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Decisional control preferences of patients with advanced cancer receiving palliative care

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ABSTRACT

Objective: Understanding patients' decisional control preferences (DCPs) is important to improving the quality of care and the satisfaction of patients who have advanced cancer with their care. In addition to passive decisional control (i.e., the patient prefers his/her doctor or family caregiver to make a decision on their behalf) and active decisional control (i.e., the patient decides alone), shared decisional control, where patients and caregivers decide together, could be more appropriate. The primary aim of our study was to describe the decision-making process and the DCPs of patients with advanced cancer receiving palliative care in France.

Method: We conducted a prospective survey with advanced cancer patients referred to a palliative care team in an outpatient setting. We collected information about patients' demographic and clinical characteristics using the Decision Control Preference Scale, the Satisfaction with the Decisions and Care questionnaire, and the Understanding of Illness questionnaire.

Results: A total of 200 patients were evaluable. The median age was 63.5 years and 53.5% female. The cancers most commonly represented were gastrointestinal and breast. A total of 72 patients (36.2%) preferred active decisional control, 52 (26.1%) preferred shared decisional control, and 75 (37.7%) preferred passive decisional control. Younger age ($p = 0.003$), higher education ($p < 0.001$), and employment status ($p = 0.046$) were found to be associated with active or shared DCPs. Some 82% of patients were satisfied with the decision-making process, 35% of whom expressed wishes that did not match the actual decision-making process. Only 23% of patients thought they could be cured of their illness, and 47% thought that their treatment would "get rid of" their disease.

Significance of Results: The decision-making processes are shared in the three models of DCPs in our cohort of French patients with advanced cancer. Further prospective studies are needed.

KEYWORDS: Palliative care, Advanced cancer, Decisional control preferences, Decision-making process

INTRODUCTION

There is a current trend in high-income countries toward a patient-centered approach in clinical practice (Janz et al., 2004). In France, patients' rights to information and informed consent are protected by law (HAS, 2002). This change is characterized by a more active role for the patient, implying that accessible and relevant information is provided to the patient through adequate communication between the "objective" caregiver and the "subjective" patient (Gafni et al., 1998; Robinson & Thomson, 2001). This approach represents a combination of active decisional control (the patient decides alone) and passive decisional control (the caregiver decides alone), that is, shared decisional control, in which patients and caregivers decide together (Charles et al., 1997).

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The World Health Organization (2012) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems—physical, psychosocial, and spiritual. Satisfactory communication between patients, caregivers, and families is essential (Bruera et al., 2001; Hagerty et al., 2005). Communication by patients of their decisional control preferences (DCPs) to the family and caregivers can be a complicated process (Bruera, 2006). However, when caregivers understand patients' DCPs, better communication can be established and patients are more likely to be satisfied about their care (Ghane et al., 2014). Additionally, a clearer understanding of DCPs in a specific population could help caregivers provide better care (Levinson et al., 2005).

For the last 10 years, an increasing number of studies have evaluated patient preferences regarding medical information and decisional control (Janz et al., 2004). However, there is a lack of knowledge about the characteristics of decision making among patients with advanced cancer who are receiving palliative care in France. It seemed important to study this process, especially in the context of French law.

The primary aim of our study was to describe the decision-making process and the DCPs of patients with advanced cancer in a French palliative care center. The secondary aim was to identify the relationship between DCPs and the demographic and clinical characteristics.

METHODS

Study Design and Population

This prospective survey was conducted among 200 patients with advanced cancer referred for palliative care at the University Hospitals in Lyon between November of 2013 and March of 2015. The institutional review board approved our protocol, and all participants provided written informed consent. Our study was part of a larger study initiated by the MD Anderson Cancer Center in Houston, Texas (United States), and conducted in 11 countries.

All patients over 18 years of age with advanced cancer and normal cognitive status who were being followed by a palliative care team were eligible.

Data Collection

The survey process was organized using four questionnaires.

The first questionnaire studied such demographic characteristics as gender, cancer diagnosis, marital status, education, employment, occupation, and religion (patients had to check either Christian, Jewish, Muslim, Hindu, Buddhist, or other) and such medical characteristics as disease, stage, treatment, and performance status (Karnofsky Performance Status Scale score).

