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Assessing the Quality of Initial Consultations Regarding Adjuvant Colon Cancer Therapy

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Abstract

Background—Adjuvant chemotherapy prevents colon cancer recurrence in a subset of treated patients; however, decisions about whether to receive chemotherapy are complex. Adequate information exchange (IE) and informed decision making (IDM) between patient and physician are essential, particularly in the elderly.

Patients and Methods—A total of 35 patients with stage II and III colon cancer were asked on a questionnaire if they discussed specific colon cancer related information and elements of IDM with their doctors during their initial adjuvant chemotherapy consultations.

Results—On average, patients reported discussing 14.6 (SD ± 6.6) of 28 information items with their doctors. Basic items about cancer stage, prognosis, and treatment were discussed more commonly (mean, 9 of 12) than information about short-term (mean, 3.5 of 8) and long-term (mean, 2.3 of 8) effects of therapy. Patients aged ≥ 70 years reported discussing fewer information items with their physicians than patients aged < 70 years (mean, 11 items vs. 16.2 items; $P = .06$). Patients reported discussing an average of 5.1 (SD ± 1.3) of 7 IDM elements with their physicians. Thirty-four percent of the patients did not recall being asked their preference about chemotherapy, and 23% did not recall their doctor checking to ensure that they understood the discussion. Concordance with patient report and coded transcripts was good among 5 available patient-transcript pairs.

Conclusion—By patient report, IE and IDM quality appeared to be very good in initial adjuvant therapy consultations, though attention to patient preference could be an area for improvement. Differences in decision quality between younger and older patients are an important area for future study.

Keywords

Information exchange; Informed decision making; Patient questionnaires; Quality of life

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Introduction

Adjuvant chemotherapy for patients with resected colon cancer can be curative; it decreases the risk of cancer recurrence or death by approximately 30% when given in the form of fluorouracil monotherapy[1] and by an additional 23% with the addition of ox-aliplatin.[2] Ensuring that adjuvant chemotherapy is available to all for whom it is indicated is important. However, the adverse effects of combination chemotherapy with oxaliplatin and fluorouracil are common and can be severe. Thus, quality care of patients with stage II and III colon cancer must also include an assessment of how the individual patient values his or her current quality of life in comparison with how they value the potential benefit offered by adjuvant therapy. Quality care, therefore, must meet criteria for informed decision making (IDM). Informed decision making could be particularly important for older patients who report being just as willing to try chemotherapy but less willing than younger patients to tolerate severe adverse effects for any given degree of anticancer benefit.[3] Older patients could also have relatively less to gain with regard to life expectancy than younger patients. Indeed, older patients have consistently been shown to receive adjuvant therapy at lower rates than their younger peers.[4–7]

Although there is no standard definition of IDM in adjuvant therapy discussions, criteria that must be met with regard to the physician-patient interaction for IDM have been suggested. For complex decisions such as these, Braddock and colleagues identified 7 items, including discussing the nature of the decision, discussing the pros and cons of the decision, and assessing the patient's understanding, as critical to adequate informed decision making.[8] In addition to these criteria, we believe that patients must have a basic understanding of their diagnosis, prognosis, and treatment in order to be able to convey their values about therapy. As such, quality adjuvant therapy discussions ought to include basic elements of IDM and ought to convey substantial information about the nature of the decision to the patient. Whether adjuvant consultations contain these items is unknown.

We conducted a cross-sectional survey of patients with stage II and III colon cancer to describe (1) elements of IDM in adjuvant chemotherapy consultations, (2) what information is most important to patients deciding about adjuvant chemotherapy, and (3) how much of this information is conveyed to patients. We also explored whether the quality of decision making and information exchange (IE) differed by age.

Patients and Methods

Patients with stage II or III colon cancer seen by the gastrointestinal medical oncology group at the University of North Carolina between January 2007 and January 2008 were approached for participation. Patients were eligible if they had been diagnosed with colon cancer within 24 months of their visit, if they spoke English, were aged ≥ 18 years, and had no diagnosis of dementia. This study was approved by the Biomedical Institutional Review Board at the University of North Carolina at Chapel Hill. All patients provided written informed consent.

