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A Pilot Trial of Decision Aids to Give Truthful Prognostic and Treatment Information to Chemotherapy Patients with Advanced Cancer

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Abstract

Most cancer patients do not have an explicit discussion about prognosis and treatment despite documented adverse outcomes. Few decision aids have been developed to assist the difficult discussions of palliative management. We developed decision aids for people with advanced incurable breast, colorectal, lung, and hormone-refractory prostate cancers facing first-, second-, third-, and fourth-line chemotherapy. We recruited patients from our urban oncology clinic after gaining the permission of their treating oncologist. We measured knowledge of curability and treatment benefit before and after the intervention. Twenty-six of 27 (96%) patients completed the aids, with a mean age of 63, 56% female, 56% married, 56% African American, and 67% with a high school education or more. Most patients (14/27, 52%) thought a person with their advanced cancer could be cured, which was reduced (to 8/26, 31%, $P = 0.15$) after the decision aid. Nearly all overestimated the effect of palliative chemotherapy. No distress was noted, and hope did not change. The majority (20/27, 74%) found the information helpful to them, and almost all (25/27, 93%) wanted to share the information with their family and physicians. It is possible to give incurable patients their prognosis, treatment options, and options for improving end-of-life care without causing distress or lack of hope. Almost all find the information helpful and want to share it with doctors and family. Research is needed to test the findings in a larger sample and measure the outcomes of truthful information on quality of life, quality of care, and costs.

Patients with incurable disease state that they want truthful information about their diagnosis, treatment options, and course even if the outlook is poor;¹ but most patients never receive information from their physicians about prognosis² or even imminent death.³ U.S. physicians do not disclose prognosis at least half the time and feel unprepared to have these discussions.⁴ Not having a discussion about imminent death is associated with worse quality of care, worse quality of life, worse caregiver quality of life,⁵ and over \$1,000 more in medical care cost in the last week of life.⁶ Physicians are reluctant to give people poor prognostic information⁷ for fear of dashing hope,⁸ and Web sites such as www.cancer.gov do not contain detailed information about prognosis, survival, palliative care options, or hospice referrals.

We designed decision aids for patients with incurable cancer and attempted to determine if people would opt for full disclosure about prognosis and treatment. If they opted for full

disclosure, we assessed current knowledge about chance of cure, survival, disease response rates, and symptom control, before and after. This pilot trial was done to see if patients would complete a decision aid about their advanced cancer, even if it contained truthful information about their limited prognosis and treatment benefits.

Methods

We created state-of-the-art tables of information for patients with advanced breast, lung, colon, and hormone-refractory prostate cancers, based on expert review, external review, and comparison with Up To Date© (available from the authors). The information was approved by all three oncologists involved. We used bar graphs to illustrate benefit, developed for patient education graphs for a randomized study of insurance types and treatment choices⁹ and in common use on the Web site Adjuvant Online (www.adjuvantonline.org).^{10,11} It is similar to what we do with the written medical record, a concise review of diagnosis, prognosis, treatment options, side effects, and when to call the doctor.¹²

We tested the intervention in a heterogeneous sample of 27 patients recruited through the Dalton Oncology Clinic, which serves a mix of patients from the most discerning third-opinion clinical trial patient to the community cancer patient and provides most of the indigent cancer care in the central Virginia area. The study was done within 3 months in early 2009.

Our primary outcome was the number of patients who would opt for full disclosure once they viewed the decision aid. Our secondary outcomes included the following: the amount of information patients have about cure, response rates, and symptom control; the impact of truthful information on hope, as measured by the Herth Hope Index©¹³ (HHI) used to assess hope in clinical studies of adults;¹⁴ whether the information was deemed helpful to the patient; and whether the patient intended to share the information with a doctor.

