

Preferences about information and decision-making among older patients with and without cancer

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Abstract

Background: information of older patients with cancer is crucial to ensure optimal care.

Objectives: to compare older patients with and without cancer regarding their preferences about medical information, decision-making and surrogate designation.

Design: an intention-to-act questionnaire was completed by patients ≥ 70 y enrolled in the ELderly CAncer PATients cohort between January and June 2013 and by patients in the same age group enrolled in a cross-sectional survey conducted in 2005 in acute geriatric wards.

Setting: Henri-Mondor Teaching Hospital in the Paris conurbation, France.

Results: the group with cancer had 133 patients [mean age, 79.6 ± 6.5 y; 54.9% women]. The main tumour sites were colorectal [24.1%], breast [23.3%] and prostate [15.8%]; 34.8% had metastases. All these patients wanted full information, 74.2% wanted to participate in decisions about their care, 87.2% would designate a family member to serve as a surrogate in life-threatening situations and 15% had already designated a surrogate. Compared to patients without cancer, those with cancer more often wanted to receive information in a life-threatening situation [93.6% versus 79.2%; $P < 0.001$]. Factors independently associated with patients wanting their informed consent to be obtained for all interventions were having children [adjusted odds ratio (aOR), 2.13; 95% confidence interval, 1.24; 3.66; $P = 0.006$], higher Mini Mental State Examination score [aOR_{per point} 1.09; 1.02; 1.17], younger age in the group without cancer [aOR_{>82 y vs. ≤ 82 y} 0.50; 0.29–0.88] and being cancer-free [≤ 82 y, aOR, 0.30; 0.14–0.63; > 82 y, aOR, 0.41; 0.17–0.97].

Conclusion: older patients with cancer expressed a strong preference for receiving information and participating in decisions about their care.

Keywords: older people, cancer, medical information, medical decision-making, surrogate

Introduction

Informing patients with cancer about their condition improves the quality of care, decision-making process and

treatment adherence [1–3], while also encouraging patients to play an active role, particularly by expressing their preferences and participating in medical decisions. Moreover, malignancies are often fatal, sometimes after a period of

loss of decision-making competence. Designating a surrogate ensures that the patient's preferences are honoured even during this period [4]. A law passed in 2002 requires French oncologists to provide formal clear information to all their patients and to ask that a surrogate be designated in writing. The surrogate can be a relative, a close friend or the general practitioner. The surrogate can provide the patient with assistance during medical appointments and advice about decisions. If the patient is unable to make decisions, the surrogate must inform the doctors of the wishes and values expressed previously by the patient and relevant to his or her healthcare.

Most patients report wanting to understand their medical conditions and treatment options. Risk factors for receiving less information include older age, low income, less education, multiple comorbidities, cognitive impairment and advanced cancer [5–7]. Preferences about sharing decisions are far more variable. In several studies, age was the strongest predictor of patient preferences about shared decision-making, with older patients being less likely to want active participation [8–11]. However, in several studies, patient preferences were not reliably predicted by demographic factors such as age [12–14], and other factors influenced attitudes about sharing decisions [15]. In a 2005 study [16], we found that older inpatients in acute geriatric wards usually wanted both information and decision sharing. Thus, the preferences of older patients about involvement in the decision-making process may differ according to the setting and to their current health status.

Few studies have focused on the preferences of older patients regarding cancer information and involvement in medical decisions. They indicate that older patients with cancer usually want to know their diagnosis [17] and perceive this information as important [18], whereas physicians and families view full disclosure with some reluctance [19].

The aims of the present study were to describe the preferences of older patients with cancer regarding medical information and decision-making, to assess their knowledge about surrogate designation and to compare these data with those from older inpatients without cancer.

Methods

Study design

We compared the data obtained in two cross-sectional surveys, one conducted in three acute geriatrics wards in 2005 and reported previously [16] and the other conducted in older patients with cancer enrolled in 2013 in the ELderly CAncer PATients [ELCAPA] cohort [20] [ELCAPA-11 survey]. Both surveys took place at the Henri-Mondor University Hospital, a tertiary referral centre with 1,000 acute-care beds and 2,000 geriatric-care beds.

