

Research Article

Preferences on Treatment Decision Making in Sarcoma Patients. Prevalence and Associated Factors – Results from the Prosa Study

Hanna Salm^{1,2*}; Markus K Schuler³; Leopold Hentschel⁴; Stephan Richter¹²; Peter Hohenberger⁵; Bernd Kasper⁶; Dimosthenis Andreou⁷; Daniel Pink^{1,2}; Luise Mütze⁹; Karin Arndt¹⁰; Christine Hofbauer⁴; Klaus-Dieter Schaser⁴; Jürgen Weitz⁴; Jochen Schmitt^{4,11}; Martin Eichler⁴

¹Department of Internal Medicine C, University Hospital Greifswald, Germany

²Sarcoma Center Berlin-Brandenburg, Helios Hospital Bad Saarow, Germany

³Clinic and Polyclinic for Internal Medicine I, University Hospital Carl Gustav Carus, TU Dresden, Germany

⁴National Center for Tumor Diseases (NCT/UCC), Dresden University of Technology, Dresden, Germany

⁵Division of Surgical Oncology & Thoracic Surgery, Mannheim University Medical Center, University of Heidelberg, Germany

⁶Sarcoma Unit, Mannheim Cancer Center, Mannheim University Medical Center, University of Heidelberg, Mannheim, Germany

⁷Department of General Orthopedics and Tumor Orthopedics, University Hospital Münster, Germany

⁸Department of Orthopedics and Trauma, Medical University of Graz, Graz, Austria

⁹Hospital Emmaus Niesky, Niesky, Germany

¹⁰German Sarcoma Foundation, Woelfersheim, Germany

¹¹Center for Evidence-based Healthcare, University Hospital Carl Gustav Carus and Medical Faculty, Technical University Dresden, Germany

¹²Department of Medicine 1, NCT/UCC, Sarcoma Center, University Hospital Carl Gustav Carus, Dresden University of Technology, Dresden, Germany

***Corresponding author: Hanna Salm**

Department of Internal Medicine C, University Hospital Greifswald, Germany.

Email: hanna.s.salm@gmail.com

Received: May 27, 2023

Accepted: June 13, 2023

Published: June 20, 2023

Abstract

Introduction: The impact of being diagnosed with a life-threatening illness may influence preferences to participate in treatment decisions. The objective of this analysis was to identify factors that are associated with sarcoma patients wanting to take a more active or passive role.

Methods: Data was obtained as part of a nationwide multi-center study (PROSa) aiming to investigate the structure and quality of medical care of sarcoma patients in Germany and their determinants. The study was conducted between 2017 and 2020 in 39 study centers.

For the present analysis, cross-sectional data of adult patients with sarcoma of any entity were analyzed. Control preference was measured with the Control Preference Scale (CPS). Preferences were divided in patient-led, shared, or physician-led-decision-making.

Associated factors were analyzed exploratively using multivariable multinomial logistic regression models. We included socio-economical and medical variables with stepwise backward variable selection.

Results: We included 1081 patients (48.6% female). 402 patients (37.2%) preferred to be in control about treatment decisions, while 400 patients (37.0%) favored shared responsibility. 25.8% (n = 279) wished to rather leave the control to the treating physician.

When comparing the patients who preferred physician-led decision making with those who favored shared responsibility, older patients were more likely to prefer shared decision-making compared to those 18 to > 40 years old (age group: > 75 years: Odds Ratio (OR) .53, 95% confidence interval (95% CI) .28; .99). Patients with a metastatic tumor desired shared decision making compared to those without metastases (metastasis: OR 1.61, 95% CI 1.09; 2.38).

When comparing the patients who preferred physician-led decision making with those who favored to be in control, older patients also preferred leaving the control to the physician and were less inclined to make the decisions by themselves: (18 to > 40 years vs > 75 years: OR .28, 95% CI .15; .55). With secondary school (8/9 years) as reference, patients holding a high school degree were more likely to prefer patient-led decision-making over physician-led decision making (OR 2.00, 95% CI 1.26; 3.09). Patients with sarcoma of the abdomen/retroperitoneum were more predisposed to taking control in treatment decisions compared to those with sarcoma of

the back/spine or lower limb (back/spine: OR .18, 95% CI .06; .54, lower limb: OR .56, 95% CI .37; .85). With an income of 1250 €/month as reference, patients with a higher income were more likely to take control (> 2750€/month: OR 1.7, 95% CI 1.0; 3.1).

Conclusion: The findings of our study demonstrate that patients with metastatic disease are more likely to seek a joint decision, while those of higher age and lower education level are less likely to actively participate in treatment decisions. The results suggest that the impact of advanced illness may influence preferences to participate. Additionally, our findings indicate differences in participation preferences based on the tumor's location, a finding that should be further investigated.

Introduction

In recent decades, the relationship between physician and patient has evolved from a classic paternalistic model to an interactive interaction [1]. This evolution towards information sharing and collaborative decision-making, aligned with patients' preferences, represents a significant paradigm shift in medicine [2]. Furthermore, this topic is gaining increasing importance in health care policy [3,4]. Shared decision making has been defined as: "an approach where clinicians and patients share the best available evidence, when faced with the task of making decisions, and where patients are supported to consider options to achieve informed preference" [4]. Patient consultations now serve not only to inform patients about their condition and treatment options but also to ensure that treatments are tailored to patients' preferences and needs [5].