Patients were accrued by reviewing the daily clinic list to find patients on treatment for incurable breast, colorectal, non-small-cell lung, or hormone-refractory prostate cancer. Treating oncologists were made aware of the study through e-mail, announcements, the Massey Cancer Center Web site, and individual meetings. All oncologists approached agreed to their chemotherapy patients participating in the study in general, and the primary nurse or treating oncologist was contacted about each eligible patient. Eligible patients were not contacted about the study when the treating oncologist or primary oncology nurse determined that a patient was experiencing significant distress or had significant psychiatric problems or difficulty with adjustment to illness or believed the patient would have great emotional difficulty with the information. The number of patients excluded by each oncologist due to concern about distress was estimated to be less than 10% of the total available but was not measured. Since these patients were not enrolled in the study, we did not collect information about them. A clinical psychologist and a chaplain were available to any patient who experienced distress during or after the interview process. The interview questions and intervention were administered by a member of the study team who was not the patient's oncologist or involved in his or her care. The interview team included a graduate student who was also a minister and chaplain (E. A. V.), a medical student with special training in empathic communication (L. A. D.), and/or the principal investigator (T. J. S.); usually one interviewer was present (L. A. D. or E. A. V.).

The interview sequence included screening questions to ensure that the patient wanted full information, sociodemographic questions, a pretest about the chance of cure and treatment effect for a patient with their illness, and the HHI. Next, the decision aid was administered.

Immediately afterward, the patient completed a posttest, the HHI, and information about how he or she would use the information.

We modeled this approach on the Ottawa Decision Support Framework, a clinically tested decision-making tool designed to inform *decisional conflict*,^{15,16} defined as uncertainty about which course of action to take when the choice involves balancing gain, risk, loss, regrets, or challenges to personal life.¹⁷

Our study was approved by the Massey Cancer Center Protocol Review and Monitoring System and the VCU Institutional Review Board for the Conduct of Human Research. Because it was not a clinical trial, no clinical trial registration was required.

Results

The patients were typical for our urban, tertiary referral, and safety net hospital and National Cancer Institute–designated cancer center, as shown in Table 1.

PRIMARY OUTCOME

Our primary outcome was to assess if patients would complete a decision aid with full disclosure. Of 27 patients, only one (4%) chose not to complete the decision aid after starting. She was a 55-year-old African American woman who had recently started first-line treatment for metastatic colorectal cancer. She had been told at another institution that she had lost too much weight and was too ill to benefit from chemotherapy, but with counseling she regained the weight and had a performance status of 2 at VCU. In her pretest, she answered that she thought a woman with metastatic colorectal cancer spread to bones and lymph glands could be cured, with a chance of cure of 50%. Once presented with the information (good treatments that prolong life and control symptoms but no chance of cure and 9% of patients with metastatic colorectal cancer alive at 5 years), she said that she did not want to finish the questions. She did complete her HHI, which did not change, and was not distressed (see Table 2, patient 12).

In the pretest, almost all the patients, including the patient above, reported wanting full disclosure about cancer, prognosis, treatment, and side effects. In response to questions beginning “How much do you want to know about ...” 27 of 27 answered “Tell me *all*” to the questions about “your cancer,” “your prognosis,” “treatment benefits,” and “treatment side effects.” Only one of 27 answered otherwise: “Tell me *a little*” about cancer, and “Tell me *some*” about prognosis.

SECONDARY OUTCOMES

Participants were overoptimistic about the results of palliative chemotherapy, as shown in Table 3. Most (14/27, 52%) people thought a person with “metastatic cancer (breast, colorectal, lung, prostate—specific to that person’s disease) spread to the bones and lymph glands” could be cured. After the decision aid, more people recognized that their cancer could not be cured (17/25, 63%) but eight of 25 (32%, $P = 0.15$, Fischer’s exact test) still thought a person with metastatic disease could be cured. Patients were particularly overoptimistic about the chance of their symptoms being helped by chemotherapy: 87% thought their symptoms would be helped by chemotherapy, and 60% thought a patient would have at least 50% shrinkage of their cancer before the exercise, which declined only slightly after the decision aid. (While the correct answer varies by disease, the number helped by chemotherapy is usually less than 50%, and response rates are always less than 50%.)

