

1 **Title:** Diet and nutrition information and support needs in pelvic radiotherapy: a systematic,
2 mixed-methods review.

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4 **Abstract**

5 **Introduction:** This study aimed to review diet and nutrition information and support needs of
6 cancer patients who receive pelvic radiotherapy to inform the development of interventions to
7 improve this area of care.

8 **Methods:** The systematic review followed the PRISMA guidelines. Six electronic databases
9 were searched for peer-reviewed studies of any design that assessed diet and nutrition needs
10 after a pelvic cancer diagnosis. Narrative synthesis was used to integrate findings.

11 **Results:** Thirty studies (12 quantitative, 15 qualitative, 3 mixed-methods) were included. Four
12 themes, “content of dietary information”; “sources of information”. “sustaining dietary change”;
13 and “views on the role of diet post-treatment”, summarised evidence about provision of
14 nutritional guidance following diagnosis, but also contrasting views about the role of diet post-
15 diagnosis. Qualitative studies contributed considerably more to the synthesis, compared to
16 quantitative studies. Included studies were of moderate to good quality; selection bias in
17 quantitative studies and poor evidence of credibility and dependability in qualitative studies
18 were highlighted.

19 **Conclusion:** There is some evidence of lack of nutrition support in pelvic cancer survivors, but
20 methodological limitations of included studies may have had an impact on the findings. Future,
21 prospective studies that focus on diet and nutrition needs post-diagnosis are warranted to
22 improve care.

23
24 **Keywords:** pelvic radiotherapy; pelvic cancers; information needs; support needs; nutrition;
25 diet; mixed methods review

26 **1. Introduction**

27 Cancer is a significant public health problem worldwide, with 18.1 million new cases estimated
28 to have occurred in 2018 (Bray et al., 2018). Cancer incidence has increased by approximately
29 4 million since 2012 (Torre et al., 2015) and is projected to further increase in both developed
30 and developing countries (Bray et al., 2018). Advances in early detection and management of
31 cancer have also led to an increasing number of people surviving their cancer (Allemani et al.,
32 2018). Pelvic cancers (anus, bladder, rectum/bowel, female and male reproductive organs)
33 show increasing survival rates, with 5-year survival estimated to be more than 50% in most
34 countries for prostate, cervical and rectal cancers (Allemani et al., 2018). Alongside increased
35 survival, it is important to address the supportive care needs of people diagnosed with cancer,
36 including adjustments in lifestyle, which may differ according to the phase of the cancer journey
37 (from diagnosis to survival) (Fletcher, Flight, Chapman, Fennell, & Wilson, 2017; Kotronoulas,
38 Papadopoulou, Burns-Cunningham, Simpson, & Maguire, 2017; Puts, Papoutsis, Springall, &
39 Tourangeau, 2012; van Mossel et al., 2012).

40 Pelvic radiotherapy is often an integral part of the multidisciplinary approach used to treat pelvic
41 tumours. Although technological advances have led to improvement of techniques, toxicity still
42 affects the gastrointestinal tract and can lead to functional damage, including malabsorption and
43 change in motility of the intestinal tract (Teo, Sebag-Montefiore, & Donnellan, 2015). These
44 adverse effects can have a significant impact on a patient's diet, subsequent nutritional status
45 and quality of life (Andreyev, Wotherspoon, Denham, & Hauer-Jensen, 2011). Moreover,
46 treatment side effects that are result of pelvic radiotherapy have been reported to affect cancer
47 survivors' daily life in the long term, as late as 11 years post-diagnosis (E. Adams et al., 2014)
48 due to structural damage of the gastrointestinal tract.

49 Furthermore, a cancer diagnosis is often viewed as a “teachable moment” when patients may
50 be considering changing current lifestyle habits, such as smoking cessation and maintenance of
51 a healthy weight through diet (Hawkins et al., 2017). There is growing evidence of the
52 importance of diet and nutrition in cancer survivorship. Dietary interventions in cancer survivors
53 are associated with reduced body weight (Mohamad et al., 2015; Pekmezi & Demark-
54 Wahnefried, 2011), improved quality of life (Mosher et al., 2009; Smits et al., 2015) and may
55 influence survival (Jochems et al., 2018; van Zutphen, Kampman, Giovannucci, & van
56 Duijnhoven, 2017). Obesity is prevalent in pelvic cancer populations and has a negative impact
57 on physical and functional well-being and quality of life (S. V. Adams, Ceballos, & Newcomb,
58 2016; Dieperink et al., 2012; Koutoukidis, Knobf, & Lanceley, 2015). Systematic reviews have
59 demonstrated increased mortality in obese ovarian (Protani, Nagle, & Webb, 2012), prostate
60 (Cao & Giovannucci, 2016) and endometrial cancer survivors (Secord et al., 2016) in
61 comparison to non-obese cancer survivors.

62 Improving the quality of nutritional care provided to people with cancer requires gaining a better
63 understanding of their needs and identifying ways to offer solutions to these needs. To date,
64 there has been no review of the literature regarding information and support needs in relation to
65 diet and nutrition in cancer patients. In line with the National Health Service initiative towards a
66 patient-centred and personalised approach in relation to management and support after a
67 cancer diagnosis (Independent Cancer Taskforce, 2015), this review focussed on cancers in
68 receipt of pelvic radiotherapy.

69 This review aims to provide answers to the following questions:

- 70 • What dietary information do patients with a pelvic cancer receive in relation to their
71 diagnosis?

- 72 • What are pelvic cancer patients' perceived information and support needs regarding diet
- 73 and nutrition?
- 74 • Are there differences in information and support needs in different survivorship stages
- 75 (during treatment and post-treatment)?

76 **2. Methods**

77 This systematic review was conducted according to the Preferred Reporting Items for
78 Systematic Reviews and Meta-Analysis (PRISMA) guidelines. The review protocol has been
79 registered at the International Prospective Register of Systematic Reviews (PROSPERO
80 CRD42018115832).

81

82 **2.1. Search strategy**

83 Six databases (MEDLINE, EMBASE, CINAHL, Web of Science, Allied and Complementary
84 Medicine, PsycINFO) were searched in February 2019. There were no restrictions in publication
85 date. The keywords and search strategy (Web of Science) are outlined in Online Resource 1.
86 Subject headings were used, where applicable. Initial database searches revealed a number of
87 studies published in specific journals: Supportive Care in Cancer; Journal of Cancer
88 Survivorship; and European Journal of Cancer Care. In addition to the search of databases, all
89 volumes and issues of these journals were searched from 2000 to February 2019 using the
90 words “diet and cancer” or “nutrition and cancer”. Finally, reference lists of two scoping (Fletcher
91 et al., 2017; van Mossel et al., 2012) and two systematic reviews (Kotronoulas et al., 2017; Puts
92 et al., 2012) of unmet needs of cancer patients were also thoroughly searched for relevant
93 publications.

