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**Title: Can models of self-management support be adapted across cancer types? A comparison of unmet self-management needs for patients with breast or colorectal cancer.**

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## ABSTRACT

**Purpose:** There is an increased focus on supporting patients with cancer to actively participate in their healthcare; an approach commonly termed 'self-management'. Comparing unmet self-management needs across cancer types may reveal opportunities to adapt effective self-management support strategies from one cancer type to another. Given that breast and colorectal cancers are prevalent, and have high survival rates, we compared these patients' recent need for help with self-management.

**Method:** Data on multiple aspects of self-management were collected from 717 patients with breast cancer and 336 patients with colorectal cancer attending one of 13 Australian medical oncology treatment centres.

**Results:** There was no significant difference between the proportion of patients with breast or colorectal cancer who reported a need for help with at least one aspect of self-management. Patients with breast cancer were significantly more likely to report needing help with exercising more, while patients with colorectal cancer were more likely to report needing help with reducing alcohol consumption. When controlling for treatment centre, patients who were younger, experiencing distress, or had not received chemotherapy were more likely to report needing help with at least one aspect of self-management.

**Conclusions:** A substantial minority of patients reported an unmet need for self-management support. This indicates that high quality intervention research is needed to identify effective self-management support strategies, as well as implementation trials to identify approaches to translating these strategies into practice. Future research should continue to explore whether self-management support strategies could be adapted across cancer types.

**Keywords:** Self-management, needs, breast cancer, colorectal cancer, bowel cancer

## INTRODUCTION

### **Self-management is key to optimising outcomes for patients with cancer**

The need for people with cancer to self-manage their condition is becoming increasingly important, given increased survival [1], and shifts to treatment in outpatient or home settings [2]. Self-management is defined as the ability to manage the consequences of living with a chronic condition, which includes coping with the impact of treatment, physical and lifestyle changes [3]. It involves providing patients with symptom management options which they can perform independently, away from the healthcare provider. Core self-management skills may include problem solving, decision making, seeking out and using available resources (e.g. printed materials and the internet), collaboration with healthcare providers, and behaviour change [4]. Strategies which support patient self-management can improve physical and psychosocial outcomes. For example, a recent systematic review and meta-analysis of internet-based self-management support interventions for patients with cancer, including strategies such as tailored feedback, peer-to-peer support, and access to an advisor [5], were somewhat effective in improving outcomes including fatigue, depression and anxiety. Despite the potential to improve patient outcomes by supporting patients to implement self-management strategies, a large proportion of patients with cancer experience problems with self-management. For example, in a sample of 807 Japanese patients with cancer of varying stages, 61% reported at least one self-management related concern [6]. Further exploration of patients' concerns in relation to self-management will enable the design of effective interventions to develop their skills in these areas.

### **Assessing unmet needs in relation to cancer self-management**

It is important to understand not just whether patients experience problems or concerns with self-management, but also the degree to which they perceive these concerns could be solved if appropriate assistance were provided. Unmet needs assessment measures the extent to which patients perceive they need help with a range of issues including self-management [7, 8]. Directly asking patients about which areas of self-management they require support with may help identify areas where providing assistance has potential to improve wellbeing. Greater unmet needs are associated with poorer quality of life among patients with cancer [9], suggesting that addressing these needs may improve patient wellbeing. The identification of patients' unmet need for help with self-management may guide the provision of individually tailored and potentially more cost-effective support for this area.

### **Why compare the unmet self-management needs of patients with breast or colorectal cancer?**

Unmet self-management needs might vary across cancer types due to differences in the demands of the disease and its associated treatment, the socio-demographic characteristics of the populations affected by different types of cancer, or the models of care used for different types of cancer. The latter may be influenced by the level of research investment in identifying strategies to improve and implement best practice symptom management, psychosocial care and patient-centred care [10]. Comparing self-management needs between two groups with different types of cancer can provide an opportunity to adapt strategies used to optimise self-management across these groups. In 2012, breast cancer was the second most common cancer, while colorectal cancer was the third most incident cancer worldwide [11]. In most developed countries, five year survival rates for both breast and colorectal cancer are increasing [12], with the majority of those with each of these cancer types now living longer and subsequently needing to engage in self-management many years after treatment completion [13]. Therefore, by ensuring that effective ways of addressing self-management needs for patients with breast cancer are adapted for those with colorectal cancer, and vice versa, there is potential to improve self-management outcomes for a large proportion of people affected by cancer.

