailed a follow-up workshop satisfaction questionnaire.

Results: Participants expressed satisfaction with the workshop and evidenced greater confidence in communicating bad news and managing difficult situations.

Conclusions: Communication workshops, though in need of longitudinal research, may be a viable means of providing training to oncologists.

Garg A, Buckman R, Kason Y. Teaching medical students how to break bad news. *Can Med Assoc J*. 1997;156:1159-1164.

Objective: To educate medical students on how to break bad news to patients and their families in an empathic and competent manner.

Design: Pre/Post test design.

Setting: Seven teaching hospitals affiliated with the University of Toronto since 1987.

Subjects: Out of 1260 medical students, 940 precourse and 503 postcourse questionnaires were completed. For the final analysis, only 359 questionnaires could be used. The course was given to all medical students in their 3rd preclinical year.

Interventions: The course consisted of 2 half-day, 3-hour-long sessions given 1 or 2 weeks apart. The course goals were to reinforce medical interviewing skills learned in the previous 2 years, to teach advance medical interviewing skills, and to give practice in those skills while providing individualized, constructive feedback. Students received a workbook containing role-play and small-group exercises, and a recommended reading list. Two 30-minute videos were produced for the class and one was shown at the beginning of each class followed by a 15-minute discussion. The second session focused on difficult questions and emotions.

Measures: Students were given pre- and postcourse questionnaires.

Results: Students found the course enjoyable and useful. Following the course, 92% of the students felt they had a firm plan for giving bad news as opposed to the precourse result of 49%. Before the course, 23% of the students felt competent as compared to 74% following the course. Students who had witnessed role models break bad news rated them highly and had a plan in mind for how to accomplish this task as well as a higher sense of competence. Only 11 questionnaires showed a loss of perceived competence or strategy or both. The precourse questionnaire showed 68% of students thought about the task of breaking bad news often or very often.

Conclusions: Courses on teaching students communication skills can be incorporated into medical school curricula successfully with students finding the courses enjoyable and useful.

Glimelius B, Birgegard G, Hoffman K, Kvale G, Sjoden PO. Information to and communication with cancer patients: Improvements and psychosocial correlates in a comprehensive care program for patients and their relatives. *Patient Education and Counseling*. 1995;25:171-182.

- Objective: To evaluate the effect of a cancer care project on patients' and relatives' total situation. To clarify the relationships between self-reported problems related to interactions with medical staff and varied problems among patients and relatives.
- Design: Implementation of a cancer care project in which information and communication interventions played a central role
- Setting: All patients who were to receive chemotherapy at Akademiska sjukhuset, Uppsala, were invited to participate in the project.
- Subjects: One hundred and seventy-seven patients participated in the project between 3/1/87 and 4/30/89. 120 patients' relatives were also interviewed with no more than 1 relative per patient interviewed. One month prior to the care project initiation, a preproject evaluation was conducted on 54 patients. Subjects were similar in demographics to the other groups.
- Interventions: The care program was a cooperative effort between a resource group and 3 wards. All ward personnel were involved in the project. Verbal information was supplemented with written information. Efforts were made to increase the relatives' participation in patient care and to improve care of the relatives by staff. An education program was conducted with the staff. In the initial months of the program, a 1-week communication course was held followed by regular meetings held on the wards. Communication skills practice involved giving first information about serious disease, and general strategies for giving information
- Measures: A Swedish version of the Cancer Inventory of Problems Situations was used for evaluation. Patients were interviewed at diagnosis, at regular intervals during treatment, and after the last treatment course. Relatives were interviewed at the same time as the patients, but separately. An additional 9 questions concerning interactions with medical staff were administered.
- Results: Scores for problems related to patient-staff interaction were low during the preproject interview, but even lower scores were seen during the project. Strong relationships were found between various aspects of patient- and relative-staff interactions and psychosocial problems, although weaker relationships were found for problems relating to information than for communication and control problems.
- Conclusions: Although the effects of specific interventions could not be measured, the education of medical staff was effective in lessening problems reported by patients and relatives.

Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. *Eur J Cancer*. 1996;32A:78-81.

- Objective: To determine which behaviors promote or which hinder disclosure.
- Design: Pre- and postworkshop simulated patient interviews.
- Setting: A series of 3- to 5-day workshops aimed at improving physician-patient communication in a residential setting in the UK.
- Subjects: Study participants were 206 health professionals experienced in cancer care and who completed one of the workshops.
- Interventions: The participants set the workshop goals by determining which communication tasks they most wished to be addressed and then using a videotape of a consultation for discussion and education. Participants practiced assessing patient concerns and other tasks through small-group role play. Another videotape session focused upon breaking collusion, emotional survival and "unfinished business."
- Measures: Participants interviewed two different simulated patients, 1 before the workshop and 1 after. Each interview was audiotaped. A rating system was developed for this study to examine verbal communications. Two raters determined agreement by rating and comparing 3 transcripts. Effective behaviors were hypothesized to include open directive questions, psychologically focused questions, clarification of psychological issues,

educated guesses used in a negotiating style, and empathic statements. Inhibiting behaviors include focusing upon physical aspects, giving advice, and offering reassurance.

Results: Questions that had psychological focus, clarification of psychological aspects, and open directive questions showed increases in disclosure of 2 and 3 fold. Leading questions and focusing upon physical aspects hindered information getting. The use of open directive questions and empathy was positively influenced by the workshop. Inhibitory behaviors decreased following workshop attendance.

Conclusions: An integrated approach is needed which combines a focus on the patient's personal world and physical aspects of cancer in order to effectively help this population. Advice-giving and reassurance needs to be delayed until the patient's concerns are elicited and understood.

Roter DL, Hall JA, Kern DE, Barker LR, Cole KA, Roca RP. Improving physicians' interviewing skills and reducing patients' emotional distress. A randomized clinical trial. *Arch Intern Med.* 1995;155:1877-1884.

Objective: To examine the effect of communication skills training on patients' emotional distress.

Design: A randomized, controlled field trial.

Setting: USA

Subjects: Six hundred and forty-eight patients and 69 of their primary care physicians.

Interventions: Two communication skills courses concerning patient emotional distress that targeted either problem-defining skills or emotion-handling skills.

Measures: Physicians were randomly assigned to either a no-course control group or one of the two 8 hour communication skills courses. Office visits of the physicians were audiotaped until five emotionally distressed and nondistressed patients were enrolled. Patients were given the General Health Questionnaire. Physicians were audiotaped during simulated patient visits to assess proficiency. Distressed patients were monitored via telephone 2 weeks, 3 months, and 6 months after their office visit to determine utilization of medical services and General Health Questionnaire Scores.

Results: Trained physicians used significantly greater amounts of problem-defining skills or emotion-handling skills with no increase in the length of the office visit. Patients of trained physicians reported a lessening of emotional distress for up to 6 months.

Conclusions: Communication skills training improved physician proficiency in reducing emotional distress in patients without any lengthening of the office visit.

B. Physician-patient relationship

Beisecker AE. Patient power in doctor-patient communication: What do we know? *Health Communication.* 1990;2:105-122.

Description of Context: To examine research that focuses on the patient's attempts to obtain information, to be assertive in communicating with physicians, and to be an active participant in medical decision-making.

Topic/Scope: Variables that affect the doctor-patient relationship include: sociodemographic characteristics of the physician and patient, attitudes of both parties, and influencing situational factors. Patient noncompliance may represent a way for patients to assert their independence and power. Compliance may be affected by the patient's communication input. The exchange of information is influenced by the amount of information-seeking behaviors evidenced during the medical encounter by the patient, or the physician's behavior, that could discourage questions. Effective patient information-seeking behavior can positively affect the medical outcome. Patient assertiveness has an impact as both patient and doctor want to maintain control, autonomy, and power in the relationship. Patient communication also involves the role of the patient in medical decision-making. Information exchange and patient question-asking may directly

influence a patient's input in medical decisions. This may affect the patient's psychological reactions to treatment, and his or her satisfaction levels.

Conclusions/Recommendations: A patient's assertive communication behaviors or attempts to control the physician-patient relationship may be explained by a variety of factors. A patient's attitude may not predict behavior, as attitudes arise from general beliefs regarding patient rights while communication behaviors arise from a specific interaction context. Although many patients desire information, few make attempts to elicit information from doctors.

Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Physician behaviors, patient perceptions, and patient characteristics as predictors of satisfaction of hospitalized adult cancer patients. *Cancer*. 1990;65:186-192.

Objective: To examine potential predictors of patient satisfaction as related to physician behaviors.
Design: Examined physician-patient interactions using a behavioral checklist, questionnaires, and visual analogue scales.
Setting: Three hundred and sixty-six In-patient hospital setting in NY.
Subjects: cases involving 6 oncologists and cancer patients.
Interventions: Physician-patient interaction during morning rounds.
Measures: One to two observers in clinical garb observed weekday morning rounds. The physician-patient interaction was timed. Following rounds, the observer returned to the patient's room. The same observers measured physician behaviors and patient responses and were given the Physician Behavior Check List, and two visual analogue scales: one assessing how the patient's needs were met by the physician, and the other assessing the overall measure of the patient's involvement in the interaction. The patient also completed the 2 visual analogues and a Patient Satisfaction Questionnaire.
Results: The physician spent, on average, 4.4 minutes in each patient's room, yet the patient approximated that same time to be 8.8 minutes. Overall, patient satisfaction was high. Patients' perceptions of behavior were found to be better predictors of patient satisfaction than actual physician behaviors. Factors related to satisfaction were emotional support or needs, and information needs being perceived as met. Older patients experienced greater satisfaction. Two physician behaviors related to patient perception of prognosis: "Identifying future tests and treatment" was related to a perceived better prognosis while "inquires about signs and symptoms" was associated with a worse prognosis. Only 5 physician behaviors were found to occur more than 60% of the time: addressing the individual, inquiring about the patient's overall state, inquiring about signs and symptoms of illness, discussing tests and treatments, and touching the patient. Touching the patient is the only behavior related to support.
Conclusions: How the patient perceives the interaction has a greater effect on satisfaction than actual physician behaviors. Older patients express greater satisfaction. The subjects the physicians inquired into also affect patient satisfaction.

D'Angelica M, Hirsch K, Ross H, Passik S, Brennan MF. Surgeon-patient communication in the treatment of pancreatic cancer. *Arch Surg*. 1998;133:962-966.

Objective: To assess long- and short-term quality of surgeon-patient communication and to determine the surgeon's role in emotional support of patients with pancreatic cancer (PC).
Design: Survey using a combination of telephone and mail.
Setting: Urban tertiary cancer referral center.
Subjects: Forty-eight patients who had experienced a pancreatic resection for PC.
Interventions: None.
Measures: Patient satisfaction.
Results: The amount of information provided both before surgery and during the hospital stay was rated as extremely satisfactory by patients. Physical actions found to be comforting to patients included direct eye contact, the surgeon sitting while speaking to the patient, and some form of physical contact.

Conclusions: Surgeons are seen as desired emotional supports by patients. Patients are ill-prepared for long-term problems following surgery.

Delbanco TL. Enriching the doctor-patient relationship by inviting the patient's perspective. *Ann Intern Med.* 1992;116:414-418.

Description of Context: Many of the problems that occur within the patient-physician relationship involve feelings of anger and sadness related to the distancing that interferes with appropriate interactions. This relationship can be improved by both parties first engaging in a "patient's review," and then using survey instruments to measure each aspect of care.

Topic/Scope: The patient's review focuses upon seven aspects that characterize the patient's perspective:

- values, preferences, and expressed needs of the patient
- the patient's coordination and integration of care
- communication and education needs of the patient
- the patient's physical level of comfort
- the patient's available emotional supports
- the level of involvement of family and friends
- the continuity and transition of care

The review allows the individual to be the focus of the report, and encourages the patient and the physician to confront and express personal differences while allowing the patient to take a more active role in his or her treatment. The review also lets the physician ascertain the patient's fears and anxieties in order to attempt alleviation.

Conclusions/ Recommendations: The patient's review should be taught in the early years of medical school as it provides structure while allowing for an understanding of the whole person. Patients should also be encouraged to learn this method to enhance their own personal understanding. Survey instruments that seek patient input will promote an understanding of how well patient needs are addressed, and how care may be improved. Addressing these areas will promote a synergism between doctor and patient.

Fallowfield LJ. Communication skills of oncologists. *Trends in Experimental and Clinical Medicine.* 1995;5:99-103.

Description of Context: Many patients are unhappy with the communication exchanges with their doctors. The process of a cancer diagnosis, treatment, and prognosis may result in possible emotional, relational, sexual, or occupational difficulties.

Topic/Scope: Oncologists often fail to recognize even significant psychological distress. The physician's lack of response leads to more stress for the patient. Patients do not understand medical jargon, which, when combined with their own ideas and information presented by the media, leads to greater confusion and resultant distress. Characteristics of the patient, the doctor, and the system of cancer care delivery also contribute to the problem. Due to the role of the physician in society, the patient may not be comfortable asking the oncologist questions. The lack of information communicated to the patient initially, combined with the number of therapeutic options, may result in long-term adverse consequences. Five areas of communication are perceived to be most difficult for physicians: breaking bad news, obtaining informed consent for clinical trials, speaking with relatives, discussing treatment options, and addressing psychosocial issues.

Conclusions/Recommendations: Skills training may help address the problem, promoting basic communication techniques such as showing respect, concern, or empathy, as well as non-verbal and verbal caring.

Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer.* 1994;70:767-770.

Objective: To assess the ability of oncologists to recognize distress in newly-referred out-patients and to measure their own satisfaction with their behavior during consultations concerning adverse news.

Design: Self-report measures and clinical interviews.

Setting: The medical oncology department of a London teaching hospital.

Subjects: Five senior oncologists were assessed concerning their interactions with 101 patients at the first interview and 94 of the 101 at the second interview.

Interventions: None.

Measures: Each patient had two clinical interviews, approximately 1 month apart, with the same oncologist. Prior to the first interview, demographic information was collected. Before both the first and second interviews, psychological functioning was determined via the General Health Questionnaire and the Hospital Anxiety and Depression scale. At the end of each interview, the oncologist subjectively rated his/her personal performance. The oncologist's perceptions of patient distress were measured using 2 visual analogue scales.

