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Review

Why do patients regret their prostate cancer treatment? A systematic review of regret after treatment for localized prostate cancer

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Abstract

***Objective*: The aim of this study was to review regret following treatment for localized prostate cancer, including factors associated with higher levels of regret, regret after specific treatments and the use of interventions to modify the likelihood of regret.**

***Methods*: Online databases including Medline, CINAHL, EMBASE, EBSCO and PsycINFO were searched in June 2014, using the terms 'prostate' and 'regret' for publications written in English and appearing in print since the year 1997.**

***Results*: Of 422 articles identified by the search criteria, 28 contained analyzable data regarding 8118 patients. The most commonly identified factors associated with regret after prostate cancer treatment were treatment toxicity factors, especially sexual and urinary function. Other factors included older age and longer time since treatment. The levels of regret were generally higher after radical prostatectomy than external beam radiotherapy or brachytherapy. Decision-making aids were the most commonly used method for reducing the likelihood of regret and were effective.**

***Conclusions*: This is the first systematic review of regret following treatment for localized prostate cancer. Suggestions for the future study of regret in this setting can be made. These include the use of a standardized scale; recognizing levels of regret as low, medium or high; and separately identifying the decision made when patients have combinations of treatments such as surgery followed by radiotherapy.**

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Background

Prostate cancer patients whose disease is confined to the prostate gland have several options when choosing curative therapy, including radical prostatectomy (RP), external beam radiotherapy (EBRT) or brachytherapy (BT). Active surveillance or watchful waiting might also be chosen for patients in whom treatment is considered to be safe to defer. These options may be undertaken alone, in combinations with each other or in combinations with hormone therapy (HT). Over the last 15 years, significant advances in RP have occurred, including the use of laparoscopic (LRP) and robotic-assisted RP (RALRP) techniques, while still recognizing that some patients are still better treated by an open procedure (ORP). Advances in EBRT have included intensity-modulated RT techniques, image-guided RT techniques and volumetric modulated arc radiotherapy.

These treatment options are discussed in detail elsewhere [1], but there are only a few studies that compare their efficacy [2–4]. Regardless of the treatment chosen, for patients with localized disease who are treated with curative intent, survival for 10 years or more after any of these treatments has become commonplace, and, when death does occur, it is more often due to causes other than prostate cancer. Although these good results are encouraging, the patient and his treatment team are required to make difficult decisions about which treatment to adopt at the outset. These treatments represent markedly different experiences for the patient and patients can sometimes experience regrets about the choice that was made [5]. These regrets may be about impaired urinary, sexual or rectal function; psychosocial effects; and recurrence of cancer. Patients can also sometimes regret the way that the decision itself was made to choose a particular treatment option [5,6].

Regret has been defined as 'the emotion we experience when realizing or imagining that our current situation may have been better, if only we had decided differently' [7,8]. Theories and concepts about regret have been published particularly in relation to marketing and gambling [9], where regret can have an effect on the profitability of a product. Regret can take various forms, including *decisional regret*, *outcome regret* and *anticipated regret*.

Outcome regret relates to the outcome of a decision, whereas *decisional* regret involves the way the decision was reached. Regret can result from having to make a choice between action and inaction. Asking a person prior to a decision about the possibility that regret may later be felt can lead to *anticipated* regret and can be a powerful behavioural influence, particularly in encouraging participation in cancer screening and organ donation [9–11]. This potential to powerfully influence a decision by just asking a prior question has been described as the 'mere measurement' effect [12].

