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Research letter to the editor

Decision regret regarding treatment choices one year after a new diagnosis of bladder cancer

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Article

Bladder cancer (BCa) care is multimodal. Patients navigate multiple treatment choices, including use of intravesical therapies, frequency of cystoscopic surveillance and radical treatment options. Little is known about how these choices are made in BCa and whether patients later regret their decisions. Guidelines recommend treatment approaches using medical evidence but pay little attention to decision-making and often favour more active interventions. Decision regret theory suggests fear of making the wrong choice dissuades individuals from making any choice and impairs rational thinking. Within BCa, most authors have focused on decision regret around cystectomy reconstruction[1] or trial involvement[2], and conclude shared informed decision-making is associated with least regret. As decision regret is an important patient-centred outcome[1], we wanted to understand this issue across the entire BCa spectrum. We asked participants within a longitudinal survey (n=13 hospitals, March 2019 to March 2020) about decision regret, 12-months after diagnosis, using a standardised approach[3,4]. Little is known on this subject and so we undertook exploratory analysis with participants stratified by treatment received (TURBT ± intravesical agents vs. radical treatment).

Responses were received at 12-months from 232/296 (78%) participants. Respondents were typical for the BCa population (Supplementary Table 1). Non-responders were similar, except for fewer responses from the youngest (<65 years) and oldest (85+ years) age groups (Supplementary Table 2). Few respondents reported moderate or severe decision regret (15%, Table 1) and this did not vary by age or sex (Supplementary Table 3). Most respondents felt their treatment was the right decision (94% Strongly agree/Agree), would make the same choice again (94% Strongly agree/Agree), and reassuringly only 4% felt harmed by their treatment choices. Higher levels of moderate or severe regret were seen with radical treatment (21% vs. 14% for TURBT), but this did not differ by modality (22% radical cystectomy vs. 20% radiotherapy, data not shown). Fewer radically treated patients felt they would make the same choice again (89%) than those receiving TURBT (95%). Higher levels of regret were seen in those with disease recurrence/progression (30% vs. 13% in those without, Supplementary Table 3). In addition, we asked whether patients felt their views were included in treatment decision-making, with 87% agreeing that they were (Yes, definitely/Yes, to some

extent). Radically treated patients felt marginally more involved in decision-making (91%) than those receiving TURBT (87%).

Our findings should reassure future patients with BCa. Few participants expressed major regret and most felt engaged in their treatment choices. These data compare well with other cancers: for example, men with localised prostate cancer often regret treatment choice (37% for radiotherapy, 23% for surgery)[5] and levels of regret increase once disease progresses despite treatment (47% in those with biochemical recurrence after prostate cancer treatment). Whilst prostate and bladder cancer patients differ in terms of demographics, disease factors and treatment options, the comparisons do provide some, and the best available, context. Limitations include sample size, short-term outcomes, and non-response bias. Inclusion in future randomised clinical trials is important to further understand treatment-decision making and subsequent regret.

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Table 1: Decision regret (overall level and individual questions) by treatment received

Response	All treatments (n=232)		TURBT ± MMC/BCG (n=188)		Radical treatment ± other (n=44)		p value*
	N	%	N	%	N	%	
Overall level of decision regret							
No regret	100	51%	88	54%	12	36%	
Mild regret	66	34%	52	32%	14	43%	
Moderate / severe regret	30	15%	23	14%	7	21%	0.16
Missing	36		25		11		
How do you feel about the decisions you made about your treatment?							
It was the right decision							
Strongly agree	162	71%	133	72%	29	67%	
Agree	52	23%	41	22%	11	26%	
Neither agree nor disagree	*	0-6%	*	0-6%	*	0-7%	
Disagree/Strongly disagree	*	0-6%	*	0-6%	*	0-7%	0.33
Missing	5		*		*		
I regret the choice that was made							
Agree/Strongly agree	16	8%	*	0-13%	*	0-20%	
Neither agree nor disagree	12	6%	*	0-13%	*	0-20%	
Disagree	41	21%	33	20%	8	24%	
Strongly disagree	128	65%	109	67%	19	56%	0.38
Missing	35		25		10		
I would go for the same choice if I had to do it all over again							
Strongly agree	150	71%	124	72%	26	68%	
Agree	48	23%	40	23%	8	21%	
Neither agree nor disagree	*	0-6%	*	0-5%	*	0-11%	

Disagree/Strongly disagree	*	0-6%	*	0-5%	*	0-11%	0.06
Missing	22		16		6		
The choice did me a lot of harm							
Agree/Strongly agree	8	4%	*	0-14%	*	0-18%	
Neither agree nor disagree	21	10%	*	0-14%	*	0-18%	
Disagree	45	23%	36	22%	9	26%	
Strongly disagree	126	63%	107	64%	19	56%	0.68
Missing	32		22		10		
The decision was a wise one							
Strongly agree	137	66%	112	66%	25	68%	
Agree	49	24%	40	23%	9	24%	
Neither agree nor disagree	*	0-10%	*	0-11%	*	0-8%	
Disagree/Strongly disagree	*	0-10%	*	0-11%	*	0-8%	0.66
Missing	24		17		7		
Do you think your views were taken into account when the doctors/nurses were discussing your treatment?†							
Yes, definitely	148	64%	118	63%	30	70%	
Yes, to some extent	54	23%	45	24%	9	21%	
No, my views were not taken into account	*	0-5%	*	0-13%	*	0-9%	
I didn't know my treatment was being discussed by a team of doctors/nurses	18	8%	*	0-13%	*	0-9%	
Not sure / can't remember	*	0-5%	*	0-13%	*	0-9%	0.8
Missing	*		*		*		

TURBT = transurethral resection of a bladder tumour; BCG = Bacillus Calmette-Guerin; MMC = intravesical mitomycin C

*Numbers suppressed to preserve anonymity. Smallest groups combined for comparison.

