

Cancer Consultation Preparation Package: Changing Patients but Not Physicians Is Not Enough

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A B S T R A C T

Purpose

This study evaluated a cancer consultation preparation package (CCPP) designed to facilitate patient involvement in the oncology consultation.

Patients and Methods

A total of 164 cancer patients (67% response rate) were randomly assigned to receive the CCPP or a control booklet at least 48 hours before their first oncology appointment. The CCPP included a question prompt sheet, booklets on clinical decision making and patient rights, and an introduction to the clinic. The control booklet contained only the introduction to the clinic. Physicians were blinded to which intervention patients received. Patients completed questionnaires immediately after the consultation and 1 month later. Consultations were audiotaped, transcribed verbatim, and coded.

Results

All but one patient read the information. Before the consultation, intervention patients were significantly more anxious than were controls (mean, 42 v 38; $P = .04$); however anxiety was equivalent at follow-up. The CCPP was reported as being significantly more useful to family members than the control booklet ($P = .004$). Patients receiving the intervention asked significantly more questions (11 v seven questions; $P = .005$), tended to interrupt the physician more (1.01 v 0.71 interruptions; $P = .08$), and challenged information significantly more often (twice v once; $P = .05$). Patients receiving the CCPP were less likely to achieve their preferred decision making style (22%) than were controls (35%; $P = .06$).

Conclusion

This CCPP influences patients' consultation behavior and does not increase anxiety in the long-term. However, this intervention, without physician endorsement, reduced the percentage of patients whose preferred involvement in decision making was achieved.

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INTRODUCTION

Models of medical decision making have shifted in recent years from emphasizing the paternalistic responsibility of physicians to ensure a good outcome, to advocating shared decision making. Shared decision making is seen as avoiding the dangers both of placing too much power in the physicians' hands and too much responsibility on patients. Participatory models acknowledge that physicians and patients may have dif-

ferent values and preferences that affect the course of clinical actions. Thus models of shared decision making propose that the decision is a process of shared understanding of personal values and subsequent negotiation to achieve an appropriate treatment decision.

The majority of cancer patients in the Western world now desire full information about their disease, although in all reported studies there is a small but significant proportion of patients who prefer minimal information and/or a passive role in decisions

about their care.¹⁻³ There is still considerable variation in the extent to which patients are informed of treatment options and participate in decision making.⁴

A number of studies have demonstrated positive patient outcomes as a result of involvement in decision making. We investigated the impact of patient roles in decision making in 274 cancer patients visiting an oncologist for the first time.⁵ The treatment decision was unresolved in 12% by 1 week postconsultation, but of the remaining patients, only 34% achieved their desired role in decision making (range, 29% to 41% among patients of the 10 oncologists involved in the study). Patients who had achieved their preferred role were most satisfied with their consultation, whereas patients who were less active than desired were least satisfied ($P = .01$).

Street and Voigt⁶ examined the relationship between perceptions of control over treatment decisions in early breast cancer patients and subsequent health-related quality of life. Patients who more actively participated in their consultations, particularly in terms of offering opinions, assumed more responsibility for treatment decisions in the year after surgery than did less expressive patients. Patients who reported more involvement in their consultation also reported higher levels of quality of life than did patients who perceived that they had less decisional control. These findings emphasize the importance of facilitating patient involvement in decision making so that they achieve their desired involvement.

A number of strategies have been proposed to facilitate patient involvement, including decision aids and training or prompts in asking questions. In three separate randomized trials we have found that a question prompt sheet given to cancer patients immediately before their initial appointment with an oncologist increased question asking, particularly about prognosis, and when endorsed by the physician, decreased patient anxiety, improved patient recall, and shortened consultation duration.⁷⁻⁹ We concluded that a question prompt sheet addressed by the physician is a simple, inexpensive, and effective means of promoting patient question asking in the cancer consultation. However, question asking is only part of patient activity and involvement.

For patients to be able to participate in decision making, they first need to understand the basis of medical decision making in general and the specific features of their situation that influence that process. Second, patient expectations of patient roles in decision making must encompass active involvement. Third, patient anxiety and distress about their situation must be sufficiently ameliorated to enable effective cognitive functioning. Fourth, patients and physicians need to come to a shared understanding of personal values and to then negotiate an appropriate treatment decision.