94

95 **2.2. Eligibility criteria**

96 Studies were considered for inclusion if:

- 97 • They investigated supportive care needs or information needs in relation to diet and
98 nutrition of people diagnosed with a cancer in the pelvic area, irrespective of disease
99 stage or time-point after diagnosis. It was decided to focus on the diagnosis, rather than
100 treatment only, as treatment may not be reported in studies.
- 101 • The study design was cross-sectional, prospective, retrospective, a randomised trial or
102 qualitative. All quantitative and qualitative research designs were considered as the aim
103 was to provide a complete picture, deduce maximum information and get a better
104 understanding of the phenomenon (Hong, Pluye, Bujold, & Wassef, 2017).
- 105 • They were conducted with adult individuals (i.e. aged ≥ 18 years)
- 106 • They were original research published in peer reviewed journals
- 107 • They were published in English (a translation service was not possible)

108 Studies were excluded if:

- 109 • They did not highlight diet and nutrition support needs of the target population
- 110 • They were an audit of a current hospital service, editorials, case studies, reviews,
111 opinion papers or conference proceedings.
- 112 • The sample was a mix of pelvic and other cancer diagnoses except when separate sub-
113 groups analyses were reported for pelvic cancers.
- 114 • Patients were in receipt of palliative care for advanced cancer.
- 115

116 **2.3. Study selection**

117 The studies were selected in two stages. First, a title and abstract screening was performed by
118 GS for all identified studies. A randomly selected subsample (10%) of the studies was also
119 screened by EW, HL or SC to ensure consistency. After title and abstract exclusion, all

120 remaining studies were considered for full-text review. Eligibility criteria were applied to full-text
121 articles by GS. In case of uncertainty or any disagreements, discussions took place among all
122 authors until a mutual decision was reached.

123

124 **2.4. Data extraction and synthesis**

125 Relevant features and results were extracted for each included study. Data were extracted by
126 one researcher (GS) and were confirmed by EW, HL or SC (Table 1). Location of study, study
127 design, study duration, aim(s), inclusion criteria, sample size, percentage of women in sample,
128 mean/median age and age range of participants, response rate and sample cancer diagnosis
129 were extracted, where possible, for all included studies.

130 In this review, a narrative synthesis informed by Popay et al. (Popay et al., 2006) was used to
131 present the findings. Narrative synthesis relies on the use of words and text to summarise and
132 explain the findings of the synthesis and is the preferred method of synthesis for results deriving
133 from studies with a diverse design (Popay et al., 2006). Studies in the data extraction table
134 (Table 1) have been grouped according to the research design and cancer diagnosis. Thematic
135 analysis was performed to develop preliminary synthesis of results and identify common themes
136 and concepts related to diet and nutrition information and support needs (Popay et al., 2006).
137 Thematic analysis was conducted according to Braun and Clarke (Braun & Clarke, 2006) which
138 involves six steps: familiarisation with the data; coding; searching for themes; reviewing the
139 themes; defining and naming the themes; and producing the report.

140

141 **2.5. Quality assessment**

142 For the assessment of cross-sectional studies, the Appraisal Tool for Cross-Sectional studies
143 (AXIS) was used (Downes, Brennan, Williams, & Dean, 2016). This comprises 20 questions,
144 seven of which relate to the quality of reporting, seven to study design and six to study biases.
145 For the assessment of qualitative studies, a previously adapted appraisal tool for qualitative
146 studies (Cesario, Morin, & Santa-Donato, 2002; Hannes, 2011) was used. The tool comprises
147 five categories: descriptive vividness (credibility); methodological congruence (dependability and
148 confirmability); analytical preciseness; theoretical connectedness (transferability); and heuristic
149 relevance (Collaco et al., 2018). A score range of 1-24 was given to each qualitative study
150 based on the scores for each of the five categories. The quality of a study was considered good
151 for a score of 18-24 (75-100% of the total criteria met), fair for a score of 12-17 (50-74% of the
152 total criteria met) and poor for a score lower than 12 (less than 50% of the total criteria met).
153 The quantitative and qualitative arm of the mixed-methods studies was assessed separately.

154 **3. Results**

155 The initial search yielded 4,529 results. After removal of duplicates (1,407), 3,048 articles were
156 excluded following review of title and abstract and a further 44 were excluded after full-text read.
157 Thirty articles are included in this review (Figure 1).

158

159 **3.1. Characteristics of selected studies**

160 Of the 30 included studies, eleven studies were conducted in the UK (Anderson, Steele, &
161 Coyle, 2013; Avery et al., 2014; Beaver et al., 2010; Beaver et al., 2011; Brown, Greenfield, &
162 Thompson, 2016; Er et al., 2017; Evans et al., 2007; Kassianos, Coyle, & Raats, 2015;
163 Koutoukidis, Beeken, Lopes, Knobf, & Lanceley, 2017; Rozmovits, Rose & Ziebland, 2004;
164 Sutton et al., 2017), five in the USA (Clark et al., 2016; Demark-Wahnefried, Peterson, McBride,
165 Lipkus, & Clipp, 2000; des Bordes et al., 2016; Tseng et al., 2015; Zaleta, Neff, McCann,
166 O'Malley, & Carpenter, 2017), four in Australia (Dunn et al., 2006; Hardcastle, Glassey,
167 Salfinger, Tan, & Cohen, 2017; Hardcastle, Maxwell-Smith, Hagger, O'Connor, & Platell, 2018;
168 Nikoletti et al., 2008), two in Canada (Fitch, Gray, & Franssen, 2000; Fitch, Gray, & Franssen,
169 2001), two in New Zealand (Cha et al., 2012; Pullar, Chisholm, & Jackson, 2012), two in South
170 Korea (Jang, Kim, Kim, & Lee, 2019; Lee, Shin, Bae, & Lim, 2016) and one each in Israel (Perl
171 et al., 2016), the Netherlands (Hoedjes et al., 2017), Sweden (Samuelsson et al., 2018) and
172 Malaysia (Lee et al., 2017). Twelve studies employed a quantitative design (Beaver et al., 2011;
173 Cha et al., 2012; Clark et al., 2016; Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp,
174 2000; Fitch, Gray, & Franssen et al., 2000; Fitch, Gray, & Franssen, 2001; Lee, Shin, Bae, &
175 Lim, 2016; Nikoletti et al., 2008; Perl et al., 2016; Pullar, Chisholm, & Jackson, 2012; Tseng et
176 al., 2015; Zaleta, Neff, McCann, O'Malley, & Carpenter, 2017), fifteen were qualitative
177 (Anderson, Steele & Coyle, 2013; Avery et al., 2014; Beaver et al., 2010; Brown, Greenfield &

178 Thompson, 2016; Dunn et al., 2006; Er et al., 2017; Evans et al., 2007; Hardcastle, Glassey,
179 Salfinger, Tan, & Cohen, 2017; Hardcastle, Maxwell-Smith, Hagger, O'Connor, & Platell, 2018;
180 Kassianos, Coyle & Raats, 2015; Koutoukidis, Beeken, Lopes, Knobf & Lanceley, 2017; Lee et
181 al., 2017; Rozmovits, Rose & Ziebland, 2004; Samuelsson et al., 2018; Sutton et al., 2017) and
182 three were mixed-methods studies (des Bordes et al., 2016; Hoedjes et al., 2017; Jang, Kim,
183 Kim & Lee, 2019). Sample size varied according to research design, with the range being 8-58
184 participants in qualitative studies and 20-1198 participants in quantitative studies. Twelve
185 studies (40%) were conducted on colorectal cancer patients (Anderson, Steele & Coyle, 2013,
186 Beaver et al., 2010; Beaver et al., 2011; Brown, Greenfield & Thompson, 2016; Rozmovits,
187 Rose & Ziebland, 2004; Dunn et al., 2006; Hardcastle, Maxwell-Smith, Hagger, O'Connor &
188 Platell, 2018; Nikoletti et al., 2008; Cha et al., 2012; Pullar, Chisholm & Jackson, 2012; Hoedjes
189 et al. 2017; Samuelsson et al., 2018), nine studies (30%) on gynaecological cancer patients
190 (Clark et al., 2016; Fitch, Gray & Franssen, 2000; Fitch, Gray & Franssen, 2001; Hardcastle,
191 Glassey, Salfinger, Tan & Cohen, 2017; Jang, Kim, Kim & Lee, 2019; Koutoukidis, Beeken,
192 Lopes, Knobf & Lanceley, 2017; Lee, Shin, Bae & Lim, 2016; Tseng et al., 2015; Zaleta, Neff,
193 McCann, O'Malley & Carpenter, 2017), five studies (17%) on prostate cancer patients (Avery et
194 al., 2014; Er et al., 2017; Kassianos, Coyle & Raats, 2015; Lee et al., 2017; Sutton et al., 2017)
195 and four studies (13%) had a sample with mixed cancer diagnoses (Demark-Wahnefried,
196 Peterson, McBride, Lipkus, & Clipp, 2000; Des Bordes et a., 2016; Evans et al., 2007; Perl et
197 al., 2016). All studies were published after the year 2000 and most (80%) after 2010. Table 1
198 shows the characteristics of the included studies, which have been grouped according to the
199 research design (qualitative, quantitative) and cancer diagnosis (prostate, colorectal,
200 gynaecological cancer).