Results: The majority of physicians tended to under-rate patient distress. The more clinicians perceived patients to be distressed, the less satisfied they were with the interviews. As the oncologists usually under-rated patient distress, they were typically satisfied with the interviews.

Conclusions: Oncologists tend to under-rate rather than over-rate patient distress and would benefit from improving their psychological assessment skills.

Goldberg R, Guadagnoli E, Silliman RA, Glicksman A. Cancer patients' concerns: Congruence between patients and primary care physicians. *J Cancer Educ.* 1990;5:193-199.

Objective: To investigate similarities and differences between physician and cancer patient perceptions of issues related to the cancer experience of the patient.

Design: Survey.

Setting: Physicians and patients in Rhode Island.

Subjects: One hundred and nineteen patients and 195 physicians returned the questionnaire.

Interventions: None.

Measures: A 43-item questionnaire was developed for this study with 8 domains of concern: physical function, social function, effects of cancer and its treatment, communication, information, emotional support, concrete services, and health behavior.

Results: The results indicate statistically significant discrepancies between physician and cancer patient views of important issues involved in treatment. Physicians underestimated how important patients consider knowing what will happen if the cancer recurs, knowing whether they are cured, and knowing whether treatment will help. In the area of communication, physicians underestimated the importance patients place on deciding what new symptoms to bring to the doctor's attention, on comprehending what the doctor is saying, and on being able to talk openly. Physicians and patients rated equally the importance of general concerns about cancer epidemiology and its impact on social and emotional functioning. However, these items were rated less important overall when compared to communication items.

Conclusions: Primary care physicians did not understand the importance placed by patients on many issues; thus, communication must improve to address these issues.

Lerman C, Daly M, Walsh WP. Communication between patients with breast cancer and health care providers. *Cancer.* 1993;72:2612-2620.

Objective: To determine the prevalence and types of deficiencies in physician-patient communication as reported by the patient prior to postoperative therapy.

Design: Used a survey methodology to identify those patients most likely to report communication difficulties, and to evaluate the relationship between patient-reported communication problems prior to postoperative therapy and psychological distress at the three month follow up visit.

Setting: Fox Chase Cancer Center in Philadelphia, PA.

Subjects: The sample included 97 women diagnosed with Stage I or II breast cancer. All had undergone primary surgical treatment for their disease, but had not begun postoperative therapy.

Interventions: None.

Measures: Demographic information was obtained from the medical records. Three coping styles were measured: fighting spirit, assertiveness, and a need for information. Measures used included the Fighting Spirit subscale of the Mental Adjustment to Cancer Scale, the Rathus Assertiveness Schedule, and the Miller Behavioral Style Scale. Patient-provider communication was evaluated using the Cancer Rehabilitation Evaluation System-Medical Interaction Subscales (CARES). Psychological distress was determined by the Profile of Mood States.

Results: The majority (84%) of the patients endorsed items reflective of difficulties communicating with medical staff. Patients had difficulty comprehending provider-given information and many patients expressed difficulties with asking questions and expressing feelings to providers. Patients most likely to report communication problems had more distress, less optimism, and greater feelings of hopelessness concerning the disease. Patients who reported more communication problems prior to postoperative treatment experienced greater psychological distress both before postoperative therapy and at the three month follow up visit.

Conclusions: Patients who ask questions receive greater amounts of information, thus reducing uncertainty, gaining reassurance, and receiving personalized advice. Improving physician-patient communication aids in improving the patient's adjustment to her disease. Communication may be enhanced through the utilization of interventions that lower patient distress and modify coping styles.

Maguire P. Improving communication with cancer patients. *Eur J Cancer* 1999;35:1415-1422.

Description of Context: A review article summarizing research (Maguire's and others) in the field.

Topic/Scope: Research is summarized by key communication tasks: eliciting patient's concerns, perceptions and feelings; breaking bad news; involving patients in treatment decisions; obtaining informed consent; and monitoring adverse reactions. Each section ends with a brief summary of findings. Barriers to effective communication and ways to improve communication with patients are reviewed, with major emphasis on training physicians.

Conclusions: Physicians fail to elicit patient concerns, or block expression of concerns once asked. This reflects lack of skills training (eg, how to move on after empathy) but also attitudes or outcome expectancy - if I do this, bad things will happen - patient will cry, take up time, etc. Maguire has done most of the basic research on this and finds that training needs about 3 days of small group work and a 2-day booster 2-3 months later. His best results have been with coaching individual physicians as they see patients, improving their self-efficacy and outcomes expectancy with interviewing skills.

Novack DH, Suchman AL, Clark W, et al. Calibrating the physician: Personal awareness and effective patient care. *JAMA*. 1997;278:502-509.

Description of Context: Proposes a "curriculum" of 4 core topics for reflection and discussion for the physician with the aim of promoting personal awareness, and increasing physician satisfaction with work, relationships, and self.

Topic/Scope: The first of the topics is the physician's beliefs and attitudes. This encompasses the core beliefs and personal philosophy of the physician, his or her family of origin, gender issues, and sociocultural influences. The second topic involves the physician's feelings and emotional responses in patient care. Inherent to this are the physician's experiences of love, caring, attraction, and boundary setting in medical care, and the physician's personal perceptions toward anger and conflict either within himself, herself or others. The third topic concerns challenging clinical situations such as difficult patients, caring

for dying patients, or medical mistakes. The last topic is physician self-care, addressing the maintenance of a balance between personal and professional lives, and prevention and management of stress, burnout and impairment.

Conclusions/Recommendations: Several methods of increasing personal awareness in physicians may be used such as group discussions, support groups, Balint groups, family of origin discussion groups, meaningful experiences discussions and personal awareness groups, literature in medicine discussion groups, and behavioral science/interpersonal skills curricula. The primary focus of each method is to facilitate personal awareness within the physician to enhance cooperation, respect, and trust among health care professionals.

C. Giving information

Baile WF, Gliner GA, Lenzi R, Beale EA, Kudelka AP. Discussing disease progression and end-of-life decisions. *Oncology* 1999;13:1021-1035.

Description of context: Applies the 6-step protocol "SPIKES" for giving bad news, to the case of disease recurrence or treatment failure. Important communication strategies at this transition include: 1) develop rapport; 2) identify the patient's preferences for receiving information; 3) ensure comprehension of key information; 4) provide empathy; 5) elicit the patient's main concerns; and 6) involve the patient in the treatment plan.

Scope: The paper alternates between examples of doctor-patient dialogue, with commentary about key communication skills illustrated, and desired outcome. Includes dialogue for making the transition to palliative care, discussing the futility of further curative treatments, and providing hope in the face of a poor prognosis.

Butow PN, Dunn SM, Tattersall MHN, Jones QJ. Patient participation in the cancer consultation: Evaluation of a question prompt sheet. *Ann Oncol.* 1994;5:199-204.

Objective: To examine the effects of a question prompt sheet designed to encourage patient question-asking and participation in the consultation.

Design: A survey given during the first consultation with 1 medical oncologist.

Setting: A university teaching hospital in Australia.

Subjects: One hundred and forty-two cancer patients with a mean time since diagnosis of 29 months, a mean of 2 months from the most recent diagnosis, and a mean of 15 days from consultation to interview.

Measures: All consenting subjects completed the Spielberger State Anxiety Scale and 2 items from the Information Styles questionnaire prior to the audiotaped consultation. One to three weeks following the consultation, patients were telephoned to assess recall. Variables included patient satisfaction, recall of information, and psychological adjustment.

Interventions: Half of the sample randomly received a handout encouraging questions, or a handout informing patients of services available through the Cancer Council.

Results: The question prompt sheet impacted patient behavior as evidenced by an increase in questions regarding prognosis. Thirty-five percent of the patients who received the question prompt sheet asked questions about the prognosis as compared to 16% of the patients who received the information handout. Patients asked 5.5 questions on average. Patients who were interested in being involved in medical decision-making spent a greater amount of time asking questions and making statements. A higher number of questions were also asked by female patients, younger patients, and out-patients.

Conclusions: The mean number of overall questions asked was not increased by the question prompt sheet. However, the number of questions about the prognosis increased.

Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ.* 1990;301:575-580.

Objective: To assess, outside a clinical trial, psychological outcomes of women who have undergone different treatment procedures for early breast cancer including either

mastectomy or breast conservation in relation to the surgeon's opinion or the patient's choice. Also, to determine whether patient psychiatric morbidity (depression) following breast conservation surgery was related to participation in a randomized clinical trial.

Design: Prospective multicentre study.

Setting: Three London teaching hospitals, 12 general hospitals, and 4 private hospitals in the south of England.

Subjects: Twenty-two surgeons who were asked their preferred choice of treatment and 269 women diagnosed with Stage I or Stage II breast cancer.

Interventions: Surgery and radiotherapy or adjuvant chemotherapy or both.

Measures: The hospital anxiety and depression scale, the Rotterdam symptom checklist, and the Spielberger state/trait anxiety inventory were administered both preoperatively and 12 months postoperatively. A semistructured psychiatric interview was conducted in the patient's home 2 weeks, 3 months, and 12 months postoperatively.

Results: Breast conserving procedures were not found to prevent psychosocial and sexual dysfunction. The woman's preoperative psychiatric state was found to influence development of psychiatric morbidity. Women with more anxiety were at a greater risk for clinical anxiety or depression. The surgeon's characteristics and manner of presenting information was found to influence both the resultant psychiatric morbidity and treatment choice. It appears that women who were offered a choice experienced less psychiatric morbidity (depression), although further research is needed due to this small sample. No evidence was found indicating that participation in a randomized clinical trial is linked to resultant psychiatric morbidity.

Conclusions: Offering a choice of treatment methods to women with breast cancer results in less psychiatric morbidity. A simple screening measure assessing anxiety traits in women prior to surgery can identify those women at greater risk for post operative psychiatric morbidity and allow for interventions to be implemented.

Fawzy RI, Fawzy NW. A structured psychoeducational intervention for cancer patients. *Gen Hosp Psychiatry*. 1994;16:149-192.

Description of Context: Provides a structured short-term psychoeducational intervention for breast cancer patients.

Topic/Scope. The manual is divided into 2 parts. The first part is for health care personnel implementing the intervention, and concerns the psychosocial impact of cancer, the history of interventions for cancer, the development of "The Structured Psychoeducational Intervention for Cancer Patients" model, the description of the model, and a review of the authors' research. The model combines health education, stress management, coping skills, and psychological support in a group format. The second part is a patient manual that provides education about the biopsychosocial model and about coping skills that may help deal with stressful scenarios.

Conclusion/Recommendations: This psychoeducational intervention has been used successfully for 2 years, and patient evaluations have been positive.

Gould SJ. The Median Isn't the Message. http://cancerguide.org/medican_not_msg.html

Description of Context: An internationally famous teacher of evolutionary biology is diagnosed with abdominal mesothelioma and is told that the median survival is 6 months. He is shocked at the embedded message ("You have 6 months to live") but as a scientist wants to see the data. He sees that despite the low median survival, the curve has a large right skew and his clinical data put him toward that tail. He enters a clinical trial and his disease is stable. He refutes reports that he has died. A great example of a man whose life work (biology research) provides him the tools he needs to foster and maintain hope, and a lesson in how to give information.

Gray RE, Greenberg M, Fitch M, et al. Information needs of women with metastatic breast cancer. *Cancer Prev Control*. 1998;2:57-62.

Objective:	To examine the informational needs of women with metastatic breast cancer.
Design:	Focus group based.
Setting:	Eight sites across Ontario over a 6 month period in 1996 and 1997.
Subjects:	The focus groups were comprised of 38 women with group size ranging from 4 to 6. The mean number of years since diagnosis was 6.5. Women were in varied physical states, with some women still feeling well and experiencing no major problems, and other women attending the group in wheelchairs.
Interventions:	None.
Measures:	The focus groups lasted between 90 to 120 minutes. Emerging themes were identified initially by all researchers. Following the first 2 groups, 4 members separately reviewed and coded the transcripts and compared results to identify themes to be systematically coded.
Results:	Themes were organized into 2 broad dimensions: the participants' expressed desire for information in specific content areas, and issues related to whether information can be either beneficial or harmful based on how it is provided. In the area of desired information, women wanted better and greater amounts of information from health care professionals. Information rated as important reflected the women's need to understand the medical situation, to understand what treatment options are available to them, and to learn how to anticipate and handle physical symptoms. Women expressed difficulty in gaining the desired types of information from physicians and nurses and suggested an auxiliary person would be helpful in filling the role. In the second dimension, information provision, many issues arose which required sensitive and appropriate handling. Topics included the personal relevance of information to each woman's situation, and the engagement of the health care team. Women did not perceive the team to be proactively seeking new treatments. A proactive approach by physicians assuring women that whatever options were available would be provided was valued. Women felt that they had to seek out information on their own and also felt inadequately supported in making specific treatment decisions. Women wanted their opinions to be valued, even when they were disagreeing with the specialist. In discussions of prognosis, information was often communicated in a problematic manner. Sustaining hope and not assessing duration of life in a probabilistic manner were rated highly. A minority of women did want to know what to expect as the illness progressed. Information needs varied over time; things that were important at one point were not considered helpful at another.
Conclusions:	Women showed a strong reliance on the cancer specialists for information and care. Women wanted information but did not want hope ruined. Palliative care was avoided as a discussion topic. Women were interested in prolonging life and only reluctantly interested in preparing for death.

Lo B, Quill T, Tulsky J. Discussing palliative care with patients. *Ann Intern Med.* 1999;13:744-749.

Description of Context: Review of communication skills at the transition.

Scope: Even experienced physicians often struggle when discussing palliative care with patients and families. Beginning discussions of palliative care and responding to difficult patient statements and questions are helped by specific communication techniques: 1) ask the patient their understanding of where things stand now with the illness; 2) use the patient's own words to ask clarifying follow-up questions; 3) allow the patient to express feelings; and 4) asking about specific concerns. Specific concerns include physical problems such as pain, nausea, shortness of breath, and psychosocial problems including depression and spiritual suffering. Physicians often "default" to information giving or reassurance before completely understanding the patient's concerns or feelings. Patients who are allowed to express feelings may feel worse temporarily but feel less alone, and physicians should restrain their natural tendency to fix or repair the feelings. Screening for psychological and spiritual needs is recommended. The paper includes examples of doctor-patient dialogues to illustrate the points.

