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SYSTEMATIC REVIEW



## A systematic review of the factors associated with regret post-cancer treatment

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### ABSTRACT

**Problem identification:** Expanding on previous work in specific cancer populations, this review aimed to explore factors associated with decisional regret following treatment for a range of cancer types.

**Literature search:** A systematic search of four databases identified 1747 studies, using search terms relating to cancer survivors and decisional regret. Following quality appraisal, correlates of regret were abstracted and analyzed using narrative synthesis.

**Data evaluation/synthesis:** Seventy-two studies met the inclusion criteria. Factors associated with treatment regret were categorized as being either modifiable or less modifiable. Regret was associated with various sociodemographic factors, physical health, treatment type, an unsatisfactory decision-making process, poorer mental health and lack of social support.


**Conclusion:** Results highlight the complex nature of regret and illustrate how this can be experienced following a range of cancer treatments. As regret can be an obstacle to full-recovery from cancer, this review suggests some ways in which the emergence of regret may be mitigated.


### KEYWORDS

cancer patients; decision-making; oncology; regret; survivors; treatment

## Introduction

A diagnosis of cancer today is not as bleak as it was in previous decades, with survival rates increasing internationally.<sup>1</sup> This is largely due to the range of treatments available to patients which, depending on cancer type and stage of diagnosis, may include surgery, radiation therapy, chemotherapy, immunotherapy, hormone therapy, and stem cell transplantation, among others.<sup>1</sup> While not all cancer treatments are preference sensitive, in many cases, more than one treatment type is available to patients, leaving them with a difficult decision to make. The decision made may have long-lasting consequences extending beyond the initial treatment period to

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survivorship. An unsatisfactory decision may also lead to the experience of regret. As regret has been found to impact cancer patients and survivors negatively,<sup>2</sup> identifying ways to mitigate this experience is an important goal for those supporting cancer survivors.

Simply put, regret is a negative feeling or emotion which is associated with thinking about a past event or choice.<sup>3</sup> In healthcare settings regret can occur in three main contexts: outcome regret—regret which comes from the outcome of a decision, option regret—regret stemming from the alternative chosen, and process regret—regret linked to the way in which the decision was made.<sup>3</sup> All three types of regret may be experienced at once, individually or in different combinations.<sup>3</sup> For example, a patient may regret the treatment decision-making process but not the actual treatment chosen or its outcomes.<sup>3</sup> Research has begun to shed light on exactly what cancer survivors regret about their treatment, as well as other aspects of their experience while ill.<sup>4</sup> Quite often, it is found that the specific treatment type chosen is the cause of regret in cancer patients.<sup>5</sup> Indeed, those who undergo cancer treatment tend to experience higher levels of regret compared to those who participate in clinical trials or undergo prophylactic breast surgery.<sup>4</sup>

It is clear, however, that treatment type is not the only factor involved in the emergence of regret. To date, a number of systematic reviews in the area suggest a broad spectrum of variables associated with regret, including age, time since treatment, experience of side effects, reduced quality of life and lower psychological wellbeing,<sup>4,6–8</sup> The provision of information<sup>6</sup> and process of shared decision-making (SDM)<sup>7</sup> also appear to decrease the likelihood of this experience in certain populations. While treatment decision-making may take various forms, SDM has become the preferred approach in recent years due to the belief that it allows patients to receive care which is right for them, therefore reducing medical errors and improving post-treatment satisfaction.<sup>9</sup> However, studies show that people's preferences around decision-making strategies vary substantially and that while SDM is a popular choice, it is not favored universally.<sup>10</sup> Some suggest that more research into the SDM strategy is needed,<sup>11</sup> especially given the lack of guidance about how best to achieve it.<sup>12</sup> Typically, more regret is displayed by patients who feel their views are not taken into account or when their role in the decision-making is not matched with their preferred role.<sup>13,14</sup>

Existing reviews have tended to focus on regret in specific cancer types (e.g. breast or prostate cancer) to the exclusion of others. While some reviews have focused on general health decisions in cancer,<sup>8</sup> little is known about the commonalities in experience of regret among cancer survivors. The current research aims to fill this knowledge gap by exploring the factors associated with the emergence of regret in a wide range of cancer survivors.

The objective is to provide a synthesis of evidence on the correlates of regret in general oncology populations across various study designs, with the intention of identifying potentially modifiable factors that may inform interventions tailored toward supporting survivors.

## **Method**

The study was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines ([supplementary material Appendix 1](#)).

### ***Search methods***

Studies in English up to April 2019 with no restriction on time period were searched using Web of Science, PubMed, PsycINFO and EMBASE. To ensure the maximum reach, the databases were searched using the following free text search terms and Boolean operators: “cancer survivors” OR “cancer patients” AND “decision” AND “regret” OR “decisional regret.” These terms were selected following an investigatory search of available literature and based on their occurrence as well as their relevance to the research question. An example of one search strategy can be found in [supplementary material Appendix 2](#). The terms were piloted in all four of the databases used in different combinations in order to ensure the literature search was not limited. Reference lists of relevant articles were also checked for additional suitable studies.

### ***Inclusion criteria***

Criteria for study inclusion were as follows: studies must collect primary data from adult participants diagnosed with any type of cancer. Studies must involve some measure of treatment decisional regret (self-reported assessment, quantitative close-ended questions, open-ended questions or qualitative measure), but the measure did not have to use the term ‘regret’ in its title or question used. Studies measuring regret about fertility preservation were not included. At least one potential correlate of decisional regret must be included. Studies must be reported in English language and come from peer-reviewed journals. Studies of any design type (qualitative, quantitative, mixed, etc.) were considered for inclusion.