We have developed a cancer consultation preparation package (CCPP) for patients, with the goal of informing patients of their rights, proposing questions that they might choose to ask, and outlining evidence-based decision making. The package aims to change patient behavior, and through these changes, alter physician behavior. It was hoped that if a relatively inexpensive patient-based intervention could achieve these aims, then more expensive, physician-based interventions (such as communication skills training) might be unnecessary. The aim of this study was to evaluate the impact of providing patients with the CCPP at least 48 hours before their initial consultation with an oncologist.

We hypothesized that patients receiving the CCPP package (compared with patients receiving a control booklet) would ask more questions and receive more information and decisional support from their physicians, and have enhanced achievement of their information and involvement preference, increased satisfaction with the treatment decision-making process, increased satisfaction with their oncology consultation, reduced anxiety, and reduced depression.

PATIENTS AND METHODS

A randomized trial design was used to investigate the effect of providing cancer patients with a CCPP versus a control booklet.

The control booklet informed patients about the physical and spatial characteristics, staffing, and procedures of the Sydney Cancer Centre (Sydney, Australia). The full CCPP contained the control booklet plus three components designed to provide a conceptual framework for patients about evidence-based clinical decision making and to inform patients about their potential role in decision making. The following three components were included. First, a booklet developed by our group, entitled *How Treatment Decisions Are Made*, introduces the notion of evidence-based medicine, outlines levels of evidence, presents a synopsis of factors other than evidence that may influence treatment recommendations, and encourages active involvement in the consultation. Second, a brochure produced by Central Sydney Area Health Service, entitled *Your Rights and Responsibilities as a Patient*, presents the legal rights of patients in an Australian hospital, and avenues for resolving complaints and disputes. Third, a question prompt sheet, developed and previously evaluated by our group,⁷⁻⁹ endorses question asking, and includes 19 suggested questions and a recommendation to prepare a list of questions.

Procedure

Consecutive patients with heterogeneous cancers attending an initial consultation with either of two medical or two radiation oncologists at a University of Sydney teaching hospital outpatient clinic were invited to participate. Exclusion criteria consisted of age younger than 18 years; inability to speak English; advanced physical incapacity, disallowing completion of questionnaires; and an oncology appointment less than 48 hours away (which would not provide sufficient time for patients to receive, process, and discuss the package).

A research nurse telephoned eligible patients to inform them of the study and invite their participation. Patients were informed that they would be offered a copy of the audiotape after their consultation. The research nurse assigned an identification to consenting patients, determined random assignment, and sent the appropriate package with a consent form at least 48 hours before the first consultation. Physicians were blinded to which package the patient received. Patients completed questionnaires assessing demographic variables, anxiety, depression, information and involvement preferences, and satisfaction with the CCPP before the consultation. Their consultation with the oncologist was audiotaped, with a copy offered to the patient and the original retained for analysis (Fig 1).

Patients completed additional questionnaires immediately and 1 month after the consultation, assessing anxiety, depression, perception of information provided and achieved involvement in decision making, satisfaction with the treatment decision (if one had been made), and satisfaction with the consultation. Each oncologist re-

corded his or her satisfaction with the decision-making process, and the extent he or she believed the patient's information and involvement preferences were met, immediately after the consultation.

Measures

Anxiety was measured using the state version of the Spielberger State Trait Anxiety Scale¹⁰ (20 items). Scores range from 20 to 80. A high score indicates greater anxiety.

Depression was measured using the Beck Depression Inventory (short form).¹¹ Scores range from 13 to 52, with a high score indicating greater depression.

Preferences for information were assessed using two items derived from the Cassileth Information Styles Questionnaire² measuring preference for greater or lesser detail, and type of information (only information needed to care for myself properly, additional information only if it is good news, or as much information as possible, good or bad).