Mazur DJ, Hickam DH. The effect of physician's explanations on patients' treatment preferences: five-year survival data. *Med Decis Making*. 1994;14:255-258.

- Objective: To examine the impact of explanations by physicians on patient choices.
- Design: A randomized design in which patients were asked to choose between 2 alternative treatments.
- Setting: A Department of Veterans Affairs Medical Center based in an university.
- Subjects: The sample was comprised of 136 patients seen in a continuity-care general medicine clinic.
- Interventions: None.
- Measurements: Patients were randomized to either a Limited Explanation group (LE), or an Extensive Explanation group (EE). The sample was then asked to choose between 2 alternative treatments that differed in survival rates for an unidentified medical condition. The LE group received a short orientation to graphs giving treatment results, while the EE group received a detailed verbal description of the graphs.
- Results: Patients in the LE group reported endpoint data, such as year 0 or year 5, as influencing their decision. Patients in the EE group reported medium point data, such as year 0 to intercept or intercept to year 5, or average life expectancy for the five-year period influenced their preference.
- Conclusions: The patients preferences for treatment was impacted by the amount of verbal information received. When medium range data was not specifically pointed out to the patients, it was minimized.

Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. *Cancer*. 1995;76:167-177.

- Description of Context: Reviews findings concerning the influence of monitoring and blunting coping styles on cancer-related distress, and health behaviors. Explores the types and amounts of cancer information appropriate for both groups of patients.
- Topic/Scope: The term "monitoring" describes patients who are alert for and sensitized to negative, potentially painful, or dangerous aspects of information or experiences. "Blunting" describes patients who distract themselves from potentially painful, or dangerous aspects of information or experiences. Monitors express extreme concern with treatment side effects, and are less satisfied with and more demanding about psychosocial aspects of care. High monitors feel a greater amount of responsibility for the course of their actions than low monitors. Blunters tend to cope with aversive medical events by using distraction to avoid threatening information. Monitors tend to be more demanding as patients, and want more medical information. Sometimes a monitor may prefer a less active role in their treatment, yet will listen more attentively to the physician and ask for more information. Monitors appear to implement physician recommendations, and take greater responsibility for their care than blunters.
- Conclusions/Recommendations: When the amount of information provided can be matched to the patient's coping style, stress levels can be reduced. Monitors tend to do better with more information while blunters do better with less information. Monitors who exhibit a pessimistic outlook about their future may need more emotional support.

O'Connor AM. Effects of framing and level of probability on patients' preferences for cancer chemotherapy. *J Clin Epidemiol*. 1989;42:119-126.

- Objective: To examine patient perceptions of probabilistic information about treatment outcomes and the resultant impact on treatment choice.
- Design: Examined the influence of level and framing of probability on preferences for cancer treatment alternatives in determining which tradeoffs are made in regards to quality and quantity of life.
- Setting: Canada.
- Subjects: One hundred and fifty-four cancer patients and 129 healthy volunteers.

Interventions: None.
Measures: One of three randomly assigned conditions were assigned to the subject: the probability of survival was given (positive frame), the probability of dying was given (negative frame), and the probability of both survival and dying were given (mixed frame).
Results: A preference for the more effective toxic treatment was seen in the cancer patients. The level of probability presented influenced the choice made. When survival rates of less than 50% were presented, preference dropped and this occurred even more when presented in a negative frame. In cases where the negative frame or probability level was below .5, the sample tended to focus on the quality of life rather than the quantity of life.
Conclusions: How information is presented to patients has a direct effect on treatment choices made.

Poulson J. A bitter pill to swallow. *N Engl J Med.* 1998;338:1844-1846.

Description of context: A senior physician and clinician-teacher, no stranger to chronic illness herself, describes her experience with diagnosis and surgical treatment of breast cancer.
Conclusion: Even experienced senior physicians are prone to the same experiences and perceptions as other people - eg, fear, anger, shame. It doesn't help to be told that medical practice has improved with technology or to be referred to by your colleagues as a "great case" when they think you can't hear. Loss of hair and nails is a "lightning rod" for more general and severe feelings of being physically ill, tired, and demoralized. Cancellation of procedures is psychologically devastating, as is "not being a candidate" or "not being eligible" for a procedure or treatment. Physicians must practice and model asking patients about their fears and emotions before talking about the more hopeful and positive aspects of treatment.

Quirt CF, Mackillop WJ, Ginsburg AD, et al. Do doctors know when their patients don't? A survey of doctor-patient communication in lung cancer. *Lung Cancer.* 1997;18:1-20.

Objective: To compare the doctor's and patient's level of agreement concerning the illness, the risks and benefits of treatment, and the intent of treatment. To assess the relationship between the doctor's and patient's assessment of illness and mental state.
Design: Prospective study using questionnaires and structured interviews.
Setting: Kingston Regional Cancer Center in Ontario, Canada.
Subjects: One hundred patients with a recent diagnosis of lung cancer and 9 senior medical staff specialists participated in the study.
Interventions: None.
Measures: Doctors were given a questionnaire focusing on the diagnosis, the intent of treatment, the expected side effects, and the prognosis. Also covered were perceptions of patient knowledge concerning diagnosis, the stage of disease, intent of treatment, expected side effects, and prognosis. The patients were questioned via a structured videotaped interview which matched the content of the physicians' questionnaire. Demographic information and the patient's performance status was assessed. Additional medical information was gathered from the clinical chart.
Results: Out of 99 patients who stated they had lung cancer, 63 patients' answers matched the physician responses, 31 patients believed the cancer was less extensive than the doctor reported, and 5 believed it was more extensive. In the area of intent of treatment, of the 63 patients whose answers matched the physician's, 19 patients incorrectly believed the treatment goal was curative instead of palliative, and 5 patients believed the reverse. Doctors stated that 98 patients had been informed of possible side effects, but only 86 recalled at least 1 possible side effect. Fifty-five patients overestimated the possibility of a cure and 3 underestimated the possibility. Eighteen patients who had previously stated that the treatment intent was palliative indicated they had a 1 to 50% chance of cure. Thirty-one patients overestimated their chances of returning to normal activities and 23

underestimated it. Fifty-five patients overestimated life prolongation probabilities and 1 patient underestimated it. Seventeen patients overestimated the probability of symptomatic benefit and 3 underestimated this. Out of 12 cases where the physician believed the patient did not know the prognosis, 4 had a realistic view of the prognosis. Physicians were rarely aware of their patients' misunderstanding.

Conclusions: Although patients are urged to take an active part in decision-making, the physician should first make sure the patient understands the diagnosis, the risks and benefits of treatment, and the intent of treatment.

Ruckdeschel JC, Blanchard CG, Albrecht T, Psychosocial oncology research. *Cancer*. 1994;74 (suppl):1458-1463.

Description of Context: The authors reviewed three presentations at the Conference on Behavioral and Psychosocial Cancer Research to ascertain current communication approaches to the areas of quality of life, symptom management, and social support. Research appeared to focus on the physician's delivery of information, or how the patient feels symptomatically upon hearing the information. A broader, multidimensional approach is needed to truly understand the process.

Topic/Scope: The authors propose a new paradigm that considers that while the physician is delivering one message, the patient may be hearing another because of a "perceptual filter" which interferes with the delivery of the message and how it is received. Also, the interaction between the physician and the patient impacts the delivery and receptiveness of the message. Four patient variables influence satisfaction: the patient's perceptions of whether their needs were being met, the patient's perceptions of emotional support during the visit, whether the physician discussed treatment, and patient age.

Conclusions/Recommendations: A better understanding of the process by which communication is delivered and received is needed. This will allow for preventative measures to be instituted that may help alleviate maladaptive coping responses.

Sardell AN, Trierweiler SJ. Disclosing the cancer diagnosis: Procedures that influence patient hopefulness. *Cancer*. 1993;72:3355-3365.

Objective: To determine the extent to which various forms of physician disclosure of a cancer diagnosis are perceived by the patient to influence hope and favorability.

Design: Naturalistic compilation of diagnosis disclosure.

Setting: Patient participants were drawn from a variety of settings in Massachusetts.

Subjects: Fifty-six patients with cancer with an average age of 55 years.

Interventions: None.

Measures: Ten physicians were asked to describe how patients have been told of cancer diagnoses. Then 10 patients with recent onset of cancer were interviewed concerning how they first learned of their diagnosis. Statements from both sets of interviews were condensed into brief descriptive items. From these came 57 statements that became part of an instrument to study the 56 participants. In addition to this, participants were also given the Mental Adjustment to Cancer (MAC) scale to assess coping responses.

Results: Patients with cancer had numerous questions and opinions on how a cancer diagnosis should be conveyed. The patients felt the diagnosis should be given with import being placed on personal individuality, intimacy, and privacy in a face-to-face encounter with a familiar physician. The presence of an oncologist was welcomed and the sample was split on whether they preferred to be accompanied by a relative or friend or not. Patients wanted to be given all of the information by physicians who instilled hope by emphasizing the patient's fight against the cancer's physical and personal effects. They also wanted to be told their treatment was the best available, and, that if that treatment were to be unsuccessful, other avenues would be pursued. Patients wanted to know their odds of winning, especially if favorable. Patients wanted their fears addressed and managed if possible. The physician's efforts at providing expert medical skill and emotional support was important to the patient. Greater hope was expressed when the patient could speak to the physician as a partner. Procedures indicative of a negative

prognosis, whether through intentional disguise or unintentional suggestion, were viewed as much less hopeful.

Conclusions: Improvements are possible in the way a cancer diagnosis is delivered. Further research is needed in this area.

Step toe A, Sutcliffe I, Allen B, Coombes C. Satisfaction with communication, medical knowledge, and coping styles in patients with metastatic cancer. *Soc Sci Med.* 1991;32:627-632.

Objective: To examine the relationships between satisfaction with communication, factual knowledge, and coping styles as related to individual differences. This study was based on the prediction that satisfaction is less related to the information given than the patient's preference for information-seeking as a coping style (monitoring), as compared to avoidance (blunting) in stressful situations. The relationship between satisfaction, coping style, and psychological disturbance was explored to assess whether monitoring is associated with more stress than avoidance.

Design: Survey.

Setting: A medical oncology ward.

Subjects: Seventy-seven participants were recruited during their 3- to 5- day hospital admission for condition assessment, tests, and treatment modification when needed. Diagnosis primarily included cancer of the breast or lung, and the median illness length was 24 months.

Interventions: None.

Measures: Patients were individually interviewed 2 to 3 days after admission. The following tests were administered: general information and medical knowledge test, ratings of satisfaction, trait anxiety, Miller Behavioral Style Scale, Medical Coping Modes Questionnaire, and the Hospital Anxiety and Depression Scale.

Results: Patients who displayed a more avoidant coping style exhibited greater satisfaction with information provided, and less anxiety. Satisfaction with communication and care in general were positively correlated. A higher degree of factual knowledge about the causes of cancer and its treatment was not related to greater communication satisfaction.

Conclusions: Patients who exhibited avoidant coping mechanisms experienced less stress. The buffering style of avoidant patients may result in less exposure to potential stress.

KKC Note: The mean age for leaving school was 15.2. This is significant as contemporary research indicates that more educated patients want, and receive, additional information satisfactorily.

Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA.* 1984;252:2990-2994.

Objective: To examine patient decision-making preferences, and physician receptiveness to these preferences.

Design: A self-administered questionnaire was given to both patients and physicians, with the patients also undergoing an interview, with one-third being an extensive interview.

Setting: Three different settings in the San Francisco, CA area were used: a community hospital clinic, a freestanding health maintenance organization, and a Veterans Administration outpatient clinic.

Subjects: Two hundred and ten hypertensive outpatients and their 50 clinicians representative of the three settings.

Interventions: None.

Measures: Patients were individually interviewed after meeting with their physicians. Both physicians and patients were administered a self-report questionnaire designed for this study.

Results: Fifty-two percent of patients reported receiving significant amounts of information about their condition and its therapy while only 38% of clinicians reported giving that high an amount of information. Clinicians tended to underestimate the amount of information reported by the patient. Forty-one percent of patients reported desiring additional information, 58% stated they received the right amount of information, and 1 patient

would have preferred less information. Clinicians perceived younger, white patients or those patients who had a diagnosis of hypertension for a longer period of time to want to have a greater role in treatment decisions. Clinicians and patients both reported higher education and income to be correlated to desiring a greater role in treatment decisions. Attending physicians and nonphysicians were more likely than residents to perceive patients as wanting to help make decisions. Many patients stated that they wanted their physicians to make initial treatment decisions, but desired to play a more active role after gaining more experience with medications. Eighty-nine percent of the patients reported being satisfied with their care and clinician.

Conclusions: Clinicians were found to underestimate the patients' wish for information and to overestimate the patients' wish to make decisions. Physicians should attempt to ascertain individual preferences, as many patients want information but may initially prefer to leave treatment decisions to the physician.

D) Empathy and support

Barsky AJ. Nonpharmacologic aspects of medication. *Arch Intern Med.* 1983;143:1544-1548.

Description of Context: Taking medication is not just a pharmacologic process but encompasses psychological, social, and interpersonal factors that influence how the patient views the medication and his or her treatment compliance.

Topic/Scope: Nonpharmacological factors are important to four types of patients: those who insist on a medication that is not indicated clinically, those who refuse a medication that is clinically indicated, patients bothered by the side effects of an array of medications, and those patients who do not adhere to their treatment regimen. The underlying cause of each behavior is influenced by factors that are nonpharmacological in nature. Pills have a psychological meaning, an interpersonal meaning, and a social meaning for each individual patient. The physician must ascertain what these beliefs are, and address them so as to incorporate possible effects of the beliefs into the treatment plan.

Conclusions/Recommendations: The physician needs to carefully explore the meaning of medications that the patient brings into treatment at a psychological, interpersonal, and social level. By defining the meaning and exploring the associated beliefs with the patient, the physician can establish a relationship that uses negotiation between the patient and the physician, and is more likely to resolve the medication problem.

Cassell E. Diagnosing suffering: A perspective. *Ann Intern Med.* 1999;131:531-534.