The second questionnaire examined decision-making preferences. A Control Preference Scale (designed by Degner and Sloan) was used to assess patients' DCPs (Degner & Sloan, 1992; Degner et al., 1997). Briefly, the patients had to select one of 15 options, including various choices of answers, about whether they preferred to decide themselves about their care or to let the family and physician decide. Each option was later categorized as a passive, active, or shared DCP. The patients were also asked how the decisions about their care were actually made. The other part of this questionnaire assessed patients' DCPs in dyadic form: patient/physician, patient/family, and family/physician. Each dyad was followed by a list of seven options, including all the decision-making possibilities as well as "I don't know" and "I prefer not to answer."

The third questionnaire studied patient satisfaction with decisions and care using a modified version of the Satisfaction with Decision Scale. Three items were utilized to determine if the patient was satisfied with the level of information he/she received, with the actual decision-making process, and with the decisions themselves.

The last part of the survey, which included three items, aimed to evaluate the patient's level of understanding of their illness, treatment, and prognosis.

The assessment tools were translated into French back and forth, following EORTC recommendations (Sprangers et al., 1998), to determine semantic and linguistic equivalence between the two versions, and the questionnaire was tested on 15 patients to ensure the correctness of the French translation.

Data Analysis

All study variables were descriptively summarized. Bivariate analyses using chi-square tests were conducted to evaluate associations between patients' DCPs and their demographic and clinical characteristics. A value of $p < 0.05$ was considered statistically significant. Analyses were performed using R software (v. 2.15.2).

RESULTS

Population

The demographics and characteristics of the study population are presented in Table 1. Both genders were

Table 1. *Population demographics and characteristics (*N = *200)*

Characteristics	*n* (%)		
Gender			
Male	93 (46.5)		
Female	107 (53.5)		
Age	Median	Interquartile range	Min–Max
	63.5	55–73	28–92
Religion			
Christian	150 (75.0)		
Muslim	10 (5.0)		
No religion/other	40 (20.0)		
Employment status			
Retired	107 (53.5)		
Medical/sick leave	52 (26.0)		
Still working	30 (15.0)		
Other	11 (5.5)		
Professional categories			
Employee	115 (57.5)		
Professional	34 (17.0)		
Unskilled worker	23 (11.5)		
Other/no data	28 (14.0)		
Education			
Less than high school	128 (64.0)		
High school/tech school	22 (11.0)		
Incomplete college or higher	47 (23.5)		
No data	3 (1.5)		
Marital status			
Married/lives with partner	134 (67.0)		
Divorced/separated	25 (12.5)		
Single	24 (12.0)		
Widowed	17 (8.5)		
Karnofsky Performance Status, %	Median	Interquartile range	Min–Max
	60	50–70	20–100
Time limit between diagnosis and inclusion, months	Median	Interquartile range	Min-Max
	25	11–68	1–391
Diagnosis			
Breast	36 (18.0)		
Gastrointestinal	37 (18.5)		
Lung	18 (9.0)		
Head and Neck	23 (11.5)		
Prostate	11 (5.5)		
Blood cancer	30 (15.0)		
Melanoma	11 (5.5)		
Genitourinary (not prostate)	15 (7.5)		
Gynecological (not breast)	5 (2.5)		
Unknown	2 (1.0)		
Multiple adenocarcinoma	12 (6.0)		

similarly distributed (53.5% of females), the median age was 63.5 years (interquartile range [*IQR*] = 55–73), 75.0% were of the Christian faith, 54.0% were retired, 64.0% had an education below high school level, and 67.0% were married or lived with a partner. The median Karnofsky Performance Status Scale score was 60.0% (*IQR* = 50–70). The main cancer types were gastrointestinal (18.5%) and breast (18.0%).

Clinical Characteristics and DCPs

Of the 199 patients (DCP data were missing for one patient), 36.2% preferred active decisional control, 26.1% preferred shared decisional control, and 37.7% preferred passive decisional control (Table 2). Concerning the actual decision-making process, 26.1% of the patients were active, 19.1% shared their decisions, and 54.8% were passive (Figure 1). Some 67.8% of patients participated in the decision-making process according to their preferences (Table 2, Figure 2).