Population

Patients with cancer

The ELCAPA cohort is described elsewhere [20]. Briefly, this prospective open cohort includes in- and outpatients aged 70 y or older who have solid or haematological malignancies. Patients in ELCAPA are referred by oncologists, for a geriatric assessment before making decisions about the anti-cancer strategy. The present ancillary study [ELCAPA-11] was done in patients who were included in ELCAPA between 1 January 2013 and 30 June 2013 at the Henri-Mondor geriatric oncology unit, were informed of their cancer diagnosis, and accepted to complete a questionnaire about preferences regarding medical information and decision-making. We excluded patients who did not speak French fluently, had not been informed about their diagnosis, or had psychiatric disorders or severe cognitive impairment or delirium.

The protocol of this observational study was approved by the appropriate ethics committee (CPP Ile-de-France I, Paris, France). Informed consent was obtained from all participants prior to inclusion.

Patients without cancer

The data from patients without cancer were obtained for a previously reported cross-sectional survey of patients aged 70 y or over admitted to any of the three acute geriatrics wards at the Henri-Mondor University Hospital between 1 January 2005 and 30 January 2006 [16]. The objective of this survey was to identify factors associated with patient preferences about receiving information and designating a surrogate. For the present analysis, we excluded the 29 patients who had active cancer.

Data collection

In both surveys, each patient was interviewed by one of three geriatricians and completed a semi-structured questionnaire with five closed questions, for which one or multiple response options were available. The interview lasted about 15 minutes and explored four domains. First, demographic and socio-economic data were collected. The 2nd domain was the extent of information the patients wanted to receive about their disease and the degree of involvement they wanted in decisions about their care [four response options, as shown in Table 2]. The 3rd domain was the amount of information the patient would want in a life-threatening situation [five response options, Table 2]. The last domain was designation of a surrogate. If the patient did not know what a surrogate was, Article L.1111-6 of the French Public Health Code defining the healthcare surrogate was read. Patients were asked whether they had designated a surrogate in writing and who they had designated, or would designate, as a surrogate to speak for them should they lose decision-making competence [four options, Table 2].

Both surveys collected data from a geriatric assessment including the Mini Mental State Examination [MMSE] score

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to assess cognition, Katz Activities of Daily [ADL] to assess function and the Geriatric Depression Scale [GDS] score to assess mood [15-item scale for the historical survey and 4-item mini-GDS score in ELCAPA-11].

Statistical analysis

Socio-demographic and medical characteristics of the two populations with and without cancer were described as number (%) for qualitative data and mean and standard deviation (SD) or median (1st–3rd quartiles) for quantitative data then compared using Pearson's chi-square test, Fisher's exact test, Student's *t*-test or the Wilcoxon Mann–Whitney test, as appropriate. Patients' preferences, perceptions of the medical information and involvement in decision-making process, level of information about the prognosis and knowledge about healthcare surrogates were described. Preferences were simplified into two categories for involvement in decision-making [my consent is required, yes/no] and extent of medical information in a life-threatening situation [I want to know the truth, yes/no]. Univariate analyses of factors associated with these categories were conducted in each of the two populations. Confounders and interactions [e.g. with age] were sought. Factors associated with the decision-making or information

category with $P < 0.20$ were considered for the multivariate analysis. Two multivariate logistic regression models were built separately, one for information and the other for decision-making. Values of P were taken to indicate significant differences when lower than 0.05 and trends when lower than 0.10. We did not perform multiple imputations for missing data.

All analyses were performed using Stata v12.0 (College Station, TX, USA).

Results

Among the 141 patients evaluated at the participating geriatric oncology unit during the ELCAPA-11 inclusion period, 3 declined to participate, 2 were not informed of their diagnosis and 3 had major cognitive or psychiatric disorders. Thus, 133 patients were enrolled in the study. The historical survey included 397 patients without cancer.