Description of Context: Physicians are trained to diagnose disease but not suffering. Suffering is related to disease but is expressed in the distress patients are experiencing, their assessment of the seriousness of the problem, and how impaired they feel themselves to be. It is impact rather than specific impairment. Suffering is subjective, personal, and individual. Asking people not just about pain but also about the worst thing about their experience elicits suffering. The task for information (subjective or objective) is to increase its precision, reliability, and predictive value. This is done by examining again, asking and listening again, enlarging the scope of inquiry, asking more questions, and thinking about the patient's answers.

Conclusions: No one likes to ask or hear about unrelieved pain, misery, suffering. Physicians are often concerned that they will be helpless in the face of the patient's answers. But little is required of the physician except to ask and listen. The gratification that follows these interactions more than repays for the discomfort and with time the conversations get easier.

Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety? *J Clin Oncology.* 1999;17:371-379.

Objective: To test the effect of physician compassion on patient anxiety levels, information recall, hypothetical treatment choice, and the assessment of physician characteristics.

Design: A randomized pretest/posttest control group design with a standardized videotaped intervention.

Setting: Maryland.

Subjects: One hundred and twenty-three breast cancer subjects recruited from 2 local support groups. These subjects recommended 87 non-cancer females who matched the demographic characteristics.

Interventions: Women were shown one of two videotapes made for this study with each showing the same basic general information. However, the experimental tape had 2 additional short segments which involved the physician acknowledging the psychological concerns of the patient, stating partnership and support, validating the woman's emotional state and the difficulty of making a decision in light of the uncertainty present, touching her hand, and trying to reassure her.

Measures: Five areas of interest were measured: physician compassion, anxiety, treatment information recall, hypothetical treatment decision, and perceptions of physician attributes. Questionnaires included one created for this study and the State-Trait Anxiety Inventory (STAI).

Results: Women who viewed the enhanced compassion video rated physicians as being warmer, more pleasant, more compassionate, more sensitive, and more caring. Although all the women experienced higher anxiety post-test, women in the enhanced video group experienced less anxiety than women in the standard video group. Of note, women in the enhanced group had lower information recall by 2 points. Enhanced compassion was not found to affect treatment choice. Finally, women who viewed the enhanced compassion video were more likely to believe the doctor cared about the patient, acknowledged the patient's emotions, encouraged questions, encouraged a partnership in treatment decisions, and wanted what was best for the patient (this last difference was not found to be significant after controlling for race). Women without cancer rated the physician higher on encouraging questions and encouraging involvement in decisions.

Conclusions: The compassion video segment involved approximately 40 seconds of compassion. Improving relationships and reducing anxiety is not time costly. It is hypothesized that women recalled slightly less information because they trusted the doctor and put their decision-making in his/her hands.

Passik SD, Dugan W, McDonald MV, Rosenfeld B, Theobald DE, Edgerton S. Oncologists' recognition of depression in their patients with cancer. *J Clin Oncol.* 1998;16:1594-1600.

Objective: To ascertain the oncologist's ability to recognize depression in a large sample of ambulatory cancer patients. To describe patient medical and demographic characteristics that influence depression ratings.

Design: Questionnaires were given to patients and physicians to rate the patient's level of depressive symptoms.

Setting: Twenty-five health care centers affiliated with Community Cancer Care, Inc. of Indiana.

Subjects: A group of 1,109 patients and 12 oncologists responsible for their treatment. The most common types of cancer were breast, colon/rectal, lymphoma, and lung. Approximately 50% of the subjects had early-stage disease at diagnosis and over 60% were disease-free or stable. The majority of patients showed no depressive psychopathology. Two hundred and thirty-eight patients responded in a manner indicative of mild levels of depressive symptoms, 139 patients responded in a manner indicative of moderate levels of depressive symptoms, and 23 patients indicated severe levels of depressive symptoms.

Interventions: None.

Measures: Patients completed the Zung Self-Rating Depression Scale before their scheduled meeting with the physician and 1 item from the Brief Pain Inventory. The physicians, unaware of patient responses, rated the degree to which they felt the patient was depressed and anxious after the visit along with the Patient Pain Rating. Sociodemographic and health characteristics were gathered from medical charts.

Results: Oncologists frequently assessed patient levels of depressive symptoms inaccurately. The greatest amount of agreement occurred when no symptomatology, or mild symptomatology, was present. The least amount of agreement occurred when patient symptomatology was moderate or severe. Physician ratings were most highly correlated with patient endorsement of more obvious symptoms such as sadness, tearfulness, or irritability, as opposed to less subtle signs such as concentration difficulties, anhedonia, and somatic symptoms. Physicians inaccurately estimated depressive levels in patients who had more pain and poorer performance. Of the 36% of patients with clinically significant depression, less than 3% were currently seeing a mental health professional.

Conclusions: As a whole, physician recognition of depressive symptoms is often inaccurate. Screening measures should be used in the clinical oncology setting.

Rose JH. Social support and cancer: Adult patients' desire for support from family, friends, and health professionals. *Am J Community Psychol.* 1990;18:439-64.

Objective: 1) To assess 11 components of support as defined by 3 definitions of support: instrumental, emotional and appraisal. Instrumental support represents relief from practical and problem-solving demands so ordinary roles can be fulfilled. Emotional support is the meeting of socioemotional needs. Appraisal support or cognitive information represents understanding and self-perceptions. 2) To assess similarities and differences in needs of the components of support from family, friends, and health professionals and to determine differences in patient needs based upon characteristics of the illness.

Design: A functional and structural perspective of social support was used to examine adult cancer patients' desire for support.

Setting: Postal-based questionnaire.

Subjects: Sixty-four women and 14 men were the final sample for this study, recruited from programs sponsored by the American Cancer Society.

Interventions: None.

Measures: Patients received a packet a few weeks before scheduled appointments with health professionals. They were asked to identify a family member, friend, and health professional whom they most depended on for support as related to the cancer experience. The members of the sample were asked to complete the health professional questionnaire before their next appointment and to fill out the other questionnaires related to friends and family on different days in the same week.

Results: Each married subject chose his or her spouse as the person most relied upon for support, and others equally chose their adult children, siblings, and parents. For the health professional, 84% chose their oncologist or family physician, 8% their surgeon and 8% the oncology nurse who administered the chemotherapy. Of the chosen health professionals, 65% differed in sex and age from the patient. Friends who were chosen were most similar in age and 25% had experienced cancer. Patients preferred tangible aid from family members, modeling from friends who had had cancer, and open communication and clarification from health professionals. Family and friends were viewed as potentially providing intimacy, opportunities to ventilate and social diversion. Health professionals, family, and friends were identified as being potential providers of reassurance, esteem, directive guidance, and advocacy support. The worse the patients' prognosis, the greater the desire for instrumental support and the more health professionals were identified as sources of support.

Conclusions: There are similarities and differences in the types and kinds of support patients want from family, friends, and health professionals which are influenced by the prognosis of the disease.

Slevin, ML, Nichols SE, Downer SM, et al. Emotional support for cancer patients: What do patients really want? *Br J Cancer.* 1996;74:1275-1279.

Objective: To assess whom patients wished to receive support from, and whether they were satisfied with the various types of support received within the oncology environment.

Design: The study evaluated patient attitudes to different sources of support and rated satisfaction with sources already used.

Setting: Patients were recruited from 7 oncology clinics, 2 medical oncology clinics, 3 radiotherapy clinics, and 2 hematology clinics at 4 hospitals in the UK.

Subjects: Four hundred and thirty-one questionnaires were returned.

Interventions: None.

Measures: The questionnaire was designed for this study and had 3 focus areas: support from individuals, support groups, and emotional support.

Results: Both family and senior doctors were rated the top source of support desired by patients (73%), followed by consultants (63%). Satisfaction was rated highest with family, senior doctor, and consultant (approximately 80%). Informational pamphlets (BACUP) were rated very highly as helpful informational sources. As patients could pick only one answer, doctors were rated as being more important than family and friends as a support choice. Older patients favored consultants, senior registrars, GPs, community nurses, and radiographers for emotional support while younger patients preferred to use family, preferred friends, and other patients.

Conclusions: The senior doctor is the preferred source of support for the patient. Thus, improving communication skills in this population will aid not only physician-patient communication, but will also greatly help the patient.

Spiegel D. Psychosocial aspects of breast cancer treatment. *Semin Oncol.* 1997;24:SI-36-47.

Description of Context: Addresses the psychological problems of breast cancer patients and the benefits of treatments that reduce anxiety and thus improve patient-doctor relationships.

Topic/Scope: Medical variables that contribute to distress in women with breast cancer include recency of diagnosis and more advanced disease. Anything that impairs the patients' ability to learn or accept information from their doctors or which magnifies their appraisal of threat adversely affects mental health. Factors associated with a higher prevalence of depression include pain, a greater level of physical disability, and more severe illness. Depression in this population is often underdiagnosed and undertreated. Predictors of adjustment may include coping style. The relationship with the physician is an important determinant of the level of patient distress, and anything that undermines the patient's trust in her physician weakens her adherence to treatment and increases general distress. Having adequate social support helps reduce rates of mortality and is a robust predictor of subsequent mortality. Social support via group and other forms of psychotherapy may affect the quantity as well as the quality of life. Psychosocial stress has been found to hasten disease progression.

Conclusions/Recommendations: The social, psychological, and medical environment is crucial to adjustment and influences the course of disease. Clear and open communication, expression of appropriate emotion and collaborative decision-making can improve outcomes for breast cancer patients.

E. Shared decision-making

Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. *Med Care.* 1995;33:1176-1187.

Objective: To identify and examine the characteristics of patients and office visits that are associated with a lesser amount of participatory decision making (PDM) between patient and physician.

Design: A cross-sectional survey.

Setting: Solo practices, multi-specialty groups, and health maintenance organizations in Boston, Chicago, and Los Angeles.

Subjects: Over a 9 day period in 1986 8,316 patients were sampled from the practices of 344 participating Medical Outcome Study physicians. The physicians represented general internal medicine, family practice, cardiology, and endocrinology.

Interventions: None.

Measures: Physicians were given a 3-item scale that was included in the baseline questionnaire completed by patients following an office visit. Patients completed the questionnaire after the office visits.

Results: Physician's PDM style increased with a longer office visit, or as the length of time the patient has been seeing the physician increased. The least participatory visits with physicians occurred with the elderly, the young adult, patients with a high school education or less, minority patients, and male patients. Male patients with male physicians had a less participatory visit than any other gender mix.

Conclusions: Interpersonal care as related to patient health outcomes may not be fully appreciated. Seven patient or visit characteristics were found that influenced, either positively or negatively, interpersonal care effectiveness.

Quill TE, Suchman AL. Uncertainty and control: Learning to live with medicine's limitations. *Humane Medicine*. 1993;9:109-120.

Description of Context: To explore the development of uncertainty in the medical field, resultant adverse consequences, and alternative ways of handling medical uncertainty.

Topic/Scope: The development of medical uncertainty is explored through the examination of the developmental perspective, the cultural perspective, the probabilistic perspective, the existential perspective and the scientific perspective. Uncertainty is a reason for the overutilization of medical techniques, the current malpractice situation, and the growing isolation and dissatisfaction in both patients and physicians. One approach to lessening uncertainty is to discuss as much information as possible with the patient, thus increasing shared decision-making. The physician should continue to educate himself or herself as much as possible, be willing to recognize personal limitations, and turn to other professionals for help when needed while keeping the patient's wishes in mind. Collaboration allows the physician and patient to develop a treatment plan uniquely suited to the patient. Facing uncertainty is difficult for the physician and is often thought of as a personal failure. Recognizing medical uncertainty as an unavoidable aspect of change that allows for discovery, creativity, and deeper insight.

Conclusions/Recommendations: Allowing uncertainty to become part of the relationship between the physician and the patient allows for less of a need of control, a deeper connection between the two parties as they work towards a treatment plan, and a chance for personal growth within the physician.

Quill TE, Brody H. Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Ann Intern Med*. 1996;125:763-769.

Description of Context: Proposes an "enhanced autonomy" model of physician-patient communication. The model that has frequently used to train physicians in the area of communication is the "independent choice" model in which the patient experiences and values dominate, while the physician serves as a passive informer. In contrast, the new model fosters a balance between patient choice and physician recommendation.

Topic/Scope: In the "enhanced autonomy" model, patients and physicians share knowledge and expertise. They work together to share decision making, with the physician serving as an active guide who is personally invested in the outcome and shares his or her personal thoughts or beliefs. This is based on competence and dialogue. Recommendations for enhancing patient autonomy are given as six separate points:

- 1) Medical information should be fully shared in language that can be understood by someone who is not involved in the medical profession, and in small digestible bits. The physician should carefully listen to the patient's perspective and strive to reach a common ground of communication. Time should be allowed for questions to be asked.
- 2) The patient's values and beliefs need to be understood and incorporated into the treatment plan along with clinical facts. The physician should express any strongly held beliefs or biases to the patient, helping the patient to understand the origin of the physician's position.

- 3) General goals of treatment should be addressed first before discussing the technical aspects of care.
- 4) Disagreements about treatment between the patient and the physician should be fully explored with both parties participating equally in the exchange to provide an opportunity for creative problem solving.
- 5) The final choice always belongs to the patient. If a serious disagreement persists and the course of treatment chosen by the patient violates the physician's values, the patient should be referred to another clinician.
- 6) Physicians must be trained to express their views openly and learn to negotiate discussions of care with patients rather than dominate the conversation.

Conclusions/Recommendations: Physicians need to be educated as to how to aid patients in determining their medical treatment by integrating patient values and beliefs, physician beliefs and clinical facts. The public needs to also be educated as to the increasing "medicalization" of people, and the overuse of medical technology as a means of eliminating uncertainty.

II. Oncologist stress and burnout

Fallowfield L, Ratcliffe D, Souhami R. Clinicians' attitudes to clinical trials of cancer therapy. *Eur J Cancer.* 1997;33:2221-2229.

Objective: To study the attitudes and clinical trial behaviors of British clinicians who work with cancer patients, and compare the results to those of US oncology physicians.

Design: Postal Survey.

Setting: United Kingdom.

Subjects: The measure was sent by regular mail to medical and radiation oncologists listed in a directory published by the National Cancer Alliance. Surgeons with an oncological focus were identified through the British Association of Surgical Oncology. The questionnaire was returned by 357 clinicians.

Interventions: None.