The measurement of regret among prostate cancer patients has been reported and validated, enabling factors associated with regret to be identified and comparisons to be made following treatment by different methods. Various scales have been used and reviewed [13], but the most commonly used scale is the Decisional Regret Scale (DRS), which was designed in 1996 and later validated by [14]. The DRS contains five questions, each with five possible answers. It includes two questions that are asked in reverse, so that regret is expressed as a low score and then inverted when marked. These items generate a score out of a possible 25 points, which can be converted to a 0–100 scale by subtracting 1 from each item and then multiplying. Currently, there are no groupings that would indicate high, medium or low levels of regret, leaving some confusion regarding the measurement of expression of regret. For example, Davison *et al*. [15] commented that their sample of 130 patients had 'no regrets' about their choice to have surgery even though four men strongly agreed with the item 'I regret the choice that was made', and the overall score on the DRS was 16.65 (indicating about a 60% level of regret overall in the sample). Soeyongo *et al*. [16] described a score of 7.9 out of 25 as both 'low' and 'minimal', but without any comparators.

Regret is also sometimes reported as a simple percentage of patients expressing regret in response to any one of a number of questions, sometimes as few as two questions. Clark *et al*. [17] studied patients with metastatic prostate cancer who were deciding between medical and surgical castration. He designed a questionnaire to study subsequent perceptions that included three questions about regret, including whether the patient wished he could change his mind about the chosen treatment, whether he felt he would have been better off with the other treatment and whether he was bothered by other patients getting a different treatment. Several authors used these questions, but Clark himself later refined his scale to just two questions [18]. Each item has five levels from 1 (*definitely false or none of the time*) to 5 (*definitely true or all of the time*), and patients who responded to any of the items with a level of 3, 4 or 5 are considered to be regretful. Other measures that are related to regret include satisfaction with decision-making [19] and the decisional conflict scale [20]; however, these do not specifically measure regret relating to a previous decision. As regret relates to a previous decision, there can be no baseline levels of regret, but it can evolve over time; for example, if toxicities evolve from treatment. Currently, there is no consensus over the length of time required for it to become established. Although many studies have measured it at 3 months, some authors have suggested not measuring it for 6 months after the decision has been made [16].

Regret has been reported in a number of medical fields including participation in clinical trials [21,22] and prophylactic breast surgery [23,24]. However, most reports of regret in medicine relate to decisions about cancer treatment [25]. Some of these relate to breast cancer [26], but most relate to prostate cancer. A few reports relate to regret by doctors [27,28]. In breast cancer studies, lower levels of regret have been related to dispositional optimism and self-efficacy [23,24].

It has been proposed that, among the other agreed forms of comparison between treatments, such as efficacy and quality of life, regret could be used as a possible method for assessing one important aspect of the available treatment options. However, it has also been noted that more research is needed before the valid use of regret can be included in patient care protocols [29]. It has been suggested that regret may be a more sensitive outcome indicator than

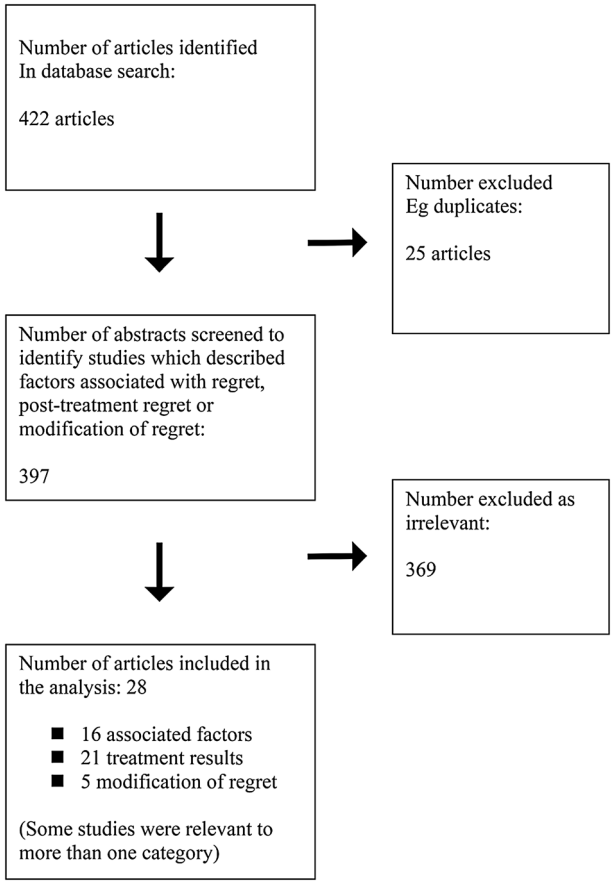

Figure 1. Flow chart

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Table 1. Association of regret with patient, disease and treatment toxicity factors