As the questionnaires were not tested for comprehension by patients of low health literacy, questionnaires were administered by a research assistant who read the questions aloud to participants in an attempt to abrogate effects of literacy on response. Participants identified at the time of their new-patient consultation were administered the questionnaire within 48 hours of their initial medical oncology consultation. Participants identified after their initial consultation were administered the questionnaire at any mutually compatible time.

The questionnaire was designed to address the following through the patient's report: (1) the information deemed by patients to be most important when making a decision about adjuvant chemotherapy, (2) the extent to which physicians conveyed information to the patients (IE), and (3) the adequacy of the informed decision-making process. Demographic information on age, self-reported race and ethnicity, level of education, income, self-reported health, marital status, and comorbidity were also collected.

Questionnaire Development

The initial 8 patients underwent cognitive testing of questionnaire items to ensure comprehensibility of unvalidated item language (eg, are the words easily understandable?) and item content (eg, does the question ask what we want it to ask?). Items were tested by retrospective probing: after the respondent completed the entire IE/IDM questionnaire, he or she was asked (1) for his or her interpretation of the meaning of each item and (2) the difficulty of each item and its response options.

After the initial 8 interviews were conducted, saturation of thoughts and ideas with regard to item language and content were attained. A summary of responses for each item was discussed by the investigators and a group of approximately 10 decision-making experts (University of North Carolina at Chapel Hill Decision-Making and Risk Communication Working Group). Based on this feedback item, wording was changed, and additional IE items were added.

Questionnaire and Measures

Patients were asked to answer all questionnaire items while recalling what was discussed at their initial medical oncology consultation.

Information Importance and Exchange

Patients were asked if elements in the domains of diagnosis and stage, prognosis, treatment options, and adverse effects were important to them and if they discussed these elements with their doctors. These domains were chosen because they have been shown to be important to the adjuvant-therapy decision-making process of patients with cancer.[9–12] Specific topics within each domain were included based upon the clinical experience of the investigators. Elements were divided into basic cancer knowledge (eg, stage, prognosis, chemotherapy options), short-term effects (eg, months after chemotherapy), and long-term effects (eg, years after treatment) on quality of life and function.

Patients were asked the importance of each item on a 5-point scale from “very important” to “not at all important.” After the first 8 respondents, this rating system appeared to offer little discrimination between the importance of items: most patients reported that almost all items were “very important.” As such, a ranking question was added to the revised questionnaire. For each category of information (eg, basic, short-term effects, long-term effects), patients were asked to rank order the 3 items most important to them when making their decision.

Patients were asked if they discussed each item with their doctor, and an IE score was generated for each patient as the sum of the “yes” responses, for a total of 28 possible points.

Informed Decision Making

Questionnaire items about IDM were designed to assess the 7 elements required for complex decisions as proposed by Braddock and colleagues (Table 1).[8] Because of the complexity of the clinical scenario that involves weighing toxicity against the potential benefit of a number of treatment options, the elements “pros” and “cons” required affirmative responses on 2 items to be considered present in the discussion (namely, both efficacy and toxicity). Response items for each question were “yes,” “no,” or “not sure.” Every Braddock element for which an affirmative response was given generated a point, with the exception of the 2-part element “pros and cons,” each of which was scored with 1/2 a point. Based on these responses, an IDM adequacy score between 0 and 7 was generated for each patient.

Comorbidity

Comorbidity was measured using a version of the Charlson Comorbidity Index (CCI) adapted by others for administration by interview.[13,14] This adapted version has shown excellent test-retest reliability (intraclass correlation coefficient, 0.91; Spearman coefficient, 0.73; $P < .001$) as well as good correlation with the original, chart-based CCI (Spearman coefficient, 0.63; $P < .001$).

Audio Taping

All patients enrolled at the time of their initial adjuvant therapy consultations were consented separately to audio taping of their consultation. Treating physician(s) were also consented. Audio files were transcribed in a de-indentified fashion. Transcripts were coded by 1 investigator (HKS) for whether IE and IDM items were explicitly discussed during the consultation. Items that seemed to be implicitly understood but were not discussed were coded as not having been discussed.

Statistical Analysis

This study was designed as a descriptive investigation of decision quality and to allow of an exploration of the differences between this quality in younger and older patients. All eligible patients who were seen at our practice in a year were approached for participation.