### ***Data extraction and screening***

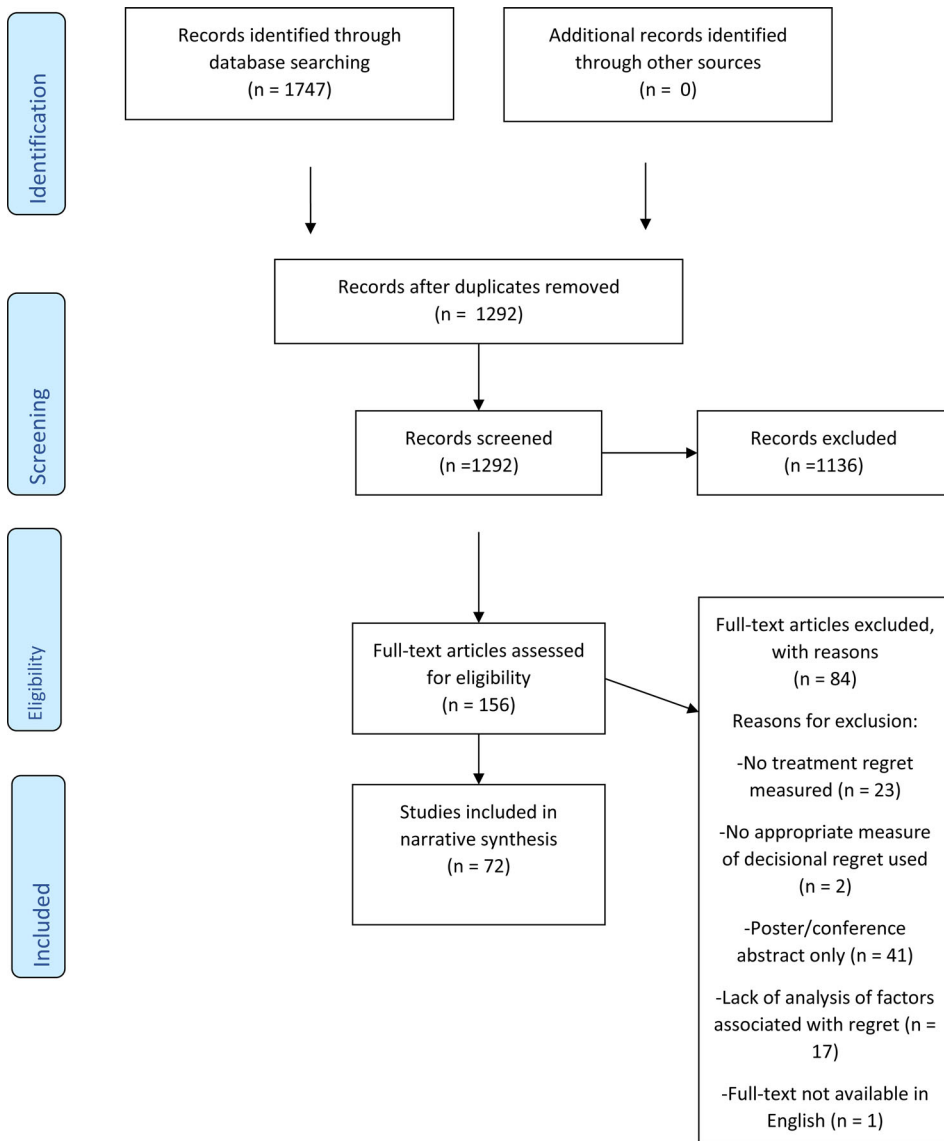
Results from the database search were transferred into Rayyan,<sup>15</sup> an open-source web application for systematic reviews. Titles and abstracts were

independently screened by both reviewers to establish whether they met the inclusion criteria. Where conflicts occurred, these were discussed until agreement was reached. Full texts were sourced from a university library database and read to ensure they met the inclusion criteria. A number of articles did not have full texts as the abstracts came from posters and conference abstracts, thus did not meet the inclusion criteria. The reference lists of included studies were also screened for relevant articles but none were included in the final review.

The database search returned 1747 articles, 455 of which were duplicates, leaving 1292 articles for the screening process. Full texts were obtained for 156 studies and, of these, a further 84 articles were excluded. This was mostly due to the lack of an appropriate measure of regret or no analysis of the factors associated with regret. The process described is further illustrated in the [Figure 1](#) (based on the flow diagram of The PRISMA Group, 2019). A description of all studies included can be found in [Table 1](#). References of all studies included can be found in [supplementary material Appendix 3](#).

Methodological quality was assessed using the Mixed Methods Appraisal Tool (MMAT) Version 2018, a tool designed for the appraisal stage of systematic mixed methods studies.<sup>16</sup> Reviewers independently assessed the quality of each study using a checklist, with individual assessments compared and discrepancies discussed. As per the MMAT user guide, studies were not awarded points or scores. Instead, the user guide advised to provide a presentation of the ratings of each criterion to better inform the quality of the included studies.<sup>16</sup> Each study was categorized and assessed using seven criteria: two screening questions and five questions relevant to the category of the study. There were three possible answers to each question: “Yes,” “No” and “Can’t tell.” A comment section beside each question allowed for a justification of each answer chosen. The two screening questions (“Are there clear research questions?” and “Do the collected data allow to address the research questions?”), required a “Yes” answer, which all studies in the review satisfied. Otherwise, it was assumed that the paper is not an empirical study and cannot be assessed using the MMAT. One of two “Yes” answers indicated low quality, three ‘Yes’ answers indicated moderate quality, four or five “Yes” answers indicated strong quality. All of the studies were found to be of strong or moderate quality. Studies of low methodological quality were not found suggesting a low risk of bias.

Results were analyzed using the process of narrative synthesis, which is a commonly explored approach followed by other researchers.<sup>17</sup> The following information was extracted from included studies by one researcher: design, setting, participants, cancer type, treatment, measure of regret, prevalence of regret, and factors associated with regret. This information



**Figure 1.** PRISMA flow diagram for various phases of the systematic review.

was then discussed and agreed with the second researcher. The assessment of each full-text revealed different types of factors associated with the emergence of regret in cancer patients/survivors. These factors were noted and later split into categories, agreed by both researchers. according to their nature, e.g., a study which found ethnicity to have an association with regret was put into the “sociodemographic factors” category. Most studies examined associates which fit into more than one category. Those categories were then further grouped into two broad sections: “modifiable factors” and “less modifiable factors” associated with regret.