First author, country	Year	N	Treatment	Scale used	Test used	When measured	Positive factors	OR	p-value
Studies using the DRS, arranged chronologically									
Davison [38], Canada	2007	130	RP	DRS	Correlation	1 year	Role function	0.34	<0.01
							Social function	0.45	<0.01
							Pain	0.29	<0.01
							Financial difficulties	0.3	<0.01
Lavery [54], USA	2012	703	RALRP	DRS	MVLRA	11 months	Older age	0.116	0.02
					Standardized	Median	Gleason score	0.098	0.04
					Coefficients		Baseline potency	−0.11	0.03
							Baseline continence	0.121	0.008
							Time interval	−0.135	0.006
							Post-op potency	0.338	<0.001
							Post-op continence	−0.176	<0.001
Berry [19], USA	2012	494	NS	DRS	MVLRA	6 months	Marital state	−4.08	0.04
							Educational level	−3.56	0.05
							State/trait anxiety	0.32	0.0001
							PrepDM scale	−0.16	0.001
							Bowel toxicity	−0.31	<0.0001
Chien [39], Taiwan	2013	40	Various	DRS	GEE	1.6 months	Psychosocial adj.	−13.37	<0.05
Collingwood [55], USA	2014	556	RALRP	DRS	MVLRA	16.6 months median	African American	−4.86	0.05
							Length of stay	−8.16	0.05
							Incontinence	−4.91	<0.001
							Erectile function	0.47	<0.001
Davison [15], Canada	2014	151	ORP/RALRP	DRS	Correlation	12 months	RALRP		
							Overall urinary	−0.239	0.037
							Urinary bother	−0.152	0.190
							Overall sexual	−0.263	0.023
							Sexual bother	−0.274	0.019
							ORP		
							Overall urinary	−0.333	0.005
							Urinary bother	−0.368	0.002
							Overall sexual	−0.364	0.002
							Sexual bother	−0.357	0.002
Studies using 2-item scales, arranged chronologically									
Hu [33], USA	2003	96	Various	2 items	MVLRA	2.8 years	Lower education	NS	0.05
				(Clark)		Mean	Lower general health	10.1	<0.01
							Low sexual function	10.0	0.03
							Health-related QOL	4.4	<0.02
Hu [30], USA	2008	195	Various	2 items (Clark)	MVLRA	18.3 months mean	Hispanic data	>7.27	NS
			Uninsured			Since biopsy	Confident of cure	0.19	NS
			Low income				Spiritual	0.86	NS
							Treatment toxicity	0.34	NS
Nguyen [56], USA	2011	795	Various	2 items	MVLRA	5.5 years median	Cardiovascular morb	1.52	0.048
				With biochem recurrence			Younger age	0.97	0.019
							Bowel toxicity	1.58	0.038
							(Black race on UR only)		
Diefenbach [5], USA	2007	793	Various	2 items	Correlation	6.12 months	Younger age	−0.08	<0.05
				From DRS			Time (12 > 6 months)	−0.09	<0.05
							Employed	2.22	<0.05
							Sexual and urinary dysfunction also significant		
Studies using other scales, arranged chronologically									
Schroek [57], USA	2008	400	RP	1 item	MVLRA	1.5 years median	African American	3.58	0.004
							Length of follow-up	1.63	0.009
							Urinary toxicity	0.58	0.017
							Bowel toxicity	0.73	0.028
							Hormonal toxicity	0.67	0.041
Lin [35], Taiwan	2011	100	RP	4 items (Clark +1)		13 months mean	Older age	−0.21	<0.05
				MRA			Sexual bother	−0.21	<0.01
							Bowel bother	−0.18	<0.05
Sidana [48], USA	2012	493	Various	Original	Chi sq	NS	Higher education	NS	0.007
		<50 years		Items NS			Lower income	NS	<0.0001
O'Shaunessy [58], Australia	2013	115	Various	Interview	UR	Usually >3 months	Erectile dysfunction	1.4	0.002