Information exchanged and decision-making elements are summarized with descriptive statistics. Because of revisions resulting from the cognitive interviews, the IE score is calculated for the 27 respondents asked the revised questionnaire. Because there was little change to the IDM items, this score is calculated based on all respondents. In calculating the IDM and IE scores, responses of “unsure” were coded as no. Bivariate comparisons of IE and IDM scores and age (dichotomized to < 70 years and ≥ 70 years), demographic, and cancer stage were explored. Comparison between items reported by patients and coded transcripts is presented descriptively as a count of discordant items.

Results

A total of 35 patients agreed to participate. Nine patients (25%) enrolled at the time of their initial medical oncology consultation, and 26 patients (75%) enrolled at the time of a follow-up visit. Median age at time of colon cancer diagnosis was 60 (SD ± 12), with 12 patients (34%) aged ≥ 65 years and 8 patients (23%) aged ≥ 70 years (Table 2). The population was generally well educated (45% college graduate or higher) and wealthy (34% annual income > $75,000). A total of 9 physicians, including 4 attending medical oncologists and 5 medical oncology fellows, performed the consultations.

Information Desired by Patients

Among the items about basic cancer information such as stage and prognosis, 17 of 27 patients (63%) ranked the “chance the cancer will come back,” 16 (59%) ranked the “stage of the cancer,” 14 (52%) ranked the “exact diagnosis and what that means” among the top 3 most important things to know when making a decision about adjuvant therapy (Table 3).

Among questions about the short- and long-term effects of chemotherapy, 21 (78%) and 18 (67%), respectively, cited the “effect of chemotherapy on the overall quality of life” as one of the most important things to know when deciding about adjuvant therapy. With regard to items about the short-term effects, 2 patients said none of these items was important to know, and 3 patients were unable to select 3 items as important to rank, citing they were not important to know when deciding about chemotherapy. When responding about long-term effects, 5 said no items were important, and an additional 5 were unable to select 3 items as important.

Information Exchange

Out of a total of 28 possible items, on average, patients reported having discussed 14.6 (range, 2–28; SD ± 6.6) of these items with their physicians (Table 4). Patients were more likely to report discussing basics about cancer (mean, 9 of 12 items; 75%) than information about short-term (mean, 3.5 of 8; 44%) or long-term (mean, 2.3 of 8; 29%) effects of adjuvant therapy. Patients aged $\geq$ 70 years reported discussing fewer information items with their physicians (11 items; 39%) than patients aged < 70 years (16.2 items; 58%; $P = .06$). Most of this difference appeared to be because of a difference in discussing basic cancer items (6.8 items vs. 9.6 items; $P = .006$).

Our exploratory analysis showed no difference in IE items discussed according to comorbidity, income, education, cancer stage, or time from consult to questionnaire administration. Black patients reported discussing more items with their physicians (19.4 items) than white patients (12.7 items). Those who received adjuvant therapy also reported speaking about more items (15.8) than those who did not receive adjuvant therapy (11.7).

Informed Decision Making

Of the 7 IDM elements proposed by Braddock et al,[8] on average, patients reported discussing 5.1 (range, 1.5–7 elements; SD ± 1.3) of these elements with their physicians (Table 5). There was no difference in number of reported elements between older and younger patients. There did not appear to be a difference between IDM elements when explored by age, sex, race, stage, or education.

Of the specific IDM elements, the fewest patients reported that their physician asked them what role they wanted to play in the decision (17%). Although the majority (66%) reported their physician asked them whether they wanted to take chemotherapy, a substantial minority reported that they were not asked about their preference about chemotherapy. Similarly, the majority of the patients reported that their physicians assessed their understanding during the consultation, although 23% said their physician did not check to ensure that they understood what he or she was saying.

Concordance Between Patient Report and Audio Tape of Consultations

A total of 6 patient-physician pairs consented to the audio taping of their adjuvant therapy consultation. One of these recordings was truncated prematurely, leaving 5 recordings available for a comparison of patient report and investigator coding of the discussed elements.