Some studies have compared the unmet supportive care needs of these patients more broadly. A recent Australian population-based study of patients with cancer who were six months post-diagnosis found that 45% of patients with breast cancer reported at least one moderate to high-level unmet need, compared to 33% of patients with colorectal cancer (across a range of domains) [14]. Similarly, Chinese outpatients with breast cancer were found to have a higher prevalence of unmet needs compared to outpatients with colorectal cancer; although no differences were found in terms of type of unmet needs [15]. However, a systematic review was unable to identify any clear trends with respect to differences in type or prevalence of unmet need by cancer type given differences in measures and time frames used across studies [16].

Studies which have examined unmet needs of patients with breast cancer and patients with colorectal cancer separately have provided some insight into the types self-management needs of these groups. For example, a systematic review of unmet needs of breast cancer patients [17] showed that 37% of patients needed help with finding information about managing the condition at home, while 22% needed help with accessing complementary therapies. A recent systematic review of colorectal cancer patients' unmet needs [18] showed that between 7-89% wanted more information about managing long term symptoms or side effects, while 46-98% wanted more information about diet or nutrition. However given heterogeneity in samples and domains of self-management assessed, self-management needs across breast and colorectal cancer patients cannot be directly compared from these studies.

Consequently we aimed to:

- 1) Compare the proportion of patients with breast cancer to those with colorectal cancer who have experienced at least one unmet self-management need over the past month;
- 2) Examine whether, after controlling for socio-demographic, psychological, disease and treatment factors, cancer type is associated with reporting at least one unmet self-management need;
- 3) Compare the proportions of patients who report unmet needs across different areas of self-management.

## **METHOD**

### **Setting**

Data were collected between September 2012 and December 2014 from 13 medical oncology treatment centres in Australia as a component of a larger study examining psychosocial outcomes for patients attending medical oncology clinics. The study method and other findings from this study have been reported elsewhere [19-21].

### **Sample**

#### ***Eligibility***

Eligible clinics were those identified as treating at least 400 new medical oncology patients each year. Patients with cancer aged at least 18 years attending one of the clinics for at least their second outpatient appointment were eligible to participate. Those who were physically or mentally incapable of completing the survey, unable to provide informed consent, or unable to complete the survey in English were excluded.

#### ***Recruitment***

Adult patients with cancer were recruited consecutively. A research assistant or member of staff at the clinic approached eligible patients while they were waiting for their outpatient appointment, provided written study information, and sought informed consent. Consenting patients were asked to complete a 30 minute pen and paper

survey. Participants were given the option of completing the survey in clinic or taking it home and returning it within one week in a reply-paid envelope. Participants were mailed a reminder letter and another copy of the survey if they had not returned it after two-three weeks. A second reminder letter was sent to non-responders after a further two-three weeks. Ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the Ethics Committees of the participating health services.

## **Outcome variable**

### ***Unmet need for assistance with self-management***

The Chronic Disease Needs Assessment Tool was developed for this study. Eleven items from this tool relevant to self-management were included in the current analysis (see Supplementary Material). Participants responded on a four point Likert scale ('Not a problem or didn't need help'; 'A problem, but got the help I needed'; 'A problem, and needed a little more help'; 'A problem, and needed a lot more help').

## **Associate variables**

**Demographics:** Participants were asked to self-report their age, gender, education, living arrangements and postcode.

**Disease and treatment characteristics:** Participants self-reported their cancer type, reason for clinic visit, time since diagnosis, and types of treatment received.