Continues

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Table 1. *Continued*

First author, country	Year	N	Treatment	Scale used	Test used	When measured	Positive factors	OR	p-value
						Post-RP	Feeling less masculine	3.09	0.001
							Loss of libido	1.79	0.048
O'Shaunessy [59], Australia	2013	193	Various	Interview	NS	Usually >3 months	<3 months post-RP	14.3%	NS
						Post-RP	<3 months post-RP	17.0%	NS
Ratcliff [60], USA	2013	95	RP	7 items	MRA	12 months	Sexual function	−0.41	<0.001
							Urinary function	−0.40	<0.001
							Cancer worry	−0.57	<0.001

NS, not stated; MRA, multiple regression analysis; MVLRA, multivariate logistic regression analysis; UR, univariate regression; LRM, logistic regression model; GEE, generalized estimating equation; Adj., adjustment; chi sq, chi-squared test; OR, odds ratio; DRS, Decisional Regret Scale; RP, radical prostatectomy; RALRP, robotic-assisted laparoscopic radical prostatectomy; PrepDM, Preparation for Decision-Making; ORP, open radical prostatectomy; QOL, quality of life.

satisfaction because the relative differences between reported treatments are greater [30]. It has also been suggested that the likelihood of regret occurring after a decision could be reduced by providing information and advice about how the decision could be made at the time of the decision [19].

Thus, regret has the potential to provide valuable insight into patients' well-being and overall treatment outcome. However, prior to that, the continued development of regret as an indicator of patient satisfaction/outcomes requires that it is standardized in some way rather than being used in different studies on the basis of different theoretical or measurement assumptions. One initial step in such standardization is to review the previous literature, identifying strengths and weaknesses of those studies that have used regret as a dependent variable of patient well-being. However, a search of the literature in June 2014 (see succeeding text) found that no previous systematic reviews of regret after prostate cancer treatment exist to date, and therefore, the present paper set out to review the extant literature on regret in prostate cancer patients, determine the reported levels of regret and identify factors that were associated with regret, including the treatments given and any interventions used. We also wished to consider potential ways to standardize assessment of regret and improve the assessment of regret in the future.

Methods

Online databases including Medline, CINAHL, EMBASE, EBSCO and PsycINFO were searched in June 2014, using the terms 'prostate' and 'regret' for publications written in English and appearing in print since the year 1997, at which time the scales for measuring regret among cancer patients were developed. The abstracts were then filtered by two of the authors to identify those relevant to the curative treatment of localized prostate cancer. Full text articles were used to derive figures for associations between regret and various patient-, disease- and treatment-related factors. Further references from the reference lists of those articles were obtained where applicable. As all of the material reviewed was already published, ethics committee approval for this project was not considered to be required.

Studies were included if they indicated that prostate cancer patients were included in the study, that those patients were primarily affected by localized disease, even if those who later developed recurrent disease were not separated. In one study [16] that focused on regret among patients receiving HT, patients with biochemical failure were also included, and one [30] included a small percentage of patients with recurrent disease. Purely qualitative studies were not included. Studies were included if they were published in English, and data extraction was undertaken by two of the authors.

Results

The literature searching process is described by a flow chart (Figure 1) and yielded approximately 422 articles; filtering reduced this number to 28, containing data on a total of 8118 men.