As the physician-patient relationship transitions towards a more collaborative partnership, there is interest in identifying factors associated with patients seeking either a more active or passive role. Research suggests that active patient participation in decision-making can positively impact well-being, increase satisfaction with care, and reduce anxiety [6-8]. Furthermore, patient involvement in decision-making has been found to contribute to better quality of care [9,10]. However, not all patients necessarily desire involvement in the decision-making process [11,12]. Understanding patients' preferences for participation is crucial for customizing patient involvement in healthcare [4,13]. However, in clinical practice, patients' preference is often unknown, so physicians may not actively engage those who would prefer to be involved in decisions about their health, and vice versa [14]. The identification of patients' preferences for information and control was found to be particularly important in oncology to avoid often occurring conflicts between patients' expectation and physicians' decision-making practices [15,16]. Patients who desire more involvement may be harmed from information deficits, while those expected to take more control than desired may experience higher distress [17]. Overall, a shared approach to decision-making in healthcare is preferred by most patients [18].

Several years ago, Degner and colleagues [19] introduced the Control Preference Scale (CPS), an instrument designed to assess the degree of control an individual patient prefers in health care decision-making. The CPS is among the most commonly used instruments for measuring patients' Decision Control Preferences (DCPs). Research on DCP has shown that sociodemographic factors, such as age, gender or education are associated with patients preferences regarding decision-making in healthcare [20]. However, data on DCP has been lacking for sarcoma patients.

The patient group studied in the present work consists exclusively of sarcoma patients, a rare form of cancer [21] with treatment strategies based on complex interventions [22]. Health-related quality of life among sarcoma patients has been understudied, prompting the initiation of the PROSa study. Preliminary findings from this study have been previously published [23-31].

In this analysis, we investigated the relevance of sociodemographic characteristics as well as disease-related factors, considering evidence suggesting that the preferred level of involvement may change over the course of the disease [32]. Existing research in this area is limited, with prior studies predominantly focusing on prostate and breast cancer [16]. To our knowledge, no studies on decision-making preferences in a sample of sarcoma patients currently exist.

Methods

Recruitment, Participation, and Data Sources

Data was obtained as part of nationwide cohort study (www.uniklinikum-dresden.de/prosastudie). The prospective PROSa (Burden and medical care of sarcoma in Germany: Nationwide cohort study focusing on modifiable determinants of Patient-Reported Outcome measures in Sarcoma patients) study was conducted between autumn 2017 and spring 2020 in 39 study centers. These centers comprised 8 office-based practices, 22 hospitals of maximum care, and 9 other hospitals. Recruitment efforts were initiated through various channels such as medical societies and research networks, utilizing tools like email lists, personal letters, and advertisements to engage participants. The study aimed to collect data on patient-reported outcomes, clinical information at the patient level, and structural details of the participating study centers. The study included incident and prevalent adult patients and survivors of all sarcoma subtypes, with a detailed list of included entities available in the paper by Eichler et al. [28]. Patients who were mentally or linguistically incapable of completing the questionnaires were excluded.

Eligible patients were approached for participation during visits to the study centers, as well as through phone calls or letters. Participants submitted patient-reported outcomes and sociodemographic data to the study coordination center at the University Hospital Dresden either by mail or online. Clinical information and structural data of the participating study centers were submitted online by the centers using case report forms. Data collection was facilitated through REDCap (Vanderbilt University, Nashville, TN, USA) electronic data capture tools hosted at the Technical University Dresden [33].

Measures

Patients' DCPs of medical decisions were measured using the standardized and validated Control Preference Scale (CPS) [19]. Patients can pick one statement out of five that best describes their preferred involvement in medical decision-making ranging from active ("I prefer to make the decision about which treatment I will receive") to passive ("I prefer to leave all decisions regarding my treatment to my doctor") role. To maintain a sufficient number of cases for statistical analysis per category, adjoining answer options were grouped to three categories: patient-led, shared, or physician-led decision-making.

Control preference scale by Degner et. al.	
Which of the following statements are you most likely to agree with?	
I prefer to make the decision about which treatment I will receive.	Patient-led decision making
I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.	
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.	Shared decision making
I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.	Physician-led decision
I prefer to leave all decisions regarding treatment to my doctor.	

The control preference scale by Degner and colleagues [19] is shown below. To provide better clarity, answers 1 and 2 were defined as patient-led decision making, response 3 as shared decision making, and responses 4 and 5 as physician-led decision making.

Compliance with Ethical Standards

This study was approved by the ethics committee of the Technical University of Dresden (AZ: EK 1790422017) and the ethics committees of the participating centers, and it was conducted in accordance with the Declaration of Helsinki. The study participants gave written informed consent.

Statistical Analysis

For the description of the study population, we evaluated the variables from the multivariable model (see below), as well as disease status and treatment intention. Categorical variables were presented in absolute numbers and relative frequencies. The variables were stratified according to the grouping of the univariate analysis (see below).