**Psychological distress:** Anxiety and depression was measured using the Hospital Anxiety and Distress Scale (HADS) [22]. The anxiety and depression subscales each include seven items. Respondents are asked to rate the extent to which they have experienced each item on a four-point response scale. The HADS has been used extensively across a number of populations, including people with cancer. It has demonstrated internal reliability, construct validity, and discriminant validity [23]. A total HADS score of 15 or more was considered to indicate the presence of distress, given that this cut off score has high sensitivity and specificity for detecting anxiety and depression [24].

## **Statistical analysis**

Analyses were conducted in SAS v9.4. The analysis presented here will only consider a subset of patients within the data who had breast cancer or colorectal cancer. Those who had both breast and colorectal cancer were removed from the sample.

Participant characteristics were expressed as counts and percentages. For each self-management item, participants were considered to have an 'unmet need for help' if they indicated any level of need for help (i.e., needed 'a little more' or 'a lot more' help). The proportion of participants who were categorised as having an unmet need for help on at least one self-management item was used to investigate Aims 1 and 2. The proportion of participants who were categorised as having an unmet need for help, separately for each self-management item, was used to investigate Aim 3.

Aim 1 and aim 3 comparisons of proportions used chi-square analyses accounting for treatment centre with standard errors estimated using the clustered-jackknife method. 95% confidence intervals (CIs) and F-transformed Rao-Scott *p*-values for the differences are reported. For aim 2, univariate logistic regression was undertaken, regressing 'unmet need for help with at least one aspect of self-management' on cancer type or each demographic, psychological, disease or treatment predictor variable. Treatment centre was accounted for in the models through the clustered-jackknife method. Predictors with *p*-values < 0.1 were analysed in a multiple logistic regression model, along with cancer type. Unadjusted and adjusted odds ratios (ORs) with 95% CIs and type 3 *p*-values are presented. Available case analysis was conducted for this aim.

## RESULTS

### Sample characteristics

The overall study consent rate was 80% (all cancer types;  $n = 2581$ ), of whom 2096 returned a baseline survey. The characteristics of those who consented but did not return the baseline survey are not known. When compared to those who completed the baseline survey, non-consenters were more likely to be male ( $p < .01$ ). However there was no significant difference in age ( $p = 0.06$ ) between those who completed the baseline survey and non-consenters. This analysis reports on the responses of a subsample of 1053 patients, comprising 717 patients with breast cancer, and 336 patients with colorectal cancer. Demographic characteristics of patients are shown in Table 1.

**Table 1.** Demographic, disease and psychological characteristics of patients with breast or colorectal cancer <sup>a</sup>

Variable	Category	Breast (n=717)	Colorectal (n=336)	Total (N=1053)
	Male	5 (1%)	200 (60%)	205 (19%)
	Female	711 (99%)	136 (40%)	849 (81%)
	Missing	1	0	1
	18 to 59	435 (61%)	109 (32%)	544 (52%)
	60 to 74	228 (32%)	169 (50%)	397 (38%)
	75+	52 (7.3%)	58 (17%)	110 (10%)
	Missing	2	0	2
	High school or less	332 (47%)	170 (51%)	502 (48%)
	>High school	381 (53%)	162 (49%)	543 (52%)
	Missing	4	4	8
	Living with other/s	584 (82%)	261 (78%)	845 (80%)
	Living on own	131 (18%)	75 (22%)	206 (20%)
	Missing	2	0	2
	Urban	636 (89%)	284 (86%)	920 (88%)
	Rural	75 (11%)	48 (14%)	123 (12%)
	Missing	6	4	10
	Treatment-related appointment	437 (62%)	211 (64%)	648 (62%)
	Follow-up	271 (38%)	120 (36%)	391 (38%)
	Missing	9	5	14
	Less than 6m	217 (30%)	93 (28%)	310 (29%)