Dyadic Decision

Patients were the only ones investigated and interviewed, meaning that neither their family nor their caregivers were interviewed. When patients were

Table 2. *Comparison between DCPs and real decision-making process*

	Real decision making			
DCPs	Active	Shared	Passive	Total
Active	46 (63.9%)	8 (11.1%)	18 (25.0%)	**72 (36.2%)**
Shared	6 (11.5%)	22 (42.3%)	24 (46.2%)	**52 (26.1%)**
Passive	0 (0%)	8 (10.7%)	67 (89.3%)	**75 (37.7%)**
Total	**52 (26.1%)**	**38 (19.1%)**	**109 (54.8%)**	**199**[a]

[a] Data missing for one patient.

asked about their DCPs in the patient/physician dyad, 40.5% preferred a shared role. When patients were asked about their DCPs in the patient/family dyad, 53.0% preferred an active role, and only 2.5% wanted their family to be actively involved. When patients were asked about their DCPs in the family/physician dyad (when the patient was excluded from the decision-making process), 43.0% would have wished the physician to decide on his/her own, but family involvement was essential for 40.0% of patients (e.g., 29.0% would have liked their family and physician to work together). However, 17.0% did not want to answer or replied "don't know" with respect to the family/physician dyad (Table 3).

Bivariate analyses found statistically significant differences in DCPs according to: (1) age, where younger age was significantly associated with active DCP ($p = 0.003$); (2) education, where patients with a high level of education had a statistically significant preference for active or shared DCPs ($p < 0.001$); and (3) employment status, where patients still working had a statistically significant preference for active or shared DCPs ($p = 0.046$). The other variables were not significantly associated with DCPs (Table 4).

Patient Satisfaction

Some 84.9% of patients were satisfied with the information they received, 82.3% were satisfied with the decision-making process, and 84.0% were satisfied with the final decisions about their care.

Patients' Understanding of Illness

Some 23% of patients thought that they could be cured despite their cancer being at an advanced stage, 20.0% did not know or did not answer, and 57.0% knew that they could not be cured. A total of 47% of patients also thought that their treatment would "get rid of" their disease, while 27.7% of this 47.0% defined their disease as incurable.

DISCUSSION

Our study aimed to analyze the DCPs of patients with advanced cancer receiving palliative care in France. In our study, the types of DCP were equally distributed between the three processes: 36.2% preferred active decisional control, 26.1% preferred shared decisional control, and 37.7% passive decisional control. These results are consistent with the metaanalysis reported by Singh and colleagues (2010) with 3,491 North American cancer patients. However, Noguera and colleagues (2014) showed a disparity between different North and South American countries. In the preliminary results of a multicenter study (Palma et al., 2014), patients in the United States preferred active DCPs (52%), while it

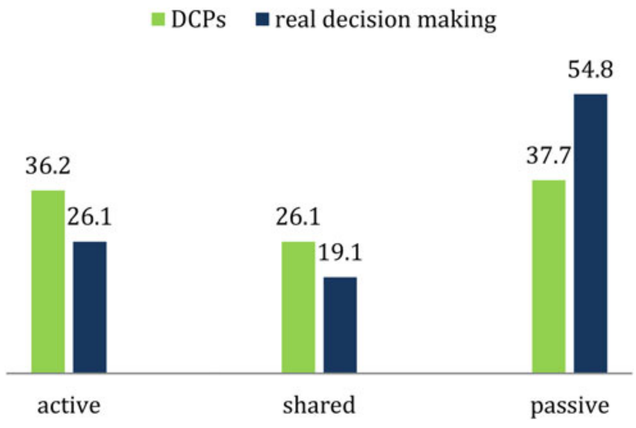

Fig. 1. DCPs versus real decision making (%).