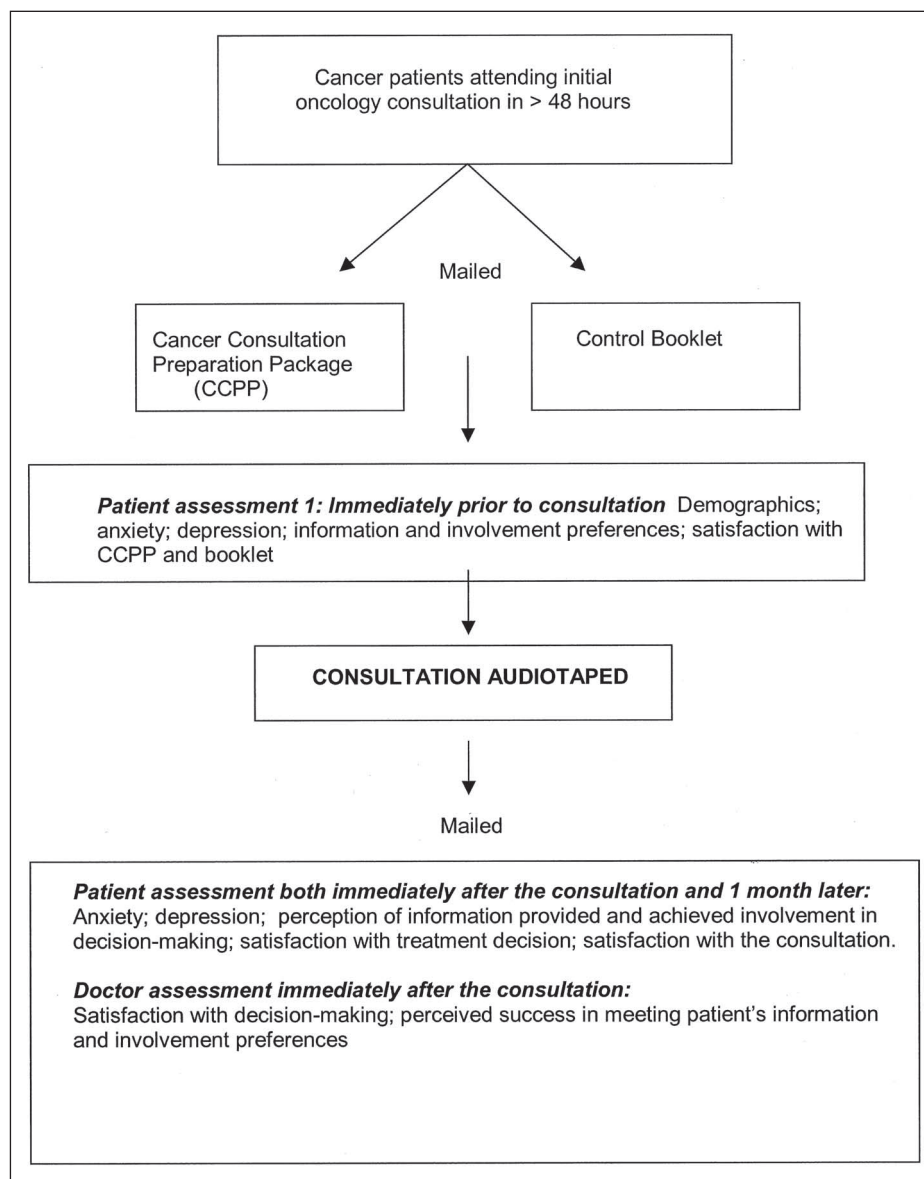


Fig 1. Study procedure. CCPP, cancer consultation preparation package.

Preferences for decisional control were assessed using a validated question from previous studies in cancer patients.¹² Patients indicated whether they wanted to play an active, passive, or collaborative role with their physician when making treatment decisions.

Patient and physician perception of information provided and role in decision making achieved were assessed using adaptations of the above items, in which patients and physicians indicated their perception of what actually happened in the consultation. Patient perceptions were compared with their stated preferences to provide a measure of achievement of desired role.

Information-seeking behavior was assessed using the information subscale of the Krantz Health Opinion Survey.¹³ Scores range from 0 to 7, with high scores indicating high information-seeking behavior.

Patient satisfaction with the booklet or CCPP was assessed using a series of Likert scales developed by our group, with high scores indicating greater satisfaction. Patients indicated whether they or others had read the information, and to what degree the intervention was useful, easy to understand, helpful to family and friends, and anxiety provoking, reassuring, disturbing, confusing, helpful, or upsetting.

Patient satisfaction with the consultation was assessed using a 25-item Likert scale adapted from Roter¹⁴ and Korsch et al¹⁵ and used extensively in our work.^{9,16} This scale assessed satisfaction with the amount and quality of information presented, the communication skills demonstrated by the physician, and the level of patient participation in the consultation. Scores range from 25 to 125, with high scores indicating greater satisfaction.

Patient and physician satisfaction with the decision-making process were assessed using a 5-point Likert scale designed for this study. Respondents indicated whether they were extremely satisfied, very satisfied, satisfied, unsatisfied, or very unsatisfied with the decision-making process.