Measures: The measure consisted of a slightly modified version of The Physician's Orientation Profile, and additional questions concerning demographical information, the trials in which the physicians were participating, patient characteristics that made them easier or more difficult to work with, and any other comments about clinical trials. They were also solicited for future collaboration of any relevant research regarding improving trial recruitment.

Results: All 3 groups were more clinically than research oriented. However, medical oncologists expressed a greater interest in research activities and being known by national and international colleagues. Surgeons were more likely to urge patients to remain part of a clinical trial following relapse when the patient wanted to leave the trial. They were also less likely to consider the benefits of clinical trials to their institutions as motivating factors for their participation. In the area of patient characteristics, most respondents listed patients with higher intelligence being easier to work with, although a few listed those patients with lower intelligence as easier. Working-class patients were felt to be easier to work with than middle class patients. Intelligence level and disease state with a poor prognosis were endorsed as impeding communication about trials. Constraints imposed by the healthcare system that impede trial participation include lack of time, communication difficulties, and conflicts between the roles of clinician and scientist. Results of US clinician studies yielded comparable results, with the few differences suggesting that the more protocol-driven culture of the US might encourage recruitment and foster a greater commitment to keeping patients on trials. Additionally, doctors overestimate the numbers of patients they will enroll in clinical trials.

Conclusions: The respondents were more oriented toward the clinical side of treatment; thus, their loyalty lay with current patients rather than future generations. The results concerning decision-making suggest a 3-step process in which the doctor first relies on clinical experience, then turns to published data, and finally feels confident about enrolling a

patient in a clinical trial. The public needs to be informed about the meaning of randomization and possible advantages of clinical trials as opposed to waiting until the individual is diagnosed with cancer.

Mount BM. Dealing with our losses. *J Clin Oncol*. 1986;4:1127-1134.

Description of Context: An overview summary of etiologic, diagnostic and therapeutic considerations regarding stresses of oncologists.

Topic/Scope: There are 3 types of stress: useful stress which promotes growth and is beneficial, cyclic stress which increases and wanes, and personal stress which can only be resolved by attending to both the self and the environment. The most important etiologic factor of stress is death, specifically the constant re-evaluation of mortality and re-examination of the oncologist's life, combined with facing and resolving multiple patient losses. The pressures of the medical model also cause stress, as the oncologist spends a large portion of time focusing on improving the quality of life remaining when its duration is beyond control, rather than curing and prolonging life. The need to recognize and respond to the full range of psychosocial issues results in a conflict between idealism and reality. The struggle to be part of an interdisciplinary team also contributes to stress. A search for meaning following numerous treatment failures may result in compromised functioning. The oncologist may experience clinical patterns characteristic of people under significant stress.

There are many techniques to manage and prevent stress. The oncologist can be encouraged to

- become aware of stress in self and colleagues
- clarify appropriate goals and establish priorities
- encourage limit setting
- mobilize collaborative input
- clarify team roles
- review team organization
- establish team support meetings
- ensure favorable working conditions
- exercise and find one's personal center

Hospice services may have equal or less stress than oncology services. An oncologist must shift gears from a therapeutic style of his or her choice with a patient population of his or her choice to one imposed by circumstance. In this setting, the oncologist must perform wide-ranging tasks, from being a medical scientist to being a whole-person physician. He or she must also guide the patient and family from anticancer treatment to supportive care, and accept a change in role from "curer" to "sustainer." Another strategy toward stress prevention and reduction is to be aware of the personal stressors involved in caring for a category III patient, and to attempt to reduce them by clarifying appropriate case-specific goals and priorities.

Conclusions/Recommendations: The oncologist must come to terms with life experiences which influence the ability to achieve potential in adulthood. In order to deal with losses successfully, it is important to find one's personal center and counter lifelong conditioning.

Ramirez, AJ, Graham J, Richards MA, et al. Burnout and psychiatric disorder among cancer clinicians. *Br J Cancer*. 1995;71:1263-1269.

Objective: To ascertain findings that could be used to propose improvements in the quality of cancer clinicians' working life and thus improve their work effectiveness.

Design: National questionnaire-based survey.

Setting: UK.

Subjects: All consultant non-surgical oncologists were solicited through the Royal College of Physicians, the Royal College of Radiologists, and the Association for Palliative Medicine. The questionnaire was returned by 393 consultants. The palliative care specialists had the largest number of women, were the youngest, and had been in post for

the shortest time. The medical oncologists had the smallest number of women and held the highest number of academic positions. Clinical oncologists were in private practice in greater numbers than the other 2 groups.

Interventions: None.

Measures: The questionnaire assessed 4 areas: 1) demographic and job characteristics involving the adequacy of training in disease treatment, symptom control, communication skills, and management skills; 2) general psychological health using the General Health Questionnaire (12 item version); 3) "burnout" symptoms using the Maslach Burnout Inventory; and 4) stressful and satisfying aspects of their jobs.

Results: This group did not achieve higher evidence of burnout (28%) than other medical specialties. Clinical oncologists appeared to experience the greatest amount of work-related stress but were not at higher risk of psychiatric disorder than the other 2 groups. Palliative care doctors had the lowest burnout level and the highest satisfaction level with work-related sources. The sources of work-related stress were similar to those of other medical specialties and included being overloaded, dealing with patients' suffering, and being involved with toxicity and treatment errors. Organizational responsibilities/conflicts were the second highest source of stress, which differed from other medical specialties. Dealing well with patients and relatives was listed as the highest source of job satisfaction. Feelings of being insufficiently trained in communication and management skills were linked to greater levels of distress.

Conclusions: Burnout and overload may be decreased by increasing training in communication and management skills.

Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM. Mental health of hospital consultants: The effects of stress and satisfaction at work. *Lancet*. 1996;347:724-728.

Objective: To examine the relationship between the consultant's job stress, mental health, and satisfaction.

Design: Questionnaire.

Setting: Sample received survey through the mail in UK.

Subjects: The survey was returned by 882 consultants: 241 gastroenterologists, 161 surgeons, 241 clinical radiologists, and 266 clinical and medical oncologists.

Interventions: None.

Measures: Consultants were sent questionnaire booklets focusing on demographic and job characteristics, psychiatric morbidity assessed using the General Health Questionnaire, burnout using the Maslach Burnout Inventory, and job stress and satisfaction using a questionnaire designed for this study.

Results: Twenty-seven percent of consultants had scores indicating psychiatric morbidity. Radiologists had lower personal accomplishment scores. Job stress was associated with high emotional exhaustion, high depersonalization, and psychiatric morbidity. Job satisfaction was associated with high personal accomplishment, and inversely related to high emotional exhaustion, high depersonalization scores, and estimated psychiatric morbidity. Four major sources of stress were found: work overload and the resultant impact on home life; poor management and resources; managerial responsibilities; and dealing with patients' suffering. Perceived sources of satisfaction were broken down into 4 factors: good relationships with patients, relatives, and staff; professional status/esteem; intellectual stimulation; and good management and resources. The physicians indicated that the training they received in treatment and symptom control was sufficient. Only 45% felt that their communication skills training was adequate and only 22% felt their management skills training was adequate. Feeling insufficiently trained in communication skills was associated with less reported job satisfaction from relationships with patients, relatives, and staff; less perceived professional status and esteem; deriving less intellectual stimulation; and feeling less managed and resourced.

Conclusions: Job satisfaction is linked to less job stress. Communication skills training may help increase job satisfaction.

Vachon MLS. Stress and burnout in oncology. *Principles and Practice of Supportive Oncology*. Philadelphia: Lippincott-Raven Publishers; 1998:833-843.

Description of Context: Describes contributing factors of burnout and stress in oncology healthcare professionals, and reviews the literature on this topic.

Topic/Scope: Burnout results from the individual occupationally overextending himself or herself for a highly demanding job situation. Oncology work is emotional labor where emotion must be regulated between the caregiver and the person being cared for. Stressors are great in oncology. Oncology health care professionals were found to experience greater stress than palliative care specialists, but equal stress amounts compared with other medical specialties. The area of oncology has a greater workload and less recognition than in the palliative care setting. Physicians rated curing cancer, learning, and advancing research as areas of greatest reward, while nurses endorsed meeting personal goals for patient care. Areas of greatest discomfort for physicians included being unable to help patients and being unable to provide optimal health care. Nurses identified areas of discomfort in ethical issues such as truth-telling, interference with patient comfort, dying in the context of medical experimentation, and the determination of Do Not Resuscitate status. Evidence indicates that oncology caregivers are faced with increasing work overload stress and limited resources, both of which adversely affect job satisfaction. A majority of oncologists report experiencing burnout. It is hypothesized that feelings of burnout are influenced by the lack of hope in oncology. Coping strategies to counter feelings of burnout include developing a sense of competence, control, and pleasure in one's work; feeling in control over one's practice; having a personal philosophy of illness, death, and one's professional role; managing one's lifestyle; and leaving the work situation. Support groups and an effective team philosophy also counter feelings of burnout.

Conclusions/Recommendations: Oncology healthcare specialists must realize the need for self-care as well as care for others. Training in management skills and communication is linked to a greater sense of professional competence, which in turn is related to lower levels of burnout.

Whippen DA, Canellos GP. Burnout syndrome in the practice of oncology: Results of a random survey of 1,000 oncologists. *J Clin Oncol*. 1991;9:1916-1920.

Objective: To examine the extent and nature of burnout in the professional lives of randomly selected oncology physicians.

Design: A questionnaire with 12 specific points.

Setting: Questionnaires randomly mailed to 1000 Journal of Clinical Oncology subscribers

Subjects: The questionnaire was returned by 598 subscribers to the journal.

Interventions: None.

Measures: The survey queried medical specialty, years since training, percentage of time devoted to practice and other activities, and practice location. The measure focused on several issues, including whether the physician's career had met his or her expectations from training and whether burnout symptoms were personally evident in his or her professional life. Targeted burnout factors included the experienced symptoms such as failure, boredom, etc, the causes, and suggestions for relief.

Results: Overall, 56% of the respondents reported some level of burnout. Rates of burnout were higher in those physicians with greater patient contact. Of those reporting burnout symptomatology, physicians whose training ended after 1980 had greater feelings of frustration or a sense of failure. Institution- or university-based oncologists reported less burnout. Causational factors of burnout included inadequate personal and/or vacation time, continuous exposure to fatal illness, frustration with therapeutic success, and qualms regarding reimbursement for physician services. Burnout symptomatology included frustration or a sense of failure, depression, disinterest in practice, and boredom. Recommendations for remedying burnout included more vacation or personal time. Physicians reported their personal and social lives as well as their professional lives were affected by burnout. Physicians favored decrease in time devoted to patient care or an increase in time devoted to teaching or clinical research to combat burnout.

Conclusions: The results indicate that a reduced workload would help reduce burnout. As medicine changes, training programs must also change to orient physicians to their growing role in palliative care

III. Communication at the end of life: Quality of life

Creagan ET. Psychosocial issues in oncologic practice. *Mayo Clin Proc.* 1993;68:161-167.

Description of Context: Describes the stages of dying and the needs of the patient with cancer.

Additionally, examines bereavement tasks of the family and significant others.

Topic/Scope: There are 5 stages of dying that the cancer patient may experience: denial, anger, bargaining, depression, and acceptance. Patients with cancer have specific needs. The physician must respect the patient's preferences and needs, communicate and educate the patient in layperson terminology, and be honest without withdrawing hope. The implications of a procedure or diagnosis should be discussed when the patient is feeling good. The patient needs emotional support from the physician, and the relationship should be viewed as a team. Families should be loosely defined and their level of involvement specified by the patient. The oncologist should understand the physical environment of the patient's home to screen for potential problems, and should make a follow-up visit or telephone call. The oncologist must also address the issues of pain, death, and dying. The patient must be reassured that pain can be managed satisfactorily. The physician must also be alert to death and dying issues of the patient and the family. The family will undergo a bereavement process which the physician should attempt to facilitate if possible. Bereavement tasks are outlined by Project Omega, which was developed in the psychiatry department at Harvard Medical School. These include accepting the reality of the loss, experiencing the pain of the loss, adjusting to an environment in which the deceased person is absent, and withdrawing emotional energy from the deceased person and redirecting and reinvesting energies. The patient should be told of their survival time by giving guidelines but stressing the differences in individuals. A sympathy letter may be sent following the death if a relationship was developed, or, if felt appropriate, the oncologist may attend the funeral. The family should be directed to supports in the community.

Conclusions/Recommendation: The clinician can facilitate appropriate grieving and help the healing process. Guilt and blame can be transformed into constructive emotions and quality issues can be emphasized as opposed to ruminating about the past.

Derrickson BS. The spiritual work of the dying: A framework and case studies. *The Hospice Journal.* 1996;11:11-30.

Description of Context: Describes a systematic approach to understanding the spiritual work of the dying.

Topic/Scope: Many dying people focus on spiritual meanings. Spiritual care responds to both patients' and their families' expressions of spirituality on a day-to-day basis. The suffering in terminal illness involves not just physical pain but mental and spiritual suffering. There are recurrent and predictable themes in the work done by the dying person. These include "remembering," "reassessing," "reconciliation," and "reunion." "Remembering" is the act of life review. "Reassessing" occurs when individuals examine how they defined themselves in life as compared to when they are currently challenged by terminal illness. There are 4 ways in which people define themselves: by their work (more typical in males), by their athletic prowess, by their mental dexterity, and by their role as a caretaker (more typical in females). "Reconciliation" occurs when the dying individual must face what has been left undone in life. Lastly, a "reunion" may possibly occur when the dying patient believes a deceased person from the spiritual world arrives to help the dying individual to disconnect from the world of the living and connect with the spiritual world. Some individuals also experience a CNS phenomenon at the very end of life where repressed memories flood their consciousness.

Conclusions/Recommendations: Understanding the recurrent theme enables the spiritual caregiver to serve the dying individual better. Diagnostic tools allow for a better understanding of the uniqueness of each individual's particular struggle.

Emanuel LL, Danis M, Pearlman RA, Singer PA. Advance care planning as a process: Structuring the discussions in practice. *JAGS*. 1995;43:440-446.

Description of Context: Five steps outline an idealized process of advance care planning.

Topic/Scope: The steps include: 1) raising the topic and giving information; 2) facilitating a structured discussion by first making initial decisions about the mode of advance planning, understanding patient treatment goals, raising specific examples and ascertaining general values, and including the proxy; 3) completing a statement and recording it, 4) periodically reviewing and updating directives; and 5) bringing prior wishes to bear on actual decisions.