**Table 1.** Summary table of studies included.

Study no.	References	Country	N	Gender	Cancer	Treatment Type	Measure of regret	Study design	Prevalence of regret
1.	Albikri et al (2018).	France	226	Male	Prostate	Surgery, radiotherapy, hormone therapy	Single item	Quantitative descriptive	27.8% undecided or regretted choice of treatment; 69.4% did not regret it.
2.	Berry et al (2012).	USA	794	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	Not provided
3.	Chien et al (2014)	Taiwan	40	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	Mean scores of decisional regret at T1 and T2 were low and did not change over time ( $\beta = 0.6, p > 0.05$ ).
4.	Christie et al (2017)	Australia	40	Male	Prostate cancer	Radical prostatectomy	The single DRS item "The choice did me a lot of harm"	Quantitative descriptive	Not provided
5.	Clark et al (1997)	USA	201	Male	Prostate cancer	Medical or surgical castration	Three items tapping misgivings about the choice that was made and a wish to reverse that decision	Mixed methods	Not provided
6.	Collingwood et al (2014)	USA	556	Male	Prostate cancer	Robotic-assisted laparoscopic prostatectomy	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
7.	Cuyppers et al (2019)	The Netherlands	382	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	After 12 months, 15% of participants regretted their treatment choice.
8.	Davison et al (2007)	Canada	130	Male	Prostate cancer	Radical prostatectomy, 30% of sample received neoadjuvant hormone therapy also	The 5-item Decisional Regret Scale	Quantitative descriptive	Men had no regrets over their decision to have surgery
9.	Diefenbach and Mohamed (2007)	USA	793	Male	Prostate cancer	3-dimensional conformal radiation therapy, brachytherapy, prostatectomy	Two items from the Decision Regret Scale	Quantitative descriptive	Not provided
10.	Fernandes-Taylor and Bloom (2011)	USA	449	Female	Breast cancer	Not mentioned	"Looking back, is there anything about your treatment that you would do differently?"	Mixed methods	43% of women regretted their breast cancer treatment.
11.	Goepfert et al (2017)	USA	1729	Male and female	Oropharyngeal carcinoma	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	38.6% of patients reported no regret (ie, proportional regret score of zero), 45.8% of patient had "mild" regret, and 15.5% of patients reported "moderate to strong" regret.
12.	Hoffman et al (2017)	USA	934	Male	Prostate cancer	Not mentioned	2-item regret questionnaire by Clark et al	Quantitative descriptive	Overall, 14.6% expressed treatment decision regret
13.	Holmes et al (2017)	USA	804	Male	Prostate cancer	Not mentioned	2-item regret questionnaire by Clark et al	Quantitative descriptive	Overall, 13% of participants reported regret concerning their treatment decision.
14.	Hu et al (2008)	USA	195	Male	Prostate cancer	Not mentioned	2-item regret questionnaire by Clark et al	Quantitative descriptive	18% were regretful of their treatment choice.
15.	Hurwitz et al (2017)	USA	652	Male	Prostate cancer	Radical prostatectomy, external beam radiation therapy, brachytherapy, or active surveillance	The 5-item Decisional Regret Scale	Quantitative descriptive	At 36 months, 13%, 18%, 9%, and 7% of patients reported low regret, and 5%, 7%, 0%, and 2% of patients reported high regret in the RP, EBRT, BR, and AS groups respectively.
16.	Kanunturi et al (2019)	USA	480	Female	Breast cancer	Endocrine therapy and chemotherapy	The 5-item Decisional Regret Scale	Quantitative descriptive	The overall weighted decision-regret score was 17.2 (95%CI 13.6–20.8) for endocrine therapy and 17.7 (95%CI 12.1–23.3) for chemotherapy.

17.	Kinsella et al (2012)	England	82	Male	Prostate cancer	Radical prostatectomy	2-item regret questionnaire by Clark et al. "If I had it to do over, I would make a different decision about what type of surgery to have"	Quantitative randomized controlled trials	Not provided
18.	Lantz et al (2005)	USA	1633	Female	Breast cancer	Not mentioned	Participants responded to seven items related to the frequency with which they had thoughts about how their current situation could have turned out more positively had they made a different treatment decision	Quantitative descriptive	Not provided
19.	Ratcliff et al (2013)	USA	95	Male	Prostate cancer	Radical prostatectomy	Regret was measured by a previously validated five-level Likert addressing whether patients wished they could have changed the kind of treatment they received.	Quantitative randomized controlled trials	Not provided
20.	Schroek et al (2008)	USA	400	Male	Prostate cancer	Retropubic radical prostatectomy or robot-assisted laparoscopic radical prostatectomy	2-item regret questionnaire by Clark et al. Women with a breast cancer experience were asked to indicate on a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree) how much she concurred with five statements regarding regret pertaining to her breast cancer treatment decisions (i.e., "I regret the choice that was made")	Quantitative descriptive	19% of men reported regret.
21.	Shakespeare et al (2017)	Australia	82	Male	Prostate cancer	Surgery and post-prostatectomy radiotherapy	18 regret statements were developed, in part derived from previous studies.	Quantitative descriptive	16.9% were regretful of their overall treatment experience.
22.	Taha et al (2011)	Canada	260	Female	Breast cancer	Not mentioned	The 5-item Decision Regret Scale	Quantitative descriptive	Not provided
23.	van Tol-Geerdink et al (2016)	The Netherlands	240	Male	Prostate cancer	Not mentioned	The original regret scale was developed by Clark et al and includes 3 items: the patient's wish that he could change his mind about the	Quantitative randomized controlled trials	Not provided
24.	Wang et al (2018)	Taiwan	154	Female	Breast cancer	Not mentioned		Quantitative descriptive	The mean score on the DRS for the study sample was 8.10. Overall, the sample reported low rates of decisional regret.
25.	Windon et al (2019)	USA	150	Male and Female	Head and neck cancer	Not mentioned		Quantitative descriptive	Participants expressed low levels of regret (median score, 5; IQR, 0-25 on a scale of 100).
26.	Lin (2011)	Taiwan	100	Male	Prostate cancer	Radical prostatectomy		Quantitative descriptive	31% of the participants reported experiencing regret.

(continued)





Table 1. Continued.