Table 1 reports the main characteristics and compares the groups with and without cancer. Of the patients with cancer, 62% were outpatients and 34.8% had metastases. Tumour sites by order of decreasing frequency were colorectal [24.1%], breast [23.3%], prostate [15.8%], haematological [9%], urinary tract [6.8%], pancreas and liver [9.8%], and stomach and oesophagus [4.5%]. In the patients

Table 1. Main characteristics of the participants in the groups with and without cancer

	Overall population (<i>n</i> = 530)	Group with cancer (<i>n</i> = 133)	Group without cancer (<i>n</i> = 397)	<i>P</i> -value*
Age, y (<i>n</i> = 529; 1/0), ^a mean (SD)	82.2 (6.5)	79.6 (5.5)	83.0 (6.6)	<0.001
Age ≥82 y (<i>n</i> = 529; 1/0), ^a <i>n</i> (%)	284 (53.7)	49 (37.1)	235 (59.2)	<0.001
Female gender (<i>n</i> , %)	334 (63.0)	73 (54.9)	261 (65.7)	0.02
Marital status (<i>n</i> = 529; 1/0) <i>n</i> (%)				<0.001
Single	42 (7.9)	4 (3.0)	38 (9.6)	
Divorced	39 (7.4)	6 (4.5)	33 (8.3)	
Married	170 (32.1)	65 (49.3)	105 (26.4)	
Widowed	278 (52.6)	57 (43.2)	221 (55.7)	
Children (<i>n</i> = 529; 1/0), <i>n</i> (%)	440 (83.2)	120 (90.9)	320 (80.6)	0.006
Number of children (<i>n</i> = 438; 14/78), median [Q1–Q3]	2 [1; 3]	2 [1; 3]	2 [1; 3]	0.05
Number of children who live near by (<i>n</i> = 426; 22/82), median [Q1–Q3]	1 [0; 2]	1 [1; 2]	1 [0; 2]	0.29
Living arrangements (<i>n</i> = 516; 3/13)				<0.001
Flat	326 (63.2)	78 (60.0)	248 (64.3)	
House	150 (29.1)	51 (39.2)	99 (25.6)	
Residential home	24 (4.6)	0	24 (6.2)	
Nursing home	16 (3.1)	1 (0.8)	15 (3.9)	
Lives at home (<i>n</i> = 518; 1/13), <i>n</i> (%)	476 (91.9)	129 (97.7)	347 (89.9)	0.003
Lives alone (<i>n</i> = 529; 1/13), <i>n</i> (%)	332 (62.8)	62 (47.0)	270 (68.0)	<0.001
Income (€/month) (<i>n</i> = 472; 34/24), <i>n</i> (%)				0.64
<1000	172 (36.2)	33 (33.3)	138 (37.0)	
1000–2000	228 (48.3)	48 (48.5)	180 (48.3)	
≥2000	73 (15.5)	18 (18.2)	55 (14.7)	
MMSE (<i>n</i> = 512; 397/115) median [Q1–Q3]	25.7 (3.2)	27.4 (2.5)	25.2 (3.2)	<0.001
MMSE < 24 (<i>n</i> = 512; 22/0), <i>n</i> (%)	131 (25.6)	11 (9.6)	120 (30.2)	<0.001
ADL (<i>n</i> = 521; 395/126), median (Q1–Q3)	5.5 [4.5–6]	6 [5.5–6]	5.5 [4–6]	<0.001
ADL < 6 (<i>n</i> = 521; 395/126), <i>n</i> (%)	301 (57.8)	37 (29.4)	264 (66.8)	<0.001
Number of daily medications (<i>n</i> = 500; 12/18), median [Q1–Q3]	5 [4; 7]	6 [3; 7]	5 [4; 7]	0.74
Depressive mood ^b (<i>n</i> = 485; 39/6), <i>n</i> (%)	186 (38.4)	5 (5.3)	181 (46.3)	<0.001

**P*-value from Chi-2 test or Fisher's exact test for qualitative variables and Student's test for quantitative variables.

^aMissing data in each group.

^bDefined as a GDS score ≥6/15 in the group with cancer (study reported in 2007) and as a mini-GDS score ≥1/4 in the group without cancer.