Coding of Audiotapes

Verbatim transcripts of audiotaped consultations were analyzed by two coders. The coding system was based on the informed decision-making and shared decision-making models,¹⁷⁻²⁰ and refined after piloting on 10 randomly selected consultations. The coders rated the presence or absence of components within four categories: patient activity in the consultation, physician rapport building, physician provision of critical information, and physician encouragement of patient participation in the consultation. The individual components are described in Table 1. Each coder coded 10% of the others' consultations and recoded 10% of their own. Inter- and intrarater reliability as measured by the κ statistic were good ($\kappa = 0.69$ and 0.67 , respectively).

In addition, total questions asked by the patient and relatives, total number of words spoken by the patient and physician, number of interruptions by both patient and physician, and duration of the consultation were recorded. Questions were also categorized and summed under nine themes: history and symptoms, diagnosis, tests, prognosis, treatment of adverse effects, treatment options, level of evidence, clinical trials, and other. Given that many patients asked no questions in each category, these variables were recoded into zero, one to two, or more than two questions. Finally, the questions were reanalyzed and categorized into two groups: new questions (introducing a new issue) versus clarification questions (concerning an issue already under discussion); these were also summed.

This project received ethical approval from the Central Sydney Area Health Service and the University of Sydney ethics committees.

Table 1. Behaviors Coded in the Consultation

Physician rapport building
Patient asked how they would like to be addressed
Social interaction and laughter
Social concerns addressed (eg, lifestyle, family)
Patient anxieties addressed
Allows patient to talk without interruptions
Physician provision of critical information
Prognosis discussed
Adverse effects and benefits of treatment discussed
Management of treatment side effects discussed
Cost of treatment discussed
Physician encouragement of patient participation in the consultation and decision-making process
Established patient agenda
Treatment choice acknowledged
Medical evidence discussed
Quality of evidence discussed
Uncertainty of achieving treatment aim acknowledged
Differences in expert opinion acknowledged
Explicit treatment recommendation given
Questions invited by physician
Patient understanding checked
Delay in making treatment decision offered
Supplementary information (eg, written) offered
Summary of consultation provided
Patient activity in the consultation
Initiated voicing their agenda for the consultation
Voices preference for quantity of information
Voices preference for involvement in decision making
Voices concerns
Discusses information from other sources (eg, web site)
Seeks supplementary information
Questions or challenges information provided by the physician
Introduces new theme
Interrupts doctor
Expresses treatment preference

RESULTS

A total of 246 patients were invited to participate and 200 consented to be randomly assigned into the study (81%). Nonconsent was primarily because patients felt too sick or stressed. Of the 200 patients randomly assigned, 18 were subsequently identified as ineligible; nine had seen another oncologist previously, one canceled the appointment, and eight withdrew primarily because they felt too ill or stressed, leaving 164 patients. Age and sex of nonparticipating patients were not significantly different from those of patients who participated. Twenty-three of the 164 patients did not complete the final questionnaire (86% retention rate). Of these, 13 had died. A total of 160 audible consultation audiotapes were available for verbatim transcription and coding. All but one patient wanted a copy of the tape to take home. Given that no significant differences were found on demographic or disease variables between control and intervention arms (Tables 2 and 3), subsequent analyses did not adjust for potential confounders.

Table 2. Demographic Characteristics of the Participants

Demographic Factors	Received Cancer Consultation Preparation Package (n = 80)		Received Control Booklet (n = 84)	
	No. of Patients	%	No. of Patients	%
Age, years				
Mean	57.5		59.1	
SD	12.9		12.7	
Sex				
Female	45	56.3	44	52.4
Male	35	43.8	40	47.6
Marital status				
Single	8	10	14	16.7
Married or defacto	55	68.8	50	59.5
Widowed	4	5	9	10.7
Divorced or separated	13	16.3	11	13.1
Education				
Year 10 or less	32	40	31	36.9
Year 12 (HSC)	18	22.5	21	25
Postgraduate	30	37.5	32	38.1
Occupation				
Managers and administrators	17	21.3	13	15.5
Professionals and paraprofessionals	26	32.6	24	28.5
Trades, clerks, sales and laborers	36	46.2	43	51.2
House duties and unemployed	1	1.3	4	4.8
Country of birth				
Australia	46	57.5	59	70.2
Other	34	42.5	25	29.8
First language				
English	71	88.8	76	90.5
Other	9	12.2	8	9.5

Abbreviations: SD, standard deviation; HSC, higher school certificate.