On the whole, there was good agreement between patient report and coding from transcripts. For the 28 IE items, there was discordance between patient reporting and coding on an average of 3.4 items (range, 3–5 items). For the IDM items, there was complete agreement for 3 patient-coding pairs, 1 discordant item for 1 pair, and 2 discordant items for 1 pair.

Discussion

In this pilot study of patients seen at a referral center for consultation about adjuvant chemotherapy, the overall quality of the adjuvant discussions as reported by patients appeared to be quite good. Physicians provided a moderate amount of information to patients during the consultations. Patients did report, however, that some of the information that was asked about on the questionnaire was not essential to their decision-making process; thus, IE might be even better than is represented by this survey. We confirmed previous findings that basic information about cancer diagnosis, stage, and prognosis are the most essential to patients.[15–17] Information about short- and long-term effects on health, work, and social function appear to be less important to patients at the time of adjuvant therapy decision making.

With regard to the quality of IDM, we used questionnaire items constructed to assess the 7 essential elements proposed by Brad-dock et al.[8] In his analysis of audio-taped patient encounters with primary care physicians and surgeons, only 1 of 217 encounters in which a complex decision was made met all 7 criteria for adequate decision making. Braddock found that the nature of the decision (84%) was the most commonly discussed element. Treatment alternatives, the second most discussed element, were included in only 30% of the investigated encounters.

In comparison, in our study, patients reported all but 2 elements (assessing preference and desired role) were discussed in > 75% of discussions. Certainly, recall of discussed elements might differ from coded audio tapes of consultations. For instance, patients satisfied with their care might be likely to answer affirmatively even if an item was not discussed. Conversely, dissatisfied patients or patients experiencing a great deal of stress at the time of their visit might say an item was not discussed even if it was. However, in our comparison of 5 pairs of patient reports and coded transcripts, there appeared to be fairly good concordance between patient report and what was actually discussed, particularly for the IDM elements. Despite this fairly good concordance, the variable length of time between initial consultation and questionnaire administration and the fact that we were unable to audio tape all consultations limits our ability to draw firm conclusions about decision quality in this group of physician-patient encounters.

One decision-making element that was notably absent was an assessment of the patient's desired decision role; however, whereas only 17% reported discussing this with their physician, 79% of the patients (27 of 35) reported a decision-making role concordant with their desired role (data not shown). Of the 7 with discordance between desired and achieved role, only 1 patient was off by > 1 level of input: a 39-year-old woman made the decision after getting the doctor's input but would have preferred the doctor to make the decision. Although it might be that patients simply do not remember being asked what role they would like to play, it is more likely that unspoken communication allows physicians to infer the desired decision role, perhaps making explicit inclusion of this question in complex decision making less crucial.

With regard to information exchanged between patients and their physicians, patients reported discussing a large number of items, mostly about basic cancer information, with their physicians. Although most respondents cited the majority of items as somewhat or very important when making their decision (data not shown), when asked to rank items from 1 to 3 in order of their importance, a number of respondents were unable to rank more than 1 or 2, and some were unable to rank any items about short- or long-term effects of treatment as important. This suggests that information about short- and long-term effects of chemotherapy on quality of life and its domains might be of less consequence to adjuvant therapy decision making.

Conclusion

The overall quality of adjuvant therapy consultations as assessed by patient report of IDM and information exchanged appeared to be quite good at our cancer referral center. We believe that this pilot study has identified a number of areas for future study, which, if performed on a larger, multicenter scale, could be performed in all patients immediately after adjuvant consultation to overcome the differential time between consult and questionnaire that is a major limitation of this pilot. Coadministration of a physician survey to confirm or refute patient recall might also strengthen this study design.

One area for future study is to continue to investigate decision quality in older patients. Patients aged ≥ 70 years reported discussing fewer information items with their physicians than younger patients did. Although we cannot draw firm conclusions about this based on the responses of so few patients, it does raise the question as to whether older patients might need to have the nature of their adjuvant therapy discussions tailored to their needs in order to achieve the same decision quality as younger patients. A large-enough study would be able to determine whether IE in older patients truly differs from that in younger patients. If so, subsequent work on the effect of patient navigators or decision aids on this difference would be warranted.