Variable	Category	Breast (n=717)	Colorectal (n=336)	Total (N=1053)
Time since diagnosis	6 to 12m	124 (17%)	63 (19%)	187 (18%)
	13 to 24m	110 (15%)	62 (19%)	172 (16%)
	Over 24m	265 (37%)	117 (35%)	382 (36%)
	Missing	1	1	2
	No	62 (8.7%)	55 (17%)	117 (11%)
	Yes	653 (91%)	278 (83%)	931 (89%)
	Missing	2	3	5
	No	134 (19%)	32 (9.6%)	166 (16%)
	Yes	581 (81%)	301 (90%)	882 (84%)
	Missing	2	3	5
	No	246 (36%)	209 (69%)	455 (46%)
	Yes	442 (64%)	94 (31%)	536 (54%)
	Missing	29	33	62
	No	295 (41%)	281 (84%)	576 (55%)
	Yes	422 (59%)	55 (16%)	477 (45%)
	Missing	0	0	0
	Yes	185 (26%)	79 (24%)	264 (25%)
	No	531 (74%)	254 (76%)	785 (75%)
	Missing	1	3	4

<sup>a</sup> Proportions may not sum to 100% due to rounding

### Proportion of patients with breast cancer and those with colorectal cancer who reported any unmet need for help with self-management

Taking treatment centre into account, 30% (95% CI: 27-32%) of patients with breast cancer, and 27% (95% CI: 21 - 33%) of patients with colorectal cancer indicated that in the last month they had experienced at least one unmet need across the 11 aspects of self-management assessed within this study. The difference in these proportions was not statistically significant ( $F(1,12) = 0.78, p = 0.40$ ).

### Factors associated with need for help with self-management

Univariate logistic regression analysis indicated that age, education, reason for visit, chemotherapy, and HADS score were associated with having at least one unmet self-management need ( $p < 0.1$ ; see Table 2). These variables were entered into an adjusted model, along with cancer type (breast or colorectal).

The adjusted model indicated that patients who were younger ( $p = 0.03$ ), who had not been treated with chemotherapy ( $p = 0.001$ ), or who were distressed ( $p < 0.001$ ) were more likely to report at least one unmet need for help with self-management. Consistent with the results of the univariate chi-square analysis, cancer type was not associated with unmet needs in the unadjusted analysis ( $p = 0.38$ ).

**Table 2.** Logistic regression model examining the effect of cancer site, socio-demographic, psychological, prognostic and treatment factors on reporting at least one unmet self-management need (n = 1020)