Univariate group comparisons were performed comparing patients who preferred patient-led, shared and physician-led decision making. Significance tests were conducted utilizing chi-square tests. A p-value less than 0.05 was considered to be statistically significant.

Associated factors with patient control preference were analyzed by multinomial logistic regression models with stepwise variable selection to control for potentially confounding variables. We compared patients with a physician-led control preference to a) patients with a patient-led preference and b) patients with a shared control preference. Odds Ratios (OR), 95% confidence intervals, (95% CI) and p-values were evaluated in a model that was adjusted for age at baseline, sex, education, income, occupational status, tumor site, received treatments, metastatic disease, tumor size, aftercare status and time since diagnosis.

Results

Participation

Patients were contacted between September 2017 and January 2019. A total of 1309 patients participated in the study, as shown in Figure 1.

Study Population

A total of 1081 patients completed the CPS, 525 (48.6%) were female and 556 (51.4%) were male. The majority of patients either had sarcoma of the abdomen/retroperitoneum (26.8%) or the lower limbs (36.4%). 31.0% of the tumors were metastasizing. At study entry, treatment intention was more often curative than palliative (74.7% vs. 23.2%), as shown in Table 1.

Preference in Treatment Decision-Making

The majority of patients preferred patient-led (37.2%) or shared responsibility (37.0%) with regard to treatment decision making. Twenty six percent favored to rather leave the control to the treating physician (Table 2). Table 2 also shows preferences in treatment decision making including all five CPS response options.

Univariate Analysis

Sociodemographic factors: Higher age (65-<75 years) was associated with increased willingness to leave the control to the treating physician (34.4% vs. 16.6%, $p < 0.001$), as shown in Table 3.

Patients with an education level of high school were more likely to make decisions by themselves than those with 8 or 9 years of school education (46.5% vs. 29.5%, $p 0.001$).

Patients with a low income (<1250 €/month) were less likely to take control compared to those with a higher income (>2750 €/month): 34.8% vs. 47.8%, $p 0.002$.

Blue collar workers were more likely to prefer physician-led decision making than white collar workers (34.0% vs. 24.3%, $p 0.066$).

Disease-related factors: If the tumor had not metastasized, patients were more likely to take control in treatment decision-making as if the tumor had already spread (40.6% vs. 32.5%, $p 0.010$).

Further differences could be shown in regard of the tumor location. Patients with sarcoma of the abdomen/retroperitoneum were more likely to take control than patients with sarcoma of the back/spine or lower limb (41.0% vs. 17.2% (back/spine) and 34.8% (lower limbs), $p 0.049$).

Patients treated with palliative intent were more likely to prefer shared responsibility with their treating physician than patients treated with curative intent (41.8% vs. 35.3%, $p 0.285$).

Further details of disease-related factors that are associated with patient's role in treatment decision making are shown in table 4 below.

Associated Factors in Multivariate Multinomial Logistic Regression

Physician-led versus patient-led decision-making: Patients in the higher age groups were significantly less likely to make decisions by themselves (65 - < 75 years: OR .37, $p < .001$; more than 75 years: OR .28, $p < .001$) compared to those in the youngest age group.

With increased educational status, patients favored to make decisions by themselves. Patients with a high school education level were more likely to make decisions of their own than those with 8/9 years of secondary school education: vocational baccalaureate/high school: OR 1.97, $p .003$.

Higher income was associated with patients preferring patient-led decisions compared to those in the low-income group. With an income of 1250 €/month as reference, patients with a higher income were more likely to take control: >2750€/month: OR 1.7, *p* .042.

We found two significant differences regarding tumor site and disease status. With abdomen as the reference, patients with sarcomas of the back/spine and lower limbs showed a higher preference for physician-led decision making: back/spine: OR .17, *p* .002; lower limbs: OR .55, *p* .006 (all results are shown in table 5).

Physician-led versus shared decision-making: Patients in the higher age groups were significantly less likely to make decisions by themselves: 65 - < 75 years: OR .50, *p* .01; more than 75 years: OR .532, *p* .04.

Patients with a metastatic tumor preferred shared decision making compared to those without metastases: OR 1.61, *p* .016 (results are shown in table 6).