Associations between regret and patient, disease or treatment toxicity factors are tabulated in Table 1. Where both univariate and multivariate analyses were carried out, only multivariate analyses demonstrating significant associations are reported to save space. Associations between regret and treatment types are summarized in Table 2. Studies that focused on interventions for the modification of regret are summarized in Table 3.

There were 16 studies that assessed the factors associated with regret. This described a total of 5349 men (Table 1). Six of these (2074 men) used the five-item validated DRS scale, and these studies generally identified a larger number of significant regret-associated factors than the remaining studies and were generally more recently published. Four studies (1879 men) used Clark's two-question scale, and seven (1396 men) used their own scales. As shown in Table 1, the factors that were most frequently identified as associated with regret were factors relating to treatment toxicity. These included sexual dysfunction when erectile dysfunction and sexual bother were combined (eight studies). They also included urinary

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Table 2. Levels of regret after specific treatments

First author, country	Year	Scale used	Test used	When measured	Treatments	*N*	Regret	OR	*p*-value
Studies using the DRS, arranged chronologically									
Davison [38], Canada	2007	DRS	NA	12 months	RP	130	16.65	NA	NA
Talcott [32], USA	2010	DRS	Wilcoxon rank sum	9.4 years median	EBRT			NS	0.02
					Std dose	139	12.7		
					High dose	141	9.2		
Lavery [54], USA	2012	DRS	NA	11.1 months median	RALRP	703	12	NA	NA
Soeyongo [16], Canada	2011	DRS	ANOVA	6–48 months	HT	85	7.9/25	NA	NA
Collingwood [55], USA	2014	DRS	NA	16.6 months Median	RALRP	556	12.3	NA	NA
Chien [39], Taiwan	2013	DRS	GEE model	1.6 months	RP	13	23.8 (1 month) 24.0 (6 months)	NA	NA
Davison [15], Canada	2014	DRS	Pearson correlation	12 months	ORP	73	21.32	NS	NSD
					RALRP	78	19.34		
Studies using 2-item scales, arranged chronologically									
Hu [33], USA	2003	2 items Clark	MVLRA	2.8 years Mean	RP	56	16% overall	NS	NSD
					EBRT	16			
					BT	13			
					WW	11			
Hu [30], USA	2008	2 items	MVLRA	18.3 months mean Since biopsy	RP	96	22.9	0.54	NSD
					EBRT	56	16.1	0.52	
					HT	43	16.3	0.45	
Nguyen [56], USA	2011	2 items	MVLRA	5.5 years median	RP	410	14.8% overall	0.80	0.377
					EBRT	237			
					BT	124		0.91	0.774
					HT	24	(ORs compared with EBRT or HT)		
Kinsella [51], UK	2011	2 items	Fisher's exact test	12 months	ORP	24	13%	NS	NS
					RALRP	49	12%		
					BT	41	0%		
Steer [61], Australia	2013	2 items	NA	23 months Median	IMRT +HT in 85%	220	3.8%	NA	NA
Diefenbach [5], USA	2007	2 items M-scores	ANOVA	6 months	EBRT	437	1.18	NS	<0.01
					BT	220	1.3		
					RP	136	1.4		
				12 months	EBRT	437	1.31	NS	<0.01
					BT	220	1.33		
					RP	136	1.62		
Others, arranged chronologically									
Clark [62], USA	2003	5 items	LRM	1–4 years	RP	131	16.9	NS	0.863
					EBRT and BT	146	15.2		
					HT	27	20.9		
					WW	30	11.1		
Gwede [47], USA	2005	1 item	MVLRA	3.4 months mean 5.1 months mean	RP	52	6% overall	NS	NSD
					BT	67			
Befort [63], USA	2005	3 items	ANCOVA	15.2 months	RP	130	94.8	NS	NSD
				34.8 months	EBRT	120	94.9		
				16.6 months Median	BT	129	94.0		
Schroeck [57], USA	2008	1 item	MVLRA	1.5 years median	ORP	219	14.9	3.02	0.031
					RALRP	181	24.1		
					(additional EBRT or HT—NS)				
Douaihy [34], USA	2010	1 item	NA	4.8 months median	RALRP	377	0.5%	NA	NA
				Regret only identified if scoring 0/6					
Lin [35], Taiwan	2011	4 items	MRA	13.7 months mean	RP	100	31	NA	NA
					EBRT	13	24 at 6 months (NSD)		
					HDR BT	13			
O'Shaunessy [59], Australia	2013	Interview	NS	Usually >3 months	RP	63	27%		
					RT	37	19%		
					WW	15	14%		
					HT	15	13%		
Sidana [48], USA	2012	Original Items NS	Chi square	3–7 years	RP	397	11% overall	NS	NSD
					EBRT	52			

