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Cancer treatment decision-making among young adults with lung and colorectal cancer: A comparison with adults in middle age

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Abstract

Objective—To understand experiences with treatment decision-making among young adults with cancer.

Methods—We studied patients with lung or colorectal cancer in the Cancer Care Outcomes Research and Surveillance Consortium, a prospective cohort study. We identified 148 young adult patients aged 21–40 who completed baseline interview questions about cancer treatment decision-making; each was propensity score matched to 3 middle adult patients aged 41–60, for a cohort of 592 patients. Patients were asked about decision-making preferences, family involvement in decision-making, and worries about treatment. An ordinal logistic regression model evaluated factors associated with more treatment worries.

Results—Young and middle-aged adults reported similar decision-making preferences (P=.80) and roles relative to physicians (P=.36). Although family involvement was similar in the age groups (P=.21), young adults were more likely to have dependent children in the home (60% younger versus 28% middle-aged adults, P<.001). Young adults reported more worries about time away from family (P=.002), and, in unadjusted analyses, more cancer treatment-related worries (mean number of responses of "somewhat" or "very" worried 2.5 for younger versus 2.2 for middle-aged adults, P=.02.) However, in adjusted analyses, worries were associated with the presence of dependent children in the home (OR 1.55, 95% CI=1.07–2.24, P=.02), rather than age.

Conclusions—Young adults involve doctors and family members in decisions at rates similar to middle-aged adults, but experience more worries about time away from family. Patients with dependent children are especially likely to experience worries. Treatment decision-making strategies should be based on individual preferences and needs rather than age alone.

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Introduction

Young adults with cancer face a number of unique challenges,[1–3] not the least of which is navigating a cancer diagnosis and treatment during major developmental and life transitions.[4] During a life stage in which many young people leave their natal homes and establish careers and families of their own, young adults with cancer may find themselves back in the homes and cities they grew up in, or navigating the cancer diagnosis as single young adults without local family support. Still others must balance their needs against those of their own young children and families.

Evidence about the unique experiences of young adult cancer patients remains somewhat limited. Yet young adults with cancer are thought to be a vulnerable population, at risk for disparities in cancer care,[1,5] including decreased clinical trial enrollment [6–8] and less use of specialty centers[9,10]. While multiple factors may contribute to these issues, a better understanding of young adults' decision-making processes may help us identify ways to mitigate these differences.

Decision-making in the broader adult cancer population has revealed several themes. Most adults with cancer wish to collaborate in decision-making with their physicians,[11–13] and most involve but do not defer decision-making to family members.[14] Patients who hold their desired roles in decision-making,[15] and those who collaborate in decision-making with physicians,[16] tend to experience greater satisfaction with decisions and care. Patients making decisions about cancer treatments also experience high levels of worry, especially about side effects. [17]

Less is known about how young adults navigate cancer treatment decision-making, or how their decision-making differs from adult patients of middle age. Data from the end-of-life setting suggests that young people are often highly focused on the needs of their family members,[18] and less invested in the specific medical decisions made,[19,20] suggesting that family involvement and social concerns could be powerful drivers of decision-making even for those beginning cancer therapy. We evaluated attributes of cancer treatment decision-making among young adults aged 21 to 40, including their decisional roles relative to physicians, the extent to which family members are involved in decision-making, and external influences on decision-making such as worries about costs of care. Findings were compared with decision-making strategies employed by middle adults aged 41–60 who were propensity score matched for clinical and demographic characteristics.

Methods

The Cancer Care Outcomes Research and Surveillance (CanCORS) study enrolled approximately 10,000 patients with lung or colorectal cancer diagnosed between 2003 and 2005. Patients were enrolled from five geographic regions (Northern California, Los Angeles County, North Carolina, Iowa, or Alabama), five participating health maintenance organizations (HMOs), and 15 Veteran's Affairs (VA) medical centers.[21,22] Each site identified incident cases using a rapid case ascertainment protocol using population-based or institutional cancer registries. The CanCORS study included patient or surrogate surveys, physician surveys, and medical record abstraction over 15 months after diagnosis. For the baseline survey, patients (or surrogates of patients who were too ill to participate) were interviewed approximately 4–6 months after diagnosis in English, Spanish, or Chinese. The study was approved by human subjects committees at all participating institutions.