Study no.	References	Country	N	Gender	Cancer	Treatment Type	Measure of regret	Study design	Prevalence of regret
27.	Maguire et al (2017)	Ireland and Northern Ireland	1229	Male	Prostate cancer	Not mentioned	Type of treatment he received, his belief that his OOL would be better if he had chosen a different treatment option, and whether he was bothered by the fact that other men had received very different prostate cancer treatments. In this study, we added 1 item to this scale: whether the man regretted that he had received an RP. The 5-item Decisional Regret Scale	Quantitative descriptive	The mean Decisional Regret score of 18.02 suggests that levels of regret amongst were reasonably low, yet there was considerable variation here (SD = 19.52). 14.5% of survivors experienced high levels of regret (a score above 50). Not provided
28.	Mahal et al (2015)	USA	484	Male	Prostate cancer	Surgery or radiation	2-item regret questionnaire by Clark et al	Quantitative descriptive	Not provided
29.	Martinez et al (2013)	USA	1536	Female	Breast cancer	Not mentioned	The 5-item Decisional Regret Scale – altered for the purpose of this study to reflect elements specific to breast cancer surgery	Quantitative descriptive	Mean regret in the overall sample was 4.9 at time 1 and 5.4 at time 2.
30.	Mollica et al (2017)	USA	1093	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
31.	Morris et al (2015)	USA	794	Male	Prostate cancer	Not mentioned	2-item regret questionnaire by Clark et al	Quantitative descriptive	12% experienced treatment decisional regret.
32.	Nicolai et al (2016)	Germany	160	Male and female	Breast or colon cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
33.	Calderon et al (2019)	Spain	403	Male and female	Not specified	Chemotherapy or radiotherapy or both	The 5-item Decisional Regret Scale	Quantitative descriptive	The mean DRS score was 10.6. Most participants (51.9%, n = 209) experienced no decision regret.
34.	Chambers et al (2018)	Australia	28	Male	Prostate cancer	Not mentioned	No specific measure of regret. However, men in the study mentioned feeling regret in the interview.	Qualitative	Not provided
35.	Davison et al (2014)	Canada	151	Male	Prostate cancer	Robotic-assisted laparoscopic radical prostatectomy or open radical prostatectomy	The 5-item Decisional Regret Scale	Quantitative descriptive	The mean total decision regret score of patients in the RRP was 19.34 (SD = 20) and the ORP group 21.32 (SD = 24.6).
36.	Hacking et al (2013)	Scotland	123	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	Not provided

37.	Hawley et al (2008)	USA	2030	Female	Breast cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	About 39% had a lot of decision regret, 30% a moderate amount of regret and another 31% reported very little regret.
38.	Lee et al (2015)	USA	123	Female	Breast cancer	Mastectomy alone (50.4%)	The 5-item Decisional Regret Scale	Quantitative descriptive	Women reported a low to moderate level of regret with their decision ( $M = 29.1$ , $SD = 19.0$ ). Not provided
39.	Lam et al (2013)	China	276	Female	Breast cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	Not provided
40.	Lam et al (2014)	China	286	Female	Breast cancer	Surgery	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
41.	Sawka et al (2012)	Canada	44	Male and female	Thyroid cancer	Adjuvant radioactive iodine treatment	The 5-item Decisional Regret Scale	Quantitative descriptive	Decision regret was generally low (mean 22.1, standard deviation [SD] 13.0).
42.	Schuemeyer et al. (2016)	USA	96	Male and female	Uveal melanoma	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	At the baseline, 10% ( $n = 10$ ) of patients had some or full decision regret. At 3 months, 17% ( $n = 11$ ) had some or full decision regret, while at 12 months, 10% ( $n = 8$ ) had some or full decision regret.
43.	Sepucha et al (2015)	USA	97	Male and female	Breast cancer	Surgery	One item assessed whether patients would choose the same type of surgery again.	Quantitative descriptive	A little more than half of respondents (60.8%) would definitely have the same type of surgery again, indicating no regret.
44.	Shepherd et al (2019)	Scotland	137	Male and female	Colorectal cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	Not provided
45.	Shuman et al (2017)	USA	57	Male and female	Laryngeal cancer	46% treated surgically, 54% nonsurgically	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
46.	Spittler (2011)	USA	102	Female	Breast cancer	Not mentioned	The 5-item Decisional Regret Scale	Mixed methods	The majority of the women reported low decision regret (79%) and of these 44% had no decision regret.
47.	Wagland et al (2019)	England	97	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Mixed methods	Not provided
48.	Watts et al (2014)	Australia	138	Male	Prostate cancer	Prostate specific antigen (PSA) testing (might need to exclude as not cancer treatment)	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	Not provided
49.	Mishel et al (2009)	USA	256	Male	Prostate cancer	Not mentioned	Decisional Regret Subscale, a 3-item subscale of the Quality of Life Scale	Quantitative randomized controlled trials	Not provided
50.	Step et al (2009)	USA	216	Female	Breast cancer	Adjuvant therapy	Decision regret likert scale (not sure what scale exactly)	Quantitative descriptive	Not provided
51.	Step et al (2009)	USA	179	Female	Breast cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
52.	Parker et al (2018)	USA	288	Female	Breast cancer	Contralateral prophylactic mastectomy (CPM)	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
53.	Repetto et al (2016)	Italy	204	Male	Prostate cancer	Active surveillance (AS), open radical prostatectomy, robotic radical prostatectomy, and brachytherapy	The 5-item Decisional Regret Scale	Quantitative descriptive	Most of the patients had a low or null degree of regret on the Treatment Regret Scale from 0 to 100 (78.1% obtained a score <30, and about 30% of the sample had a score equal to zero). Only 4.7% scored 60 or more, indicating some degree of regret.

(continued)

Table 1. Continued.