Table 3. Disease Characteristics of the Participants

Disease Factors	Received Cancer Consultation Preparation Package (n = 80)		Received Control Booklet (n = 84)	
	No. of Patients	%	No. of Patients	%
Medical training				
Yes	8	10	8	9
No	72	90	76	90
Diagnosis				
Breast	22	28	26	31
Lung	12	15	17	20
Prostate	8	10	9	11
Other	38	47	32	38
Extent of disease				
Primary, NED	33	41	36	44
Locoregional	7	9	9	11.0
Locally advanced	9	11	10	12
Metastatic	29	36	25	30
Unknown	2	3	2	2.4
ECOG status				
0	53	66	46	55
1	25	31	30	36
2 or more	2	3	7	9
Estimated prognosis				
Months	23	30	32	40
Years	44	57	39	49
Normal life expectancy	9	13	9	11
No. of physicians seen				
1	27	27	35	35
2	48	49	40	40
3	19	19	18	18
4	5	5	6	6

Abbreviations: NED, no evidence of disease; ECOG, Eastern Oncology Group.

A treatment recommendation was made in 93% of the consultations; however, in 14% of cases, patients subsequently reported that no treatment decision was made, perhaps because this was a second opinion. Of the recommendations made, 24% were for no treatment, 4% were for observation, 29% were for palliative care, and 42% were for treatment with curative intent. There were no differences between groups in the distribution of type or presence of recommendation.

Before the Consultation

Use of the CCPP. Of 80 patients receiving the CCPP, 78 (98%) reported reading the information, as did all patients receiving the control booklet. Patients receiving the CCPP were significantly less likely to show it to another person (usually their spouse; 52.5%) compared with those receiving the booklet alone (75%; $\chi^2_1 = 9.0$; $P = .002$).

Satisfaction with the CCPP. No significant differences were found between groups in terms of reported anxiety

provoked, perceived utility, or ease of understanding of the materials. Approximately half the patients reported that the material made no difference in their anxiety levels and one third reported a reduction in anxiety. Approximately one third reported that these materials were extremely useful, one third reported that these materials were very useful, and one third reported that these materials were a little useful. Approximately 50% of both groups found the material very easy to understand, with about one third reporting that they were easy to understand, and 13% reporting that they were reasonably easy to understand.

However, there was a significant difference in the reported usefulness of the CCPP and control booklet for the family ($\chi^2_2 = 10.9$; $P = .004$). Of those who showed the material to their family ($n = 107$), 65% in the CCPP arm reported that the family found it very useful, compared with 33% of those receiving the control booklet. Ten patients receiving the control booklet (16%) reported that it was not

at all useful to family, compared with three patients (7%) receiving the CCPP.

Information and involvement preferences. There were no significant differences between the groups in information and involvement preferences measured before the consultation (Table 4). Eighty-seven percent of patients preferred as much information as possible, good or bad, whereas 37% wanted the physician to take the primary role in decision making, 49% wanted shared decision making, and 14% wanted to take the primary role.

Anxiety and depression. Before the consultation, patients who had received the CCPP were significantly more anxious than those who received the control booklet (mean, 42 v 38, respectively; $t = -2.0$; $P = .04$). Therefore, we controlled for anxiety before the consultation in subsequent analyses by computing change scores. The groups' depression levels were similar at baseline; both were in the low range (mean, 16.25).

Behavior During the Consultation

Patient behavior. Patients receiving the CCPP asked significantly more questions overall than those receiving the control booklet (mean, 13 v 9; $t = -2.6$; $P = .009$). When we explored categories of question, a significant difference between groups was found only on prognosis questions (median, one v zero; $\chi^2_2 = 14.25$; $P = .001$). The number of clarification questions asked was similar between groups, but CCPP patients and their relatives combined asked significantly more new questions (mean, 12.9) than those in the booklet group (mean, 9.3; $t = 2.45$; $P = .015$).

Ten active patient behaviors were coded. The percentages of consultations in which patient active behaviors oc-

curred are listed in Table 5. When summed, no significant difference between groups was found ($t = -0.94$; $P = .35$). CCPP patients showed on average five active behaviors, whereas booklet patients showed 4.76 active behaviors. Four of these behaviors were examined individually (initiates agenda, voices concerns, questions or challenges, and interrupts) because these were judged to be particularly challenging for patients, and had some variability. Expression of agenda and concerns were not significantly different between groups. However, patients in the CCPP group tended to interrupt more often (median, 1.01 times compared with 0.71 times; $z = -0.17$; $P = .08$) and challenged information significantly more often (median, two v one time; $z = -2.4$; $P = .05$).