NA, not applicable, for example, where no statistical comparisons between treatments were performed; NSD, no significant difference; Std, standard; HDR, high dose rate; OR, odds ratio; DRS, Decisional Regret Scale; EBRT, external beam radiotherapy; ANOVA, analysis of variance; RALRP, robotic-assisted laparoscopic radical prostatectomy; ORP, open radical prostatectomy; NS, not stated; MVLRA, multivariate logistic regression analysis; IMRT, intensity-modulated radiotherapy; LRM, logistic regression model; GEE, generalized estimating equation; ANCOVA, analysis of covariance; MRA, multiple regression analysis; BT, brachytherapy; RT, radiotherapy; WW, watchful waiting; HT, hormone therapy.

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Table 3. Effect of interventions on modification of regret in prostate cancer

First author, country	Year	*N*	Treatment	Scale used	Test used	When measured	Intervention	Score	OR	*p*-value
Studies using the DRS, arranged chronologically										
Feldman-Stewart [65],	2012	156	Various	DRS	ANOVA	3 months	Values exercises	7.2 vs 7.7	NS	NSD
Canada			MDA for all			12 months	Values exercises	7.2 vs 8.5	NS	0.047
Berry [19], USA	2012	494	NS	DRS	MVLRA	6 months	Web-based decision support system			
							Personal patient profile – prostate (P3P)			
								NS	NS	NSD
Hacking [66], UK	2013	123	Various	DRS	ANOVA	6 months	MDA 'navigator'	10.8	$t = -2.13$	0.036
							Controls	17.1		
Other studies, arranged chronologically										
Mishel [64], USA	2009	256	NS	3 items	Fisher	3 months	MDA	3.93	$F = 4.73$	0.01
					Least sig diff method		MDA (incl spouse)	3.83		
							Controls	4.17		
Kinsella [46], UK	2011	82	RP, BT	2 items	Fisher	12 months	ED instruction	2%	NS	0.03
							Usual care	20%		

OR, odds ratio; DRS, Decisional Regret Scale; ANOVA, analysis of variance; NS, not stated; NSD, no significant difference; MDA, medical decision aid; MVLRA, multivariate logistic regression analysis; RP, radical prostatectomy; BT, brachytherapy; ED, erectile dysfunction.

function (combining incontinence and urinary bother—six studies). For sexual and urinary dysfunction, the associations were strong with most *p*-values measured at <0.01. Bowel dysfunction was associated with regret in four studies, but all of these had *p*-values >0.01, suggesting a significant but less powerful association with regret. Other factors that were associated with regret more than once included non-White race, longer time since treatment (three studies each) and lower educational level (two studies). Age was inconsistently associated with regret, as two studies identified older age as significant [31,32] and two indicated younger age [5,33]; all of these associations were mild. Of those factors that were only identified once, those that were most strongly associated were anxiety, the score on the Preparation for Decision-Making scale, cancer worry and lower income (all $p < 0.001$).

There were 21 studies that assessed levels of regret after specific prostate cancer treatments (Table 2). These studies included 6421 men. Seven of these studies used the DRS (1918 men), six used a version of Clark's two-item scale (2213 men) and eight used original scales (2290 men). The levels of regret reported varied widely depending on the methods used to measure it. For example, regret following RALRP varied from 0.5% [34] to 31% [35], using different scales. There were six studies in which single treatments were described alone, preventing comparisons between treatments. The other 21 studies included more than one treatment and in some cases more than two treatments, thus enabling comparisons to be made between treatments.