Study no.	References	Country	N	Gender	Cancer	Treatment Type	Measure of regret	Study design	Prevalence of regret
54.	Shahzad and Seyedeh Najjes (2019)	Iran	60	Female	Breast cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative randomized controlled trials	Not provided
55.	van Stam et al (2018)	The Netherlands	454	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
56.	Noyan et al (2006)	Turkey	125	Female	Breast cancer	Mastectomy (and breast reconstruction)	Satisfaction/regret likert scale	Quantitative descriptive	Not provided
57.	Advani et al (2019)	USA	421	Female	Breast cancer	Lumpectomy plus whole-breast irradiation, brachytherapy, or endocrine therapy or mastectomy with or without radiation	The 5-item Decisional Regret Scale	Quantitative descriptive	23.8% of respondents reported experiencing local therapy decisional regret
58.	Hu et al (2003)	USA	96	Male	Prostate cancer	Not mentioned	2-item regret questionnaire by Clark et al,	Quantitative descriptive	16% of participants reported regret.
59.	Steer et al (2013)	Australia	220	Male	Prostate cancer	Image-guided intensity modulated radiation therapy and 3-dimensional conformal radiation therapy	2-item regret questionnaire by Clark et al,	Quantitative descriptive	3.8% of patients expressed decision regret for their choice of treatment.
60.	Lavery et al (2012)	USA	703	Male	Prostate cancer	Robot-assisted laparoscopic prostatectomy	The 5-item Decisional Regret Scale	Quantitative descriptive	Of the patients 88% did not regret the decision to undergo robot-assisted laparoscopic prostatectomy.
61.	Clark et al (2003)	USA	747	Male	Prostate cancer	Not mentioned	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
62.	Clark et al (2001)	USA	201	Male	Prostate cancer	Orchiectomy (29%) or chemical castration (71%)	Two items asking if a patient wished he could change his mind and the belief that he would have been better off with the treatment not chosen.	Quantitative descriptive	23% of participants reported regret.
63.	Drevdahl and Dorcy (2012)	USA	45	Male and female	Hematologic malignancies	Stem cell transplant	Interview questions about regret	Qualitative	Noting that they had "no other choice," participants expressed no regret posttransplant.
64.	Shaverdian et al (2017)	USA	276	Male	Prostate cancer	Stereotactic body radiation therapy, intensity modulated radiation therapy, or high-dose-rate brachytherapy.	"A validated tool"	Quantitative descriptive	13% expressed regret with their treatment.
65.	Daum et al (2017)	USA	201	Male	Prostate cancer	Not mentioned	The satisfaction with decision scale (Holmes-Rovner et al., 1996)	Quantitative descriptive	Not provided
66.	Dawson, B. J., and Goldenberg, S. L. (2003)	Canada	67	Male	Prostate cancer	Radical prostatectomy External beam radiation, Brachytherapy, Watchful waiting	The 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
67.	Diefenbach et al (2008)	USA	391	Male	Prostate cancer	External beam radiation	Three items from the 5-item Decisional Regret Scale	Quantitative descriptive	Not provided
68.	Dogan et al (2017)	Turkey	162	Male	Prostate cancer	Not mentioned	Interview question: Do you regret having undergone this surgery?	Qualitative	16% regretted having undergone surgery, while another 1.7% had indecisive thoughts on regret.

69.	Mohamedali et al (2010)	Canada	35	Male and female	Acute myeloid leukemia	Chemotherapy	The 5-item Decision Regret Scale	Quantitative descriptive	Decisional regret scores were low among respondents, with a mean score of 8.67 out of 25.
70.	Reamer et al (2017)	USA	160	Male	Prostate cancer	Surgery, radiation, active surveillance (AS)/watchful waiting (WW).	"Existing scales modified for study"	Quantitative descriptive	Men in the sample had little regret (median score: 1.0 on a 5-point scale, SD: 0.8) with their treatment decision-making process.
71.	Sawka et al (2015)	Canada	70	Male and female	Thyroid cancer	Not mentioned	The 5-item Decision Regret Scale	Quantitative randomized controlled trials	Not provided
72.	Swanick et al (2018)	Canada	1650	Female	Breast cancer	Lumpectomy plus whole-breast irradiation, lumpectomy plus brachytherapy, lumpectomy alone, mastectomy without radiation therapy, and mastectomy plus radiation therapy	The 5-item Decision Regret Scale	Quantitative descriptive	Not provided

## Results

### *Description of studies*

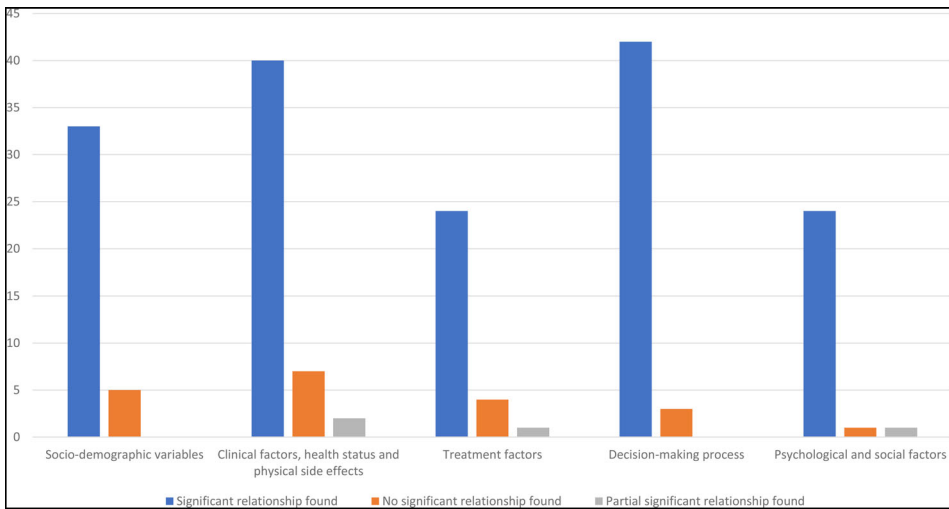
Of the 72 studies included, 3 were qualitative, 12 quantitative randomized controlled trials, 53 quantitative descriptive and 4 mixed methods (as per MMAT categorization).

The studies were conducted in a range of countries, with the most common being the USA ( $n=39$ ), Canada ( $n=8$ ), and Australia ( $n=5$ ). There were 3 each in Taiwan and The Netherlands, 2 in England, Scotland, Turkey and China, and 1 in France, Ireland, Germany, Spain, Italy and Iran. Sample sizes ranged from 28 to 2030 participants, with a total of 27,982 participants in all studies combined. Most studies in the review involved patients/survivors with prostate cancer (42) or breast cancer (20). However, a number of studies focused on less prevalent cancer types: thyroid cancer (2), colorectal cancer (2), oropharyngeal carcinoma/head and neck cancer (2), uveal melanoma (1), and acute myeloid leukemia (1). One study involved patients suffering from more than one cancer type (specifically, cancer patients with a tumor who underwent adjuvant chemotherapy). Treatment types undertaken included: surgery, radiotherapy, hormone therapy, brachytherapy, active surveillance, endocrine therapy, adjuvant radioactive iodine treatment, stem cell transplant, orchiectomy, chemical castration and watchful waiting. Many studies were inclusive of treatments, while others focused on specific treatment types only. Some did not provide any details of the treatment type undertaken by participants or provided limited information about this.