201 Table 2 describes the main findings reported across the papers in relation to diet and nutrition
202 information needs, the tool(s) used to collect data and the related themes from the thematic

203 analysis. Ten cross-sectional studies, including one mixed-methods study, used non-validated
204 questionnaires developed by the study authors (Cha et al., 2012; Clark et al., 2016; Demark-
205 Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000; Fitch, Gray & Franssen, 2000; Fitch,
206 Gray & Franssen, 2001; Hoedjes et al., 2017; Lee, Shin, Bae & Lim, 2016; Nikoletti et al., 2008;
207 Pullar, Chisholm & Jackson, 2012; Tseng et al., 2015). Three studies, including one mixed
208 methods, used validated tools for one or more of their research questions (Jang, Kim, Kim &
209 Lee, 2019; Perl et al., 2016; Zaleta, Neff, McCann, O'Malley & Carpenter, 2017) and two
210 (including one mixed-methods study) used adapted validated questionnaires (Beaver et al.,
211 2011; Des Bordes et al., 2016). Twelve qualitative studies (including two mixed-methods)
212 conducted interviews (Beaver et al., 2010; Brown, Greenfield & Thompson, 2016; Des Bordes et
213 al., 2016; Er et al., 2017; Evans et al., 2007; Hardcastle, Glassey, Salfinger, Tan & Cohen,
214 2017; Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Jang, Kim, Kim & Lee,
215 2019; Kassianos, Coyle & Raats, 2015; Rozmovits, Rose & Ziebland, 2004; Samuelsson et al.,
216 2018; Sutton et al., 2017), two (including one mixed-methods) conducted focus groups
217 (Anderson, Steele & Coyle, 2013; Hoedjes et al., 2017) and four used a combination of
218 interviews and focus groups (Avery et al., 2014; Dunn et al., 2006; Koutoukidis, Beeken, Lopes,
219 Knobf & Lanceley, 2017; Lee et al., 2017). Four main themes were identified: "content of dietary
220 information"; "views on the role of diet in survivorship", "sustaining dietary change"; and
221 "sources of information".

222 All studies included participants that had completed treatment and seven of these, all qualitative
223 studies, also included patients undergoing treatment at the time of the study (Avery et al., 2014;
224 Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000; Er et al., 2017; Evans et al.,
225 2007; Kassianos, Coyle & Raats, 2015; Pullar, Chisholm & Jackson, 2012; Sutton et al., 2017).
226 The studies that include participants in different treatment stages did not present results
227 according to treatment status, so it was not possible to identify any sub-themes related to

228 differences in information and support needs according to treatment status. The four themes
229 provided insights in relation to the first two research questions: “What information do pelvic
230 cancer patients receive in relation to their diagnosis?” and “What are their information and
231 support needs?”.

232

233 **3.2. Theme 1: Content of dietary information**

234 A total of 27 studies discussed patients’ receipt of information on diet and nutrition. Quantitative
235 studies presented mixed results; in six studies, more than half of participants reported receiving
236 dietary advice (Beaver et al., 2011; Clark et al., 2016; Fitch, Gray & Franssen, 2000; Fitch, Gray
237 & Franssen, 2001; Nikoletti et al., 2008; Tseng et al., 2015) but the content of the advice was
238 not specified. Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp (2000) reported that
239 29% of prostate and breast cancer survivors were advised to follow a low-fat diet and only 16%
240 to increase their fruit and vegetables intake to 5 portions daily. Similarly, in the Pullar et al. study
241 (2012), 33% of participants received dietary advice in relation to their cancer and in the Zaleta,
242 Neff, McCann, O’Malley & Carpenter study (2017), 14% of the sample got advice regarding
243 weight management. In four studies, three of which asked for receipt of unspecified dietary
244 advice, levels of satisfaction with received information were available (53-88%) (Beaver et al.,
245 2011; Fitch, Gray & Franssen, 2000; Fitch, Gray & Franssen, 2001; Tseng et al., 2015). In
246 Tseng et al. (2015), when asked about the effectiveness of weight management counselling,
247 88% of gynaecological cancer survivors were achieving or were highly motivated to make
248 lifestyle changes.

249 Eighteen studies, with a qualitative or mixed-methods design, highlighted diet and nutrition
250 counselling as an unmet need (Anderson, Steele & Coyle, 2013; Avery et al., 2014; Beaver et
251 al., 2010; Brown, Greenfield & Thompson, 2016; Cha et al., 2012; Des Bordes et al., 2016;

252 Dunn et al., 2006; Er et al., 2017; Evans et al., 2007; Hardcastle, Glassey, Salfinger, Tan &
253 Cohen, 2017; Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Hoedjes et al.,
254 2017; Jang, Kim, Kim & Lee, 2019; Kassianos, Coyle & Raats, 2015; Koutoukidis, Beeken,
255 Lopes, Knobf & Lanceley, 2017; Lee et al., 2017; Rozmovits, Rose & Ziebland, 2004;
256 Samuelsson et al., 2018; Sutton et al., 2017. Participants reported receipt of vague and often
257 contradictory advice in six studies (Anderson, Steele & Coyle, 2013; Er et al., 2017; Hardcastle,
258 Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Kassianos, Coyle & Raats, 2015;
259 Koutoukidis, Beeken, Lopes, Knobf & Lanceley, 2017; Lee et al., 2017). Patients also reported
260 being advised or following themselves a "trial and error" approach, particularly in relation to diet
261 adaptation to altered bowel habits (Anderson, Steele & Coyle, 2013; Beaver et al., 2010;
262 Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018), which was perceived as
263 "unhelpful" (Anderson, Steele & Coyle, 2013). In Avery et al.'s study (2014), lack of reliable
264 information was considered to be a barrier to dietary change for prostate cancer patients. It was
265 highlighted across studies that patients look for simple, clear messages (Anderson, Steele &
266 Coyle, 2013; Avery et al., 2014; Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018;
267 Hoedjes et al., 2017; Rozmovits, Rose and Ziebland, 2004) and reliable, evidence-based
268 information (Avery et al., 2014; Kassianos, Coyle & Raats, 2015; Koutoukidis, Beeken, Lopes,
269 Knobf & Lanceley, 2017; Sutton et al., 2017) which could influence dietary change. Also,
270 tailored advice was expected and should be provided (Anderson, Steele & Coyle, 2013; Avery
271 et al., 2014; Beaver et al., 2010; Brown, Greenfield & Thompson, 2016; Evans et al., 2007;
272 Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Hoedjes et al., 2017; Kassianos,
273 Coyle & Raats, 2015; Koutoukidis, Beeken, Lopes, Knobf & Lanceley, 2017; Lee et al., 2017;
274 Samuelsson et al., 2018; Sutton et al., 2017). Hoedjes et al. (2017) reported that not only
275 content, but also format, intensity and timing of counselling should be individualised.