The most common treatment comparison was RP versus EBRT (nine studies, Table 2). Among these, seven studies described results for each treatment, and five of these showed higher regret with RP (one reported statistically significant effects [5]). Two studies showed higher regret with EBRT, but the differences were not significant in one study, and the significance was not tested in the other. Two studies did not state results separately but reported the differences were not significant. Considering only those studies that used the DRS, the range of absolute values for EBRT was 9.2–12.7, and for RP, it was 12–24.0

The second most common comparison was between RP and BT, described in seven studies. In one of these [5], regret following BT was significantly lower than for RP, but in the other six studies, the differences were either not significant or they did not report results by treatment separately.

Four studies included either watchful waiting or active surveillance among comparisons of more than two treatments, and none of these showed any significant differences in regret. Three studies compared ORP with RALRP, two of these showed no significant difference and one showed significantly lower regret with ORP.

There were five studies that described interventions to modify levels of regret, incorporating a total of 1111 men. Three of these studies described the effect of a medical decision aids (MDAs), and the other two described educational programs, including values exercises and erectile dysfunction training. Four of the five studies reported significant lowering of the levels of regret after treatment when the intervention was applied prior to a treatment decision being made.

Conclusions

This review of studies of regret in prostate cancer patients has yielded some useful information. However, we must acknowledge some limitations of the literature that affected our ability to study it. These also represent opportunities to define ways that it could be improved.

Firstly, we found that widely differing scales for measuring regret had been used and even different applications of the same scale, creating some difficulty in

making legitimate comparisons between studies and across treatments. The most commonly used scale was the DRS with five items, scored out of 100 [13]. It is easy to use, and results are easy to calculate. As it is the only validated scale, it may be recommended for future studies so that results can be compared between studies and over time. In at least one of the shorter scales, a lack of reliability has been evident [36]. As there are already a multitude of scales in use, it is probably unnecessary to develop new scales at this point unless new models of regret are to be tested.

Secondly, when factors were identified that had been significantly associated with regret, these were often not included in subsequent studies of regret. The most commonly identified factors related to treatment toxicity, but the standard common toxicity scales were not applied [37]. Instead toxicity was defined as it is incorporated into a variety of quality of life scales, which measure the patients' perceived effects of toxicity rather than being a direct and objective measure of that toxicity itself.

Thirdly, absolute levels of regret (or mean values within a group) were often not reported in studies, but instead, their associations with various factors or treatments were expressed in terms of odds ratios and significance levels. This makes it impossible to combine data from different studies into a meta-analysis, or even to express the range of levels that has occurred across studies.

Fourthly, there currently exists no scale in which levels of regret can be categorized as low, medium or high. This has resulted in several authors describing the levels they have measured as 'low' or that regret was 'common' [5,31,38,39], without making any comparison to the findings of other reports. As results from the DRS scale varied from around 5 to 30, it would be reasonable to suggest that levels below 10 are low, 10–20 are medium and over 20 are high, but this suggestion requires validation in the field before acceptance.

Fifthly, it is common to classify patients into single treatment options, but in reality, combinations of treatment are very common, for example, patients who undergo RP but are found to have cancer extending to the edge of the resected specimen (a positive margin) and are eligible for EBRT as soon as they recover from their operation. As this can affect a large proportion of patients undergoing RP, it would be reasonable to assume that this would cause some regret because the patient may consider that he would have been well treated by EBRT alone, without surgery. Most studies describing patients having RP did not describe the effect of needing subsequent EBRT on their levels of regret. Similarly, prior to undergoing EBRT, many patients receive up to 6 months of HT, which has significant additional toxicities, but the regret associated with the decision to have HT is not usually assessed separately. BT was often not further specified as either one of the two common types (low dose rate or high dose rate), even though these are very different treatments. Further, there has been no previous attempt to compare levels between groups of patients with different cancers, so it is not known how prostate cancer treatments compare with others.