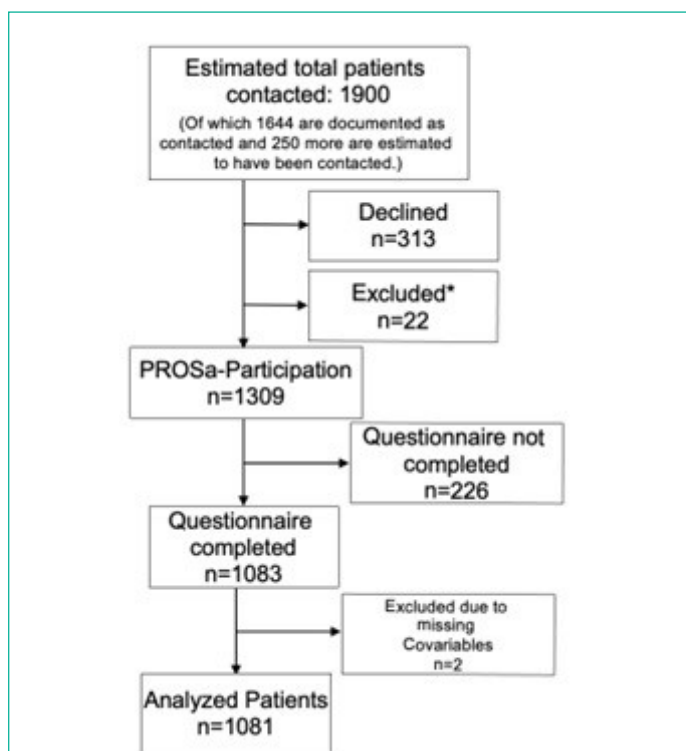


Figure 1: Study participation. Number of patients contacted overall had to be extrapolated from numbers of reporting study centers because not every study center documented contacted patients. Reasons for exclusion: language (2), mental capacity (1), double recruitment (8), withdrawal consent (2), histology (9).

Table 1: Description of study population at baseline.

Variable	Value	N	%
Sex	female	525	48.6
	male	556	51.4
Age	18-<40	181	16.7
	≥40-<55	257	23.8
	≥55-<65	293	27.1
	≥65-<75	221	20.4
	≥75	129	11.9
Tumor site	abdomen/retroperitoneum	290	26.8
	thorax	87	8.0
	pelvis/urogenital	158	14.6
	lower limbs	394	36.4
	upper limbs	84	7.8
	head & neck	33	3.1
	back/spine	29	2.7
	other/unknown	6	0.6
Metastasis	no metastasis	596	55.1
	metastasis	335	31.0
	unknown	150	13.9
Disease status	complete remission	482	44.6
	partial remission + stable disease	320	29.6
	tumor progress	155	14.3
Treatment intent	unknown	124	11.5
	palliative	251	23.2
	curative	808	74.7
	unknown	22	2.1

Table 2: Preference in treatment decision.

Preference in treatment decision-making	N	%
Patient-led	402	37.2
Shared	400	37.0
Physician-led	279	25.8
All	1081	100.0
Preference in treatment decision-making including all five CPS response options		
Decision by the patient alone	16	1.5
Decision by the patient with the involvement of the physician	386	35.7
Shared decision	400	37.0
Decision by the physician with the involvement of the patient	232	21.5
Decision by the physician alone	47	4.3
All	1081	100.0

Table 3: Socio-demographic factors. The p-values were calculated using the Chi-Square test.

Variable	Value	Patient-led N (%)	Shared N (%)	Physician-led N (%)	All N (100%)	p-value
sex	female	200 (38.1)	202 (38.5)	123 (23.4)	525 (48.6)	0.22
	male	202 (36.3)	198 (35.6)	156 (28.1)	556 (51.4)	
Age	18-<40	83 (45.9)	68 (37.6)	30 (16.6)	181 (16.7)	< 0.001
	≥40-<55	113 (44.0)	90 (35.0)	54 (21.0)	257 (23.7)	
	≥55-<65	101 (34.5)	120 (41.0)	72 (24.6)	293 (27.3)	
	≥65-<75	72 (32.6)	73 (33.0)	76 (34.4)	221 (20.4)	
	≥75	33 (25.6)	49 (38.0)	47 (36.4)	129 (11.9)	

Education	secondary school (8-9 years)	72 (29.5)	87 (35.7)	85 (34.8)	244 (22.6)	< 0.001
	secondary school (10 years)	121 (33.0)	148 (40.3)	98 (26.7)	367 (34.0)	
	vocational baccalaureate/ high school	201 (46.5)	149 (34.5)	82 (19.0)	432 (39.1)	
	other	8 (21.1)	16 (42.1)	14 (36.8)	38 (3.5)	
Income	<1250 €/month	79 (34.8)	81 (35.7)	67 (29.5)	227 (21.0)	0.002
	1250-<1750 €/month	78 (37.0)	70 (33.2)	63 (29.9)	211 (19.5)	
	1750-<2250 €/month	79 (32.6)	106 (43.8)	57 (23.6)	242 (22.4)	
	2250-<2750 €/month	41 (46.1)	34 (38.2)	14 (15.7)	89 (8.2)	
	>2750 €/month	86 (47.8)	59 (32.8)	35 (19.4)	180 (16.7)	
	unknown	39 (29.5)	50 (37.9)	43 (32.6)	132 (12.2)	
Occupational status	blue collar worker	56 (27.6)	78 (28.4)	69 (34.0)	203 (18.8)	0.066
	civil servant	32 (40.5)	32 (40.5)	15 (19.0)	79 (7.3)	
	white collar worker	234 (38.9)	221 (36.8)	146 (24.3)	601 (55.6)	
	self employed	42 (40.4)	38 (36.5)	24 (31.1)	104 (9.6)	
	not applicable/unknown	38 (40.4)	31 (33.0)	25 (26.6)	94 (8.7)	

Table 4: Disease-related factors. The p-values were calculated using the Chi-Square test.