276 Patients frequently asked about dietary support in relation to physical symptoms, such as
277 management of bowel problems and weight changes. Queries about management of bowel
278 problems were reported in ten studies with colorectal cancer patients (Anderson, Steele &
279 Coyle, 2013; Beaver et al., 2010; Brown, Greenfield & Thompson, 2016; Dunn et al., 2006;
280 Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Hoedjes et al., 2017; Nikoletti et
281 al., 2008; Pullar, Chisholm & Jackson, 2012; Rozmovits, Rose & Ziebland, 2004; Samuelsson et
282 al., 2018) and two studies with gynaecological cancer patients (Koutoukidis, Beeken, Lopes,
283 Knobf & Lanceley, 2017; Lee, Shin, Bae & Lim, 2016). In particular, patients expressed
284 concerns on which specific diet would be appropriate after removal of part of the bowel (Beaver
285 et al., 2010; Rozmovits, Rose & Ziebland, 2004). In the Rozmovits, Rose & Ziebland study
286 (2004), patients reported difficulties adjusting their dietary habits to the altered bowel function
287 but could not find the information they wanted. Anderson et al. (2013) reported that patients
288 sought practical dietary advice on which foods to avoid for controlling diarrhoea and flatulence,
289 which affected them on a daily basis. According to two studies, dietary support was more
290 frequently provided to colorectal cancer patients with a stoma, in comparison to those who did
291 not have a stoma (Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Rozmovits,
292 Rose & Ziebland, 2004). Regarding weight changes, Anderson et al. (2013) showed that
293 colorectal cancer patients experience both weight loss and weight gain during their treatment
294 and attribute these changes to a lack of guidance. In Samuelsson et al. study (2018), older
295 patients lost weight during treatment and were experiencing difficulties regaining weight; yet few
296 of them reported dietetic support. In two studies of gynaecological cancer survivors, most
297 participants (85 and 90%) were largely receptive to weight management counselling, which
298 would reinforce the importance of attempting weight loss (Tseng et al., 2015; Zaleta, Neff,
299 McCann, O'Malley & Carpenter, 2017).

300 Apart from dietary information in relation to physical symptoms, a number of other education
301 needs were highlighted across several studies. Patients requested advice in relation to recipes
302 (Des Bordes et al., 2016; Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018; Lee,
303 Shin, Bae & Lim, 2016), shopping practices (Des Bordes et al., 2016), classification of foods
304 (Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018), portion sizes (Hardcastle,
305 Maxwell-Smith, Hagger, O'Connor & Platell, 2018), energy intake (Hardcastle, Maxwell-Smith,
306 Hagger, O'Connor & Platell, 2018), food labels (Hardcastle, Maxwell-Smith, Hagger, O'Connor
307 & Platell, 2018), supplements (Evans et al., 2007; Des Bordes et al., 2016; Hoedjes et al.,
308 2017), general healthy eating (Anderson, Steele & Coyle, 2013; Hardcastle, Glassey, Salfinger,
309 Tan & Cohen, 2017) and healthy lifestyle (Koutoukidis, Beeken, Lopes, Knobf & Lanceley,
310 2017).

311

312 **3.3. Theme 2: Views on the role of diet post-treatment**

313 Implementation of dietary changes following counselling was viewed as returning control and
314 allowing patients "to do something after diagnosis" or as adjunct therapy by some studies in
315 prostate and colorectal patients (Anderson, Steele & Coyle, 2013; Avery et al., 2014; Kassianos,
316 Coyle & Raats, 2015). Three studies also highlighted the need for a holistic package of
317 survivorship care, including diet alongside physical activity, and mental, sexual and
318 psychological wellbeing (Anderson, Steele & Coyle, 2013; Evans et al., 2007; Koutoukidis,
319 Beeken, Lopes, Knobf & Lanceley, 2017).

320 Although dietary support is valued as an important topic of discussion with health professionals
321 across most included studies, a few qualitative studies conducted with prostate and colorectal
322 cancer patients showed that diet was not always perceived as an important aspect of
323 survivorship, particularly after curative surgery (Anderson, Steele & Coyle, 2013; Avery et al.,

324 2014; Er et al., 2017; Kassianos, Coyle & Raats, 2015; Sutton et al., 2017). Anderson et al.
325 (2013) also reported that some colorectal cancer survivors did not believe that a healthy diet
326 would reduce the risk of recurrence, since it had not prevented its development. In another
327 study, prostate cancer patients who underwent radical treatment were less likely to consider
328 dietary changes than those on active surveillance (Avery et al., 2014). In the Er et al. pilot study
329 of assessing prostate cancer survivors' interest in a dietary intervention program (2017),
330 participants perceived their current diet to be healthy and questioned which further changes
331 could be made to improve it.

332

333 **3.4. Theme 3: Sustaining dietary change**

334 Several studies reported lack of dietary counselling during follow up (Hardcastle, Glassey,
335 Salfinger, Tan & Cohen, 2017; Hardcastle, Maxwell-Smith, Hagger, O'Connor & Platell, 2018;
336 Koutoukidis, Beeken, Lopes, Knobf & Lanceley, 2017; Samuelsson et al., 2018) and highlighted
337 the need for regular ongoing monitoring as a means of sustaining healthy behaviours, including
338 dietary changes and weight management (Hardcastle, Glassey, Salfinger, Tan & Cohen, 2017;
339 Hoedjes et al., 2017; Kassianos, Coyle & Raats, 2015; Samuelsson et al., 2018; Zaleta, Neff,
340 McCann, O'Malley & Carpenter, 2017). In two quantitative studies participants reported
341 receiving dietary counselling in more than one clinic visit, 25% in Tseng et al. (2015) and 6% in
342 Zaleta, Neff, McCann, O'Malley & Carpenter (2017).

343 Also, patients expressed an interest in having their current dietary habits assessed and
344 receiving feedback on what could improve in their diets (Hoedjes et al., 2017; Kassianos, Coyle
345 & Raats, 2015; Sutton et al., 2017). Patients perceived health professionals to have an
346 important role in engaging them in regular conversations that could help them sustain healthy
347 dietary habits (Hardcastle, Glassey, Salfinger, Tan & Cohen, 2017; Zaleta, Neff, McCann,

348 O'Malley & Carpenter, 2017). In a study conducted in endometrial cancer survivors, participants
349 expressed a need for accountability and external support to commit to lifestyle behaviour
350 change (Hardcastle, Glassey, Salfinger, Tan & Cohen, 2017). On the other hand, one study
351 showed that self-management was another important aspect of keeping a healthy diet (Hoedjes
352 et al., 2017).

