

Cancer Control  
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### **Palliative Care, Pain & Cancer Pain**

1. Introduction: the imperative for palliative care
  - a. most patients want to live as long as possible, symptom free, but don't
  - b. most doctors don't get much training
  - c. costs are a problem
    - 1) rapidly escalating
    - 2) 15% of GNP spent on health care, and rising
    - 3) unlimited wants, limited means
    - 4) hospitals full, esp. ICUs, with small margins
2. What we did
  - a. 11 bed inpatient unit
  - b. concentrate on the goals defined by the patient
    - 1) complete honesty about what medical science can/cannot do
    - 2) change the services
    - 3) concentrate on symptom management
    - 4) social work and chaplain involvement
3. Results
  - a. better service delivery
  - b. markedly better symptom relief
  - c. markedly less cost (see J Pall Med October 2003 article)
    - 1) case control method
    - 2) pre- post-inception cohort method
    - 3) replicated at 6+ other centers now
  - d. Replication at other centers...1500+ and counting

### **Patient and Physician Decision Making near the end of life**

1. The conflict between limited means and unlimited desires
  - a. Health care and cancer care costs are escalating rapidly – 15% of GNP
  - b. More people with cancer
  - c. More expensive regimens
  - d. Health care policy that allows for higher co pays, higher premiums, higher everything – will price many patients out of the market
2. What we know about patient decision making
  - a. the available studies all show that patients will do almost anything for (what healthy people perceive as) small benefits (See Matsuyama R, Reddy S, Smith T. J Clin Oncol, in press)
  - b. “decision making under duress is not entirely rational”

- c. Patients don't like to discuss bad news (Helft's concept of "necessary collusion" between doctor and patient to avoid prognostication and use "forecasting". "Here's what could happen...")
  - d. Patients would prefer discussing bad news with
  - e. Patients have a hard time getting straight answers about prognosis and treatment effect
    - 1) The et al study of 35 lung cancer patients: patients learned more about their illness from other patients than the doctors
    - 2) Belgium study documented that only 39% of patients ever had any discussion about prognosis. Most of the visit was about treatment
    - 3) Vermont study (Silvestri et al, BMJ)
    - 4) NCI website Cancer.Gov
    - 5) ALCASE lung cancer website
    - 6) American Cancer Society website
3. What we know about physician decision making
- a. doctors won't give realistic prognosis, if they know it, 67% of the time
  - b. doctors overestimate survival by 43% or more (5.1 x in one large study)
  - c. doctors don't like to give really bad news
  - d. reimbursement all towards doing, not talking
  - e. average hospital doctor visit is 3 minutes...not much time for discussion
4. Potential solutions. Recognizing **decisional conflict**, defined as uncertainty about which course of action to take when the choice involves balancing gain, risk, loss, regrets or challenges personal life

## 9. RESEARCH PLAN (SECTIONS A-E)

### A. Specific Aims *(This is written as a grant specifically for African-American patients.*

*We know that African American patients are more likely, compared with Caucasians, to:*

- *start chemotherapy closer to death. 20% or more within 2 weeks of death*
- *get worse pain relief (not clear whose fault that is)*
- *get referred to, or accept, hospice much later if at all. Traditionally, hospice use has been half of expected)*

We will develop and test an intervention to give full information over the Internet to patients *with advanced metastatic cancer* about their cancer prognosis, treatment options, treatment effectiveness, benefits and side effects. This trial will first assess what people want to know about prognosis and treatment. If they opt for full disclosure, we will assess current knowledge, intended actions, hope, and desire for more knowledge; after the intervention, we will assess knowledge, intended actions, desire for more knowledge, hope, and satisfaction.