Other considerations:

- whether an advance directive is appropriate for everyone
- handling time constraints
- choosing where and when to have the discussion
- defining the role of nonphysician healthcare professionals
- facilitating understanding of the proxy role
- addressing the perceived risks of placing the advance directive in the patient chart
- addressing legal concerns.

Conclusions/Recommendations: This is a useful model for practitioners, teachers, medical students, researchers, and institutional policy makers.

Escalante CP, Martin CG, Elting LS, Rubenstein EB. Medical futility and appropriate medical care in patients whose death is thought to be imminent. *Support Care Cancer*. 1997;5:274-280.

Description of Context: Integrates ethical guidelines associated with the termination of aggressive medical care and 3 issues that physicians typically find difficult.

Topic/Scope: The 4 basic ethical principles are autonomy, beneficence, nonmaleficence, and justice. In the first of 3 issues in medical futility and appropriate care the physician must decide if aggressive care is to be offered. Second, the physician applies outcomes research in clinical decision-making. The physician should analyze both subjective and objective factors. Last, the cost of treatment choice is considered.

Conclusions/Recommendations: The integration of ethical principles and outcomes research allows the physician, patient, and the family to make end-of-life choices in a more systemic and objective manner.

Frei E, Kass F, Weeks J. Quality of life in cancer patients: Clinical considerations and perspectives. *Oncology*. 1990;4:204-208.

Description of Context: The concept of quality of life is multidimensional and changes over the course of the patient's disease with differences seen at each phase. Quality of life in the patient diagnosed with cancer can be examined in 4 different phases: precancer, pretreatment, treatment and its various subcategories, and long-term follow-up.

Topic/Scope: At the precancer phase, the individual has premorbid characteristics that are brought into the experience of cancer and may influence quality of life. A problem may be attributed to the cancer when, in fact, it was already present.

The pretreatment phase is important as the physician's interactions with the patient and family may have long-term effects on quality of life. The medical staff must provide both information and hope. The physician should give the information with compassion and discretion, timing when and where the information is given and if the patient wishes others to be there. The patient's background should be carefully noted and the information tailored to each person. Quality of life differs for each person, based on whether hopes and expectations are fulfilled by current life experiences. Being honest with people with the poorest prognosis may enhance their quality of life and compliance.

When palliation is the only option, information-giving is central and should be addressed by a multidisciplinary team.

The treatment phase should center on "total patient care." The whole of the patient and the family should be considered. The medical staff should be chosen and trained to be attentive to the individual as a whole. Having one physician is key, as the multidisciplinary team may result in the patient feeling overwhelmed. Two communication forums that have proven helpful are introducing another individual who had the same experience and is in long-term follow up, and urging the patient to write down and tape information.

The last phase is the post-treatment, long-term follow-up phase. As approximately 20% of cured patients experience significant anxiety and depressive problems, better long-term support is needed.

Conclusions/Recommendations: Quality of life research is ongoing and measures should be used carefully until further quantifiable results identify accurate, appropriate instruments.

Hall P, Stone G, Fiset VJ. Palliative care: How can we meet the needs of our multicultural communities? *J Palliat Care*. 1998;14:46-49.

Description of Context: Presents a framework to help clinicians understand the needs of terminally ill patients and their families who have different cultural influences from the health care staff. Of importance are the patient's perceptions of the illness, its personal meaning, and the patient's expectations. These are then compared to the views of health care workers in order to develop a shared model.

Topic/Scope: Differences that influence palliative care exist between cultural traditions, especially in the area of communication. The statistics reveal that incidence of disease, mortality rates, and physiological responses differ between certain populations. The needs of cultural minorities who are ill aren't being fulfilled. Nurses feel frustration and stress in caring for these patients due to poor communication, a lack of cultural understanding, and inadequate resources. The nurses' ethnocentric beliefs influence their relationships with patients and are further exacerbated by clinical ethics based on Western philosophy. Cultural brokerage in palliative care aids in the understanding of and communication with terminally ill persons with differing cultural influences. In this model, health care personnel must be aware of their own personal beliefs, attitudes and values, and understand how these might influence relationships with patients. An open, non-threatening relationship with the family and the patient must be developed in order to elicit important information regarding their personal beliefs, attitudes, and values. Using effective communication skills will allow the caregiver to impart important aspects of their framework and negotiate a common ground in which to work.

Conclusions/Recommendations: The health professional must establish a non-threatening and open relationship where necessary questions are asked and important information is shared. This will allow for the development of an effective working relationship where different cultural needs are met.

Kahn SB, Houts PS, Harding SP. Quality of life and patients with cancer: A comparative study of patient versus physician perceptions and its implications for cancer education. *J Cancer Educ*. 1992;7:241-249.

Objective: To assess which needs physicians believed to be unmet in patients with cancer.

Design: A follow-up survey was sent to physicians who had participated in a study designed to assess unmet needs of patients with cancer. A group of 300 patients with cancer were matched with their physicians. Both groups were interviewed to determine perceptions of the effects of the disease and treatment on the patient's quality of life.

Setting: Patients were interviewed via telephone and physicians were sent a questionnaire.

Subjects: Patients were gathered from the Pennsylvania Cancer Registry listings for 2 years prior to data collection. At the end of their interview, patients were asked for the name of the physician involved in their care. The first 353 different physicians were then sent a questionnaire and 300 matched pairs of patients and physicians were used.

Interventions: None.
Measures: Multiple regression analyses were used to determine whether physicians' beliefs regarding quality of life issues matched the patients' views in five problem categories: physical problems, emotional-social problems, economic problems, problems with medical staff, and community problems.
Results: Physicians and patients highly rated the stage of disease at diagnosis with physical and emotional-social problems. This was the only area of similarity. Physicians rated stress as greater in older populations, when, in fact, younger populations experienced greater amounts of stress across all five problem areas. Also not reflected in physician ratings was that females rated emotional-social problems higher than males.
Conclusions: Current teachings of patient needs and stressors do not fully encompass individual differences such as age or gender, and do not confront the differing problems confronting the patient with cancer.

Markson L, Clark J, Glantz L, Lamberton V, Kern D, Stollerman G. The doctor's role in discussing advance preferences for end-of-life care: Perceptions of physicians practicing in the VA. *J Am Geriatr Soc.* 1997;45:399-406.

Objective: To examine the amount of experience physicians have with advance preferences and how physicians perceive their role in the advance preference decision-making process.
Design: Mail survey in 1993.
Setting: Department of Veterans Affairs.
Subjects: Veterans Administration physicians (1050) including internists, family physicians and generalists were contacted; questionnaires were returned by 67%.
Interventions: None.
Measures: A letter describing the survey was sent out 1 week prior to the questionnaire mailing. The participants returned a postcard with a number assigned to ensure anonymity.
Results: Written directives to make decisions for at least 1 incompetent patient were used by 73% of the sample. Advance directives were discussed with at least one patient by 79% of physicians and 19% with at least 25 patients. In the area of initiating advance directive discussions, 59% of physicians initiated the discussion, 55% reported the discussion occurred in an inpatient setting, and 31% of the discussions occurred in an outpatient setting. The majority of respondents (82%) felt the physician should be responsible for initiating the discussion. The occurrence of an advance preference discussion was independently associated with younger age, board certification, and less time spent in outpatient settings. Most of the physicians (91%) reported they would try to persuade a patient to change a decision that was not well informed, not medically reasonable, or not the best decision for the patient. Only 14% would attempt to change decisions that morally conflicted with their own beliefs.
Conclusions: Physicians are and should be an active part of the decision for care at the end of life.

Schneiderman LJ, Kaplan RM, Rosenberg E, Teetzel H. Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences? A second look. *Camb Q Healthc Ethics.* 1997;6:131-137.

Objective: To compare physicians' predictions of their patients' end-of-life choices to the choices they would make for themselves.
Design: Correlational.
Setting: The University of California, San Diego.
Subjects: The patients were drawn from a larger study involving AIDS and cancer patients. Thirty-five patient-physician pairs were included in this study. Twenty-eight physicians participated with their involvement limited to no more than 2 patients. There were 11 patients with cancer and 24 patients with AIDS.
Interventions: None.
Measures: Patients completed a California Durable Power of Attorney for Health Care, a procedure-oriented questionnaire (PDQ) which was an advance-directive instructional supplement

adapted from Emanuel and Emanuel, and a quality-of-life questionnaire. Patients were asked to provide their own personal preferences while physicians described both their own treatment preferences given the clinical circumstances and what their patients' choices would be. Three alternative choices were analyzed: no--would not want the treatment, yes--would want the treatment, or trial--would experiment with the treatment.

Results: Overall, the most common response was a refusal of treatment. Physicians were more likely than their patients to refuse treatment. In a comparison of physician responses for themselves and patient responses of their preferences, there was an agreement of 54% that treatment should be refused. In a comparison of physicians' responses concerning their own preferences and those of the patients, the level of agreement rose to 68% that treatment should be refused. In a base comparison of physicians' responses concerning their own preferences compared to patient preferences, there was an agreement of 66%. In a base comparison of physician responses concerning their own preferences and their predictions of patient preferences, agreement rose to 82%. Agreement between the 2 groups was highest in scenarios where there was unconsciousness and no chance of recovery, or when the patient was in deep pain. Agreement was lowest when the scenario involved unconsciousness with a small chance of recovery. Higher rates of agreement were evidenced in cases of CPR, mechanical breathing, and major surgery. Lower rates of agreement were evidenced in cases of pain medication, use of antibiotics and blood donation

Conclusions: Physician perceptions of what patients want in terms of advance directives are influenced by their own personal preferences.

Singer P, Martin D, et al. Quality end-of-life care. *JAMA* 1999;281:163-168.

Objective: To specify and depict elements of quality end-of-life care from the patient's viewpoint.

Design: In-depth, open-ended, face-to-face interviews with content analysis

Setting: Toronto, Ontario

Subjects: Dialysis (48), HIV(40), and long term care patients (38)

Interventions: Interviews conducted until no new concepts were found on qualitative analysis.

Measures: Qualitative and content analysis

Results: Five domains of quality care were identified: 1) sufficient pain and symptom management; avoiding inappropriate prolongation of dying; having a voice in care; relieving the burden of care from others; and strengthening relationships with loved ones. These are compared with domains from 3 physician expert panels.

Conclusions: Current practices don't address patient views well - eg informed consent for specific procedures is a poor proxy for realistic, achievable goal setting. Importance of intimacy, reconciliation, and closure within families is largely ignored Patient-derived domains are concise and practical and can be a checklist by clinicians.

Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: How do physicians communicate about advance directives? *Ann Intern Med.* 1998;129:441-449.

Objective: To examine how physicians in outpatient practices discuss advance directives with their patients, and whether these discussions adhere to an acceptable pattern of informed consent.

Design: Descriptive.

Setting: Two university-based general medicine practices, 2 Veterans Affairs general medicine practices, and 1 university-based geriatrics practice in Durham, NC, and Pittsburgh, PA.

Subjects: Fifty-six physicians, and 56 patients with serious medical illness with the focus on 1 physician with 1 patient. The median chance of 5-year patient survival was 72%.

Interventions: A discussion of advance directives introduced by the physician. Patients were randomly assigned.

Measures: Physician-patient encounters were audiotaped, transcribed, and coded as to how the physician introduced the topic, discussed 3 scenarios (dire, reversible, and chronic

disability) and treatments, provided information, sought patient values, and identified surrogate decision makers. Demographic and attitudinal data was obtained from patients through personal interviews.

Results: Ninety-five percent of the physicians felt comfortable initiating advance directive discussions, but 61% rarely had this discussion in the outpatient setting. Discussions about advance directives lasted a median time of 5.6 minutes, with physicians speaking for a median time of 3.9 minutes and patients speaking for a median time of 1.7 minutes. Only 29% of the physicians acknowledged the emotional difficulty of the subject. Related to the 3 possible scenarios, 91% of the cases mentioned involved a dire scenario, 55% of the cases mentioned involved an uncertain scenario, 48% of the cases mentioned involved a reversible scenario, and 29% of the cases mentioned involved a chronic disability. Physicians discussed treatment options in 96% of the cases. Physicians did not explore the reasons for preferences or query the patient's personal definition of quality of life or what "being a burden" meant. Living wills were mentioned in 88% of the cases. The discussion was viewed as a positive experience by 96% of the patients, and 95% of the patients agreed the discussion was a good idea. Physicians rarely gave details when describing a scenario. Surrogate decision making and documentation to aid in advance care planning were rarely mentioned.

Conclusions: Most physicians have not received proper training in how to communicate with patients about advance directives. Communication skills need to be improved and conversations about advance directives encouraged.

IV: Hope and spirituality

Ballard A, Green T, McCaa A, Logsdon MC. A comparison of the level of hope in patients with newly diagnosed and recurrent cancer. *Oncol Nurs Forum*. 1997;24: 899-904.

Objective: To examine and compare hope in patients with newly diagnosed cancer and those with recurrent cancer.

Design: Descriptive study.

Setting: Two outpatient hematology/oncology private practices and 1 gynecologic/oncology practice in 2 urban areas in the southern U S.

Subjects: A convenience sample of 20 newly-diagnosed individuals and 18 patients with recurrent cancer.

Interventions: None

Measures: The Herth Hope Scale (HHS) and one open-ended question.

Results: There were no significant differences between the 2 groups. Items concerning the "presence of loved ones" and "support" received the highest endorsements. "Scared about the future" received the lowest score. "Interconnectedness" received higher scores in both groups. Five themes emerged as sources of hope: family support, nonfamily support, faith, outlook, and health care/professionals. Although not statistically significant, patients with a recurring cancer identified faith as a source of hope, and patients initially diagnosed identified health care/professionals as a source of hope. Married individuals and males had higher hope scores.

Conclusions: Hope can be fostered by health care professionals, faith, and social support.

Delvecchio MJ, Good BJ, Schaffer C, Lind SE. American oncology and the discourse on hope. *Cult Med Psychiatry*. 1990;14:59-79.

Objective: To explore several dimensions of the cultural foundations of American oncology.

Design: Semistructured interviews.

Setting: Harvard Medical School.