353

354 **3.5. Theme 4: Sources of information**

355 Eleven qualitative studies and three quantitative studies provided data about sources of support.
356 Where information and support were provided, this was primarily done by health professionals,
357 such as oncologists (Avery et al., 2014; Clark et al., 2016; Er et al., 2017; Hardcastle, Maxwell-
358 Smith, Hagger, O' Connor & Platell, 2018; Lee et al., 2017; Tseng et al., 2015), specialist nurses
359 (Beaver et al., 2010; Rozmovits, Rose & Ziebland, 2004), dietitians (Hardcastle, Maxwell-Smith,
360 Hagger, O' Connor & Platell, 2018; Kassianos, Coyle & Raats, 2015; Pullar, Chisholm &
361 Jackson, 2012; Samuelsson et al., 2018) and Primary Care Practitioners (PCP) (Anderson,
362 Steele & Coyle, 2013; Clark et al., 2016; Tseng et al., 2015), followed by family members (Avery
363 et al., 2014), friends (Pullar, Chisholm & Jackson, 2012) the internet (Kassianos, Coyle & Raats,
364 2015; Koutoukidis, Beeken, Lopes, Knobf & Lanceley), 2017, the media (Avery et al., 2014) and
365 support groups (Sutton et al., 2017). In five of these studies, the mode of delivery is mentioned;
366 face-to face (Hardcastle, Maxwell-Smith, Hagger, O' Connor & Platell, 2018; Kassianos, Coyle
367 & Raats, 2015) telephone (Samuelsson et al., 2018), or leaflets (Beaver et al., 2010; Hardcastle,
368 Maxwell-Smith, Hagger, O' Connor & Platell, 2018; Sutton et al., 2017).

369 In quantitative studies, more information was available. Clark et al. (2016) reported that 52% of
370 gynaecological cancer patients were counselled a PCP and 38% by a Gynae-oncologist to lose
371 weight. Tseng et al. (2015) reported lower numbers of gynaecological cancer patients receiving

372 such advice (33%). In Pullar, Chisholm & Raats (2012) study of colorectal cancer survivors,
373 15% received advice from friends and 15% from dietitian. It was unclear in these studies
374 whether support was face-to-face or booklets.

375 Healthcare professionals were considered the most reliable sources of information (Avery et al.,
376 2014; Brown, Greenfield and Thompson, 2016; Clark et al., 2016; Er et al., 2017; Hardcastle,
377 Glassey, Salfinger, Tan & Cohen, 2017; Hoedjes et al., 2017; Koutoukidis, Beeken, Lopes,
378 Knobf & Lanceley, 2017; Sutton et al., 2017); however, in some studies patients noted that
379 health professionals were lacking adequate knowledge in this topic (Kassianos, Coyle & Raats,
380 2015; Koutoukidis, Beeken, Lopes, Knobf & Lanceley, 2017; Rozmovits, Rose & Ziebland,
381 2004) or were uncertain about the role of diet in survivorship (Er et al., 2017). It was not
382 possible to compare experiences of information and support according to different healthcare
383 disciplines (e.g. oncologist Vs dietitian) due to insufficient information from the included studies.

384

385 **3.6. Quality of the included studies**

386 The results of the quality assessment of the included studies are presented in Online Resource
387 2. Quality of reporting and quality of study design were generally high across the quantitative
388 (cross-sectional) studies. Aims, population, recruitment settings and basic data were presented
389 clearly and study design was appropriate in all quantitative studies. Most studies provided
390 adequate information regarding statistical analysis, conflicts of interest, ethical approval and
391 study limitations; however, no studies justified sample size and only three described the
392 characteristics of non-respondents. Non-response bias may have occurred in 13 studies
393 (including all mixed-methods). Most studies used non-validated questionnaires. Results were
394 internally inconsistent in four studies.

395 Quality was overall characterised as “fair” (score 12-17) in nine qualitative and three mixed-
396 methods studies and “good” (18-24) in seven qualitative studies. No studies scored lower than
397 12 points and no studies achieved the maximum score of 24. All studies provided an adequate
398 description of the methods and ethical procedures and most referred to policy and research
399 recommendations. All studies had enough information to ensure transferability (fair or good
400 scores) and most of them to ensure confirmability. On the other hand, several studies scored
401 “poor” on assessment of credibility and dependability.

402 **4. Discussion**

403 This review collected evidence on information and support needs in relation to diet and nutrition
404 after a pelvic cancer diagnosis. To our knowledge, this is the first systematic review to focus on
405 patients' support needs in diet and nutrition after a cancer diagnosis. The review has highlighted
406 that diet and nutrition is a topic of interest and importance to many cancer survivors, yet findings
407 suggest that information and support in this area is not routinely provided to patients. Also, in
408 some studies, participants questioned the importance of diet following (curative) therapy in
409 preventing recurrence. The somewhat contrasting findings regarding provision of information
410 and support derived from studies of different research design, but most of them highlighted diet
411 and nutrition as an unmet need in survivorship.

412 The information and support that patients would like (future wellbeing, management of
413 gastrointestinal side effects and weight changes) varied across cancer diagnoses, with advice in
414 relation to the management of bowel symptoms being sought mostly from colorectal cancer
415 survivors. Although radiotherapy is a common treatment for pelvic tumours, each pelvic cancer
416 may be treated with combinations of different treatments; hence bowel problems may be a more
417 serious problem for colorectal cancer patients in comparison to prostate cancer patients. People
418 diagnosed with prostate cancer often follow additional hormone therapy, which may lead to
419 muscle wasting, fat accumulation and weight gain (Cleeland et al., 2012). On the contrary,
420 receipt of chemotherapy is common in rectal and gynaecological cancers, and is linked with loss
421 of appetite, weight loss and increased risk for malnutrition (Cleeland et al., 2012). Irrespective of
422 the treatment regimens, patients diagnosed with pelvic cancers face side effects which affect
423 nutritional status and body weight.

424 Patients sought evidence-based information that would prompt them to change their current
425 dietary behaviours and improve their quality of life (Theme 1). According to a recent Cochrane

426 review, dietary interventions may help survivors improve Quality of Life and lead a healthier
427 lifestyle (Burden et al., 2019); however, this review highlighted the lack of comprehensive
428 research in this area. Concerns about the lack of consistent evidence about the role of diet or
429 weight loss in outcomes following a cancer diagnosis were also expressed (Theme 2). This lack
430 of evidence may, in part, account for the reported lack of information provision or provision of
431 generic advice about a healthy diet. To date, dietary recommendations for cancer survivors that
432 have been developed by the World Cancer Research Fund (WCRF) (World Cancer Research
433 Fund/American Institute for Cancer Research, 2018) and the European Society for Parenteral
434 and Enteral Nutrition (ESPEN) (Arends et al., 2017) are based on limited evidence. Also, to
435 date, no recommendations tailored to a specific cancer diagnosis have been published. Lack of
436 strong evidence further contributes to the differing views about the role of diet in the
437 survivorship phase for patients (Theme 2) and the “trial and error” approach sometimes
438 recommended by health professionals or used by patients independently (Themes 1 & 4). Coa
439 et al. (2014) also note that healthcare providers also hold varied beliefs about lifestyle changes
440 in the survivorship phase because of the lack of evidence base and therefore are hesitant in
441 engaging in conversations about diet. On the contrary, nutritional support in malnutrition has
442 been found to be “*crucial*” in treatment outcomes among oncologists in a recent survey in Italy
443 (Caccialanza et al., 2020). Irrespective of their beliefs, health professionals are perceived by
444 patients as the most suitable sources to provide dietary support. In some of the included studies
445 there was patient dissatisfaction with health professional’s knowledge or attitude towards diet
446 and nutrition, indicating that health professionals may not be adequately trained on nutritional
447 care of cancer patients (Dempsey, Findlay, & MacDonald-Wicks, 2011; Koutoukidis, Lopes, et
448 al., 2017).