In the pilot trial, we will create state-of-the-art tables of information for patients with the following types of advanced cancer: breast, lung, colon, and hormone-refractory

prostate cancers. Next, we will put this information into easy to understand single page sheets such as used with Adjuvant! ([www.AdjuvantOnline.com](http://www.AdjuvantOnline.com)). Patients will complete the information session, then print their individualized sheets containing their prognosis, treatment effects, options, and the four most common side effects. We will pre-test the intervention in 25 patients recruited through the Dalton Oncology Clinic, which serves about 50% African American patients and is the largest provider of indigent care in Virginia. We have readily available internet access in our on-site Patient-Family Library, with trained “navigators” to help patients who do not have access at home.

In the internet trial, we will post the information on the Massey Cancer Center webpage with links to the National Coalition of Cancer Survivors, Cancer.Gov, and the American Society of Clinical Oncology People Living with Cancer, linkages all pending but supported by parent organizations) and test in consecutive patients until we reach 100 African American patients. For all patients, we will first assess what the patient wants to know about their prognosis and treatment. If the patient opts for full disclosure, then we will answer the following questions, much as an experienced clinician would do at the bedside:

- What is my chance of cure?
- What is the chance that chemotherapy will make my cancer shrink?
- What is the chance that chemotherapy will relieve my primary symptoms?
- How much will treatment improve my chance of being alive at a relevant time, usually 1 year?
- How long will patients like me live, on average?
- What is the chance that I will feel better or worse? (Impact on formal quality of life, if known)
- What are the main side effects?
- What are the options, including chemotherapy and non-chemotherapy options such as hospice or palliative care?

Our primary aim is to determine the number of patients who will opt for full disclosure. The hypothesis is the following:

H<sub>1</sub>: Patients will opt for full disclosure about their condition, including actual prognosis, actual treatment effect estimates, and discussion of options.

Our secondary aims are: 2) to measure the information that patients access and process, 3) to assess satisfaction with the information and their choices, 4) to assess if patients intend to share the information with their doctor; and 5) to assess the impact of truthful information on hope, as measured by a commonly used index. The secondary hypotheses are the following:

H<sub>2</sub>: Patients who complete the information will be better informed about their disease prognosis, treatment benefits, and treatment side effects after the decision aid.

H<sub>3</sub>: Patients who complete the intervention will be more satisfied with their information than they were before the intervention.

H<sub>4</sub>: Patients who complete the intervention will intend to share the information with their doctor.

H<sub>5</sub>: Patients who complete the intervention will have no change in their hope.

This is a pilot study that will be conducted at the Massey Cancer Center (MCC) of Virginia Commonwealth University, and on the internet including the MCC and linked websites. This study will inform a randomized trial to test our intervention, a decision aid for truthful and honest information about advanced metastatic cancer, against standard care.

**D.3. How will the information be presented?**

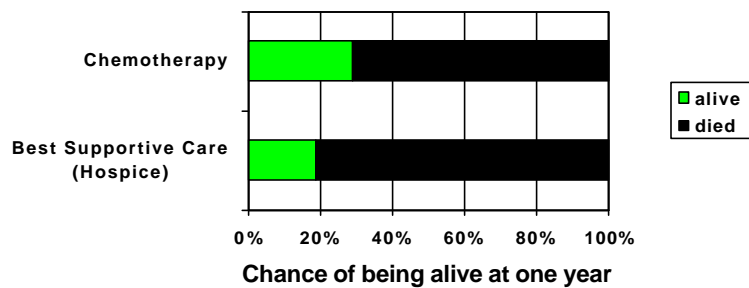
We will present the information both as text answers, and when possible as Figures from showing the impact on 100 people, an understandable and preferred format (Staytor 1998), and one that is in use with Adjuvant!Online and Numeracy (Whelan & Loprinzi 2005). Each patient will review the data on the screen, and receive a printed handout. A partial sample is given below.

Patient Name: \_\_\_\_\_

Age 60 Non small cell lung cancer Performance Status 0-2 (from patient query)

Status: 2<sup>nd</sup> line chemotherapy

**What is my chance of being alive at one year if I take chemotherapy, or do best supportive care such as hospice?** Chemo improves the chance of being alive at one year by 10 out of 100 people.