There was no change in responses to the HHI after the intervention as we have previously reported.¹⁸ Participants did not appear to be visibly distressed by the intervention. A psychologist and chaplain were made available, but no one requested their services. In our small clinic, the primary nurses and doctors have frequent interactions during visits and chemotherapy. No patient was reported to be distressed in any way, during that visit or subsequent visits.

The comments recorded by the patients or the interviewers at the end of the exercise showed that most patients would share the information, as shown in Table 4.

In some cases, the average prognosis and treatment benefit, although small, was bigger than the person thought before the exercise. Nearly all found it helpful. Some illustrative comments are shown in Table 2.

We did not formally measure the time to complete the screening questions, pre- and posttests, pre- and post-HHI, and decision aid; but in most cases it took less than 20 minutes to complete the whole package including the preand post-tests. Review of the decision aid with the patient always took less than 5 minutes, even when we were reading it with the patient and family. This is consistent with work showing that oncologists state that completing an advance directive will take too much time but, in fact, it takes less than 10 minutes.^{19,20}

Discussion

Historical data show that patients know little about their prognosis and the effect that treatment will have on their cancer. Yet, this knowledge is essential to making informed choices about treatment benefits, risks, and even costs. When tested in randomized controlled trials, decision aids led to more involvement in decision making.^{21,22} However, there were *no* decision aids available about metastatic incurable disease, despite some promising early starts^{23–28} and only one about first-line treatment,²⁹ so we made a simple one. A successful decision aid may allow patients to discuss their situations with their physicians and develop management strategies that best concur with personal goals and preferences and help patients make plans in other areas of life.

Our findings suggest that most people do want honest information, even if the news is bad. We found that 27 of 27 enrolled patients initially reported wanting to know *all* the available information about their cancer, prognosis, treatment benefits, and treatment side effects. Also, 26 of 27 patients were able to complete the decision aid fully, our main outcome measure. While approximately 10% of available patients were excluded from accrual by their oncologists or oncology nurses due to preexisting distress, fear of distress in the patient or family member, uncontrolled symptoms, or psychiatric illness, in general there was excellent acceptance of the study by patients and oncologists. In this pilot study we did not investigate the attitudes of nonparticipants nor were we able to collect sociodemographic data to determine non-response bias, that is, whether certain types of patients are more likely to decline participation in the study.

Participants in the study were overoptimistic about their chances of cure, potential treatment response, symptom relief, and survival. None of these patients had curable disease, but 63% thought that a person with metastatic cancer of their type could be cured and gave the average chance of cure as 52%. Inaccurate assessment of cure rates decreased postintervention. At the pretest 14/27 (52%) believed a person with cancer similar to theirs could be cured, which changed to 8/26 (31%) at the posttest. This agrees with other studies that showed that patients mistook palliative radiation for curative radiation about one-third of the time, even when provided with accurate information.^{1,30,31}

Knowledge of prognosis and planning for the future is important as there is evidence of benefit to having the discussion about treatment outcomes. Recent data show improved quality of care, improved quality of life, and improved caregiver quality of life if the physician discusses death with the patient and family.⁵ Transplant patients with advanced directives had more than a twofold survival advantage over those without them.²⁷ Conversely, over- or underestimating survival or treatment benefit can lead to bad health outcomes. Stem-cell transplant patients who were overoptimistic lived no longer than those with realistic views.^{32,33,34} Cancer patients who overestimated their survival were more likely to die a “bad” death (defined as death in an intensive care unit, on a ventilator, or with multiple hospitalizations and emergency room visits) without achieving life extension.³⁵ It may be that the 16%–20% of patients with incurable solid tumors who start a new chemotherapy regimen within 2 weeks of death,³⁶ when they are unlikely to benefit, simply do not know the prognosis or treatment effect or have different perspectives.³⁷ Alternatively, we do not know how many patients decline second- and *n*th-line chemotherapy without knowing the full benefits and risks and who might choose chemotherapy if they knew second- or *n*th-line chemotherapy improved survival, pain scores, or quality of life. For instance, 40% of breast cancer patients will have some disease control from fourth-line chemotherapy for up to 4 months even if there is no evidence of improved survival.³⁸