449 Another important finding in this review was the perception from patients that they should have
450 their dietary behaviour and weight monitored on a regular basis in order to sustain dietary

451 changes (Theme 3). A recent systematic review and meta-analysis showed that supervision and
452 social support improved adherence to a weight loss program in overweight and obese
453 populations (Lemstra, Bird, Nwankwo, Rogers, & Moraros, 2016). A qualitative study in breast
454 cancer survivors who followed a 12-month weight loss program showed that regular monitoring
455 by dietitians was viewed as a facilitator for sustaining healthy behaviours (Terranova, Lawler,
456 Spathonis, Eakin, & Reeves, 2017). This is an important point for future interventions evaluating
457 nutritional education and weight loss in pelvic cancer survivors. It should, however, be noted
458 that regular monitoring may have feasibility and cost implications which need to be taken into
459 consideration.

460 There was a considerable difference in the amount and type of information extracted from the
461 qualitative and quantitative studies included in this review. Qualitative studies examined issues
462 and concerns around diet and nutrition in more depth and contributed more information to this
463 narrative synthesis compared to quantitative studies. Therefore, it is possible that qualitative
464 design features, such as sampling procedures (purposive sampling) and researcher bias in data
465 collection and interpretation may have influenced the findings. Also, some studies focussed
466 exclusively on diet and nutrition issues whereas some assessed follow-up care needs in
467 general. Consequently, available data extracted from follow-up care studies was limited and, in
468 some quantitative studies, in a form of statement about receipt of dietary information (Beaver et
469 al., 2011; Demark-Wahnefried, Peterson, McBride, Lipkus & Clipp, 2000; Nikoletti et al., 2008),
470 importance of receiving dietary information (Fitch, Gray & Franssen, 2000; Fitch, Gray &
471 Franssen, 2001; Nikoletti et al., 2008) or need for receiving more dietary information in relation
472 to cancer (Cha et al., 2012; Jang, Kim, Kim & Lee, 2019; Perl et al., 2016). Although limited, the
473 data could clearly be extracted and therefore the studies were eligible for inclusion in this
474 review. Due to the large heterogeneity of the studies, it was decided that a narrative synthesis
475 was the best approach of presenting the results in this review.

476 It was not possible to extract any information from the included studies about dietary support
477 needs for patients currently undergoing treatment. Studies in breast cancer patients have shown
478 that information needs may vary according to the survivorship stage. A study by Halbach et al.
479 (2016) showed that breast cancer respondents were more interested in information about
480 nutrition shortly after surgery compared to 40 weeks later. Overall, health promotion needs were
481 increased during or shortly after treatment and decreased over time (Halbach et al., 2016).
482 Future prospective, observational studies could provide more robust evidence on cancer
483 survivors' unmet needs in diet and nutrition, the findings of which could feed in to the
484 development of supportive interventions to improve patients quality of life and wellbeing.

485

486 **4.1. Strengths and limitations**

487 This review has a number of strengths and limitations. A comprehensive systematic search of
488 the literature was conducted according to the PRISMA guidelines. Searching was performed
489 across six big databases, eligibility criteria were applied and the quality of all included studies
490 was assessed. Any unclear abstracts were included for full-text review. Findings were
491 synthesised using narrative synthesis, which is an effective way of combining results from
492 quantitative and qualitative studies (Popay et al., 2006). Synthesis of findings was conducted in
493 an unbiased manner, although it is acknowledged that thematic analysis may induce
494 personal/researcher bias.

495 It should be acknowledged that this review includes cancer diagnoses that share common
496 characteristics (e.g. obesity rates, pelvic radiotherapy) but can also vary considerably. Findings
497 are also limited by the scientific quality of the papers. Quality appraisal showed that cross-
498 sectional studies presented high potential for selection and non-response bias. Furthermore, in
499 most of these studies, the measurement tools were developed by the authors and no

500 information on validity and reliability of these tools was reported. Similarly, most qualitative
501 studies failed to provide adequate evidence of credibility and dependability. Data from qualitative
502 studies contributed considerably more to the narrative synthesis compared to the included
503 quantitative studies.

504 The search was not exhaustive, as it was limited in large databases and grey literature was not
505 explored. The search was also limited to English language publications only due to lack of
506 translation options; however, initial screening did not reveal any non-English publications.

507

508 **5. Conclusion**

509 This review has highlighted the need for provision of information and support in diet and
510 nutrition after a pelvic cancer diagnosis. Patients sought evidence-based, clear information on
511 how to improve their future wellbeing and manage physical symptoms arising from their
512 diagnosis and treatment. Future observational studies with stronger methodological designs are
513 warranted to provide robust answers to the questions regarding unmet needs in diet and
514 nutrition in survivorship and to inform the development of interventions. Future clinical practice
515 should take into account patients' needs for quality evidence and tailored advice with the aim of
516 sustaining healthy behaviours and overcoming disease problems in the long term. Stronger
517 evidence from prospective studies on the role of diet in outcomes related to cancer survivorship
518 is also needed, in order to support the quality of information and support provided to pelvic
519 cancer populations.

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753 **Table 1: Characteristics of the selected studies, grouped according to cancer diagnosis (colorectal, prostate, gynaecological) and study design**
 754 **(qualitative, cross sectional, mixed)**

| First author and country | Design & study duration | Aim of study | Sample, N, sex, age | Response rate | Inclusion criteria | Cancer type | Treatment |
|--------------------------|-------------------------|--|--|---------------|--|-------------------------|---|
| Anderson (UK) | Qualitative, NS | To explore patient needs for advice on diet, activity and lifestyle; patient beliefs about the role of diet, activity and lifestyle for reducing disease risk; and preferred formats, timings and routes of delivery for such guidance | N=40, 50.0% women; mean age (SD) 60 (12.2) years; range 27-84 | NS | Diagnosed with and treated for colorectal cancer and not undertaking active cancer treatment | Colorectal | NS |
| Beaver (UK) | Qualitative, NS | To explore patient perceptions of their experiences of follow-up care after treatment for colorectal cancer | N=27, 48.1% women; mean age 72 years; range 59-86 | NS | Patients diagnosed with colorectal cancer who completed active treatment and had no current clinical problems | Colorectal | Surgery (n=27), RT (n=4), CT (n=7) |
| Brown (UK) | Qualitative, 3 months | To explore awareness of long-term and late treatment consequences of colorectal cancer survivors when they are nearing discharge from oncology | N=19, 42.1% women; mean age 67.1 years; range 37-84 | NS | Participants with a colorectal cancer diagnosis, at least 12 months post treatment, over 18 years old, able to communicate in English and without a terminal diagnosis or dementia | Colorectal | Surgery (n=19), RT (n=5), CT (n=10) |
| Dunn (Australia) | Qualitative, NS | To examine quality of life and psychosocial variables most salient to colorectal cancer patients | N=20, 60% women; mean age and range not reported | 28% | Diagnosed with colorectal cancer within the past 18 months, under 80 years old, spoke English, and had no mental or intellectual impairment | Colorectal | NS |
| Evans (UK) | Qualitative, NS | To investigate why men choose to use Complementary and Alternative Medicine (CAM), and the extent to which CAM is used to fill 'gaps' in conventional care provision | Total sample N=34. Prostate cancer survivors: N=10; colorectal cancer survivors N=10; Mean age and range not reported for the subsamples | NS | Men with a cancer diagnosis and Complementary and Alternative Medicine (CAM) users | Prostate and colorectal | NS |
| Hardcastle (Australia) | Qualitative, 3 months | To explore colorectal cancer survivors' information and support needs in relation to health concerns and the promotion of healthy eating and physical activity | N=24, 45.8% women; mean age 69.4 years; range 63-77 | 19% | Colorectal cancer diagnosis within the past two years and presence of comorbidities which put them at high risk for cardiovascular disease | Colorectal | RT (n=3), CT (n=10), combination of RT and CT (n=3) |
| Rozmovits (UK) | Qualitative, 12 months | To describe current hospital follow-up policy and to explore patients' needs and preferences for follow-up | N=39; 48.7% women; mean age 60.1 years; range 33-87 | NS | People with a colorectal cancer diagnosis | Colorectal | Surgery (n=15), surgery plus RT and/or CT (n=21), CT only (n=3) |
| Samuelsson (Sweden) | Qualitative, NS | To describe older patients' experiences from diagnosis of colorectal cancer, to recovery and aftercare and evaluate how information provision was perceived by patients | N=16, 50% women, median age 82.5 years; range 76-89 years | 84% | People aged 75 years and above who had undergone elective CRC surgery with curative intent at least 3 months prior to the interview | Colorectal | Surgery (n=16), no information on adjuvant therapies |