Another area for study of this decision is to investigate how processes of care affect decision quality. For instance, does quality differ based on provider type (oncology fellow, academic faculty, community practitioner)? What about based on ancillary education available in the office through nursing staff, literature, etc?

Finally, a separate but important theme is the failure of physicians to assess patient preference with regard to chemotherapy. We found that physicians failed to ask a sizable minority if they understood the information that was being told to them and failed to ask their preference for chemotherapy. Although it is possible that patients might simply have failed to remember discussing these elements with their physicians, if patients do not remember having their preference assessed, that is tantamount to having them feel as though their preference was not considered in the decision. Either way, this likely represents an area for improvement in decision-making quality. Future work on how patients value the risks and benefits of chemotherapy, and how values assessment is performed during the physician-patient encounters, will help address the extent to which our observations represent a failure of decision quality.

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Table 1

Elements of Informed Decision Making From Braddock et al[8]

Discussion of the patient’s role in decision making
Discussion of the clinical issue or nature of the decision
Discussion of the alternatives
Discussion of the pros and cons
Discussion of uncertainties associated with the decision
Assessment of the patient’s understanding
Exploration of the patient’s preference

Table 2

Table 2A Patient Characteristics

Characteristic	**All Patients (N = 35)**	**Age < 70 Years (n = 27)**	**Age ≥ 70 Years (n = 8)**
Median Age at Diagnosis, Years (Range)	60 (36–88)	56 (mean)	76 (mean)
Sex, n (%)			
Female	19 (54)	15 (56)	4 (50)
Male	16 (46)	12 (44)	4 (50)
Race, n (%)			
White	27 (77)	21 (78)	6 (75)
Black	8 (23)	6 (22)	2 (25)
Marital Status, n (%)			
Married	25 (71)	19 (70)	6 (75)
Partner	1 (3)	1 (4)	0
Divorced	3 (9)	3 (11)	0
Widowed	3 (9)	1 (4)	2 (25)
Never married	3 (9)	3 (11)	0
Annual Income, n (%)			
< 15K	5 (14)	4 (15)	1 (13)
15–29K	5 (14)	3 (11)	2 (25)
30–44K	6 (17)	4 (15)	2 (25)
45–59K	3 (9)	2 (7)	1 (13)
60–74K	3 (9)	3 (11)	0
75–89K	1 (3)	1 (4)	0
> 90K	11 (31)	10 (37)	1 (13)
Refused to answer	1 (3)	0	1 (13)
Education, n (%)			
< 8th grade	2 (6)	2 (7)	0
Any high school	3 (9)	1 (4)	2 (25)
High school graduate/GED	6 (17)	5 (19)	1 (13)
Some college	5 (14)	5 (19)	0
Associate degree	3 (9)	2 (7)	1 (13)
College degree	7 (20)	5 (19)	2 (25)
Masters or professional degree	9 (25)	7 (26)	2 (25)

Table 2B Patient Characteristics

Characteristic	**All Patients (N = 35)**	**Age < 70 Years (n = 27)**	**Age ≥ 70 Years (n = 8)**
Self-Reported Health[a], n (%)			
Much better	15 (43)	11 (41)	4 (50)
Better	10 (29)	7 (26)	3 (38)
Average	3 (9)	3 (11)	0

Table 2B Patient Characteristics

Characteristic	**All Patients (N = 35)**	**Age < 70 Years (n = 27)**	**Age ≥ 70 Years (n = 8)**
Worse	6 (17)	5 (19)	1 (12)
Much worse	1 (3)	1 (4)	0
Charlson Comorbidity Score[b], n (%)			
2	24 (69)	20 (74)	4 (50)
3	7 (20)	4 (15)	3 (38)
4	2 (6)	1 (4)	1 (12)
5	0	0	0
6	1 (3)	1 (4)	0
7	1 (3)	1 (4)	0
Received Adjuvant Therapy, n (%)			
Yes	23 (66)	18 (67)	5 (62)
No	12 (34)	9 (33)	3 (38)
Interval From Consultation to Survey, n (%)			
< 1 Month	10 (28)	7 (26)	3 (37)
1–3 Months	8 (23)	5 (19)	3 (37)
4–6 Months	6 (17)	4 (15)	2 (25)
> 6 Months	11 (31)	11 (41)	0

[a] Compared with average for age.