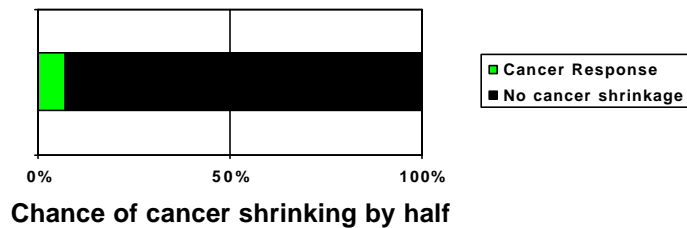


**What is the chance of my cancer shrinking by half?**

About 7 of 100 people will have their cancer shrink by half.

If the cancer grew on the first treatment, the chance of the cancer shrinking is lower (None, 0%, in Shepherd’s trial.)

If many symptoms are due to the cancer, the chances are less. (All the patients whose disease shrank in Shepherd’s trial were Performance Status 0 or 1)



**What is the chance of my being cured by chemotherapy?**

Very few people are cured by chemotherapy.  
 In this group of patients, none of them were cured. You may want to ask your doctor for your own chances.

This is a representative sample. The data from all Table 3 questions will be presented in the simple question/answer format, with answers in “Of 100 people....”.

Table: Available studies that address the choices actual cancer patients would make about palliative treatment (Reprinted from Matsuyama R, Reddy S, Smith TJ. J Clinical Oncol in press

Author, Country, year	Clinical situation	Results	Conclusion
Slevin, England, 1990	Median benefit required to make intensive chemotherapy treatments worthwhile for patients	Patients would do toxic treatment for a 1% chance of cure; 10% chance of symptom relief; chance to prolong life 12 months Their doctors and nurses would require 50% chance of cure, 75% chance of symptom relief, and 24-60 months added survival.	Patients are more willing to risk side effects than their health care providers, for a smaller benefit.
Bremnes, Norway, 1995	Willingness of patients to accept toxic chemotherapy as compared to non-patients	Patients under 40 years old would accept the toxic treatment with only a small benefit: chance of cure (7% median), life prolongation (3 months) and symptom relief (8%).	Patients are more likely to choose chemotherapy with a small chance of success than their providers.
Davies et al., Great Britain, 1996	Randomized trial in which patients with malignant cerebral glioma were treated with moderate dose radiation or not	No effect of radiation on survival, and 68% experienced negative side effects. The majority of patients would still do radiation even knowing it had no effect on survival.	Patients may choose treatments that do not show objective benefit, even with full disclosure. “Conceptualising the question as a rational choice ignores the social and emotional context of life threatening disease.”
Tamburini, Buccheri et al 2000	Proposed chemotherapy for 102 NSCLC patients	Patients would be willing to do chemotherapy for small benefit, even if the doctor presents the results pessimistically.	“The choice between accepting and rejecting chemotherapy is very difficult for patients with NSCLC, much more so than for healthy people, and it is often independent of the way the information is provided.”
Silvestri et al, US, 1998	Assessed the benefit that previously treated NSCLC patients would require to do treatment	The median survival threshold for accepting chemotherapy was 4.5 months for mild toxicity and 9 months for severe toxicity. When given the choice between supportive care and chemotherapy 22% chose chemotherapy for a survival benefit of	When given the choice between supportive care and chemotherapy, only 22% of previously treated patients would choose chemotherapy for a survival benefit of 3