†Question taken from the National Cancer Patient Experience Survey (https://www.ncpes.co.uk/)

Supplementary file

Decision regret regarding treatment choices one year after a new diagnosis of bladder cancer

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Supplementary Table 1: Population characteristics of participants at Time 1 (3-months) who returned a Time 4 (12-months) survey

Characteristic	Participants (n=232)	
	N	%
Sex		
Male	181	78%
Female	51	22%
Age at diagnosis		
<65	43	19%
65-74	97	42%
75 - 84	82	35%
85+	10	4%
No. of other long-term conditions		
None	69	30%
1	74	32%
2	40	17%
3	36	15%
≥4	13	6%
IMD Income Quintile		
1 (least deprived)	73	32%
2	63	27%
3	40	17%
4	26	11%
5 (most deprived)	29	13%
Not known	1	
Employment status		
Employed	42	19%
Unemployed	8	3%
Retired	176	78%
Not known	6	
Marital status		
Married/Civil partnership	170	73%
Separated/Divorced	16	7%
Widowed/Surviving Partner	32	14%
Single/Other/Not known	14	6%
Treatment		
TURBT only	85	37%
TURBT ± BCG/MMC	103	44%
Radical Cystectomy ± Other†	28	12%
Radical Radiotherapy ± Other	16	7%

†19 out of 28 patients who had Radical Cystectomy had an ileal conduit. No patients underwent bladder reconstruction.
IMD = Index of Multiple Deprivation; TURBT = transurethral resection of a bladder tumour; BCG = Bacillus Calmette-Guerin; MMC = intravesical mitomycin C.

Supplementary Table 2: Responders vs non-responders to Time 4 (12 months) survey

Characteristic	Responders (n=232)		Non-responders (n=57)		p value
	N	%	*N*	%	
Sex					
Male	181	80%	46	20%	
Female	51	82%	11	18%	0.66
Age at diagnosis					
<65	43	69%	19	31%	
65-74	97	84%	19	16%	
75 - 84	82	85%	14	15%	
85+	10	67%	5	33%	0.03
No. of other long-term conditions					
0 - 1	143	83%	29	17%	
2+	89	76%	28	24%	0.14
IMD Income Quintile					
Least deprived (1, 2)	136	82%	29	18%	
Most deprived (3,4,5)	95	77%	28	23%	0.27
Not known	1		0		
Treatment					
TURBT ± BCG/MMC	188	79%	50	21%	
RC/RT ± Other	44	86%	7	14%	0.33
Disease recurrence/progression					
No	186	81%	44	19%	
Yes	40	77%	12	23%	0.52
Not known	6		1		

IMD = Index of Multiple Deprivation; TURBT = transurethral resection of a bladder tumour; BCG = Bacillus Calmette-Guerin; MMC = intravesical mitomycin C

Supplementary Table 3: No/mild decision regret vs. Moderate/severe decision regret

Characteristic	No/mild decision regret (N=166)		Moderate/severe decision regret (N=30)		p value
	N	%	*N*	%	
Sex					
Male	132	85%	24	15%	
Female	34	85%	6	15%	1.00
Age at diagnosis					
<65	32	86%	5	14%	
65-74	74	86%	12	14%	
75+	60	82%	13	18%	0.45*
No. of other long-term conditions					
0 - 1	105	87%	16	13%	
2+	61	81%	14	19%	0.30
IMD Income Quintile					
Least deprived (1, 2)	103	87%	16	13%	
Most deprived (3,4,5)	62	82%	14	18%	0.35
Not known	1		0		
Treatment					
TURBT ± BCG/MMC	140	86%	23	14%	
RC/RT ± Other	26	79%	7	21%	0.30
Disease Recurrence / Progression					
No	140	87%	21	13%	
Yes	21	70%	9	30%	0.03
Not known	5		0		

IMD = Index of Multiple Deprivation; TURBT = transurethral resection of a bladder tumour; BCG = Bacillus Calmette-Guerin; MMC = intravesical mitomycin C

* <65 and 65-74 years age categories combined for comparison due to small numbers

Ethics Approvals and Consent to Participate: The study received the following ethical approvals: Yorkshire & Humber, South Yorkshire Research Ethics Committee (17/YH/0095), Health Research Authority Confidentiality Advisory Group (17/CAG/0054); Office for Data Release (ODR1718_089, ODR1718_137 and ODR1920_114), and NHS Digital Data Access Request Service (DARS-NIC-129819-V5P5Z-v2.4, DARS-NIC-194387-K3H5K-v1.0 and DARS-NIC-374924-C8S5Y). Participants consented to the cross-sectional study by returning a completed questionnaire. Participants to the longitudinal study were consented at the recruiting NHS hospital. Participants declined to participate in the study by (a) not responding (b) returning a blank survey or (c) By telephone using the freephone helpline.

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