Patients consistently tell us to be truthful, compassionate, and clear and to stay the course with them.^{39,40} Despite nearly all American patients stating that they want full disclosure about their prognosis, treatment options, and expected outcomes, most patients do not receive such information⁴¹ or receive such information far too late in their course.⁴² Even if terminally ill patients with cancer requested survival estimates, doctors would provide such estimates only 37% of the time, often an overestimate;⁷ and a recent meta-analysis showed that cancer physicians consistently overestimated prognosis by at least 30%.⁴³ Honest information respects the autonomy of a patient to make decisions based on what is known about the outcomes of such decisions.⁴⁴ Such information should not be forced on a patient, but the patient should be told that the information is available and that he or she has the right to accept or decline the information.⁴⁵

When we started this project, colleagues were concerned about whether patients would want such information, that patients would be distressed by poor prognosis, that patients would give up hope, and that the procedures would take too much time. We also were concerned about the effect of giving such bad news on the provider, when prior research showed negative effects on the information-giver's mood and affect from such encounters⁴⁶ and that doctors in general protect themselves by not giving bad news.⁴⁷ Completion of the decision aid was difficult for the interviewers, too. Some commented on how hard it was to give “bad” information about chance of cure and expected survival, even for patients they did not know. While patients may be more comfortable having advance directive discussions with a doctor they do not know rather than their oncologist,⁴⁸ it can still be hard for the provider. Surprisingly, it rarely took more than 20 minutes to discuss the information including the tests since the information was preprinted.

Patients vary in their approach to decision making, but the decisions should at least start with good information. Based on these preliminary findings, the piloted intervention is significant because it can lead to measurable impacts on knowledge about prognosis and appears to be judged helpful. We do not know the impact of full and truthful information on patient knowledge, decision making, hope, attendant choices about advanced medical directives, chemotherapy use, or hospice use. The next steps are to make the information available directly to patients on the Internet, which is in progress. The purpose is not to increase or decrease the use of palliative chemotherapy or hospice care; the lack of research into the decisions fully informed patients make precludes any such prediction. Since the

intervention appears to be successful in this pilot trial, it will be tested in conjunction with standard care in a randomized clinical trial with measurement of quality of care, quality of life, and health-care cost outcomes.

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Appendix A

Decision Aids

Patient Name: ____

Date: ____/____/____

Lung Cancer Second Line Chemotherapy

What is my chance of being alive at one year if I take chemotherapy, or do best supportive care such as hospice?

Chemotherapy with a drug like docetaxel (Taxotere®) or pemetrexed (Alimta®) improves the chance of being alive at one year by 18 out of 100 people. With chemotherapy, 37 of 100 people were alive at one year. Without chemotherapy, 11 of 100 were alive.

Patients receiving docetaxel (Taxotere®) chemotherapy lived an average of 7.5 months, versus 4.6 months if they did not take chemotherapy. In other words, they lived 2 to 3 months longer.

If you are having cancer-related symptoms that limit your daily activities, the chances of being alive at one year are less than that described above.

The numbers given here are what happens to the average person with this disease in this situation. Half the patients will do better than this, and half will do worse. Your situation could be better or worse. The numbers given for the chance of cure are very accurate. The numbers are given to help you with your own decision making.

What is the chance of my cancer shrinking by half?

About 6 of 100 people will have their cancer shrink by half. If you are having cancer-related symptoms that limit your daily activities, the chances are less than that described above.