As per the inclusion criteria, the studies in this review were required to incorporate a measure of regret. The most common tool used was the five-item Decision Regret Scale ( $n=39$ ),<sup>18</sup> or the two-item regret questionnaire by Clark et al ( $n=9$ ).<sup>19</sup> Many of the studies used adapted versions of those scales or other validated Likert scales. Other studies assessed regret using a single item question or, in the case of qualitative studies, asked participants to discuss their experience of regret, e.g., “Looking back, is there anything about your treatment that you would do differently?”. Description of all methods used can be found in [Table 1](#).

### *Narrative synthesis*

Overall, the level of regret experienced by participants was low. Of the 22 studies reporting the percentage of regret experienced, results ranged from 0%-56% ( $M=21\%$ ). Four additional studies reported percentages of participants experiencing low ( $M=26.3\%$ ), moderate ( $M=37.9\%$ ) or high ( $M=10.5\%$ ) regret, while a single study reported percentages of regret



**Figure 2.** Number of studies which investigated the relationship between regret and five types of factors.

experienced by participants at three time points (baseline post-treatment = 10%, 3 months post-treatment = 17.3%, 12 months post-treatment = 10%). Ten studies reported regret obtained from the DRS with scores ranging from 4.9 to 22.1 ( $M = 14.4$ ). A number of studies, however, did not provide information on regret prevalence and simply discussed correlates of this.

There were a number of factors found to be associated with the emergence of regret suggesting that some survivors may be more at risk of experiencing this following treatment. Factors were initially categorized according to their nature, e.g., gender, age and ethnicity were classified as sociodemographic factors (see Figure 2 for studies finding effects in the different category groupings). These were then further grouped into two broader classifications based on their potential controllability. Specifically, modifiable factors were considered to be those that may be changed from the patient's perspective (e.g., a patient feeling distressed post-treatment may reach for professional help in order to mitigate this feeling). Less modifiable factors were those which the patient has little or no control over (e.g., sociodemographics or physical side effects). Table 2 provides a detailed overview of results.

### ***Theme 1: Sociodemographic and health-related factors—less modifiable factors associated with regret***

#### ***1. Regret associated with sociodemographics***

Twenty-two (31%) studies reported an association between regret in cancer patients/survivors and specific sociodemographic factors. Associations were found with: marital status (higher levels of decisional regret were reported



**Table 2.** Studies which investigated the relationships between regret and five types of factors.

Category	Factor	No. of study with sig. relationship	No. of study with no sig. relationship	No. of study with partial relationship
Sociodemographic variables	Marital status	2, 14		
	Education level	2, 3, 16, 18, 50, 51, 56, 57, 58	30, 37, 68	
	Socioeconomic status		6	
	Race/Ethnicity	6, 14, 15, 16, 18, 28, 29, 30, 31, 37, 57	20	
	Age	9, 12, 16, 31, 50, 51, 60		
	Employment status	9		
	Income level/financial difficulties	8, 18, 56		
	General physical health condition/HRQoL scores/ QoL scores	14, 26, 33, 35, 58, 60, 67	53	
	Non-obesity	6		
	Cancer stage	24, 64	20	
Clinical factors, health status and physical side effects	Gleason score	30, 64	20	
	Biochemical recurrence		20	
	Lower EPIC domain scores		20	
	Health utility	20		
	Sexual dysfunction/ incontinence/ erectile dysfunction	6, 9, 12, 15, 17, 19, 26, 35, 60, 61	57	
	PSA level/ PSA concern		62, 68	
	Urinary dysfunction	12, 61, 64		
	Pain	9, 19, 26, 31		15, 35
	Bowel dysfunction	8		
	Hormonal dysfunction	12, 14, 26		
Treatment factors	Nausea	15		
	Premature menopause	62		
	Second diagnosis of cancer	10		
	Difficulty swallowing	29		
	Voice-related quality of life	11		
	Perceived decreased cognitive abilities	45		
	Surgical complications	63		
	Prostate cancer treatment	6	66	
	Breast cancer treatment	6, 9, 17, 20, 21, 26, 31, 58, 59, 62, 64		
	Head and neck cancer treatment	10, 11, 19, 24, 29, 56	52, 72	57
Thyroid cancer treatment	25	41		

Longer interval since treatment	14, 60, 69	
Longer stay in hospital post-treatment	6	
Treatment modality	9	
Being well-informed	1, 2, 10, 12, 13, 26, 62, 68	
Decision uncertainty	38	
Confidence level	46	
Communication difficulty	38	
Matched goal	43	
Understanding potential side effects	10, 31, 47, 68	
Decisional conflict	30, 40, 46	
Little SDM	40, 41	
Being offered multiple treatment options	40	
Greater duration of consultation	10, 32, 34	
Blaming health-care professionals	23, 36, 39, 44, 48, 49	
Use of decision aid	17	7, 54, 71
Preoperative counseling	18, 24, 32, 47, 51, 55, 68	
Preferred level of involvement	47	
Unchallenged treatment preferences	47	
Lack of clinical recommendations	15, 19	
Overall poor mental health scores	2, 7, 40, 42	
Anxiety	7, 42	
Depression	5, 26, 33	4
Distress	3, 14, 30	
Emotional domains of QoL	63	
Wanting to return to "normal"	14, 27	
Fear of cancer recurrence	22	
Blaming oneself for negative events	10, 37, 68	70
Social support	10	
Poor self-care habits	8	
Changes in QoL with decreases in role and social functioning		
Psychological and social factors		



by single/not in a relationship men compared to married/in a relationship men), education level (higher education associated with less regret while less educated individuals reported higher regret), ethnicity (Caucasian patients in the USA tended to regret less compared to other races), income level (higher income associated with less regret) and post-treatment financial difficulties (financial difficulties associated with higher regret). No clear pattern was found regarding age, with both younger and older patients experiencing regret in different studies.

## ***2. Regret associated with clinical factors, health status, and physical side effects***

Twenty-four (33%) studies found an association between the patient's health status pre and/or post-treatment and the emergence of regret. Prostate cancer patients reported regret associated with poorer physical health, lower health-related quality of life (HRQoL) scores, surgical complications, sexual dysfunction, pain, urinary dysfunction, bowel function, poor hormonal function, nausea, lower Expanded Prostate Cancer Index scores, poorer perceived physical condition, higher Gleason score, PSA level/concern lower scores on the functional and global QoL subscales and T1c disease. In contrast, one study found that regretful men less frequently reported sexual dysfunction. Interestingly, one study found that obesity in African men was associated with lower regret levels.