Variable	Value	Patient-led N (%)	Shared N (%)	Physician-led N (%)	All N (100%)	p-value
Tumor site	abdomen/retroperitoneum	119 (41.0)	98 (33.8)	73 (25.2)	290 (26.8)	0.049
	thorax	28 (32.2)	36 (41.4)	23 (26.4)	87 (8.0)	
	pelvis	65 (41.1)	62 (39.2)	31 (19.6)	158 (14.6)	
	lower limbs	137 (34.8)	150 (38.1)	107 (27.2)	394 (36.4)	
	upper limbs	34 (40.5)	26 (31.0)	24 (28.6)	84 (7.8)	
	head and neck	12 (36.4)	17 (51.5)	4 (12.1)	33 (3.1)	
	back/spine	5 (17.2)	10 (34.5)	14 (48.3)	29 (2.7)	
	unknown	2 (33.3)	1 (16.7)	3 (50.0)	6 (0.6)	
Treatment combinations	all other (radiotherapy + systemic therapy/no therapy (yet)/other therapy)	22 (33.3)	26 (39.4)	18 (27.3)	66 (6.1)	0.173
	systemic therapy only	17 (26.2)	32 (49.2)	16 (24.6)	65 (6.0)	
	OP + radiotherapy + systemic therapy	76 (33.5)	88 (38.8)	63 (27.8)	227 (21.1)	
	OP + radiotherapy	56 (34.8)	67 (41.6)	38 (23.6)	161 (14.9)	
	OP + systemic therapy	107 (38.9)	98 (35.6)	70 (25.5)	275 (25.4)	
	OP only	124 (43.2)	89 (31.0)	74 (25.8)	287 (26.5)	
Metastasis	no metastasis	242 (40.6)	199 (33.4)	155 (26.0)	596 (55.1)	0.010
	metastasis	109 (32.5)	148 (44.2)	78 (23.3)	335 (31.0)	
	unknown	51 (34.0)	53 (35.3)	46 (30.7)	150 (13.9)	
T-stage	small (T1)	68 (40.0)	62 (36.5)	40 (23.5)	170 (15.7)	0.306
	large (T2-T4)	186 (37.1)	173 (34.5)	142 (28.3)	501 (46.3)	
	other/unknown	148 (36.1)	165 (40.2)	97 (23.7)	410 (40.0)	
Disease status	complete remission	194 (40.2)	168 (34.9)	120 (24.9)	482 (44.6)	0.019
	partial remission + stable disease	129 (40.3)	108 (33.8)	83 (25.9)	320 (29.6)	
	tumor progress	42 (27.1)	73 (47.1)	40 (25.8)	155 (14.3)	
	unknown	37 (29.8)	51 (41.1)	36 (29.0)	124 (11.5)	
In aftercare	not in aftercare	149 (32.7)	184 (40.4)	123 (27.0)	456 (42.1)	0.053
	in aftercare	247 (40.5)	213 (34.9)	150 (24.6)	610 (56.4)	
	unknown	6 (40.0)	3 (20.0)	6 (40.0)	15 (1.5)	
Treatment intent	palliative	82 (32.7)	105 (41.8)	64 (25.5)	251 (23.2)	0.285
	curative	312 (38.6)	285 (35.3)	211 (26.1)	808 (74.7)	
	unknown	8 (36.4)	10 (45.5)	4 (18.2)	22 (2.1)	
Time since diagnosis	0-<0.5 years	74 (36.1)	72 (35.1)	59 (28.8)	205 (19.0)	0.559
	0.5-<1 years	50 (40.3)	39 (31.5)	35 (28.2)	124 (11.5)	
	1-<2 years	51 (32.5)	62 (39.5)	44 (28.0)	157 (14.5)	
	2-<5 years	115 (40.2)	103 (36.0)	68 (23.8)	286 (26.5)	
	more than 5 years	112 (36.2)	124 (40.1)	73 (23.6)	309 (28.5)	

Table 5: Physician-led versus patient-led decision-making.

Variable	Value	OR	95% CI (l;u)	p
Age at study entry	18 - < 40 years <i>reference</i>			
	40 - < 55 years	.75	.43; 1.32	.332
	55 - < 65 years	.47	.27; .82	.008
	65 - < 75 years	.37	.21; .66	<.001
	more than 75 years	.28	.14; .54	<.001
Sex	male vs. female	.84	.60; 1.17	.311
Education	secondary school (8/9 years) <i>reference</i>			
	secondary school (10 years)	1.08	.69; 1.68	.712
	vocational baccalaureate/high school	1.97	1.26; 3.09	.003
	other (non (yet)/unknown)	.62	.24; 1.62	.336
Income	< 1250 € <i>reference</i>			
	1250 € - < 1750 €	1.17	.71; 1.92	.526
	1750 € - < 2250 €	1.10	.67; 1.82	.694
	2250 € - < 2750 €	2.01	.97; 4.17	.060
	> 2750 €	1.79	1.02; 3.14	.042
	unknown	.87	.49; 1.55	.659
Tumor location	abdomen <i>reference</i>			
	back/spine	.17	.05; .53	.022
	head&neck	1.40	.41; 4.74	.586
	upper limbs	.72	.38; 1.36	.315
	lower limbs	.55	.36; .84	.006
	pelvis	1.07	.62; 1.83	.806
	thorax	.59	.30; 1.16	.129
	unknown	.41	.06; 2.87	.375
Metastasis	no metastasis <i>reference</i>			
	metastasis	1.01	.67; 1.52	.954
	unknown	.82	.50; 1.32	.423
Aftercare	not in aftercare <i>reference</i>			
	in aftercare	1.38	.96; 1.98	.080
	unknown	1.01	.29; 3.54	.981

Note: Results of multinomial logistic regression models. OR= Odds Ratio, 95% CI: 95% confidence interval. Variables not included in the stepwise inclusion: time since diagnosis, occupational status, received treatments, tumor size.