What is the chance of my being cured by chemotherapy?

In this setting, there is no chance of cure. The goal may change to controlling the disease and any symptoms for as long as possible. You may want to talk with your doctor about your own chances and goals of therapy.

How long will chemotherapy make my cancer shrink, if it does?

For all patients who did not get chemotherapy, the average time before the cancer grew was 7 weeks. For patients who got chemotherapy, the average time before the cancer grew was 11 weeks.

What did chemotherapy do to quality of life?

Chemotherapy helped reduce pain scores and did not make quality of life worse.

What are the most common side effects?

The most common side effects will vary with the type of treatment given.

Some of the most common ones include the following: Mucositis (mouth sores).

Nausea/vomiting; usually controllable.

Alopecia (hair loss).

Neutropenia (low white blood cell count) and infection requiring antibiotics.

Neuropathy (numbness and pain in the hands and feet).

Are there other issues that I should address at this time?

Many people use this time to address a life review-what they have learned during life that they want to share with their families, and planning for events in the future like birthdays or weddings).

Some people address spiritual issues.

Some people address financial issues like a will.

Some people address Advance Directives (Living Wills).

For instance, if you could not speak for yourself, who would you want to make decisions about your care?

If your heart stopped beating, or you stopped breathing, due to the cancer worsening, would you want to have resuscitation (CPR), or be allowed to die naturally without resuscitation?

Some people use this time to discuss with their loved ones how they would like to spend the rest of their life. For instance, where do you want to spend your last days? Where do you want to die?

Do you want to have hospice involved?

These are all difficult issues, but important to discuss with your family and your health care professionals.

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Table 1**Patient Demographic and Disease Characteristics, n = 26**

Age (years)	
Mean	63 ± 5
Range	46–74
Gender	
Male	12 (44%)
Female	15 (56%)
Marital status	
Married or committed relationship	15 (56%)
Divorced	6 (22%)
Widowed	2 (7%)
Single/never married	2 (7%)
Ethnicity	
Caucasian	12 (44%)
African American	15 (56%)
Education completed	
Less than high school	5 (9%)
Some high school	1 (4%)
HS diploma/GED	8 (30%)
Some college	10 (37%)
Completed college	1 (4%)
Completed postgrad	2 (7%)
Total household income	
<\$15,000	10 (37%)
\$15,000–\$34,999	8 (30%)
\$35,000–\$74,999	6 (22%)
>\$75,000	1 (4%)
Don't know	2 (7%)
Average number of people in household	2.3 (SD 0.9)
Type of cancer and line of chemotherapy	
Breast 1st, 2nd, 3rd, 4th line	5, 2, 1, 1 = 9 total
Colorectal 1st, 2nd, 3rd, 4th line	8, 5, 1, 0 = 14 total
Lung 1st, 2nd, 3rd, 4th line	2, 0, 0, 0 = 2 total
Hormone-refractory prostate 1st, 2nd, 3rd, 4th line	1, 1, 0, 0 = 2