Subjects: Fifty-one oncologists practicing in the teaching hospitals of Harvard Medical School.

Intervention: None.

Measures: Interviews were 45 to 90 minutes in length and consisted of open-ended questions with a set of closed questions given at the end of the interview for completion. Interviews were

tape recorded and transcribed, and closed question responses were tabulated and analyzed.

Results: The pace for disclosure was typically governed by the phasing of therapeutic interventions, and somewhat by the course of the disease. The extended process of disclosure was considered at each stage as it pertains to the level of hope that patients and their families should be encouraged to maintain. The first step in disclosure was framed as an exchange from patient to physician. The type of "partnership" that the specialist constructs with the patient affects the staging of disclosure and the flow of information between the two. The primary unit of treatment is the patient rather than the family, in contrast with cultures such as Japan and Italy. The aim of instilling and maintaining hope in patients regulates and justifies the level of disclosure. All physicians in this study believed instilling hope in their patients was a critical dimension of their care; however, their understanding of hope and its influence on illness often differed from that of "popular medical literature." The physicians viewed hope as a staged process, given in calibrated, achievable and realistic bits.

Conclusions: The ability of the physician to maintain hope or optimism is key to the essence of a meaningful medical practice. Physicians also need hope. Oncologists enter this field because of the biomedical challenge and also the challenge of the profession. "Hopefulness" is grounded in the biomedical dimension of the oncologist's work. Full disclosure is not possible or seen as therapeutic. Hope is central for both the oncologist and the patient. Further research of oncology and its relation to cultural implications of cancer is needed.

Ersek M. The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. *Oncol Nurs Forum*. 1992;19:883-889.

Objective: To explore the processes of hope in people who are confronted with information that emphasizes possible negative outcomes of illness and treatment.

Design: Exploratory--descriptive design with grounded theory methodology.

Setting: A large bone marrow transplant (BMT) center in the Pacific Northwest.

Subjects: Purposive sampling was used in the study. Twenty adults who underwent BMT were included in the sample.

Interventions: None.

Measures: Patients were interviewed 3 times while hospitalized. The interviews occurred during the preadmission period, between days 9 and 12 post-transplant, and again during days 25 to 28 post-transplant. The interviews were audiotaped and transcribed verbatim. 2 core categories were used to elaborate the process of maintaining hope: "dealing with it" and "keeping it in its place."

Results: Patients were found to use elements of each structure alone or interconnectedly. The structure of "keeping it in its place" has 8 components:

- appraising the illness in a nonthreatening manner
- managing the cognitions related to the illness experience
- managing the emotional response to the illness experience
- managing the sense of control
- taking a stance toward the illness and treatment
- managing uncertainty
- managing the focus on the future
- managing the view of the self in relation to the illness.

"Dealing with it" involves 4 components in the recognition of the negative possibilities inherent in the illness and allowing the full range of thoughts, behaviors and emotions resulting from the recognition. The 4 components are appraising the illness as a threat, allowing the emotional response, working through it, and moving on. The 2 core categories were presumed to be at odds with each other but it was found patients used components of both to successfully manage the process of hope. Thus, an overarching system was developed to integrate the 2: "Dialectic of Maintaining Hope." This system reconciles but does not eliminate the tension between both categories, presenting the

threat in such a way as to limit it, allowing the person to deal with it. Neither tactic was in itself sufficient, but the use of both strategies allowed hope to be maintained.

Conclusions: The "Dialectic of Maintaining Hope" was constructed through constant comparative analysis of the data. This theory describes the interplay between the recognition and acknowledgement of multiple threats resulting from illness and treatment and managing the impact of the threats.

Herth K. Fostering hope in terminally-ill people. *J Adv Nurs*. 1990;15:1250-1259.

Objective: To explore the meaning of hope and to identify strategies used to foster hope.

Design: A cross-sectional and longitudinal design combined with method triangulation using qualitative and quantitative measures.

Setting: Three hospices in the midwestern and southwestern US.

Subjects: A convenience sample of 30 terminally ill patients was studied.

Interventions: None.

Measures: Twenty participants took part in 1 cross-sectional semi-structured interview and were administered 5 open-ended questions about hope, the Herth Hope Index (HHI), and the Background Data Form (BDF). Interviews took place in the patients' homes with only the investigator and the patients present. The other 10 subjects finished the interview, HHI and BDF at 3 intervals before dying. These patients had entered the hospice program in the previous 2 weeks and had only minimal interference with their daily living activities. The BDF was only administered in the first interview. The second interview was conducted when severe impairment of daily activities were present, and the third interview occurred when physical signs and symptoms indicated the probability of death within 2 weeks. An independent qualitative analysis was used to establish relationships

Results: Hope-fostering strategies described by the patients were sorted into 7 unidimensional but not mutually exclusive strategies. 1) Interpersonal connectedness refers to the presence of a meaningful shared relationship with another person. 2) Attainable aims are characterized by purpose or a sense of direction. Participants who were able to maintain daily activities specified aims that were specific, tangible and focused on a short-term time period not longer than about two months. As patients became impaired, aims were focused less on the self and more on others. When death became imminent, aims reverted back to the self but more in terms of "being" rather than "doing" or "having". 3) The spiritual base refers to the presence of active spiritual beliefs and spiritual practices. 4) Personal attributes are those attributes within the self which foster uplifting feelings and thoughts. Determination, courage and serenity were specifically identified by the patients. 5) Lightheartedness is described as feelings of delight, joy, or playfulness communicated verbally and nonverbally. The remaining categories were 6) uplifting memories, and 7) affirmation of worth. Three categories of hope-hindering factors included abandonment and isolation, uncontrollable pain and discomfort, and devaluation of personhood.

Hope, as defined by terminally ill persons, is an inner power which facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being. In the first and second interviews, 6 key factors of hope and all 3 hope hindrance factors were mentioned. In the third interview, participants stressed interpersonal connectedness, spiritual base and attainable aims. No hindrances to hope were identified and the question was avoided. A trend was evidenced showing a slight increase in hope from the second to the third interview. There were no significant differences in level of hope according to age, sex, ethnic origin, family income, educational level, activity level, or fatigue level. Patients with a diagnosis of AIDS had significantly lower levels of hope. Family, friends, health care professionals, and God were the most frequently identified sources of hope.

Conclusions: Nurses can foster hope through facilitating caring relationships with patients, providing support, sharing information, and encouraging closeness.

Koopmeiners L, Post-White J, Gutknecht S, et al. How healthcare professionals contribute to hope in patients with cancer. *Oncol Nurs Forum*. 1997;24:1507-1513.

- Objective: To assess how health care professionals influence hope, as perceived by persons with cancer.
- Design: Descriptive and qualitative.
- Setting: An adult oncology/hematology unit in the MN area.
- Subjects: Thirty-two subjects completed the interviews.
- Interventions: None.
- Methods: A 20-item semistructured interview which focused on 4 categories: meaning of hope to the person, inner strengths/resources/faith, people and things that contribute to or lessen hope, and other questions on hope.
- Results: The health care workers who contributed most to hope in order of highest percentage were doctors (75%), nurses (63%), chaplains (28%), social workers (19%), and others (19%) with dietician, volunteers, housekeepers, and receptionists receiving lower percentages. The top ways health care professionals increase hope are by taking time to talk (46%), giving information in a respectful, honest, and sensitive manner with statistics being given compassionately and questions being answered (41%), being friendly and polite (38%), exhibiting caring behaviors (34%), being helpful (34%), just "being there" (25%), being respectful (22%), being honest (19%), and by being on the "leading edge" of treatment (19%). Fifteen patients responded to queries concerning how health care professionals decreased hope. Their answers included doctors giving discouraging medical facts, being candid without being positive, having poor communication skills, presenting information in a disrespectful manner, and being cold or feeling sorry for the patient. Patients also attributed loss of hope to receiving conflicting information from different physicians and having their situation trivialized. How information is written also affects hope. Finally, mean and disrespectful nurses lessen hope.
- Conclusions: Health care professionals have the ability to influence hope, both in a positive and negative manner.
- KKC note: Post-White wrote her dissertation on hope and found that patients with cancer who had increased hope had a higher quality of life and significantly less disease progression over 5 months.

Links M, Kramer J. Breaking bad news: Realistic versus unrealistic hopes. *Support Care Cancer*. 1994;2:91-93.

- Description of Context: To provide practical suggestions for offering realistic hope at various points in the stages of cancer disease.
- Topic/Scope: This article focuses on 3 stages of the disease. In the first, the initial stage, clinicians are advised to be open about whatever diagnosis the physician is testing the patient for, including the possibility that the diagnosis is not cancer. Patient fears and concerns should be discussed and brought out into the open. The more likely possibilities should be emphasized. Individual patients should be monitored for their comfort with openness. Once the initial work-up is complete and a cancer diagnosis is certain, realistic cures or hopes should be discussed such as prolonged disease-free survival or palliation of symptoms.
- The second stage is the transitional stage when definitive treatment fails and a purely palliative approach is needed. As successive attempts at cure fail, this can be a gradual process of slowly helping change patient expectations in a realistic yet supportive way. This allows for the discussion of future goals without completely taking away hope. Some realistic hopes are that the disease remains stable and the symptoms can be well controlled. The patient must be reassured that they will not be abandoned.
- The third stage is the advanced stage when there is no hope that patients will remain well or in a stable condition. The greatest hope is that symptoms will be well controlled and suffering will be minimized. Clinicians should not challenge what seems to be inappropriate hope unless it causes major problems. Instead, they should emphasize

more realistic hopes such as focusing on spiritual issues, family, prolonged survival, or even that death will come quickly.

In all of these stages, there are communication basics which must be implemented. These include not being rushed with the patient, being supportive and interested in the patient as a person, and using simple language and avoiding jargon. Caregivers should avoid extremes of optimism or pessimism, but should emphasize probabilities instead and let the patient have a plan for the immediate future. The patient remembers the attitude of the person who communicates the message as much as the message. When the doctor maintains appropriate hopes and communicates them to the patient, common goals can be shared.

Conclusions/Recommendations: It is important to have some hope paired with appropriate realism so as to facilitate a gradual transition. The physician should emphasize appropriate hopes as opposed to contradicting inappropriate ones.

Penrod J, Morse JM. Strategies for assessing and fostering hope: The Hope Assessment Guide. *Oncol Nurs Forum*. 1997;24:1055-1063.

Description of Context: Morse and Doberneck's (1995) conceptual framework was applied in developing The Hope Assessment Guide for women who survived breast cancer. The guide describes how to develop hope, and can be used by the nursing staff.

Topic/Scope: There are 6 stages of hope. Stage 1 involves recognizing the threat and is manifested by reiteration, either to self or others. The nursing staff assesses whether the impact of the event was realized by the patient, then fosters this by educating the patient and responding to her feelings. Stage 2 involves making a plan. The nursing staff should assess whether the patient has a plan, and whether she is prepared for an adverse outcome. Strategies to facilitate the completion of these tasks include exploring options, finding appropriate supports, and sharing the plan. Stage 3 involves taking stock or assessing personal/external resources. The nursing staff should examine what resources the patient has identified, support a realistic self-assessment, monitor the support network, and help orient the woman to external resources. Stage 4 involves reaching out for mutually supportive relationships. Although this is not exhibited behaviorally, the nursing staff should check that adequate support exists. Stage 5 involves continuously looking for signs of reinforcement in which the woman is clarifying information, reviewing history, frequently conducting a self-examination of the breast, and comparing herself to other survivors. The nursing staff should check to see what reinforcing signs are being received and point them out to the patient. Stage 6 consists of holding on and persevering. The patient will be using coping techniques, focusing energy, and expressing a new perspective on life. The nursing staff should assess whether the woman has appropriate stamina and will, and should provide encouragement and support the woman's endurance.

Conclusions/Recommendations: Hope is fluid, changing throughout the process of diagnosis and treatment. The conceptual model accounts for this and provides a means of clinically assessing the patient's level of hope.

Rustoen T. Hope and quality of life, two central issues for cancer patients: A theoretical analysis. *Cancer Nurs*. 1995;18:355-361.

Description of Context: To examine different ways of defining quality of life (QOL) and hope, and to discuss the relationship between the 2 concepts.

Topic/Scope: Definitions of quality of life that are relevant to health care include normal life, happiness/satisfaction, achievement of personal goals, social utility, and natural capacity. QOL is a multidimensional construct and encompasses both affective and cognitive aspects. As there are both objective and subjective areas as well, patients must evaluate their own lives and present situation. Hope is not normally present in the conscious portion of the individual but rises to consciousness when a person is faced with a crisis or conflict. It is a feeling of the possible, an inner readiness and an unused resource. Motivation plays an important role as hope is future-oriented, with goal attainment and

choice a focus. The possible and realistic are related to hope as it is also affected by interpersonal relationships, trust, and faith. Hope and QOL can be viewed separately or intertwined. Common characteristics shared by both include the focus on interpersonal relationships, multidimensionality, time, and realistic expectations. Hope is an important factor in influencing QOL, because it increases coping abilities in regards to stress, and decreases illness that affects QOL. Hope is used as a strategy for coping, a resource for coping, or a coping task.

Conclusions/Recommendations: As a coping strategy, hope can be used to reduce stress caused by cancer and to improve QOL.

Spirituality

Post SG, Puchalski CM, Larson DB. Physicians and patient spirituality: Professional boundaries, competency, and ethics. *Ann Intern Med.* 2000;132:578-583

Sloan RP, Bagiella E, VandeCreek L, et al. Should physicians prescribe religious activities? *N Engl J Med.* 2000;342:1913-1916

Two "spirited" but opposing views about whether or not physicians should discuss spirituality with patients. First paper (by ethicist and 2 MD's) outlines four topics: importance of spirituality in clinical outcomes; need for a brief spiritual needs assessment; maintaining professional boundaries as physician vs. spiritual counselor; and dealing with patient requests for prayer by the physician. The second paper (mostly by chaplains) criticizes the evidence that spirituality plays a role in clinical outcomes, argues that physicians are unskilled as spiritual counselors, and warns that the philosophical bases of science and spirituality are too disparate to join.

Cella D. Health promotion in oncology: A cancer wellness doctrine. *J Health Care Chaplain* 2000;4:87-101

Description of context: Presents 8 central beliefs of the cancer wellness doctrine.