Sixthly, many studies and reviews of the psychosocial effects of prostate cancer do not include regret as a factor [40]. It is not incorporated in quality of life scales or assessments of suicidal ideation [41]. Regret could be expected to be a significant indicator of distress and modification of it could be beneficial. In the absence of well-designed randomized trials comparing treatment efficacy outcomes, regret could be a useful method of comparison between such studies. Without serving as a substitute for assessment of toxicity or quality of life, measurement of it should be encouraged.

As in all systematic reviews, the tendency not to publish negative results (the 'file drawer' effect) may have also been present; however, as the studies were generally not conducted by those performing the treatments, this seems unlikely to be a major limitation. Despite these limitations, some useful conclusions are possible from the current literature. The review of factors associated with regret showed that treatment toxicity is a recurring theme, especially sexual and urinary toxicity, which were seen in eight and six studies, respectively. The predominance of these toxicities as factors predicting regret suggests that these toxicities and the effects they have on quality of life should be discussed in detail during the consent process. There were many factors that were only identified in single studies, but increasing regret with lower educational level, non-White race and longer time since treatment were noted more than once. The association with age was inconsistent. Future studies of factors associated with regret should include these in any multivariate analysis. When choosing a treatment for prostate cancer, the possibility that a patient may later regret his choice due to these factors should be explained to him. Regret of both the way the decision was made and the outcome should be considered.

The higher levels of regret described after RP than either EBRT or BT warrants consideration and are consistent with the toxicity factors associated with regret. Currently, more patients by far with localized disease undergo RP than the other treatments [2,42]. As there are more publications that relate to RP than other treatments, publication bias could be present. Although many patients acknowledge involvement in active decision-making, the outcome of the decision is dependent on the information that is presented, and if the first opportunity to present treatment options is in the context of a surgical consultation, then the opportunity for discussion of other options with the specialists that would be supervising those treatments may not eventuate. Several studies indicated the strong effect that the specialist has on the decision that is made by patients [43–46]. Some of those studies showed that the proportion of patients seeing a radiation

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oncologist was less than half, especially in patients under 50 years of age [43,47,48]. Doctors vary widely in the information they consider should be important to the patient [49], and misconceptions and anecdotes are common [50]. Ensuring that patients get the opportunity to see specialists that could offer other treatments, especially radiation oncologists, may be a way to reduce levels of post-treatment regret. Multidisciplinary clinics may help prevent the omission of information about treatment options from the communication with the patient. These issues were well demonstrated in the study by Kinsella *et al*. [51], which compared regret after RP and BT. It was found that all men that expressed regret had undergone surgery, and all cited sexual dysfunction as the principle reason for it. The notion that advances in RP would reduce levels of regret was not supported by the results of studies comparing ORP and RALRP.

The review of interventions for the modification of regret showed that these could be very successful and most commonly involve MDAs. These have been extensively studied in medicine in general [52] and prostate cancer in particular [6,53]. They have been shown to improve knowledge, encourage active participation in decision-making and decrease levels of anxiety and distress. When MDAs are used, fewer patients choose RP, suggesting that the MDA may compensate for poor communication about other treatment options. Although these interventions at the time of the decision might reduce the likelihood of regret later, it has yet to be shown whether established regret can be modified.

In summary, this is the first systematic review of the literature describing regret after prostate cancer treatment. Although there are limitations to the conclusions that can be drawn, it is suggested that standardized methods of assessing regret are used in future. Categories for low, medium and high levels of regret using the standard method are suggested. RP tends to be associated with more regret than other treatment options including EBRT and BT. Regret after prostate cancer treatment is likely to be reduced by incorporating an MDA at the time of decision-making.

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