Table 2. Preferences of patients with and without cancer regarding information about their healthcare

	Overall population (<i>n</i> = 530)	Group with Cancer (<i>n</i> = 133)	Group without Cancer (<i>n</i> = 397)	<i>P</i> -value*
Information and medical decision-making (<i>n</i> = 522; 3/5 missing data)				0.005
(a) Doctors can take all medical decisions and do not have to inform me	18 (3.5)	0	18 (4.6)	
(b) Doctors can take all medical decisions but must inform me	92 (17.6)	33 (25.8)	59 (15.0)	
(c) Doctors must inform me and ask for my consent only for invasive procedures	245 (46.9)	58 (45.3)	187 (47.4)	
(d) Doctors must inform me and ask for my consent for all diagnostic and therapeutic interventions	167 (32.0)	37 (28.9)	130 (33.0)	
Medical decision-making (<i>n</i> = 522; 3/5 missing data)				0.13
(c + d) Doctors must ask for my consent for medical decisions	412 (78.9)	95 (74.2)	317 (80.4)	
If you were too ill to make critical medical decisions about your care, who would you want as your surrogate for making these decisions? (<i>n</i> = 484; 359/125)				0.69
A legally-appointed arbitrator	3 (0.6)	0	3 (0.8)	
A member of my family	415 (85.8)	109 (87.2)	306 (85.2)	
My general practitioner	37 (7.6)	8 (6.4)	29 (8.1)	
Another person	29 (6.0)	8 (6.4)	21 (5.9)	
If you are in a life-threatening situation, what do you want? (<i>n</i> = 510; 384/126)				<0.001
(e) I do not want to know the truth	20 (3.9)	1 (0.8)	19 (4.9)	
(f) I do not want to know my prognosis, but I want the doctor to inform the person of my choice	68 (13.3)	7 (5.6)	61 (15.9)	
(g) I want to be fully informed and (<i>n</i> = 417)	422 (82.8)	118 (93.6)	304 (79.2)	
(h) I want to be the only one to know the truth	63 (15.1)	6 (5.3)	57 (18.7)	<0.001
(i) I want the doctor to also inform the person of my choice	279 (66.9)	83 (73.5)	196 (64.5)	
(j) I want to inform the person of my choice and /or my family by myself	75 (18.0)	24 (21.2)	51 (16.8)	

Data are presented in *n* (%).

**P*-value from Chi-2 test or Fisher's exact test.

without cancer, the main acute diagnoses were cardiopulmonary disease [24%], fall-related injury [20.6%], neurologic syndrome [14.3%], infection [12.8%], rheumatic disorder [12%], depression [5.2%], metabolic disease [4.7%] and thromboembolic disease [3.2%].

Table 2 compares preferences in the two groups. All patients with cancer wanted to receive comprehensive information about their disease and treatment. Similarly, high proportions of patients in the two groups wanted their informed consent to be obtained for all or some interventions.

Table 3 lists the factors associated with requiring informed consent, as assessed by univariate analysis of the two populations pooled.

By multivariate analysis, factors independently associated with requiring consent in the two groups pooled were having children [adjusted odds ratio (aOR), 2.13; 95% confidence interval (95% CI), 1.24;3.66; *P* = 0.006], higher MMSE score [aOR per point, 1.09; 95% CI, 1.02;1.17] and not having cancer in both age categories [≤ 82 y: aOR cancer vs. no cancer, 0.30; 95% CI, 0.14–0.63; and age > 82 y, aOR cancer vs. no cancer, 0.41; 95% CI, 0.17–0.97]. The last result indicates that, among patients with cancer, the proportion requiring that their consent be obtained was not different between the two age groups. Conversely, being younger in the group without cancer was associated with a higher proportion requiring that their consent be obtained [aOR > 82 y vs. ≤ 82 y, 0.50; 95% CI, 0.29–0.88]. The results were not changed after adjustment for ADL, living alone and gender [data not shown].

The proportion of patients who wanted full information in the event of a life-threatening situation was higher in the

group with than without cancer [93.6% (*n* = 118) versus 79.2 (*n* = 304); *P* < 0.001] [Table 2]. By univariate analysis of the two populations pooled, none of the patient characteristics was associated with wanting to know the truth in a life-threatening situation.