Table 2

Comments Made by Patients about the Decision Aids

PATIENT	SITUATION (1ST-, 2ND-, 3RD-, 4TH-LINE CHEMOTHERAPY)	COMMENT
1	CRC, 1st	"Feel little bit better." "Didn't upset."
2	BC, 2nd	"It gave me information on my condition."
3	BC, 4th	"If I've got 6 months to live, I want to know so I can party"
3	LC, 1st	"It let me know I have longer than a year, possibly longer than that. Helpful."
5	PC, 2nd	"Well, Dr. R said it couldn't be cured ... I've done well for 16 months so far."
6	CRC, 2nd	"We've already discussed everything. All information I think is helpful."
7	CRC, 1st	"... happy that my life expectancy might be better than I thought." At the end, he said "how good it was to talk and not hold things in."
8	CRC, 3rd	"Verification of what I have been told."
9	CRC, 2nd	"I know all this, but it was helpful. Especially for people who haven't heard it."
10	CRC, 1st	
11	CRC, 2nd	"Helpful ... just to think about my goals and that kind of thing."
12	CRC, 1st	"Wouldn't know [about cure]. I can't answer those ... [questions about cure rates, response rates after reviewing data]. Tell them to give people hope, not take away hope ... not to just go smell the roses."
13	CRC, 1st	"There were some things I didn't know—I didn't know about the 1–2 years—I'm not going to accept it though—I'm planning on more."
14	BC, 1st	"Gave me info based on stats that I didn't know before."
15	BC, 1st	"It's hard to explain. It's about what I have already known."
16	BC, 2nd	"Helped me to understand That chemo is better than not having chemo."
17	CRC, 1st	
18	CRC, 2nd	"Helpful to know what will happen, given strength, how to feel about things ... to get to talk about things."
19	BC, 1st	"Helpful. It opened my eyes, made me aware. I would want to know that."
20	BC, 1st	Helpful. "It gave me a lot to think about. A whole lot of it I didn't know about."
21	CRC, 1st	Helpful. "Knowing that I was doing something to help someone else. It made me think about what I have to look forward to in life."
22	CRC, 2nd	"In a way, you're saying what the possibilities are. I just hope that I keep on trucking."
23	BC, 3rd	"Always helpful to discuss prognosis."
24	LC, 1st	"Helpful to know what chances I get, with or without (chemotherapy) treatment."
25	PC, 1st	"Because the odds are a hell of a lot less than I thought, it's a bummer."
26	BC, 1st	"It gave me a chance to see the percentage of things with breast cancer. I have a better understanding of the time line."
26	CRC, 1st	"Made me understand some things." On change in survival from >3 years to "don't know," "I hope to live a right good while."

BC = breast cancer; CRC = colon or rectal cancer; LC = non-small-cell lung cancer; PC = hormone-refractory prostate cancer

Table 3**Patient Knowledge about Palliative Chemotherapy before and after the Decision Aid**

	PRE	POST	CHANGE	COMMENT
Can this person with cancer in the bones and lymph nodes be cured by medical treatment?	Yes = 14 No = 11 Don't know = 2	Yes = 8 No = 17 Don't know = 2	Changed from yes to no = 6; changed from no to yes = 1	Correct answer "no" $P=0.15$ Fischer's exact test
	52.5 ± 32	47 ± 26	-5.8 ± 28	The correct answer is 0%; all overoptimistic
What is the chance of her ___ cancer shrinking by half? In %	60 ± 32	57.5 ± 17.6	-4.2 ± 28	All overoptimistic
What is the chance of ___ cancer symptoms being helped? In %	87 ± 19	74.2 ± 21	-6.7 ± 26	All overoptimistic
How long does the average person live with advanced ___ cancer (using the choices from the breast cancer sheet for example)?				More realistic, but 2 people increased their expected length of survival
More than 3 years	18	14	-4	
About 2 years	6	11	5	
About 6 months	0	0	0	
Just a few weeks	1	0	-1	
Don't know/NA	2	2	2	
Distress observed by interviewer, nurse, or oncologist	No	No		

Categorical variables Yes and No analyzed by Fischer's exact test

Numerical variables analyzed by Student's *t*-test, unpaired; none significant

Table 4**Intent to Share the Information**

Will you share it with anyone?	Yes = 20
	No = 6
	NA = 1
If so, who?	All (family, ONC, PCP) = 14
__ My family	Family only = 2
__ My oncologist	Oncologist = 12
__ My oncology nurse	PCP = 14, one said "not PCP"
__ My primary care doctor	
__ Other ____	
Was this patient information sheet helpful to you?	Yes = 25
	No = 1, "Bummer"
	NA = 2

NA = no answer; ONC = oncologist; PCP = primary care provider