| First author and country | Design & study duration | Aim of study | Sample, N, sex, age | Response rate | Inclusion criteria | Cancer type | Treatment |
|---------------------------|----------------------------------|---|--|--|--|-------------|---|
| Beaver (UK) | Cross sectional survey, NS | To explore patient satisfaction on different aspects of follow-up service provision following treatment for colorectal cancer | N=187, 43.3% women; mean age (SD) 72.8 (8.5) years; range 46-90 | 63% | Adults (>18 years) who had received resection with curative intent for either cancer of the colon or rectum | Colorectal | Surgery (n=145), RT (n=20), CT (n=43) |
| Cha (New Zealand) | Cross sectional survey, NS | To describe dietary intakes and dietary patterns of colorectal cancer patients in the Auckland region, and to investigate what the current information resources are, and patient satisfaction with these resources | N=29, 31% women; Age band most frequently selected 70+ years | 73% | Participants with a diagnosis of colorectal cancer who had received surgical resection (with curative intent) of their tumour in the last 1-4 months | Colorectal | Surgery (n=29), no information on RT or CT |
| Nikoletti (Australia) | Cross sectional survey, NS | To explore long-term information needs and self-care practices relating to bowel management after sphincter-saving colorectal surgery | N=101, 29.7% women; mean age 66.2 years; range 40-88 | 56-86% across different settings | Adults (>18 years of age), diagnosed with a colorectal cancer, undergoing sphincter-saving surgery in the past 6-24 months and able to speak and understand English | Colorectal | Surgery only (n=57), CT and surgery (n=43), RT and surgery (n=18) |
| Perl (Israel) | Cross sectional survey, NS | To characterize gastrointestinal cancer patients' specific physical and psychosocial needs and quality of life concerns | Total sample N=50. Colorectal cancer N=40, 50% women. Mean age and range not reported for the subsample | 94% | Young adults (18-40 years old) diagnosed with cancer of the GI tract (oesophagus, gastric, colon, rectum, anal) between 6 months and two years prior to enrolment; had a Karnofsky Performance Status of 80 or above or an Eastern Cooperative Oncology Group (ECOG) score of 0 or 1 | Colorectal | Information for subsample unavailable |
| Pullar (New Zealand) | Cross sectional survey, 2 months | To establish the dietary patterns of colorectal cancer patients, the level of dietary advice they currently received and its impact on their behaviour | N=40, 47.5% women; 70% were 60 years or older | NS | Adults (>18 years of age), diagnosed with colorectal cancer (stages II, III or IV), with sufficient literacy to comprehend the survey | Colorectal | Surgery only (n=5), CT only (n=3), surgery and CT (n=32) |
| Hoedjes (the Netherlands) | Mixed, NS | To explore needs and preferences for dietary support among colorectal cancer survivors | Survey: N=1198; 40.0% women; mean age (SD) 69.1 (9.5). Focus groups: N=16; 37.5% women; mean age and range not reported for the qualitative arm | Survey: 68%; focus groups: 27% | Survey: a colorectal cancer diagnosis between 2000-2009 and no cognitive impairments. Focus groups: at least one year after a colorectal cancer diagnosis and a Body Mass Index >27 kg/m ² | Colorectal | For survey sample only: surgery only (n=820), surgery and RT (n=419), surgery and CT (n=379), surgery and RT and CT (n=147) |
| Avery (UK) | Qualitative, 4 years | To explore views about diet and motivations for and barriers to dietary change in men at elevated risk and those diagnosed with PC | At elevated risk: N=21, all men; mean age 65.4 years; range 52.5-72.3. Diagnosed with cancer: N=37, all men; mean age 66.5 years; range 54.4-75.4) | 95% (58/61 in phase 1), 56% (5/9 in phase 2) | At elevated risk: prostate specific antigen (PSA) level of 2.0-2.9 ng/ml or ≥3.0 ng/ml with a negative biopsy. Diagnosed with cancer: diagnosis (PSA ≥3.0 ng/ml) and either treatment of prostate cancer, active monitoring or active surveillance | Prostate | Active surveillance (n=15), RT (n=12), surgery (n=9) |

| First author and country | Design & study duration | Aim of study | Sample, N, sex, age | Response rate | Inclusion criteria | Cancer type | Treatment |
|--------------------------|---------------------------------|--|---|---------------|--|-------------|-----------------------------------|
| Er (UK) | Qualitative, 12 months | To explore the facilitators and barriers to dietary and lifestyle changes and the acceptability of a dietary and physical activity intervention among African Caribbean prostate cancer survivors | N=14, all men; mean age 69.6 years; range 52-80. | NS | Men aged 18 and above who self-identified as African Caribbean and had a clinically confirmed prostate cancer diagnosis | Prostate | RT/HT (n=9), surgery (n=3) |
| Kassianos (UK) | Qualitative, NS | To identify factors that are believed to be associated with changes in diet following diagnosis | N=8, all men; mean age 64.9 years; range 55-76 | NS | A prostate cancer diagnosis and resident in the UK | Prostate | RT (n=4), surgery (n=2), NS (n=2) |
| Lee (2017). (Malaysia) | Qualitative, 3 months | To explore the post-treatment impact and related needs of prostate cancer survivors in Malaysia | N=24, all men; mean age not reported, range 58-79 years | NS | Diagnosis of prostate cancer | Prostate | NS |
| Sutton (UK) | Qualitative, 6 months | To explore the opinions about, and experiences of men with prostate cancer, and their partners on the provision of dietary and physical activity advice following diagnosis of, and treatment for, prostate cancer | N=16, all men; age range 53-79 years | NS | Men diagnosed with prostate cancer, who had recently undergone radical prostatectomy or were undergoing radiotherapy for localised prostate cancer | Prostate | Surgery (n=12), RT (n=4) |
| Demark-Wahnefried (USA) | Cross sectional survey, 5 weeks | To assess health behaviours among cancer survivors; readiness to make changes and interest in lifestyle interventions | Total sample N=978. Prostate cancer survivors N=447, all men; mean age and range not reported for the prostate cancer subsample | 60% | Patients with early stage (in situ or localized) prostate carcinoma diagnosed between January 1, 1992 and December 31, 1997 | Prostate | NS |
| Des Bordes (USA) | Mixed, 7 months | To assess information needs on bone health in survivors of prostate and breast cancer and identify the preferred method to deliver health information | Survey: Total sample N=20; prostate cancer survivors N=10, all men. Interviews: Total sample N=20; prostate cancer survivors N=10, all men. Mean age and range not reported for the prostate cancer subsample | 31% | Diagnosed with prostate cancer, adults and no cognitive deficit, English speaking and access to telephone | Prostate | NS |
| Hardcastle (Australia) | Qualitative, NS | To investigate survivors' recollections regarding the content of lifestyle advice received following cessation of their active treatment and explore the factors that impact on lifestyle behaviour change | N=22, all women; mean age 62.6 years; range 49-72 | 20% | Adult (25-80 years old) participants who had completed active treatment of endometrial cancer within the preceding 3 years and were deemed to be in remission; had at least one risk factor for CVD (i.e. body mass index [BMI] of 30 or more; hypertension; hypercholesterolemia; and diabetes mellitus); and were able to speak and comprehend English | Endometrial | NS |