Among the patients with cancer, 71 [53%] said they knew what a surrogate was but only 37 [28%] knew the definition of a surrogate used in French law and only 20 [15%] reported having designated a surrogate. Finally, 87.2% of patients with cancer would designate a family member as their surrogate should they be unable to make decisions.

Discussion

Our study showed that older patients with cancer wanted to be fully informed about their diagnosis and treatment and that 74.2% wanted to be involved in making decisions about their care. Furthermore, 93.6% wanted to know the truth should they be in a life-threatening situation and 87.2% would designate a family member as their surrogate should they be unable to make decisions. However, only 15% had already designated a surrogate. Compared to patients without cancer, those with cancer more often wanted to be fully informed in life-threatening situations. Factors independently associated with patients wanting their informed consent to be obtained for all interventions were having children, higher MMSE score, being cancer-free and younger age in the group without cancer.

The very high proportions of older patients with cancer who wanted full information are consistent with previous

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Table 3. Factors associated with patients wanting their informed consent to be obtained before diagnostic and/or therapeutic interventions, in the overall populations of patients with and without cancer, by univariate analysis

	Interventions		P-value*
	Informed consent required (<i>n</i> = 412)	Decisions left to the physicians (<i>n</i> = 110)	
Age, mean (SD)	81.8 (6.5)	83.5 (6.6)	0.02
Age ≥82 y (i.e. median)	213 (51.7)	66 (60.5)	0.10
Female gender	263 (63.8)	67 (60.9)	0.60
Marital status			0.75
Single	30 (7.3)	11 (10.0)	
Divorced	30 (7.3)	9 (8.2)	
Married	137 (33.3)	33 (30.0)	
Widowed	214 (52.1)	57 (51.8)	
Children: yes	348 (84.7)	83 (75.4)	0.02
Number of children, median [Q1–Q3]	2 [1; 3]	2 [1; 3]	0.73
Number of close children	1 [0; 1]	1 [0; 2]	0.23
Lives at home	371 (92.3)	98 (90.7)	0.60
Lives alone	256 (62.3)	69 (62.7)	0.93
Income (€)			0.39
<1000	128 (34.8)	41 (42.3)	
1000–2000	182 (49.5)	42 (43.3)	
≥2000	58 (15.8)	14 (14.4)	
MMSE, median [Q1–Q3]	26 [24–28]	26 [22–28]	0.04
MMSE <24	96 (24.1)	34 (32.4)	0.08
ADL, median [Q1–Q3]	5.5 [4.5–6]	5.5 [4–6]	1.00
ADL <6	230 (56.9)	64 (58.7)	0.74
Number of drugs per day, median [Q1–Q3]	6 [4–8]	5 [3–7]	0.16
Depressed mood ^a (<i>n</i> = 478; 380/98) ^b	149 (39.2)	34 (34.7)	0.41

Data are *n* (%) unless otherwise indicated.

*P-value from Chi-2 test or Fisher exact test for qualitative variables and Student's test for quantitative variables.

^aDefined as a GDS score ≥6/15 in the group with cancer (study reported in 2007) and as a mini-GDS score ≥1/4 in the group without cancer.

^bMissing data in each group.

studies [17, 21, 22]. Of 270 community-dwelling individuals in the UK, of whom 54% were older than 75 y, 88% wanted to be told if they were diagnosed with cancer [17]. In West Scotland, among 250 inpatients or outpatients with cancer who were younger than 75 y [44% were aged 65–74 y], over 90% wanted to know their diagnosis, their chance of cure and the possible treatment side effects [21]. In a heterogeneous population of 2,331 patients in the UK, 98% wanted to know whether the disease was cancer [22]. The proportion of patients who wanted to leave details up to the doctor was higher in the age group older than 70 y than in younger patients. In Italy, in contrast, older patients with cancer usually did not want full information about their disease [23]. Other studies also found that older patients with cancer wanted less information about their disease progression and predicted survival time compared to their younger counterparts [8, 19]. Older patients' preferences about information may vary depending on cancer stage and/or site and may also differ across countries. The perception of cancer as a fatal disease may influence preferences about information. Thus, in our study, the proportion of patients who wanted to know the truth in the event of a life-threatening situation was higher in the group with than without cancer.