Breast cancer patients reported regret associated with: premature menopause, later breast cancer stage and a second diagnosis of breast cancer. Difficulty swallowing was a factor associated with regret in oropharyngeal carcinoma patients. Laryngeal cancer patients reported regret associated with lower voice-related QoL. A study of patients with hematologic malignancies study found that regret was associated with the patient's perceived decreased cognitive abilities.

## ***3. Regret associated with the treatment type received***

Treatment type was found to be associated with regret in 26 (36%) of the studies in this analysis. Treatments associated with higher regret in prostate cancer individuals were: medical or surgical castration, robotic-assisted laparoscopic prostatectomy, brachytherapy, androgen-deprivation therapy and radical prostatectomy. Breast cancer patients regretted radiation, chemotherapy, hormone therapy, surgery, mastectomy, lumpectomy, axillary nodal dissection and others. Some head and neck cancer patients regretted therapeutic combination treatment while others regretted undergoing surgery or radiation therapy alone instead of a combination of treatments.

One study found regret in breast cancer patients who decided to not undergo breast reconstruction post-mastectomy. Three studies found that a longer interval since treatment in cancer patients was associated with greater regret, while another found that longer stay in hospital post-treatment resulted in higher regret. The same study found that African-American men who received secondary therapy reported more decisional regret than white men, suggesting not only an association between regret and treatment type but also ethnicity. One study found an association between regret and treatment modality.

### ***Theme 2: Contextual, psychological and social factors—modifiable factors associated with regret***

Two categories of modifiable factors emerged from the analysis: regret associated with the decision-making process and regret associated with social/psychological factors. For some patients experiencing regret, it may be too late to alter some factors discussed below in order to mitigate their regret, i.e., a patient reporting regret cannot go back in time to change the treatment decision-making process. However, this research allows for the possibility of changes being made in the future. Unlike the factors discussed above, modifiable factors give hope that regret may be prevented or mitigated.

#### ***1. Regret associated with the decision-making process/the consultation/level of understanding of information received or searched for (internet vs. doctors)/counseling/etc***

Thirty studies (42%) investigated relationships between regret and aspects of the decision-making process. Regret was frequently associated with levels of information provided, with regretful patients more likely to report receiving incomplete information regarding their diagnosis, had unchallenged treatment preferences, an absence of clinical recommendations, received too many treatment options, or had less satisfaction with understanding potential treatment side effects. Similarly, lower levels of information seeking by patients associated with regret.

Regretful patients reported low perceived preparation for decision-making, low quality in establishing a shared decision-making framework, decision uncertainty, decision conflict, low confidence level in the decision, and more difficulty communicating with health care professionals (HCPs). In contrast, lower regret was found in patients who received treatment which matched their goal, and in patients who were given a decision aid, and/or preoperative counseling.

Other aspects of HCP interactions were found to influence regret. In one qualitative study, women expressed regret associated directly with the doctor in charge of their treatment, with one participant noting her doctor did not have enough time for her and another one stating that her doctor had no “bed-side manner.” Patients in another study described feeling regret about late diagnosis or treatment which was commonly attributed to delays by clinicians. More regret was found in patients who reported not feeling empathy from their physician.

## ***2. Regret associated with psychological and social factors***

Twenty-one studies (29%) in the analysis found an association between psychological and social factors and the emergence of decisional regret in cancer patients. A pattern suggesting that regret is associated with poorer mental health was evident in all of these. Higher regret was associated with: higher anxiety and depression, more distress, including distress emerging from surgical complication, and fear of cancer recurrence. Regret was also associated with feelings of wanting to “return to normal” and the extent to which survivors blamed themselves for negative events occurring during the illness. Emotional domains differed between regretful and non-regretful people and patients with those reporting greater psychosocial adjustment also experienced less regret. Patients who displayed higher optimism and resilience also reported less regret.

In the social context, higher levels of regret were associated with: less social support perceived poorer self-care habits (for example in the form of not joining a support group), changes in QoL in men with decreases in role and social functioning.

## **Discussion**

The aim of this review was to understand the complexity of factors which may have an impact on the emergence of decisional regret in cancer patients. While, overall, the level of regret found in the studies analyzed was low, a large number of correlates of regret were observed, pointing to ways in which this may be mitigated. Our finding that a considerable number of associates may be modifiable highlights potential mechanisms for health care providers to reduce the likelihood of experienced regret in cancer survivors. The decrease in well-being in the presence of regret suggests that research of this topic is a vital aspect in helping to support those on their journey toward better and healthier cancer survivorship.

Analysis of less modifiable factors, such as sociodemographic characteristics, gives some insight into those who may be at greater risk of experiencing regret. While no studies in the review examined gender differences,

survivors who were in a relationship, had a higher education, higher income, and less financial difficulty were less likely to experience this. In all studies examining race/ethnicity, white individuals were found to report less regret than nonwhite cancer patients/survivors,<sup>20</sup> suggesting that this group may require additional support. However, as these studies were conducted in the USA, it is unsure whether a similar pattern would occur in other contexts. No clear pattern was found in relation to age, with conflicting findings suggesting both older and younger patients may be at risk of regret. Our findings also highlight the variety of cancer treatment types which may be associated with regret, suggesting that, regardless of treatment, all survivors are at risk of this experience.<sup>5</sup>

Overall, the review findings indicate that those reporting poorer physical health and more side effects from cancer treatment experienced greater levels of decisional regret.<sup>21</sup> Patients also tend to regret side-effects which they were not aware of while making their treatment decision, which highlights the importance of providing information to survivors about what may come after treatment. This may be done in consultation with HCPs and with appropriate decision aids which have been found to improve satisfaction post-treatment.<sup>22</sup>

A robust finding from the review is that the better patients are informed before making their treatment decision, the less regret they report post-treatment.<sup>23,24</sup> However, this also may depend on whether patients' wishes regarding their desired level of involvement in decision-making are met, a finding echoed in a review of cancer patient's involvement preferences.<sup>25</sup> Patient involvement preferences vary<sup>26,27</sup> and, while in the minority, some patients do not feel the need to be involved in the decision-making process, preferring to leave the decision to their doctors. Honoring this leads to less regret in such patients.<sup>28</sup> Future interventions should aim to assess patient involvement preferences, which would allow HCPs to establish the most appropriate method of decision-making.