The CanCORS study included 2,182 patients who were aged 21 to 60 years at diagnosis (148 patients aged 21–40 at diagnosis, and 2,034 patients aged 41–60) whose baseline interviews included items on decision-making (Supplemental Figure 1). In order to ensure that younger adults were compared to middle adults with similar clinical characteristics, each younger adult was matched to three middle adults from the larger cohort using propensity score matching based on all variables listed in Table 1 (including race/ethnicity, education, stage, performance status (measured by EQ-5D [23]; defined as “good” for patients who had no mobility problems, no self-care problems, and no or some problems with their usual activities), and days between diagnosis and survey completion. Matching was performed separately by cancer site (i.e. young adult lung cancer patients were matched to middle adult lung cancer patients).

Survey items

Patients were asked to report their preferred role in decision-making with respect to physicians (“Which statement best describes the role you would prefer to play when decisions about treatment for your cancer are made?”) Patients who received chemotherapy (N=515/589) were asked, “Which statement best describes the role you played when the decision was made about chemotherapy?” Patients were also asked, “How often did your doctors give you as much information as you wanted about your cancer treatments, including potential benefits and side effects?” Family involvement in decision-making was assessed using the question, “Which statement best describes the role your family played when decisions about treatment for your cancer were made?” Patients were asked how many children under the age of 18 were living in their household and supported by their total household income. Response categories for all questions are shown in Table 2.

Worries about treatment were elicited by asking patients: “At the time you were making decisions about your treatment for your cancer, how much were you worried about:” “side effects from treatment;” “cost of treatment;” “taking time away from family;” “taking time away from work;” and “transportation to treatment” (Table 3.) These questions were based on previously devised questions,[24] with additional development and validation for the CanCORS study.[25] Additional findings on worries in the CanCORS population have been previously published.[17]

Additional interview data included age, race/ethnicity, income, education, and marital status. Medical record abstraction data included cancer type and stage, insurance, HMO and integrated network membership, and geographic region.

Statistical analysis

Patient age at diagnosis was categorized as young adult (21–40 years) versus middle-aged adult (41–60 years). Responses to questions about preferred and actual roles in chemotherapy decision-making were compared directly. Patients whose preferred and actual role choices were identical were categorized as holding their preferred role in decision-making. Those whose actual roles involved less physician input than desired (for example, a patient preferred shared decision-making, but made the decision with little or no input from doctors) were categorized as being more involved than desired. Those whose actual roles involved more physician input than desired (for example, a patient preferred shared decision-making, but the doctors made the decision after considering the patient's decision) were classified as less involved than desired.

Responses to questions about treatment-related worries were dichotomized for analysis between "not at all" or "a little" worried, and "somewhat" or "very" worried.

Unadjusted associations between age category and variables of interest were evaluated using Chi-squared tests; Fisher's exact tests were used when frequency counts of less than 5 were encountered. An ordinal outcome variable for the number of worries, ranging from 0 to 5, was constructed by summing the number of items where the patient responded that they were somewhat or very worried. A multivariable ordinal logistic regression model examined whether younger patients experienced more worries than older patients, adjusting for other patient and tumor characteristics. All variables of interest were entered into the multivariable model, regardless of statistical significance. Analyses for the outcome of number of worries included 531 patients who completed every survey item about worry (138/148 [93%] young adults and 393/444 [89%] middle adults). Logistic regression analyses were performed on multiply imputed datasets to adjust for survey nonresponse;[26] however, imputed values were not used for the outcome variables. Statistical analyses were conducted using Stata v13.1 (StataCorp LP, College Station, TX), CanCORS core data v1.16, and patient survey data v1.12.

Results

Eighty percent of cohort patients had colorectal cancer (Table 1). Middle-aged adults were well-matched to younger adults for clinical characteristics, as specified by our matching algorithm. Among the younger adults, 17% were age 21–30 and 83% were age 31 to 40 at diagnosis. Among the middle-aged adults, 37% were age 41 to 50 and 63% were aged 51 to 60 at diagnosis.