Preferences about involvement in decision-making were more variable than those about information [10, 12, 19, 24, 25]. Involvement in decision-making can be categorised into three

main groups: the patient may want to make choices alone [active role], in conjunction with their physicians [collaborative role] or not at all [passive role] [19, 26]. Previous studies [10, 12, 24, 25], including ours [16], usually showed that most older patients with cancer preferred a collaborative or active role over a passive role. In the present study, only 25.8% of patients wanted a passive role. Conversely, among patients older than 70 y with metastatic colorectal cancer receiving care in New York City, about half wanted a passive role [19]. In Canada, 59% of patients with cancer wanted a passive role [26]. To the best of our knowledge, this study from Canada [26] and ours are the only comparisons of patients with and without cancer. In our study, the proportion of patients who wanted decision-making involvement was not different between these two groups. In contrast, in the study from Canada, only 36% of patients without cancer said they would want a passive role should they be diagnosed with cancer [26]. This apparent discrepancy may be ascribable to the difference in the populations without cancer, who were members of the general public in the Canadian study and admitted patients in our study.

Our findings suggested that being diagnosed with a potentially fatal illness such as cancer might influence preferences about information but perhaps not about involvement in decisions. Also, patients who want information may not want to use that information to make decisions about their care [27]. In both populations pooled, factors

independently associated with requiring that their consent be obtained were having children, a higher MMSE score, being younger than 82 y, and not having cancer. Other studies found that preferring an active role in decision-making was more common among patients who were younger and had a higher level of education and fewer comorbidities [11, 19].

More than 10 y after healthcare surrogate legislation was enacted in France, awareness of the surrogate concept remained low. Only 15% of older patients with cancer had designated a surrogate, and a family member would usually be designated. In Italy, in a study of 622 patients aged 65 y or over and receiving chemotherapy for cancer, 86.5% of patients felt their family was their main source of support and 79.1% wanted a family member to be present at their oncologist visits [5].

The designation and role of surrogates differ across countries. A recent study of Italian, Spanish, Belgian and Dutch patients showed that 6%, 5%, 16% and 29% designated a surrogate in the last 3 months of life [28]. Some countries, including Spain and France, require a written document by the patient; whereas others, including Germany and Belgium, require confirmation by a judge. The role of the surrogate may be consist either in participating in decisions (e.g. Belgium, Denmark, England and Germany) or in providing advice (e.g. France) [29].

Our study has several strengths. The data were collected prospectively. Patients with a wide range of cancer sites were included. Our data fill a knowledge gap. Finally, all participants were ill at the time of the study and therefore completed the questionnaire with their own current condition in mind, rather than with reference to clinical vignettes or possible future illnesses. Limitations of our study include the variability in cancer stage in the ELCAPA-11 survey. Furthermore, patient characteristics were not identical in the groups with and without cancer. Moreover, our results may apply only to those patients who are aware of their diagnosis. However, in a previous study, we found that the vast majority of older patients with cancer knew their diagnosis [7]. We cannot rule out a birth-year cohort bias, as the decade of birth was most often 1920–29 in the historical sample and 1930–39 in the study sample. This difference in birth cohort may have translated into differences in wishes regarding information and decision-making [30]. Finally, we did not examine the actual decisions faced by individual patients. A study of preferences about involvement in specific decisions [e.g. chemotherapy] might yield different results [27].

Conclusion

Our study underlines the importance given by older patients with cancer to information about their diagnosis and treatment. These patients should be offered a role in decisions about their care.

Key points

- Older patients with cancer want comprehensive information, even in life-threatening situations.
 - Up to 70% of older patients with cancer want a role in decisions about their care and feel their informed consent should be obtained for all diagnostic and therapeutic interventions.
 - Older patients with cancer are usually willing to designate a surrogate—usually a family member—to speak for them should they lose decision-making competence during a life-threatening event.
 - Compared to patients without cancer, patients with cancer more often want full information in life-threatening situations.
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Conflicts of interests

There is no conflict of interest; none of the authors received consultant or speaker fees and none has any company holdings or patents.

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