Physician behavior. There was no significant difference between groups in the total number of critical information items provided by the physician. Zero of four critical items were given in 8% of consultations, one item was given in 16% of consultations, two to three items were given in 71% of consultations, and in only 5% of consultations were all four items given. One of the items (cost of treatment) was rarely discussed ($n = 19$; 12%).

The frequency of behaviors encouraging patient participation is listed in Table 6. On average, oncologists demonstrated about 7.5 of the 12 behaviors, with no significant differences between the groups. Physicians' rapport-building behaviors are listed in Table 7. No significant differences were observed between groups. Physicians commonly initiated social topics and issues, and addressed patient anxiety, but less commonly asked patients how they would like to be addressed, and often interrupted the patient. Consultation length was

Table 4. Number of Patients Within Each Preferred Role Achieving Their Involvement Preference in Each Group (CCPP, $n = 62$); Ctl, $n = 69$)

	Actual Role Reported After Consultation					Total
	Physician Makes Decision	Physician Makes Decision Taking Into Account My Needs	Shared Decision Making	I Make Decision Considering Physician's Opinion	I Make Decision Using What I Know	
Preferred role before consultation						
Physician makes decision	CCPP: 3 Ctl: 6	CCPP: 1 Ctl: 0	CCPP: 3 Ctl: 3	CCPP: 0 Ctl: 1	CCPP: 0 Ctl: 0	CCPP: 7 Ctl: 10
Physician makes decision taking into account my needs	CCPP: 9 Ctl: 5	CCPP: 5 Ctl: 4	CCPP: 2 Ctl: 2	CCPP: 1 Ctl: 3	CCPP: 0 Ctl: 0	CCPP: 17 Ctl: 14
Shared decision making	CCPP: 10 Ctl: 3	CCPP: 6 Ctl: 5	CCPP: 10 Ctl: 17	CCPP: 4 Ctl: 9	CCPP: 1 Ctl: 2	CCPP: 31 Ctl: 36
I make decision considering my physician's opinion	CCPP: 0 Ctl: 1	CCPP: 1 Ctl: 0	CCPP: 2 Ctl: 0	CCPP: 3 Ctl: 3	CCPP: 0 Ctl: 1	CCPP: 6 Ctl: 5
I make decision using what I know	CCPP: 0 Ctl: 0	CCPP: 0 Ctl: 0	CCPP: 0 Ctl: 0	CCPP: 1 Ctl: 2	CCPP: 0 Ctl: 2	CCPP: 1 Ctl: 4
Total	CCPP: 22 Ctl: 15	CCPP: 13 Ctl: 9	CCPP: 17 Ctl: 22	CCPP: 9 Ctl: 18	CCPP: 1 Ctl: 5	CCPP: 62 Ctl: 69

NOTE. Bolded data indicate perfect agreement. Twelve patients in the CCPP group and 11 in the Ctl group had not made a decision by the end of the consultation and are not included in this analysis.

Abbreviations: CCPP, cancer consultation preparation package; Ctl, control.

Table 5. Percentage of Consultations in Which Active Patient Behaviors Occurred

Patient Behavior	% Consultations in Which Behavior Occurred
Initiated voicing their agenda	38
Voices information preference	84
Voices involvement preference	85
Voices concerns	80
Discusses information from other sources	27
Seeks supplementary information	4
Questions or challenges information	13
Introduces new themes	19
Interrupts physician	53
Expresses treatment preference	84

similar between groups—on average, 36 minutes per consultation. Similarly, physicians and patients spoke for about the same amount of time in both groups (with physicians speaking on average twice as long as patients).

After the Consultation

Achievement of preferred decision-making style. No significant differences were found between groups in reported involvement in decision making after the consultation (Table 4). A new variable was created, with patients receiving a score of 1 if their reported involvement matched their preferred style stated before the consultation, and a score of 0 if their actual decision-making style did not match their preferred style. There was a trend for significant differences between the groups, but this was against expectations. Patients receiving the CCPP were less likely to achieve their preferred decision-making style (22%) than those receiving the control booklet (35%; $\chi^2 = 3.56$; $P = .06$).