Decision-making preferences and experiences with physicians were similar regardless of age category. Most younger and middle-aged adults preferred to make decisions together with their doctor (58% and 61%, respectively, Table 2) and held the role they wished with respect to physicians when making decisions about chemotherapy (59% and 66%, respectively.) More than two-thirds of patients in both age groups reported that they had received the information they wanted about cancer treatments, including risks and benefits.

About half of both younger and middle-aged adults reported that they made decisions about cancer treatment together with their family. Most of the remainder reported either considering the opinions of family members or making decisions without family input. Although family involvement in decision-making was similar in the two age groups (P=.21), young adults were more likely to report having dependent children living in their household (60% among young versus 28% among middle-aged adults, P<.001).

Younger patients reported more cancer treatment-related worries than middle adults (mean number of responses of “somewhat” or “very” worried 2.5 for younger versus 2.2 for middle-aged patients, unadjusted P=.02). Young adults were more likely to report worrying about taking time away from family for treatment (P=.002). Greater absolute proportions of young adults also reported worrying about side effects and taking time away from work, but differences were not statistically different from the middle-aged.

In adjusted analyses, the number of worries was no different between younger and middle-aged adults (OR=1.20 for younger versus middle-aged adults across increasing levels of worry, 95%CI=0.83–1.73, P=.34, Table 4). However, patients with dependent children reported more worries (OR=1.55, 95% CI=1.07–2.24, P=.02). In addition, patients with higher educational attainment reported fewer worries (OR=.50, 95%CI=.28–.90 for high school education or higher, P=.02).

Discussion

Despite recognition that young adults experience cancer care at a uniquely challenging life stage, we know little about their experiences with cancer treatment decision-making. Our findings offer some important insights.

First, young adults employ similar decision-making strategies to those used by middle-aged adults when it comes to involving doctors and family members. Most want to share in decision-making with physicians, and about half make treatment decisions together with family members, while the rest involve family in a more limited way. Very few, regardless of age, defer decisions to family members.

Second, younger adults’ decisions about cancer treatment are more likely than middle adults’ to be informed by worries about time away from family. 60% of the young adults we studied had dependent children at home, and patients with dependent children were particularly vulnerable to treatment-related worries. Previous work has found that parents of dependent children have more anxiety and are less likely to engage in care planning at the end of life,[27] and our findings suggest related challenges for parents engaging in initial treatment-decision-making. While these findings apply to all parents of dependent children, the experience of parenting children in the home was disproportionately borne by younger adults.

These findings remind us that young adults make decisions about cancer treatment in a complex landscape of considerations, including worries about the people they love. Young adulthood is also a complex time in identity development where the ability to perform tasks related to work or family can threaten a young person’s sense of self. While these issues are likely to be salient for all patients, young people appear to be particularly vulnerable, especially when they have children in the home. In addition, such worries could underlie known disparities in care among young people, such as decisions to receive care close to home rather than at specialty centers, for example.

Findings should be considered in light of limitations. We studied an unusual population of young adults with cancer—young people with lung and colorectal cancer, which are more common among older adults. However, the CanCORS population, which is limited to patients with lung and colorectal cancer, is broadly representative of the US population, including those with lung and colorectal cancer.[28] In addition, about two-thirds of the young adults we studied were married or had live-in partners, and most were in their thirties. We cannot be sure that our findings apply to all young adults with cancer, especially single patients in their twenties. Further study with focused efforts to include the youngest adults would be useful. In addition, the survey was administered 4–6 months after diagnosis, even though early experiences with treatment may have led patients to reappraise their feelings about decision-making over time.[29] Items about worries were developed based on patient interviews and subjected to pilot-testing;[24,25] however, psychometric data are not available, and response options were close-ended, without an opportunity for patients to expand on their experiences. We have performed multiple analyses despite limited power to do so; thus, some associations might best be considered exploratory. Finally, although our survey identified treatment-related worries, we do not know whether worries changed decisions about care.