Discussion

The purpose of this study was to examine the decision-making preferences in a sample of sarcoma patients and to explore associations between these preferences and sociodemographic characteristics as well as disease-related factors.

To our knowledge, this study is the first to explore the impact of disease related factors, such as tumor site, associated with preferences in treatment decision making in sarcoma patients.

The majority of our sample showed a preference for active (37.2%) or collaborate (37.0%) participation in medical decision-making, while only 25.8% preferred the health care professionals to take control. This demonstrates the value of personal autonomy and aligns with prior research indicating that a collaborative approach to decision-making in healthcare is the preferred choice for the majority of patients [18].

Sociodemographic Factors

We found that being younger was associated with increased desire for involvement in medical decisions. This aligns with

Table 6: Physician-led versus patient-led decision-making.

Variable	Value	OR	95% CI (l;u)	p
Age at study entry	18 - < 40 years <i>reference</i>			
	40 - < 55 years	.779	.44; 1.37	.38
	55 - < 65 years	.743	.42; 1.28	.29
	65 - < 75 years	.509	.28; .89	.01
	more than 75 years	.532	.28; .99	.04
Sex	male vs. female	.787	.56; 1.08	.14
Education	secondary school (8/9 years) <i>reference</i>			
	secondary school (10 years)	1.184	.77; 1.80	.43
	vocational baccalaureate/high school	1.444	.92; 2.24	.10
	other (non (yet)/unknown)	1.191	.53; 2.65	.67
Income	< 1250 <i>reference</i>			
	1250 - < 1750	1.044	.63; 1.70	.86
	1750 - < 2250	1.554	.96; 2.50	.07
	2250 - < 2750	1.809	.86; 3.76	.13
	> 2750	1.281	.72; 2.26	.39
	unknown	1.041	.60; 1.79	.88
Tumor location	abdomen <i>reference</i>			
	back/spine	.522	.21; 1.28	.15
	head&neck	2.925	.91; 9.32	.07
	upper limbs	.794	.41; 1.51	.49
	lower limbs	.998	.65; 1.51	.99
	pelvis	1.334	.77; 2.29	.29
	thorax	1.035	.55; 1.93	.91
	unknown	.250	.02; 2.59	.24
	Metastasis	no metastasis <i>reference</i>		
metastasis	1.612	1.09; 2.38	.01	
unknown	1.012	.63; 1.62	.96	
Aftercare	not in aftercare <i>reference</i>			
	in aftercare	1.076	.75; 1.52	.68
	unknown	.366	.08; 1.56	.17

Note: Results of multinomial logistic regression models. OR= Odds Ratio, 95% CI: 95% confidence interval. Variables not included in the stepwise inclusion: time since diagnosis, occupational status, received treatments, tumor size.

previous studies showing younger age [14,34-37] to be a predictor for active involvement. Additionally, higher age was shown to be significantly associated with an increased willingness to leave the decision control to the physician [38]. Moreover, a correlation emerged between decision preferences and educational background. Those in the highest educational category tended to express a greater inclination towards making decisions autonomously, while patients in the lowest educational category showed a preference for a more passive role, entrusting control to the physician. This is in line with previous research showing higher educational status [37,39] to be a predictor for active involvement. Furthermore, higher income was associated with patients preferring patient-led decisions compared to those in the low-income group. This finding aligns with previous studies [40].

The relationship between gender and preferences in decision-making was less clear, which is consistent with previous re-

search demonstrating a difference by gender [34,41] but mostly reporting no gender differences [35,36,42,43].

Disease-Related Factors

Significant variations were observed among different tumor sites, underlining the notable heterogeneity of the disease. However, explaining these differences in relation to tumor location are not easy.

Patients with sarcomas of the abdomen/retroperitoneum were more inclined to take an active role in decision-making compared to patients with sarcomas of the back/spine or lower limb. As patients with sarcomas of the back/spine comprised only 2.7% of the patient population, we cannot draw reliable conclusion from this result.

With respect to the tumor location in the lower limb, this observation may find partial explanation by results from the main PROSa study [28], which indicates differences in quality of life and symptom burden across different tumor sites: Patients with sarcomas of the lower extremities felt generally worse, possibly influenced by the functional limitations associated with the tumor location. Moreover, patients with sarcomas of the trunk (thorax, abdomen) demonstrated better outcomes in terms of symptom burden than those with lower extremity tumors. Therefore, it is conceivable that the reduced participation in decision-making of patients with tumors in the extremities is related to their poorer well-being in general.

Moreover, the specific location of a tumor can influence the range of available treatment options, often necessitating more in-depth discussions and collaborative decision-making between healthcare providers and patients. Consequently, it is reasonable to suggest that shared decision-making becomes more prevalent when addressing sarcomas at certain sites, where treatment strategies tend to be more extensive and intricate.