Table 6. Percentage of Consultations in Which Physician Behaviors Facilitating Patient Involvement Occurred

Doctor Behavior	% Consultations in Which Behavior Occurred
Asked for patient agenda	77
Treatment choice acknowledged	75
Discussed medical evidence	45
Discussed quality of medical evidence	13
Discusses information from other sources	27
Acknowledges uncertainty of treatment achieving its aim	43
Acknowledges differences in expert opinion	15
Makes explicit treatment recommendation	76
Invites questions	64
Checks patient understanding	71
Offers delay in making treatment decision	21
Offers supplementary information	21
Summarize the consultation	68

Table 7. Percentage of Consultations in Which Physician Behaviors Establishing Rapport Occurred

Physician Behavior	% Consultations in Which Behavior Occurred
Asks how patient would like to be addressed	18
Social interaction and laughter	73
Addressed social and lifestyle concerns	68
Addressed patient anxiety	89
Did not interrupt patient	35

Satisfaction. Satisfaction with the consultation and the treatment decision were both high and not normally distributed, so nonparametric Mann-Whitney tests were conducted. No significant differences were found between the groups in satisfaction with either the consultation or treatment decision. Physicians were also equally satisfied with decision making whether or not their patients had received the CCPP or the control booklet.

Anxiety and depression. In both groups, anxiety decreased by 3 points after the consultation, and there was no significant difference between the groups immediately after the consultation and 1 month later. No significant differences between groups were observed in raw or change scores on depression immediately after the consultation or 1 month later.

Interaction With Information Style

We thought that response to the intervention may vary according to whether the patient preferred to be active versus passive in the consultation. We divided the sample into those scoring above and below the median on the Krantz scale, and repeated the analyses. No significant results were obtained. There did not seem to be an interaction between information style and the intervention.

DISCUSSION

We had hypothesized that a comprehensive package including elements designed to facilitate patient question asking and understanding of medical decision making, delivered well before the first oncologic consultation to allow time for review, would result in patients asking more questions, and being more likely to achieve their involvement preference.

This relatively inexpensive intervention did change patient behavior. As in all previous studies evaluating question prompt lists (QPLs), patients receiving the full package (which included a QPL) asked significantly more questions about prognosis. They also raised significantly more new topics, challenged information more often, and asked more questions overall. The number of questions asked (13 questions) by these patients is much higher than we have noted

in previous QPL studies, in which an average of nine questions were asked.⁹ Although a direct comparison is not possible, this result does suggest that providing patients with more time to consider, show their family, and use such an intervention allows it to have a greater impact. (In our earlier studies, patients were provided the QPL in the waiting room, just before their oncology consultation).

Although patients' questions did increase, patients receiving the comprehensive package did not request, and oncologists did not provide, more information about the evidence base behind treatment recommendations. Because this theme was targeted specifically by one of the booklets included in the full package, this was somewhat disappointing. It seems that simply receiving a booklet through the mail is not sufficient to empower patients to seek clarification of the basis for treatment recommendations. Overall, discussion of this issue was limited. Although the physicians in our study performed some facilitative actions commonly (eg, asking the patient for their agenda and checking their understanding), they were much less likely to discuss the quality of evidence, refer to treatment guidelines, acknowledge differences of medical opinion, or offer decisional delay. This is not surprising, given that the notion of evidence-based, patient-centered care is a relatively new concept in medicine.

Although patients receiving the full package changed their behavior, this did not result in them being more likely to believe they had achieved their involvement preference. Although approximately one third of patients in the control group reported achieving their involvement preference, a figure similar to that reported in our previous study,⁵ only one fifth of patients receiving the full package reported achieving their involvement preference. Thus the intervention actually seemed to decrease the likelihood of patients participating in decisions in the way they preferred. In particular, within the group receiving the full package, more of the patients who had declared they wanted to share decision making believed that the physician had made the decision. Perhaps these better-informed patients judged their physician's behavior more stringently.

Although physicians in this study were aware of, and supportive of, the intervention being tested, they were not asked or trained specifically to respond to more active patients and they were blind to the intervention. In our earlier study of a QPL, physicians were randomly assigned to ignore or actively endorse and work through the question prompt sheet.¹¹ Positive outcomes for patients who received the question prompt sheet were experienced only when they saw a physician randomly assigned to the endorsement condition. It seems that interventions need to target both parties, and oncologists need to endorse the intervention and/or be trained to respond adequately to more active patients. Furthermore, this suggests that interventions that do not involve the physician, such as by nurses or administrative assistants, also might not be effective.