Nonetheless, for oncologists who care for young people, a conversation about both physician and family involvement may be helpful- who should be involved? How can he or she be brought into the conversation? How can I help you make a good decision for yourself, with or without the help of loved ones? In addition, the unique stresses of young adulthood create special worries about treatment, especially when it comes to taking time away from family; patients with children living at home are particularly vulnerable, regardless of age. In order for patients to make good decisions for themselves, these issues may need to be addressed. Ultimately every patient should be considered as an individual with unique preferences and considerations around treatment decision-making. Young adult patients are no different.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic and clinical characteristics, stratified by age at diagnosis.

	Age 21 to 40	**Age 41 to 60**
Number of patients	148	444
Cancer type		
Colorectal	119(80)	357 (80)
Lung	29(20)	87 (20)
Stage at diagnosis		
I	24(18)	75 (18)
II	31(23)	105 (26)
III	50(37)	144 (35)
IV	30(22)	85 (21)
Gender		
Male	61(41)	180 (41)
Female	87(59)	264 (59)
Race/Ethnicity		
White	73(50)	226 (51)
Hispanic/Latino	29(20)	85 (19)
African-American	18(12)	45 (10)
Asian or Pacific Islander or other	27(18)	85 (19)
Income ($)		
<19,999	31(23)	94 (23)
20,000 to 39,999	31(23)	96 (23)
40,000 to 59,999	24(18)	71 (17)
60,000+	48(36)	152 (37)
Education		
<High school	20(14)	53 (12)
High school/some college	74(50)	226 (51)
College degree/higher	53(36)	162 (37)
Marital status		
Married/living as married	98(66)	287 (65)
Not married	50(34)	154 (35)
Performance status (EQ-5D)		
Poor	39(28)	119 (28)
Good	102(72)	309 (72)
Insurance		
Private	101(69)	309 (70)
Not private *	46(31)	132 (30)
HMO member		
No	123(83)	368 (83)
Yes	25(17)	76 (17)
Integrated network		

	Age 21 to 40	**Age 41 to 60**
No	121(82)	364 (82)
Yes	27(18)	80 (18)
Region		
Midwest	12(8)	40 (9)
South	44(30)	130 (29)
West or Northeast	92(62)	274 (62)
Months between diagnosis and baseline interview		
Median	4.3	4.4
25th, 75th percentiles	3.6,5.5	3.6, 5.7

Stage missing for 48 patients; race/ethnicity for 4; Income for 45; education for 4; and insurance for 4.

[*] “Not private” includes Medicaid (n=8), Medicare (n=49), and other insurance sources (N=121; e.g. state-based low-income insurance programs).

Table 2

Decision-making with physicians and with family members, stratified by age at diagnosis. Values in the table represent frequencies (column percentage).

	Age 21 to 40 N=148	**Age 41 to 60 N=444**	**P Value**
Which statement best describes *the role you would prefer* to play when decisions about your treatment for your cancer are made? **(N=584)**			0.80
You prefer to make the decisions with little or no input from your doctors	1(1)	2 (0)	
You prefer to make the decisions after considering your doctor's opinion	53(36)	140 (32)	
You prefer that you and your doctors make the decision together	85(58)	267 (61)	
You prefer that your doctors make the decisions after considering your opinion	7(5)	21 (5)	
You prefer your doctors make the decision with little or no input from you	1(1)	7 (2)	
Which statement best describes the *role you played* when the decision was made about *chemotherapy*? **(N=501)**			0.36
You made the decision with little or no input from your doctors	5(4)	5 (1)	
You made the decision after considering your doctors' opinions	56(41)	147 (40)	
You and your doctors made the decision together	53(39)	163 (45)	
Your doctors made the decision after considering your opinion	11(8)	21 (6)	
Your doctors made the decision with little or no input from you	11(8)	29 (8)	
Relationship between preferred role in treatment decision-making and actual role in chemotherapy decision-making **(N=499)**			0.24
Patient more involved than desired	28(21)	68 (19)	
Patient held preferred role	80(59)	240 (66)	
Patient less involved than desired	28(21)	55 (15)	
How often did your doctors give you as much information as you wanted about your cancer treatments, including potential benefits and side effects? **(N=587)**			0.30
Always	109(74)	305 (69)	
Usually	22(15)	76 (17)	
Sometimes	15(10)	44 (10)	
Never	1(1)	15 (3)	
Which statement best describes the role that your family played when decisions about treatment for your cancer were made?[1]			0.21
You made the decisions with little or no input from your family	34(23)	130 (30)	
You made the decisions after considering your family's opinion	35(24)	101 (23)	
You and your family made the decisions together	75(51)	202 (46)	
Your family made the decisions after considering your opinion or with little or no input from you	3(2)	3 (1)	
How many children under the age of 18 are living in your household and are supported by your household income?			<0.001
None	59 (40)	318 (72)	
1 or more	89 (60)	126 (28)	