Strength and Limitations

Through the PROSa study, we established an extensive network of recruiting study centers across Germany, enabling us to enroll a significant number of sarcoma patients. Participation rates were notably high, estimated at 69%, reflecting strong patient motivation. Our descriptive data highlight the wide spectrum of the disease, demonstrating recruitment across all sarcoma subtypes, except for skin sarcomas. Given that most participants were recruited from high-volume centers, it's important to acknowledge that our sample may not fully represent the typical landscape of sarcoma care in Germany, suggesting a potential selection bias at the institutional level. Consequently, it's likely that small and well-differentiated tumors were under-represented in our study cohort.

Primarily, participants were recruited during hospital or practice visits, with clinical contacts becoming less frequent over time for survivors. This trend raises the possibility of a sick survivor bias, wherein selected patients with more severe disease courses were included in our study.

Conclusion

While decision control preference has been investigated in different patient populations, there has been no evidence regarding sarcoma patients. Therefore, our analysis provides important new insights in a large sample of patients with sarcoma. Our study demonstrated that patients' preferences in decision-

making are associated with both disease and sociodemographic factors, providing valuable insights for understanding patients' involvement in clinical decisions.

The insights gained could assist physicians in adjusting their approach to decision-making to meet the specific needs of sarcoma patients. Doctors should be mindful of how these factors may impact decision processes to ensure care that is centered around the patient. A more thorough integration of the patient perspective has the potential to enhance both care and communication between physicians and patients.

Author Statements

Funding

The PROSa study was funded by the German Cancer Aid (grant No. 111713).

References

1. Emanuel EJ, Emanuel LL. Four Models of the Physician-Patient Relationship. *JAMA J Am Med Assoc.* 1992; 267: 2221-6.
2. Mihalj M, Carrel T, Urman RD, Stueber F, Luedi MM. Recommendations for Preoperative Assessment and Shared Decision-Making in Cardiac Surgery. *Current Anesthesiology Reports.* 2020; 10: 185-195.
3. O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR, et al. Toward the "tipping point": Decision aids and informed patient choice. *Health Affairs.* 2007; 26: 716-25.
4. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. *BMJ (Online).* 2010; 341: c5146.
5. O'Mahony S, Mazur E, Charney P, Wang Y, Fine J. Use of multidisciplinary rounds to simultaneously improve quality outcomes, enhance resident education, and shorten length of stay. *J Gen Intern Med.* 2007; 22: 1073-1079.
6. Ford S, Fallowfield L, Lewis S. Doctor-patient interactions in oncology. *Soc Sci Med.* 1996; 42: 1511-9.
7. Flynn D, Knoedler MA, Hess EP, Murad MH, Erwin PJ, Montori VM, et al. Engaging patients in health care decisions in the emergency department through shared decision-making: A systematic review. *Acad Emerg Med.* 2012; 19: 959-67.
8. López ME, Kaplan CP, Nápoles AM, Hwang ES, Livaudais JC, Karliner LS. Satisfaction with treatment decision-making and treatment regret among Latinas and non-Latina whites with DCIS. *Patient Educ Couns.* 2014; 94: 83-9.
9. Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: The importance of clinician-patient relationships. *Journal of General Internal Medicine.* 2010; 25: 741-745.
10. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: Is the information good enough? *BMJ.* 1999; 318: 318-22.
11. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making: A national study of public preferences. *Journal of General Internal Medicine.* 2005; 20: 531-5.
12. Deber RB, Kraetschmer N, Irvine EJ. What role do patients wish to play in treatment decision making? *Arch Intern Med.* 1996; 156: 1414-20.
13. Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *British Medical Journal.* 1999; 319: 766-71.

14. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, et al. Information needs and decisional preferences in women with breast cancer. *JAMA*. 1997; 277: 1485-92.
15. Blinman P, Hughes B, Crombie C, Christmas T, Hudson M, Veillard AS, et al. Patients' and doctors' preferences for adjuvant chemotherapy in resected non-small-cell lung cancer: What makes it worthwhile? *Eur J Cancer*. 2015; 51: 1529-37.
16. Tariman JD, Berry DL, Cochrane B, Schepp AD. Preferred and actual participation roles during health care decision making in persons with cancer: A systematic review. *Annals of Oncology*. 2009; 21: 1145-1151.
17. Gattellari M, Voigt KJ, Butow PN, Tattersall MHN. When the treatment goal is not cure: Are cancer patients equipped to make informed decisions? *J Clin Oncol*. 2002; 20: 503-13.
18. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: Past research and future directions. *Am J Prev Med*. 1999; 17: 285-94.
19. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res*. 1997; 29: 21-43.
20. Florin J, Ehrenberg A, Ehnfors M. Clinical decision-making: Predictors of patient participation in nursing care. *J Clin Nurs*. 2008; 17: 2935-2944.
21. Rensing M, Wardelmann E, Hohenberger P, Jakob J, Kasper B, Emrich K, et al. Strengthening health data on a rare and heterogeneous disease: Sarcoma incidence and histological subtypes in Germany. *BMC Public Health*. 2018; 18: 235.
22. Casali PG, Abecassis N, Bauer S, Biagini R, Bielack S, Bonvalot S, et al. Soft tissue and visceral sarcomas: ESMO-EURACAN Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann Oncol*. 2018; 29: iv51-iv67;
23. Jakob J, Hentschel L, Richter S, Kreisel I, Hohenberger P, Kasper B, et al. Transferability of Health-Related Quality of Life Data of Large Observational Studies to Clinical Practice: Comparing Retroperitoneal Sarcoma Patients from the PROSa Study to a TARPS-WG Cohort. *Oncol Res Treat*. 2022; 45: 660-669.
24. Eichler M, Pink D, Menge F, Jakob J, Hentschel L, Richter S, et al. Quality of life of GIST patients with and without current tyrosine kinase inhibitor treatment: Cross-sectional results of a German multicentre observational study (PROSa). *Eur J Cancer Care (Engl)*. 2021; 30: e13484.
25. Eichler M, Hentschel L, Singer S, Hornemann B, Hohenberger P, Kasper B, et al. Distress in soft-tissue sarcoma and gastrointestinal stromal tumours patients—Results of a German multicentre observational study (PROSa). *Psychooncology*. 2022; 31: 1700-1710.
26. Eichler M, Singer S, Hentschel L, Richter S, Hohenberger P, Kasper B, et al. The association of Health-Related Quality of Life and 1-year-survival in sarcoma patients—results of a Nationwide Observational Study (PROSa). *Br J Cancer*. 2022; 126: 1346-1354;
27. Büttner M, Singer S, Hentschel L, Richter S, Hohenberger P, Kasper B, et al. Financial toxicity in sarcoma patients and survivors in Germany: results from the multicenter PROSa study. *Support Care Cancer*. 2022; 30: 187-196.
28. Eichler M, Hentschel L, Richter S, Hohenberger P, Kasper B, Andreou D, et al. The health-related quality of life of sarcoma patients and survivors in Germany—cross-sectional results of a nationwide observational study (Prosa). *Cancers (Basel)*. 2020; 12: 3590.
29. Eichler M, Andreou D, Golcher H, Hentschel L, Richter S, Hohenberger P, et al. Utilization of Interdisciplinary Tumor Boards for Sarcoma Care in Germany: Results from the PROSa Study. *Oncol Res Treat*. 2021; 44: 301-312.
30. Eichler M, Singer S, Hentschel L, Hornemann B, Hohenberger P, Kasper B, et al. The psycho-oncological care situation of patients with soft tissue sarcomas: Results of a German multicenter observational study (PROSa). *Onkologie*. 2023.
31. Eichler M, Schmitt J, Schuler MK. Die Dauer von Ethikvoten in Deutschland - am Beispiel einer nicht-interventionellen Beobachtungsstudie mit 44 teilnehmenden Zentren (PROSa). *Z Evid Fortbild Qual Gesundheitswes*. 2019: 146.
32. Brom L, Pasma HRW, Widdershoven GAM, Van Der Vorst MJDL, Reijneveld JC, Postma TJ, et al. Patients' preferences for participation in treatment decision-making at the end of life: Qualitative interviews with advanced cancer patients. *PLoS One*. 2014; 25: e100435;
33. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009; 42: 377-81.
34. Arora NK, McHorney CA. Patient preferences for medical decision making: Who really wants to participate? *Med Care*. 2000; 38: 335-41.
35. Mah HC, Muthupalaniappen L, Chong WW. Perceived involvement and preferences in shared decision-making among patients with hypertension. *Fam Pract*. 2016; 33: 296-301.
36. McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BMJ*. 2000; 321: 867-71.
37. Wallberg B, Michelson H, Nystedt M, Bolund C, Degner LF, Wilking N. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol (Madr)*. 2000; 39: 467-76.
38. Schuler M, Schildmann J, Trautmann F, Hentschel L, Hornemann B, Rentsch A, et al. Cancer patients' control preferences in decision making and associations with patient-reported outcomes: a prospective study in an outpatient cancer center. *Support Care Cancer*. 2017; 25: 2753-2760.
39. Janz NK, Wren PA, Copeland LA, Lowery JC, Goldfarb SL, Wilkins EG. Patient-physician concordance: Preferences, perceptions, and factors influencing the breast cancer surgical decision. *J Clin Oncol*. 2004; 22: 3091-8.
40. Gu XF, Xu HF, Liu Y, Li L, Yu YQ, Zhang X, et al. Involvement in treatment decision-making and self-reported efficacy among patients with advanced colorectal cancer: a nationwide multicenter cross-sectional study. *Front Oncol*. 2023; 13: 1168078.
41. Seo J, Goodman MS, Politi M, Blanchard M, Kaphingst KA. Effect of Health Literacy on Decision-Making Preferences among Medically Underserved Patients. *Med Decis Mak*. 2015; 36: 550-6.
42. Bruera E, Willey JS, Lynn Palmer J, Rosales M. Treatment decisions for breast carcinoma: Patient preferences and physician perceptions. *Cancer*. 2002; 94: 2076-80.
43. Wong F, Stewart DE, Dancey J, Meana M, McAndrews MP, Bunston T, et al. Men with prostate cancer: Influence of psychological factors on informational needs and decision making. *J Psychosom Res*. 2000; 49: 13-9.