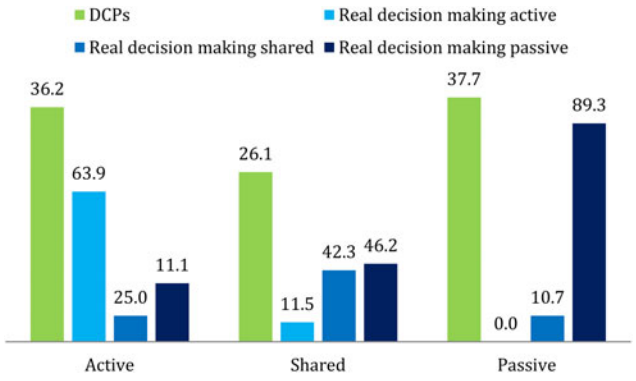

Fig. 2. DCPs based on the real decision making (%).

Table 3. *DCPs based on the patient/physician, patient/family, and family/physician dyads*

DCPs	Dyads	
	Patient/physician	Patient/family
Active	16.5%	53.0%
Shared	40.5%	39.5%
Passive	39.0%	2.5%
Not answered/ don't know	4.0%	5.0%
	Family/physician	
Family active	11.0%	
Family passive	43.0%	
Shared	29.0%	
Not answered/ don't know	17.0%	

was the opposite in Chile, where patients preferred shared DCPs (60%).

Patients with a high level of education in our study had a statistically significant preference for active or shared DCPs. These results are consistent with the study conducted by Noguera and colleagues (2014), who found a higher education level in the United States than in South America. Patients with a high education level could have easy access to medical information as well as access to the internet and medical websites. Further studies to explore the influence of the internet on DCPs would be interesting. Younger age was also significantly associated with a preference for an active DCP as reported in the United States (Singh et al., 2010), which could be related to cultural differences, with older patients maintaining a passive relationship with their physicians (Robinson & Thomson, 2001; Moreau et al., 2012). Degner et al. (1992) revealed that age was the most important predictor of DCP preferences and that older subjects preferred less control (Degner & Sloan, 1992). There was a similar finding for those still at work, but this is likely related to age (Lechner et al., 2016). In our study, DCPs were not influenced by gender. Various findings have been reported in the literature. Some studies have shown that women with breast cancer would like either a shared or active DCP (Degner et al., 1997; Bruera et al., 2002; Janz et al., 2004). A study among men with prostate cancer showed that they preferred to have a shared DCP (Davison et al., 2004). Some studies comparing the DCPs of males and females with a terminal illness have shown results that were not statistically significant (Nolan et al., 2005; Florin et al., 2006). The religious beliefs of our population were mostly Christian (75.0%), as in the Chilean study by Palma et al. (2014). We therefore cannot use these demographic data for comparison. However, it seems that spirituality does play a role in patient satisfaction (Mollica et al., 2016). We can suppose that these results would have been different in another religious context. This suggests that future studies that investigate level of spirituality as well as religious beliefs could be interesting.

Marital status in our study was not statistically significantly associated with any of the DCP types. This result is consistent with the report by Noguera et al. (2014), but not with the Chilean study by Palma et al. (2014), suggesting that more research is needed to better understand the role of marital status.

In our study, 67.8% of the patients participated in the decision-making process according to their preferences. This is consistent with previous reports: 74% in the Chilean study (Palma et al., 2014), 69% in the report by Noguera et al. (2014), and 71% in patients with advanced lung cancer as reported by Pardon et al. (2009). However, Degner et al. (1997) and Bruera et al. (2002) found overall agreement between 42 and 45%. This result shows a gap between patient DCPs and the final decision. This suggests that many factors at the time of decision making will modify the process, including the clinical situation (Bruera et al., 2001; Davison et al., 2004), the attitude of the referring oncologist (Butow et al., 1997), or some cultural influence (Blackhall et al., 2001). More studies are needed.