Relating to the above, a number of studies in the review showed the important role of HCPs in mitigating regret. Individuals reported more regret if they felt their doctors were not empathetic enough, or had no bedside manner,<sup>28</sup> suggesting that the provision of training in communication skills may have positive implications for the well-being of patients.<sup>29</sup> Effective doctor-patient communication is also essential for patient understanding,<sup>30</sup> and, as discussed above, this may minimize the emergence of regret.

Additionally, lower regret was found in those who reported less decision uncertainty at the time of the treatment decision-making, those who felt like the treatment they selected matched their goal, and those who used a decision aid. Taken together, these findings suggest the importance of

enhancing the provision of supports prior to decision-making, as this alone may influence the emergence of decisional regret.<sup>31</sup> Again, this implies that honoring patient input, feelings and knowledge is important for their well-being.

Consistent with previous work, we found a clear relationship between higher levels of regret and poorer mental health scores.<sup>32</sup> A cancer diagnosis can lead to considerable psychological strain for patients,<sup>33</sup> and the link between poor mental health and high levels of regret was evident throughout this review. Only one study assessed the longitudinal relationships between depression and regret,<sup>34</sup> suggesting that those experiencing depression were more likely to experience feelings of regret at follow up. Caution should be exhibited when drawing conclusions from this single example, however, as no other study included in the review examined the directionality of relationships between depression and anxiety. Nevertheless, this finding does highlight the need for doctors to be mindful of not only the physical well-being of their patients, but also the psychological impact that a cancer diagnosis and treatment may have.<sup>33</sup> There are a number of interventions which may aid psychological well-being in cancer patients, including music interventions,<sup>35</sup> meaning-centered group psychotherapy<sup>36</sup> or mindfulness stress reduction training.<sup>37</sup> One study included in the review also suggested that optimism may play a protective role in wellbeing, leading to less regret in survivors. Interventions which foster positive psychological appraisals may therefore offer another means of mitigating later regret.

Social support and higher levels of spirituality<sup>38</sup> were also found to be associated with less regret, although only a handful of studies have investigated this to date. Identifying means of increasing social support, through either online or offline means<sup>39</sup> may offer important pathway for helping survivors cope after treatment.

Surprisingly, caregiver and family influence on decision-making and related regret was not a factor identified in the studies reviewed. Family members are often involved before, during, and after the medical consultation and may stimulate discussion at home, away from the medical expert.<sup>40</sup> They may also stimulate patient autonomy as they help to breakdown difficult to understand or overwhelming information.<sup>40</sup> However, as with personal involvement in decision-making, patients hold preferences on the level of involvement of their caregivers and family members.<sup>40</sup> An unsatisfactory level of involvement in decision-making as seen by the patient may affect the emergence of decisional-regret.

The current review highlights the complexity of factors associated with decisional regret which may inform future interventions aimed at mitigating regret in this group. Findings imply that each cancer patient should be

viewed as an individual who brings their own experiences, knowledge and feelings into the treatment decision-making process and that post-treatment regret and reduced quality of life can occur for various reasons. Findings highlight the importance of providing patients with sufficient information by their healthcare professionals so that they can access a range of sources of knowledge and support.

Findings also highlight the need for continuous care for cancer survivors, as the negative effects of cancer and its treatment can reduce wellbeing even during survivorship. A well-established concept of care for individuals transitioning from being a cancer patient to being a cancer survivor is Person Centered Care which puts the individual's needs, values and preferences first.<sup>41</sup> This component of care responds to the need to view each survivor as an individual with personal experiences as well as the need to continue the provision of care during survivorship.

Lastly, the findings from this review may allow healthcare providers, carers or support service workers to identify individuals most likely to experience treatment regret. This knowledge may alter the care and support provided according to individual needs, for example, by making sure people have access to appropriate supports and resources, and that they are not disadvantaged based on their financial situation.<sup>42</sup>

### **Limitations**

The main limitation of the review was that the majority of studies involved a cross-sectional design. Very few studies were prospective, which makes assumptions regarding causality difficult. Another limitation may be that the database search focused only on decisional regret, which may have excluded a number of relevant studies. Studies which captured regret with various means (self-reported measures, qualitative measures, open-ended questions, close-ended questions) were included in the review. However, the search terms may not have picked up various measures with single items measuring regret, for example patient-reported outcomes. While this review attempted to inspect the factors associated with decisional regret in patients suffering from various types of cancer, in comparison with other systematic reviews on the topic, most of the studies which met the inclusion criteria sampled prostate cancer patients only (42/72) or breast cancer patients only (20/72). This result mirrors the prevalence of prostate and breast cancers worldwide, with breast cancer being the second most common cancer worldwide (2.09 million cases) and prostate cancer being the fourth (1.28 million cases).<sup>43</sup> Lung and colorectal cancers are also very prevalent, but not as much research is being conducted about the regret in survivors of these cancer types, perhaps owing to the higher mortality rate

in these groups.<sup>43</sup> Nevertheless, this review highlights the need for researchers of well-being in cancer survivors to be more inclusive, as sufferers of less prevalent cancers are currently being overlooked.

## Conclusion

Most systematic reviews of regret in cancer patients to date have concentrated on one cancer type only which may restrict the generalizability of results.<sup>43,44</sup> This review has provided a broader overview of the complex reasons why different cancer patients may report regret post-treatment. Interestingly, no clear pattern of the factors associated with regret was found, suggesting that any type of cancer warrants the possibility for regret to occur, due to a range of sociodemographic, health-related and contextual factors. As regret can be an obstacle to full-recovery from cancer, more research into mitigating its emergence is needed. Specifically, the development of interventions which will inform both the patient and doctor, as well as interventions which will work to mitigate regret, are merited.

## Implications for psychosocial oncology

- A minority of survivors will experience regret following treatment and some are more at risk than others. HCPs should work to mitigate the likelihood of this experience, especially in those most at risk.
  - Providing information about treatment and side effects, as well as acknowledging patient preferences in relation to decision-making, should reduce the likelihood of regret across all cancer survivors.
  - Interventions targeting a number of modifiable factors, such as the provision of social support, and fostering positive psychological appraisals, may help survivors cope after treatment.

## Disclosure statement

The authors have no conflict of interests to declare.

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