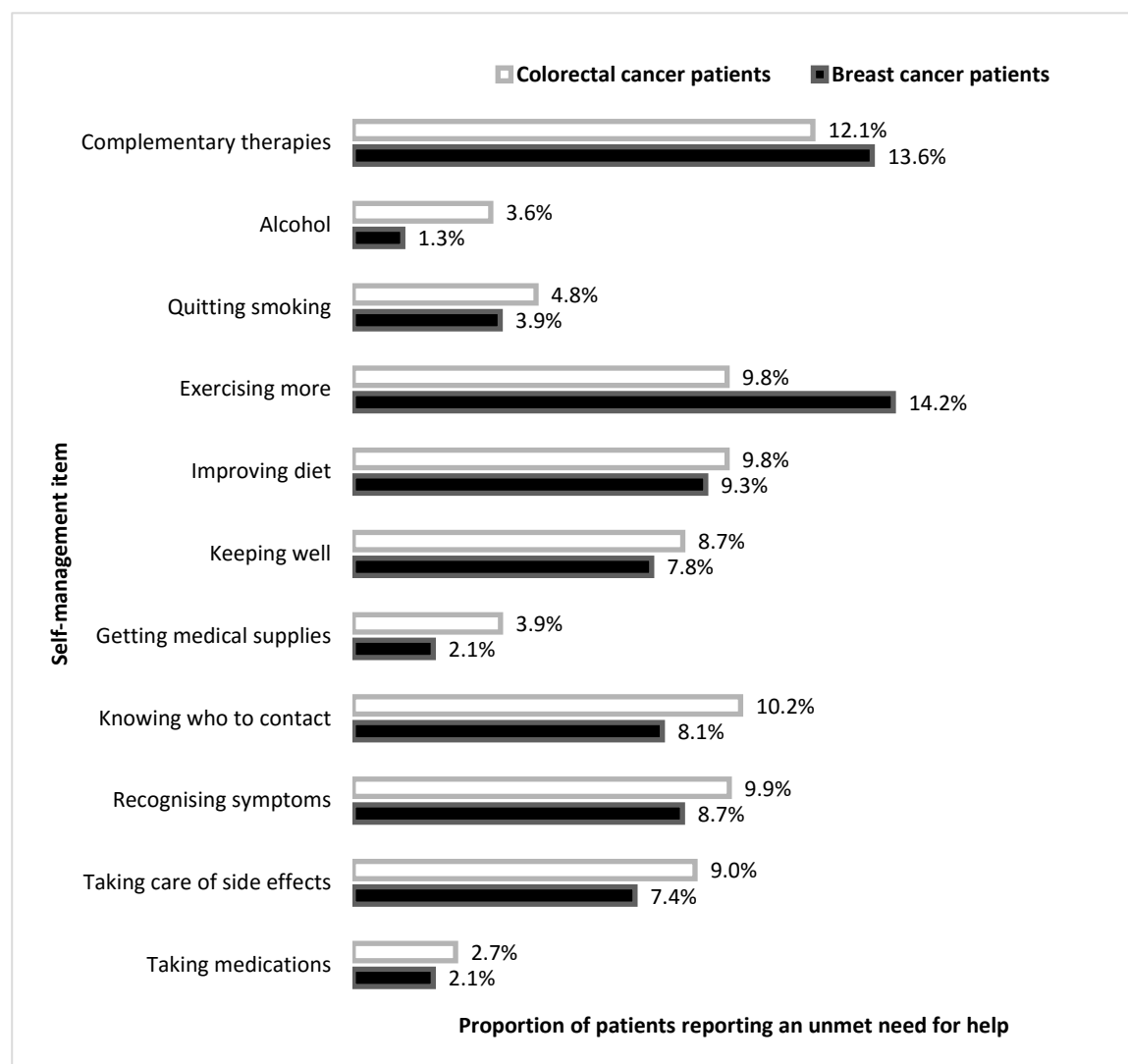
Predictor	Category	Unadjusted odds ratio		Adjusted odds ratio	
		Crude OR (95% CI)	Crude P	Adjusted OR (95% CI)	Adj. P
	Breast	1.15 (0.82, 1.60)	0.376	0.79 (0.59, 1.05)	0.445
	Colorectal	ref		ref	
	Male	0.85 (0.56, 1.29)	0.395	-	.
	Female	ref		-	
	High school or less	0.72 (0.49, 1.06)	0.063	0.74 (0.48, 1.16)	0.144
	>High school	ref		ref	
	18 to 59	1.88 (1.31, 2.69)	<.001	1.47 (0.96, 2.27)	0.03
	75+	0.80 (0.47, 1.38)		0.68 (0.37, 1.26)	
	60-74	ref		ref	
	Living on own	1.14 (0.89, 1.45)	0.258	-	-
	Living with other/s	ref		-	
Location	Rural	1.37 (0.87, 2.15)	0.127	-	-
	Urban	ref		-	
Reason for visit	Treatment-related appointment	1.38 (1.04, 1.84)	0.013	1.32 (0.96, 1.81)	0.054
	Follow-up	ref		ref	