With regard to dyadic decisions, the physician's opinion seemed to be important in decision making for each dyad. Contrary to the results in the Chilean study, in which 66% wanted the decision to be shared in the patient/family dyad (Palma et al., 2014), our French patients wanted to be active without the family's opinion. These results are different from those reported in Korean studies conducted by Shin et al. (2013; 2016) in which the majority of patients (63.5 and 77%) preferred family involvement in the decision-making process. The role of the family, which is probably culturally different in Western countries, could explain greater involvement during the medical decision-making process (Kelley et al., 2010). In France, the family could have less importance in the decision-making process due to recent sociological evolution, with the development of individualism and the variegation of family structures (Shrank et al., 2005; Yennurajalingam et al., 2013). It is also important to note that a sixth of the patients answered "I do not know" to the question about the physician/family dyad or did not want to answer it, which may highlight the fact that these patients had never thought about situations in which their clinical state would not allow them to make decisions. We can also assume that some patients do not want to discuss this, and by not thinking about this possibility they can avoid having to confront it—as if they could "magically" escape reality by not thinking about it (El-Jawahri et al., 2014).

Table 4. *DCPs based on population study characteristics (N = 200)*

Population study characteristics	*n* (%)	Active	Shared	Passive	Other	Value of *p*
Gender						
Male	93 (46.5)	35 (37.7)	21 (22.6)	37 (39.8)	0	
Female	107 (53.5)	37 (34.6)	31 (29.0)	38 (35.5)	1 (0.9)	**0.616**
Age						
<60 year	72 (36.0)	33 (45.8)	23 (31.9)	16 (22.2)	0	
≥60 year	128 (64.0)	39 (30.4)	29 (22.6)	59 (46.1)	1 (0.8)	**0.003**
Religion						
Christian	150 (75.0)	51 (34.0)	40 (26.7)	58 (38.7)	1 (0.7)	
Muslim	10 (5.0)	4 (40.0)	1 (10.0)	5 (50.0)	0	
None/other	40 (20.0)	17 (42.5)	11 (27.5)	12 (30.0)	0	**0.703**
Education						
Less than high school	128 (64.0)	45 (35.2)	31 (24.2)	51 (39.8)	1 (0.8)	
High school/tech school	22 (11.0)	10 (45.4)	3 (13.6)	9 (40.9)	0	
Incomplete college or higher	47 (23.5)	16 (34.0)	17 (36.2)	14 (29.8)	0	
Other/no data	3 (1.5)	1 (33.3)	1 (33.3)	1 (33.3)	0	**<0.001**
Professional categories						
Employed	115 (57.5)	38 (33.0)	33 (28.7)	44 (38.3)	0	
Professional	34 (17.0)	15 (44.1)	6 (17.6)	12 (35.3)	1 (2.9)	
Unskilled worker	23 (11.5)	11 (47.8)	4 (17.4)	8 (34.8)	0	
Other/no data	28 (14.0)	8 (28.6)	9 (32.1)	11 (39.3)	0	**0.466**
Employment status						
Retired	107 (53.5)	30 (28.0)	25 (23.4)	51 (47.7)	1 (0.9)	
Medical/sick leave	52 (26.0)	24 (46.1)	17 (32.7)	11 (21.1)	0	
Still working	30 (15.0)	14 (46.7)	8 (26.7)	8 (26.7)	0	
Other/no data	11 (5.5)	4 (36.4)	2 (18.2)	5 (45.4)	0	**0.046**
Marital status						
Married	120 (60.0)	40 (33.3)	26 (21.7)	54 (45.0)	0	
Lives with partner	14 (7.0)	8 (57.1)	4 (28.6)	2 (14.3)	0	
Not alone	**134(67.0)**	**48 (35.8)**	**30 (22.4)**	**56 (41.8)**	**0**	
Divorced/separated	25 (12.5)	9 (36.0)	6 (24.0)	9 (36.0)	1 (4.0)	
Single	24 (12.0)	9 (37.5)	9 (37.5)	6 (25.0)	0	
Widowed	17 (8.5)	6 (35.3)	7 (41.2)	4 (23.5)	0	
Alone	**66 (33.0)**	**24 (36.4)**	**22 (33.3)**	**19 (28.8)**	**1 (1.5)**	**0.090**
Karnofsky Performance Status score						
<70%	122 (61.0)	40 (32.8)	33 (27.0)	49 (40.2)	0	
70–100%	78 (39.0)	32 (41.0)	19 (24.4)	26 (33.3)	1 (1.3)	**0.353**
Diagnosis						
Breast	36 (18.0)	12 (33.3)	14 (38.9)	10 (27.8)	0	
Gastrointestinal	37 (18.5)	12 (32.4)	7 (18.9)	17 (45.9)	1 (2.7)	
Lung	18 (9.0)	10 (55.6)	3 (16.7)	5 (27.8)	0	
Head and neck	23 (11.5)	10 (43.5)	7 (30.4)	6 (26.1)	0	
Prostate	11 (5.5)	5 (45.4)	5 (45.4)	1 (9.1)	0	
Hematologic	30 (15.0)	8 (26.7)	6 (20.0)	16 (53.3)	0	
Melanoma	11 (5.5)	4 (36.4)	2 (18.2)	5 (45.4)	0	
Genitourinary (not prostate)	15 (7.5)	7 (46.7)	4 (26.7)	4 (26.7)	0	
Gynecological (not breast)	5 (2.5)	0 (0)	2 (40.0)	3 (60.0)	0	
Unknown	2 (1.0)	1 (50.0)	0 (0)	1 (50.0)	0	
Multiple carcinoma	12 (6.0)	3 (25.0)	2 (16.7)	7 (58.3)	0	**0.228**