[b] All had baseline Charlson Comorbidity Index score of 2 because of diagnosis of cancer.

Values in the columns might not add up to 100% because of rounding error.

Table 3

Information Desired When Making Decisions About Adjuvant Therapy (n = 27)

Basic Cancer Information, (%)	**Most Important**	**Second Most Important**	**Third Most Important**
Chance Cancer Will Come Back	8 (30)	8 (30)	1 (4)
Stage of Cancer	7 (26)	4 (15)	5 (19)
Exact Diagnosis and What That Means	6 (22)	6 (22)	2 (7)
Effect of Chemotherapy on Chance of Cancer Recurrence or Death	4 (15)	4 (15)	4 (15)
Chance of Dying From Cancer Without Chemotherapy	1 (4)	2 (7)	1 (4)
Specific Side Effects of Chemotherapy	1 (4)	–	10 (37)
Different Chemotherapy Options	–	2 (7)	1 (4)
What to Do if Chemotherapy Makes You ill	–	1 (4)	–
Length and Frequency of Chemotherapy Treatments	–	–	2 (7)
How Much Work You or Family Would Miss for Treatments	–	–	1 (4)
Short-Term Effects			
Overall Quality of Life	15 (58)	2 (7)	4 (15)
Ability to Continue Normal Social Activities	4 (15)	3 (11)	2 (8)
Ability to Continue Normal Work Activities	3 (11)	4 (15)	2 (8)
Ability to Take Care of People Who Depend on You	2 (7)	1 (4)	3 (12)
Ability to Take Care of Your Basic Needs Without Help	1 (4)	5 (19)	2 (8)
Ability to Continue Normal Chores at Home	0	4 (15)	2 (8)
Ability to Maintain a Sexual Relationship	0	1 (4)	2 (8)
Ability to Take Care of Everyday Needs Without Help	0	2 (8)	4 (15)
None of These Was Important	2 (7)	5 (19)	6 (22)
Long-Term Effects			
Overall Quality of Life	15 (56)	2 (7)	1 (4)
Ability to Continue Normal Work Activities	2 (7)	3 (11)	3 (11)
Ability to Take Care of Basic Needs Without Help (ADLs)	2 (7)	5 (19)	2 (7)
Ability to Take Care of People Who Depend on You	2 (7)	1 (4)	5 (19)
Ability to Take Care of Everyday Needs Without Help (IADLs)	1 (4)	1 (4)	4 (15)
Ability to Continue Normal Chores at Home	0	4 (15)	0
Ability to Maintain a Sexual Relationship	0	1 (4)	1 (4)
Ability to Continue Normal Social Activities	0	2 (7)	1 (4)
None of These Was Important	5 (19)	8 (29)	10 (37)

Abbreviations: ADLs = activities of daily living; IADLs = instrumental activities of daily living

Table 4

Information Items Discussed With Physician

Domain	All Patients (N = 27)	Age < 70 Years (n = 18)	Age ≥ 70 Years (n = 9)
Mean Items Discussed (28 Items)	14.6 (range, 2–28)	16.2	11[a]
Basic Cancer (12 Items)	9	9.6	6.8[b]
Short-Term Effects (8 Items)	3.5	3.9	2.6
Long-Term Effects (8 Items)	2.3	2.6	1.6

[a] $P = .06$

[b] $P = .006$

Table 5

Informed Decision-Making Elements

Variable	**All Patients (N = 35)**	**Age < 70 Years (n = 27)**	**Age ≥ 70 Years (n = 8)**
Mean Score	5.1 (range, 1.5–7)	5.3	4.7
Proportion Reporting Each Element, n (%)			
Discuss Desired Role	6 (17)	5 (19)	1 (13)
Discuss Issue, Nature of Decision	33 (94)	26 (96)	7 (88)
Discuss Alternatives	32 (91)	25 (93)	7 (88)
Discuss Pros	30 (86)	24(89)	7 (88)
Discuss Cons	31 (89)	26 (96)	5 (63)
Discuss Uncertainties	29 (83)	23 (85)	6 (75)
Assess Understanding	27 (77)	21(84)	6 (75)
Explore Preferences	23 (66)	18 (67)	5 (63)