Time since diagnosis	Less than 6m	0.95 (0.70, 1.29)	0.317	-	.
	6 to 12m	1.00 (0.72, 1.40)		-	
	13 to 24m	1.16 (0.85, 1.59)		-	
	Over 24m	ref		-	
Surgery	Yes	1.40 (0.80, 2.47)	0.19	-	-
	No	ref		-	
Chemotherapy	Yes	0.75 (0.53, 1.05)	0.066	0.69 (0.51, 0.94)	0.001
	No	Ref		ref	
Radiation therapy	Yes	0.92 (0.73, 1.14)	0.389	-	-
	No	ref		-	
Other treatment	Yes	0.86 (0.71, 1.06)	0.117	-	-
	No	ref		-	
	Yes	5.35 (3.35, 8.55)	< .0001	5.38 (3.24, 8.93)	< .0001
	No	ref		ref	

### Proportion of patients with breast and those with colorectal cancer who reported an unmet need for help with different types of self-management

Figure 1 shows the proportion of patients with breast or colorectal cancer reporting an unmet need for help with each of the self-management items included in this study. Significantly more patients with breast (14%; 95% CI: 11-17%) than colorectal (10%; 95% CI: 6-14%) cancer reported an unmet need for assistance with exercising more ( $F(1,12) = 5.95$ ,  $p = 0.03$ ). In contrast, significantly more patients with colorectal (4%; 95% CI: 1-6%) than breast (1%; 95% CI: 0-2%) cancer reported an unmet need for help with drinking less alcohol ( $F(1,12) = 15.02$ ,  $p = 0.002$ ). No significant differences between the proportions of patients with breast cancer compared to those with colorectal cancer were found for the other self-management items assessed as part of this study.

**Figure 1.** Proportion of patients with breast (n = 717) or colorectal cancer (n = 336) who reported an unmet need for help with each self-management item <sup>a</sup>



<sup>a</sup> Maximum scale value is 20%.

## DISCUSSION

### **No significant differences between the proportion of patients with breast cancer and those with colorectal cancer reporting unmet self-management needs**

A substantial minority (just under one third) of patients with breast or colorectal cancer reported experiencing a problem or needing help with at least one aspect of self-management (out of 11) in the month prior to survey completion. There was no significant difference between the proportion of patients with breast cancer (30%) and those with colorectal cancer (27%) who reported self-management related unmet needs. This finding was further supported by the logistic regression analysis, which showed no statistically significant relationship between cancer site and self-management unmet needs, when adjusting for other factors. These findings are inconsistent with previous studies showing that patients with breast cancer are more likely to report unmet needs compared to patients with colorectal cancer [14, 15].

These findings are somewhat surprising, given that in recent years there has been comparatively more research, advocacy and investment relating to the quality of life of patients with breast cancer, as compared to patients with colorectal cancer [10]. For example, there has been increased focus on the development of service delivery models such as breast cancer care co-ordination [25, 26]. The substantial research investment is reflected in recent systematic reviews of self-management interventions [5, 27], which show that 40% of the included interventions were developed specifically for patients with breast cancer. Interventions developed for patients with breast cancer have been shown to be effective in improving outcomes such as psychological adjustment [28] and fatigue [29]. Another systematic review of the effectiveness of survivorship care plans, which are designed to enhance patient self-management following treatment completion, showed that 50% of included interventions were developed for patients with breast cancer [30]. Provision of a survivorship care plan had some evidence for effectiveness in assisting patients to identify the clinicians responsible for their follow-up care. Therefore it is possible that the lack of difference in unmet needs between patients with breast and those with colorectal cancer in the current study reflects failure to implement evidence-based strategies to support self-management among women with breast cancer into routine clinical practice. Patient barriers, such as symptom distress, comprehension of self-management advice, and financial problems [31, 32], may limit uptake of effective interventions. Similarly, provider barriers such as lack of training, other competing priorities, and lack of systems to support provision of self-management education may also adversely affect implementation of effective strategies to support self-management [4, 33].

An alternative explanation for the lack of difference in unmet self-management needs across these cancer types is that historically, patients with breast cancer may have experienced greater unmet needs than those with colorectal cancer. The increased research effort and resource allocation may have reduced breast cancer patients' self-management needs so that they are now at a comparable level to patients with other cancer types. This interpretation is supported by a prior Australian study with data collected in 2006, which reported a higher prevalence of unmet needs for patients with breast compared to those with colorectal cancer [14]. Our data, collected from 2012-2014, did not replicate this finding. However, the current data does not allow us to determine which of these explanations is more likely to be correct.