Patient satisfaction was very high in the three studied areas. Gattellarie and coworkers (2001) showed an association between satisfaction and the decision-making process, particularly regarding shared decisions, an association that was not found in our study. It was not significant either in the multicenter American study (Noguera et al., 2014). The satisfaction expressed by patients could be inherent in palliative care, where communication is primordial. Interestingly, 26.4% of patients were satisfied by a decision that did not match their wishes. In the study reported by Strull et al. (1984), which investigated participation in the decision-making process among hypertensive patients, similar results were found, where physicians tended to underestimate how much patients wanted to receive information and to overestimate how much patients wanted to make decisions. In palliative care, communication that is appropriate to each patient and his/her personality is fundamental. We can hypothesize that the most important thing for the patient is to be listened to. The patient's psychological process in these cases could change over time. Patients are sometimes ambivalent. Patients have been observed to be extremely passive in medical encounters even when they want to play an active role (Degner & Sloan, 1992). We can even assume that the patient gives more importance to information and discussion than to the decision-making process itself.

Some 23% of our patients thought that they could be cured of their illness, even though they had cancer of an advanced stage, and 47% thought that their treatment would "get rid of" their disease. During their cancer journey, patients are coping with bad news, and some need to maintain hope and need to believe that this treatment could "get rid of" the disease. Even if that seems irrational, hope is essential (Nierop-van Baalen et al., 2016). Temel et al. (2011) conducted a study of patients with metastatic lung cancer and found that 32% thought they could be cured and 69% thought their treatment would "get rid of" their cancer. Two-thirds of the patients in Temel et al. (2011) study answered positively to both questions, and 90% of the other third answered that their cancer was not curable but thought the treatment would "get rid of" it. These contradictory opinions can result from confusion about the nature of anticancer therapy: patients understand that their disease is incurable but nevertheless hope that the chemotherapy will lead to complete remission (Smith et al., 2011). We do not know if these answers are due to a lack of information, to a communication or comprehension problem, or to a defense mechanism on the part of the patient (Hagerty et al., 2005; Burns et al., 2007; Vos & de Haes, 2007; Ferguson & Rodrigues, 2013). There could be a gap between the information that the patient receives and what he/she can/will hear.

Bias

Our study has not been formally powered to statistically assess sociodemographic data and expressed preferences about decisions. However, when all the results from the international study are reported, we will be able to compare the French results with the rest of the multicenter study. One limitation of our study is that it was difficult to find patients with an unaltered cognitive state who were willing to take part in the study. This attrition level, always very important in such a population, is one of the obstacles to performing research in palliative care and has already been identified in other studies (Rhondali et al., 2013).

CONCLUSIONS

The patient sample in our study, treated in a particular center in France, had a mixed attitude toward DCPs. With regard to their real decision-making process, patients mostly adhered to a traditional passive decision-making model. The majority of our patients were satisfied about the decision-making process even if it was not concordant with their DCPs. Age, education, and employment status were statistically linked with DCPs. As one in three patients with advanced cancer believed that the disease is curable, future studies about perceptions of the curability of the disease are needed.

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