[1] Responses of "don't know" or" refused" were given for 1 patient and "N/A (e.g. I don't have any family)" for 4 patients, all age 41 to 60 at diagnosis.

Table 3

Influences on patients' decisions about cancer treatment, stratified by age at diagnosis. Values in the table represent frequencies (column percentage).

	Age 21 to 40 N=148	**Age 41 to 60 N=444**	**P Value**
Worried about…			
Side-effects from treatment			0.20
Not at all or a little worried	35(25)	128 (30)	
Somewhat or very worried	107(75)	294 (70)	
Missing	*6*	*22*	
Cost of treatment			0.96
Not at all or a little worried	84(60)	247 (60)	
Somewhat or very worried	56(40)	163 (40)	
Missing	*8*	*34*	
Taking time away from family			0.002
Not at all or a little worried	52(37)	214 (52)	
Somewhat or very worried	90(63)	199 (48)	
Missing	*6*	*31*	
Taking time away from work			0.31
Not at all or a little worried	66(46)	211 (51)	
Somewhat or very worried	76(54)	199 (49)	
Missing	*6*	*34*	
Transportation to treatment			0.71
Not at all or a little worried	112(80)	333 (81)	
Somewhat or very worried	28(20)	76 (19)	
Missing	*8*	*35*	

Table 4

Entire cohort: factors associated with increased cancer treatment-related worries by multivariable ordinal logistic regression.

N=531	**Unadjusted mean number of worries**	**Adjusted**[†]		
		Odds Ratio	**95% CI**	**P Value**
Age at diagnosis				0.34
21–40	2.5	1.00		
41–60	2.2	1.20	0.83–1.73	
Cancer type				0.20
Colorectal	2.3	1.00		
Lung	2.4	0.73	0.44–1.19	
Stage at diagnosis				0.17
I	2.4	1.00		
II	2.1	0.72	0.44–1.17	
III	2.2	0.83	0.55–1.27	
IV	2.6	1.35	0.77–2.36	
Performance status (EQ-5D)				0.09
Poor	2.5	1.00		
Good	2.2	0.68	0.43–1.07	
Time between diagnosis and baseline interview				0.83
<4 months	2.4	1.00		
4–5 months	2.2	0.94	0.60–1.48	
>5 months	2.3	1.09	0.74–1.60	
Gender				0.29
Male	2.4	1.00		
Female	2.3	0.83	0.59–1.17	
Race/Ethnicity				0.79
White	2.2	1.00		
Non-white	2.4	0.95	0.67–1.36	
Income ($)				0.32
<40,000	2.5	1.00		
≥40,000	2.1	0.80	0.51–1.25	
Education				0.02
Less than high school	3.0	1.00		
High school or higher	2.2	0.50	0.28–0.90	
Marital status				0.49
Married or living as married	2.3	1.00		

N=531	**Unadjusted mean number of worries**	**Adjusted**[†]		
		Odds Ratio	**95% CI**	**P Value**
Not married	2.3	0.86	0.57–1.30	
Number of dependent children				0.02
None	2.2	1.00		
One or more	2.5	1.55	1.07–2.24	
Insurance				0.14
Private	2.2	1.00		
Not private	2.7	1.42	0.89–2.27	
HMO member				0.16
No	2.4	1.00		
Yes	1.9	0.70	0.43–1.15	
Region				0.27
West or Northeast	2.3	1.00		
Midwest or South	2.4	1.21	0.86–1.70	

[†] Due to collinearity, integrated network (collinear with ‘HMO’) was not included in the multivariable model.