### **Differences in the type of unmet self-management needs reported by patients with breast cancer and those with colorectal cancer**

There were differences in the proportion of patients with breast cancer and those with colorectal cancer reporting a need for help for two of the self-management needs included in our survey. Patients with breast cancer were more likely than

those with colorectal cancer to report a need for help with exercising more, but less likely to report a need for help with drinking less alcohol. These findings may be explained, at least in part, by the differences in the characteristics of people affected by these two types of cancer. For example, weight gain and lower levels of physical activity are common among younger patients with cancer [34]. As patients with breast cancer were more likely to be younger, this may explain the increased likelihood of their reporting a need for help with exercising. In addition, females may be more concerned with body image than males, which may also at least partly account for this finding. Similarly, males are more likely to report risky levels of alcohol consumption, as compared to women [35]. Sixty percent of the sample of patients with colorectal cancer were male, which may explain their increased likelihood of needing help with alcohol consumption.

### **Factors associated with experiencing unmet needs for help with self-management**

Consistent with other studies examining the relationship between age and unmet needs [14, 36, 37] younger age was significantly associated with needing help with at least one aspect of self-management. It is possible that older patients have more experience in engaging in self-management activities related to other chronic conditions; or that healthcare providers provide better education to older patients regarding self-management. Conversely, younger patients may have higher expectations of healthcare and so are more likely to report unmet needs. The latter interpretation is consistent with a large body of work on patient satisfaction which has consistently shown lower levels of satisfaction among younger people [38, 39]. Finally, as younger patients are more likely to be in the work force, or still caring for children, they may have less time to learn self-management skills.

Similar to other studies [37, 40, 41] our study found that those with elevated levels of distress were also more likely to report unmet needs. Given the cross sectional nature of the data, the direction of causality cannot be inferred, however, it is possible that this reflects that distressed patients are less likely ask for help. Conversely, high levels of unmet self-management needs may contribute to elevated levels of distress.

Patients who had undergone chemotherapy were less likely to experience unmet needs compared to patents who had not received chemotherapy. This finding does not align with a previous studies [42, 43] showing higher levels of needs for patients who had received chemotherapy relative to other types of treatment. However, these studies asked about ‘treatment received in the last month’, while in the current study, we asked about ‘treatments ever received’, which may at least partially explain this divergence in findings.

### **Implications for practice**

A substantial minority (approximately one third) of patients with breast or colorectal cancer report at least one unmet need related to self-management. Consequently healthcare providers should ensure they provide comprehensive self-management advice to deal with all relevant physical, treatment and lifestyle changes experienced by patients with either breast or colorectal cancer. Our findings also suggest that patients with breast or colorectal cancer who are younger, who are experiencing elevated distress and who are undergoing treatment types other than chemotherapy may require additional support to develop their skills and confidence in self-management.

### **Limitations**

This study explored differences across cancer types in unmet need for help with 11 aspects of self-management. Given that the concept of self-management covers a broad range of lifestyle and physical changes, our study may not have

captured all relevant self-management tasks. For example, some have argued that self-management also encompasses maintenance of psychological wellbeing [27, 44]. It is possible that inclusion of a greater range of self-management skills may have revealed additional differences between patients with breast cancer and those with colorectal cancer in the types of self-management needs reported.

## **Conclusion**

Patients with breast cancer appear to have a similar level of need for support with self-management to those with colorectal cancer. Future research should further explore differences in the level and type of unmet self-management needs across patients with different types of cancer. This may reveal opportunities for exploring whether self-management strategies could be adapted across cancer types to improve self-management support. There is also a need to produce high quality evidence for the effectiveness of strategies to improve patient self-management, and to ensure that this evidence is translated into practice.

## **Compliance with Ethical Standards**

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. The authors have no conflicts of interest to declare.

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