This is an important finding of our study, showing that a shared or collaborative approach cannot be achieved by targeting patients alone, but will require a change in physician behavior and training. We had hoped that empowered patients would stimulate a concomitant change in physician behavior without the need for a physician-based intervention. It is perhaps not surprising that this was not a successful approach. As other authors have noted, patients are in a relatively low status position in the consultation room, and both patients and physicians have long-standing and hard-to-shift expectations of a physician-led interaction. Cancer patients are especially vulnerable because they are facing a life-threatening illness, and are looking primarily for reassurance from their physician. Therefore, expecting patients to not only change their own behavior (which these patients did), but to effect a change in consultation behavior toward the ideal shared decision-making model, is perhaps naive. It seems that we cannot escape the necessity for properly conducted communication skills training programs for physicians, which incorporate the principles of shared decision making and provide the skills for facilitating this model.

Although most patients reported no influence on anxiety, patients receiving the full package were significantly more anxious before seeing the oncologist than those receiving the control booklet. At that time, patients in both groups reported similar preferences for information and involvement, so it did not seem that the package had succeeded in changing patients' preference to a more active role. Perhaps those receiving the full package thought more would be expected of them and this gap between preferences and expectations increased their anxiety.

Many patients viewing similar materials on the Web may similarly be more anxious if they believe that more participation will be expected of them. Many Web sites are publishing lists of questions and promoting behaviors similar to those described in the CCPP. Thus these findings have implications beyond the current study.

In this study, the heightened anxiety was reduced after the consultation. Either the oncologists (who behaved similarly toward both groups) successfully allayed the heightened anxiety, the patients discovered they were not actually expected to be more active, or those patients who were more active found the experience less worrying than expected. In any case, it seems important that patients exposed to such materials are reassured that the physicians they are about to see are happy to, and have been trained to, meet their needs, whatever their preferences. This again emphasizes the need for concomitant physician training.

We found that the package was welcomed, deemed useful, and read by almost all patients. The fact that patients' and physicians' self-reports of the utility of the intervention did not show differences between groups, whereas measures of consultation behavior did, emphasizes the importance of obtaining direct observations of behavior,

rather than relying on possibly unreliable self-reflection. We have found consultation audiotapes to be an invaluable audit tool in studies of this kind.

Only half of the patients receiving the full package showed it to their spouse or other close person, compared to three fourths of those receiving a much shorter control booklet. However, significantly more family members were reported to find the full package useful. Patients may have believed the information was too long and/or controversial to show their family members; however, those who assumed their family members would be interested in this material judged correctly.

Limitations of the Study

Ideally, baseline measures would have been obtained on patients before they received the intervention to ensure that differences observed between the groups were not due to pre-existing differences. The research group decided that it was important to ensure that patients received the intervention at least 48 hours before they saw the oncologist for the first time, to allow them time to consider the issues and discuss them with their partner or family. Thus patients were sent the intervention at home after giving verbal consent to a research nurse over the phone. We believed that it would not be appropriate to ask patients to complete questionnaires without an opportunity to discuss the study face to face with the research nurse; thus, the first assessment did not take place until they actually attended for their first appointment. We relied on randomization to equalize the groups; on all measures taken, it seems that randomization was successful in achieving this end. However, it is possible that the groups differed on other, unmeasured variables, and thus the results must be viewed with some caution.

Because decision making sometimes occurs over time, it would have been interesting to monitor patient and physician behavior over several consultations. This was beyond the capacity of this study and would be a worthwhile addition to future research in this area.

It is possible that some or all of the components of the consultation preparation package were difficult for patients to understand and retain, thus limiting their impact. This may have been true, in particular, of the booklet explaining evidence-based medicine—a difficult concept to portray in a few pages. The materials were constructed for comprehension by a person with a reading level below grade 10. During the pilot study, patients reported that the materials were easy to understand (as they did in the current study), and they were able to summarize the points made. However, direct evaluation of understanding and recall (not included in the current study) would increase confidence that patients had understood the material.

In conclusion, this CCPP, delivered at least 2 days before the initial consultation with an oncologist, was successful in increasing patient question-asking behavior and level of activity in the consultation without increasing anxiety by the end of the consultation. Patients valued the package, for both themselves and their families. It seems that active endorsement of patient activity in the consultation by the physician is needed to allow such interventions to have their full impact. Additional research is needed to identify more effective ways of facilitating patient involvement in decision making.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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