Scope: 8 central beliefs, each with a modifier, are:

My health is my responsibility

I did not cause my disease

I will always have hope

What I hope for may change over time

My doctor and I are partners

We both have things to learn

Death is not failure

Personal dignity and quality of life are better measures of success

Cancer provides me with an opportunity

I don't have to be grateful for that opportunity

I am willing to change the way I deal with stress

The past is unimportant unless I make it so

Cancer is a family illness

My family needs my attention now

I have the power to make a difference in my care

I need to look within myself for the proper direction

Lynn J. Serving patients who may die soon and their families: The role of hospice and other services. *JAMA* 2001;285:925-932

Description of Context: Review of elements of palliative care. Organization and financing of

health care makes it difficult to integrate some elements, particularly hospice, into routine primary care of many patients with chronic progressive disease.

Topic/Scope: Serious chronic illness at the end of life follows 1 of 3 courses: 1) short period of obvious decline (cancer); periodic acute exacerbations amenable to aggressive treatment (organ system failure); or slow “dwindles” (dementia). Hospice as a model of care provides competent, continuity, and comprehensive care but current health care organization and financing limit its application in diseases where one isn’t clearly “dying” or “not dying.”

Conclusions/ Recommendations: The basics of palliative care (prevention and relief of symptoms, treatment methods accountable to goals, advance planning, and preparation for the time near death) need to be integrated into routine care. Current enrollment and billing guidelines for hospice care in a wide variety of diseases are reviewed, and changes are proposed in organization and financing of end of life care.

Lee SJ, Fairclough D, Antin JH, Weeks, JC. Discrepancies between patient and physician estimates for the success of stem cell transplantation. *JAMA* 2001;285:1034-1038

Objective: Measure expectations of physicians and patients prior to SCT and correlate them with actual outcomes

Design: Prospective cohort study with questionnaires

Setting: Tertiary transplant center in U.S.

Subjects: 313 patient / physician pairs

Interventions: none

Measures: Pre-treatment expectations of: treatment mortality; cure with and without STC; actual treatment-related mortality and disease-free survival at 1 year

Results: Patient and physician estimates of treatment mortality are in agreement when actual mortality was <30%. When mortality was higher than 30%, physician expectations for treatment-related mortality and for disease-free survival were lower than patient expectations, which remained high and constant.

Conclusions: Patients (and doctors) have the most concordant and accurate expectations of results of STC when the outcome is favorable. Patients with more advanced disease fail to recognize the higher risks to them.

Comment: Authors note that dr & pt may avoid discussions of discouraging statistics, instead focusing on curative potential of procedure. Drs worry about destroying patient’s hope and will to live, and may selectively withhold or minimize some details, use qualitative rather than numeric probability statements, emphasize optimistic info, or suggest that grim prognostic estimates apply to groups of people but not to them as individuals. Pts may have powerful psychological incentives to be optimistic and if forced to face grim statistics, develop anger, denial, distrust, distress. They call for greater dr-pt dialogue about treatment choices to encourage attention to personal, financial and family arrangements, and preparation for the most likely outcome (death).

Munch S, deKryger L. Moral wounds: complicated complications. *JAMA* 2001;285:1131-1132

Description of context: A joint essay by a patient and her doctor, documenting their recollection of informed consent and their reaction to a surgical complication: vocal cord paralysis after resection of a thyroid nodule.

Topic/Scope The patient doesn’t recall hearing that irreversible hoarseness from vocal cord paralysis can happen with this surgery. The doctor recalls identifying the responsible nerve during surgery and being careful not to cut it. He has never had this complication happen in his practice but did tell the patient she could have temporary hoarseness after surgery. The patient feels that full disclosure of risk wouldn’t have changed her mind about the surgery but she lost faith and

trust in the doctor after learning that this complication was among the most common.

Conclusions/Recommendations: It's hard to impart large chunks of information and exact outcomes, even when dr and pt are both trying. Patients get lots of information from sources other than doctors. For drs, "routine spiels" for informed consent may be heard differently by the sender and the receiver; it's hard to convey explicit meanings because of limitations of language and lack of shared assumptions.

Faulkner A. ABC of palliative care: Communication with patients, families, and other professionals. *BMJ* 1998; 316:130-132

Description of context: Brief but comprehensive overview of communication problems at end of life.

Topic/Scope: Brief principles for dealing with breaking bad news, denial, difficult questions about prognosis and hope, and strong emotions. Also detecting "collusion" with patient and family to avoid addressing upsetting issues.

Conclusions/Recommendations: Collusion also occurs between professionals. Common problems include defining roles, boundaries, and differing philosophies of care. Helpful to try to see the issue from colleague's point of view, starting with their perceptions and assumptions. Burnout can contribute to this problem.

Dunn SM, Patterson PU, butow PH, Smartt HH, McCarthy WH, Tattersall MHN. Cancer by another name: A randomized trial of the effects of euphemism and uncertainty in communicating with cancer patients. *J Clin Oncol* 1993;11:989-996

Objectives: Does using the word "cancer" (vs "illness") affect anxiety or coping?

Design: Main focus was development of a self-rated measure of emotional adjustment to cancer. RCT of 1) self-report vs interview; 2) "cancer" vs "illness", 3) clinic vs home.

Setting: Tertiary cancer center in NSW, Australia

Subjects: 165 patients with heterogeneous cancer diagnoses

Interventions: Self-rated measure of emotional adjustment, variables above

Measures: New measure of psychological adjustment to cancer; Spielberger state-trait anxiety measure

Results: Use of the word "cancer" increases anxiety a bit but doesn't affect adjustment.

Conclusion: In the cancer clinic and hospital, use of "cancer" by patient and staff decreases fear and shame, enables people to think more clearly about the disease and treatment, even though it may increase anxiety somewhat.

Yuval R, Halon DA, Lewis BS. Patients' point of view in heart failure trials (letter). *JAMA* 2001;285:883-884.

Objectives: Explore patients' motivation to join a clinical trial; understanding of trial's purpose; perceived clinical benefit; and interest in future trials.

Design: Anonymous mailed questionnaire

Setting: Tertiary care center in Israel

Subjects: 70 of 78 consecutive patients enrolled in 1 or more heart failure trials

Interventions: none

Measures: Perceived comprehension of study; recollected duration of explanation of study; reason for enrolling; degree of perceived improvement and why; inconvenience of the trial; interest in future trials.

- Results:** Reasons to join included: better followup (61%), better treatment (20%), help medical research (17%). Only half recalled the content of the oral consent and 3% recalled content of the written consent. Perceived comprehension of the study was related to recollected duration of explanation, with peak efficacy at 5-15 minutes of explanation. 78% felt moderately to markedly improved by the trial; 64% said it was from better followup vs 25% from the treatment intervention. Possibility of placebo effect on improvement was of no concern to 90% of patients.
- Conclusions:** Patients remember less than half of what they hear and little of what they read about a clinical trial. They enter largely for better followup, and are likely to report clinical improvement. The optimal duration of the informed consent discussion is 5-15 minutes, after which recall suffers.

Friedrichsen MJ, Strang PM, Carlsson ME. Breaking bad news in the transition from curative to palliative cancer care – patient’s view of the doctor giving the information. *Support Care Cancer* 2000;8:472-478

- Objectives:** Explore how patients experience the news from a physician that their disease is disseminated and incurable.
- Design:** Qualitative analysis of semi-structured interviews
- Setting:** Swedish hospital-based home care unit
- Subjects:** 30 patients
- Interventions:** none
- Measures:** “phenomenography” method of content analysis
- Results:** Patients described their doctors as experts in different ways. Six subcategories were identified: 1) inexperienced messenger; 2) emotionally burdened; 3) rough and ready expert; 4) benevolent but tactless expert; 5) “distanced” doctor; and 6) empathic professional. The doctor-patient relationship was felt to be central and built up over time. It was described in four subcategories: 1) personal between well-acquainted individuals; 2) impersonal between unacquainted individuals; 3) personal between unacquainted individuals; and 4) impersonal between well-acquainted individuals.
- Conclusions:** Patient coping depends on 2 physician features: character traits and ability to create personal relationships. Patients need to feel trust and security from an experienced doctor who gives practical guidance. The doctor must show commitment to both the disease and the person. Empathy is important and is a balance between closeness and distance. Patients spend time and energy analyzing their doctors, getting to know them and assessing what confidence they feel. Doctor’s communication skills and attitude determine patient’s coping.

Barroso P, Osuna E, Luna A. Doctors’ death experience and attitudes towards death, euthanasia and informing terminal patients. *Med Law* 1992;11:527-533

- Objectives:** Analyze the influence of personal biographic circumstances on physicians’ attitudes towards death and terminal patients.
- Design:** 1-time questionnaire administration
- Setting:** All practicing physicians in Cordova, Spain
- Subjects:** 153 doctors, ages 22-77, all specialties
- Interventions:** none

- Measures: 74-item questionnaire on sociopersonal data, leisure time activities, biographical antecedents, and attitudes towards terminal patients and death. Discriminant analysis was done for specific variables.
- Results: Physicians who believe that dying patients should never be told they are dying are likely to have greater fear of their own death, to avoid references to their own death, and to express more rigid attitudes towards end of life care. The later in life a physician's first encounter with death good place, the more difficulty he/she experienced with patient death. Physicians raised in rural environments expressed less fear and anguish over their own death.
- Conclusions: Physicians' attitudes toward end of life care are determined in part by the timing and nature of their personal exposure to death. Doctors with greater fear of death favor not discussing death, treating pain aggressively, wanting to be unconscious at the time of death, and belief in God.

The A, Hak T, Koeter G, van der Wal G. Collusion in doctor-patient communication about imminent death: An ethnographic study. *BMJ* 2000;321:1376-1381

- Objectives: To discover and explore the factors resulting in "false optimism about recovery" seen in some patients with small cell lung cancer.
- Design: Qualitative observational study in 2 stages over 4 years
- Setting: University hospital in the Netherlands
- Subjects: 35 patients, mostly men, with recurrent small cell lung cancer after initial chemo
- Interventions: none
- Measures: In-depth continuity observations and interviews of doctors and patients, including clinic, hospital, and home visits, by one investigator
- Results: Doctors outlined the nature and prognosis of small cell lung CA, indicating that it was not curable, at the initial visit. Prognosis is avoided by stating that "every patient is unique." Then there is an immediate shift to further treatment and tests. Patients assumed treatment would not be given without good reason. Prognosis was not discussed again – patients didn't ask and doctors assumed that meant they didn't want to know. Doctors, patients, and families colluded in a "recovery plot" especially if treatment normalizes the xray. Patients assumed they were cured, even though doctor said they were cured (when doctors said treated and in remission). Recovery stories and optimism helped patients and families through treatment but there was often regret when they realized that they were incurable and didn't take time to do more important things. Retrospectively both doctors and patients stated they knew, and at the same time didn't know, that the patient would die within a year or two.
- Conclusion: The doctor does and does not want to tell the patient of a dismal prognosis, and the patient does and does not want to know. Doctors and patients (and families) collude with each other to avoid talking about treatment failure. Treatments, testing, and checkups provide short term, optimistic end points, to the exclusion of discussing broader prognostic issues and treatment goals. This leads to regret for patients and families, and frustration for doctors when patients deny obvious progression of disease. Communication training for practitioners may not be adequate to correct the problem since the patient also plays an active role in the collusion. The authors suggest that a new role, "treatment broker," could help all parties stay on the same page.

Smith TJ. Tell it like it is. *J Clin Onc* 2000;18:3441-3445

Description of context: A practicing oncologist describes the use of written treatment plans to enhance communication.

Topic/scope: Review of patient and system barriers to effective communication. Patient barriers: unrealistic expectations; being too complacent, or too fearful, to question treatment goals. System barriers: time, angst, lack of skill, physical office setup, reimbursement disincentives. Lack of empathy, and inattention to patients' lists and concerns, are also mentioned. Author shows 3 templates: 1) overview of diagnosis, prognosis, treatment goals and plan; 2) plan for curative treatment; 3) plan for palliative treatment. Doctor completes the form with the patient. Templates are blanks to fill in, eg: call office if _____. Copies to medical record, patient, consultants and consultees.

Conclusions/recommendations: Author's colleagues find that using the plans leads to better patient comprehension, honest communication, and saves time. Author also recommends patient fill out a standardized QOL instrument to remind both parties to broaden treatment goals. Author notes patients facing life-threatening illness have different values and make different choices than those who are not. Specifically, cancer patients are willing to undergo chemo with major toxicity for a 10% chance of symptom relief, while their doctors and nurses would require a chance of >50%. Also notes that doctors overestimate prognosis by a factor of 5.

Butow PN, Dunn SM, Tattersall MHN, Jones QJ. Patient participation in the cancer consultation: Evaluation of a question prompt sheet. *Ann Oncology* 1994;5:199-204

Objectives: Comparison of question prompt sheet vs. general info sheet on question-asking, recall, satisfaction, and adjustment in the oncology visit

Design: Randomized controlled trial

Setting: University hospital in NSW, Australia

Subjects: 142 patients at first consultation with a single oncologist

Intervention: Question prompt sheet vs. general info sheet 10 min prior to visit

Measures: CT-LOGIT analysis of audiotaped encounters; patient satisfaction, recall, psychological adjustment. Multiple regression to explore predictors of duration and number of questions patients asked during visit.

Results: Patients asked an average of 5.5 questions, taking up 32 seconds during consultations of avg 28 minute duration. The prompt sheet doubled the percent of patients asking questions about prognosis (from 16% to 35%) but did not increase the number of questions asked overall. More question asking was related to being young, female, outpatient, and wanting to be involved in decisions.

Conclusion: A question prompt sheet can help doctors and patients address prognosis. This is a difficult area to discuss and doctors and patients often "collude" to avoid it.

Tobin D, Larsen D. Conversations at the end of life. *JAMA* 2001

VonGunten CF, Ferris FED, Emanuel LL. Ensuring competency in end-of-life care: communication and relational skills. *JAMA* 2000;284:3051-3057

Finucane T. How gravely ill becomes dying: A key to end of life care. *JAMA* 1999;282:1670-1672

Slevin ML, Stubbs L, Plant HJ, et al. Attitudes to chemotherapy: Comparing views of patients with cancer with those of doctors, nurses, and general public. *BMJ* 1990;300:1458-1460