		3 months, the expected benefit. If it substantially reduced symptoms without prolonging life, 68% would choose chemotherapy. Only one quarter remembered hearing any options about treatment that did not involve chemotherapy such as palliative care.	months, the actual benefit compared with best supportive care. Most did not remember any other option besides chemotherapy.
Brundage et al, Canada, 2001	Cancer patients faced with hypothetical choices	57% of patients would choose chemotherapy for a survival benefit of 10% at one year. Some chose more toxic treatments even if it offered no survival advantage and others declined chemotherapy regardless of perceived advantage of treatment. It was difficult to predict what individual patients would choose	Much variation among patients, and difficult to predict who would choose chemotherapy or not.
Balmer et al. Great Britain, 2001	Patients with cancer queried about second line chemotherapy.	Patients accepted a lower chance of benefit than their doctors or nurses, even when treatment involved greater toxicity.	Patients are more willing to undergo second line chemotherapy than most providers imagine.
Hirose et al, Japan, 2005	NSCLC patients facing chemotherapy.	If their lives would be prolonged by 3 months, 19% would choose to receive intensive treatment, and 21% would choose less intensive treatment. With a 70% chance of symptom relief, 73% of patients were willing to choose intensive chemotherapy	More patients would do treatment to reduce symptoms, and more cancer patients would do treatment than students or other patients with respiratory disease.

Table 3: Conceptual framework of decision support for Decisional Conflict (Modified from Murray et al, 2004)

<b>Assessment of Patient and Family Information Needs</b>	<b>Provide decision support to the patient and family</b>	<b>Evaluate</b>
<p><b>Stage of disease</b>  <b>How much does the patients want to know about the prognosis?*</b>  <b>How much does the patient want to know about the effectiveness of treatment?*</b>  <b>How much does the patient want to know about the natural history and what is likely to happen?*</b></p>	<p><b>Provide access to information about</b>                      Health situation (Stage, prognostic factors)*                      Options*                       Outcomes*                       Other's opinions and choices*</p>	<p><b>Decision making</b>                      Reduced decisional conflict                      Improved knowledge                      Realistic expectations and norms                      Clear values                      Agreement between values and choices                      Implementation of chosen options                      Satisfaction with decision making</p>
<p><b>Perception of the decision*</b></p> <ul style="list-style-type: none"> <li>• Knowledge*</li> <li>• Expectations*</li> <li>• Values</li> <li>• Decisional conflict</li> <li>• Stage of decision making</li> <li>• Predisposition</li> </ul>	<p><b>Re-align expectations of prognosis, treatment outcomes, life outcomes to reality*</b></p>	<p><b>The outcomes of the decision, or decisions</b></p>
<p><b>Perception of others</b></p> <ul style="list-style-type: none"> <li>• Others opinions and practices</li> <li>• Support</li> <li>• Pressures</li> <li>• Roles in decision making</li> </ul>	<p><b>Assess the personal values and meanings for outcomes such as survival, quality of life</b></p>	<p>Persistence with choice</p>
<p><b>Resources to make decision</b></p> <ul style="list-style-type: none"> <li>• Personal</li> <li>• Previous experience</li> <li>• Self confidence</li> <li>• Motivation</li> <li>• Skill</li> <li>• Resources to make decision</li> <li>• External: Support – information from social networks and agencies</li> </ul>	<p><b>Provide decision support (Coaching or guidance)</b></p>	<p>Improved quality of life</p>
<p><b>Characteristics: person</b></p> <ul style="list-style-type: none"> <li>• Age, sex, marital status, education, culture, diagnosis, other health status</li> <li>• External Support – information from social networks and agencies</li> </ul>	<p>Steps in decision making</p>	<p>Reduced distress</p>
<p>Personal</p> <ul style="list-style-type: none"> <li>• Previous experience</li> <li>• Self confidence</li> <li>• Motivation</li> <li>• Skill</li> <li>• Resources to make decision</li> </ul>	<p>Communication with others</p>	<p>Reduced regret</p>
<p><b>Characteristics: practitioner</b> Age, sex, practice style, education, personality style, counseling style, practice style (early vs. late adopter, willingness to use Phase I, II or III trial information, financial restraints on practice)</p>	<p>Handling pressure, especially from family</p>	<p>Informed use of resources</p>
	<p>Using available support measures (will vary from culture to culture)</p>	<p>More dignity</p>