| First author and country | Design & study duration | Aim of study | Sample, N, sex, age | Response rate | Inclusion criteria | Cancer type | Treatment |
|--------------------------|----------------------------------|---|--|---------------|--|---|--|
| Koutoukidis (UK) | Qualitative, 3 months | (1) To examine the perceived importance of health behaviours after endometrial cancer treatment, and the factors influencing adherence to a healthy lifestyle after treatment and (2) to explore the information that endometrial cancer survivors obtain after treatment, and their preferred method of information delivery | N=16, all women; median age 57 years; range 33-84 | 47% | Endometrial cancer survivors within 5 years post-active treatment | Endometrial | Surgery (n=7), surgery and RT (n=5), surgery and RT and CT (n=4) |
| Clark (USA) | Cross sectional survey, 2 months | (1) To assess patient's knowledge of the role of obesity in endometrial cancer and to determine patient perceptions of provider's counselling with regard to obesity, weight loss and health improvement and (2) to characterize lifestyle changes made by patients after diagnosis and barriers to change | N=108, all women; mean age 66.0 years; range 41-91 | 46% | Any patient with a diagnosis of endometrial cancer between June 2011 and June 2012 and without evidence of active disease | Endometrial | NS |
| Fitch (Canada) | Cross sectional survey, 6 weeks | To investigate the experiences of younger women with ovarian cancer | N=39, all women; mean age 38 years; range 21-45 | NS | Women under 45 years old with a diagnosis of ovarian cancer and ability to read either English or French | Ovarian | NS |
| Fitch (Canada) | Cross sectional survey, 6 weeks | To investigate the experiences of older women with ovarian cancer | N=146, all women; mean age 70 years; range 61-93 | NS | Women over 61 years old with a diagnosis of ovarian cancer and ability to read either English or French | Ovarian | NS |
| Lee (2016) (South Korea) | Cross sectional survey, 2 months | To investigate diet-related problems and nutritional care needs according to the survival stage among female cancer survivors in South Korea | Total sample N=186; gynaecological cancer survivors N=82. Extended stage (2-5 years since diagnosis) mean age (SD) 49.7 (8.0) years; long-term stage (>5 years since diagnosis) mean age (SD) 51.2 (7.3) years | NS | Adult women (18-65 years old) at least 2 years after a gynaecological cancer diagnosis who have finished active treatment (except for hormone treatment) | Uterine, endometrial, in situ of uterine, uterine cervical, or ovarian cancer | NS |
| Tseng (USA) | Cross sectional survey, 2 months | (1) To describe the experiences, attitudes, and perceived barriers of uterine cancer survivors related to weight loss and lifestyle counselling and (2) to characterize survivor preferences for physician intervention in this regard | N=180, all women; median age 58 years; range 29-76 | 28.3% | Women diagnosed with uterine cancer | Uterine | NS |
| Zaleta (USA) | Cross sectional survey, 3 months | To examine perceptions of weight management counselling among gynaecologic cancer survivors | N=244, all women; mean age (SD) 57.1 (12.4) years | NS | All women diagnosed with a gynaecological cancer diagnosis presenting at the clinic for a follow up visit | Endometrial, ovarian, cervical, vaginal, vulvar | Surgery (n=201), CT (n=160), RT (n=59), HT (n=3) |

| First author and country | Design & study duration | Aim of study | Sample, N, sex, age | Response rate | Inclusion criteria | Cancer type | Treatment |
|--------------------------|-------------------------|--|--|-----------------------------------|---|-------------------------|-----------|
| Jang (South Korea) | Mixed, 10 weeks | To evaluate the information requirements for knowledge and self-management health behaviours related to metabolic syndrome | Survey: N=70, all women, mean age (SD) 58.7 (9.2) years, range 36-81. Interviews: N=27, all women, mean age (SD) 58.3 (10.1) years, range 36-75 | 36% (survey), 39% (interviews) | Women older than 18years with a diagnosis of ovarian or endometrial cancer, and diagnosis of MetS according to the NCEP-ATP III criteria, capacity to communicate and understand the questionnaire and ability to provide informed consent with no cognitive deficits | Ovarian and endometrial | NS |

755 NS: Not stated; SD: Standard Deviation; RT: radiotherapy, CT: chemotherapy; HT: hormone therapy

Table 2: Summary of diet and nutrition information and support needs.

| Study first author | Tool used | Description of provision (or lack of) of information and identification of needs | Themes |
|--------------------|--|--|---|
| Anderson | Focus groups | Diarrhoea and flatulence were daily problems for which patients sought simple practical dietary advice on foods to avoid. Participants reported mixed messages which created anxiety and confusion, such as messages opposite to general healthy eating (e.g. counter intuitive to 5-a-day) and eating high fat, low quality foods. Participants were advised to adopt a "trial and error" approach while they were looking for solid advice/parameters to work with. Some participants also expressed the need for dietary advice to reduce disease recurrence or progression; however, others were sceptical about how diet could reduce the risk of disease in the future, since it did not prevent the development. | Content of dietary information Views on the role of diet in survivorship |
| Beaver | Face-to-face interviews | A commonly expressed concern was related to diet and what specific type of diet would be appropriate following removal of part of the bowel.. There was an expectation that specific dietary advice was important and should be provided. Support and advice are not mentioned by participants. | Content of dietary information |
| Brown | Face-to-face interviews | Respondents highlighted gaps in information provision and support services, the biggest of which was related to changes in bowel habit and diet adaptation. Bowel changes and their associations with diet had the biggest impact in patients' life. Input from a dietitian was regarded as helpful. | Content of dietary information |
| Dunn | Face-to face interviews and focus groups | A difficulty reported by participants was about obtaining information about what they could expect in the long term. The most frequent concern expressed was that they did not receive any information on diet. Most found that they had difficulty digesting a number of foods after their treatment, yet they had not been advised about what they should and should not be eating. Although a nutritionist visited some of them in hospital, there was no follow up. | Content of dietary information |
| Evans | Face-to-face interviews | As part of a more holistic approach, participants wanted advice on diet and lifestyle, so that they could keep themselves as fit as possible and reduce the chance of disease recurrence. Emphasis was also given to mental wellbeing. These topics were rarely discussed in their conventional consultation. | Content of dietary information Views on the role of diet in survivorship |
| Hardcastle | Face-to-face interviews | Participants felt unsupported regarding bowel changes and management of bowel movements, especially the ones without stoma. They didn't know what kinds of foods they should or should not be eating, so they had to use trial and error to work out which foods are appropriate. Some participants mentioned receiving conflicting and inconsistent information after discharge in relation to bowel management. They also reported lack of knowledge as to what constitutes a healthy diet (classification of foods and portion sizes). Some participants wanted to know why some foods are not very healthy. Participants needed knowledge of nutrition and calorie intake in order to understand food labels. Monitoring would be beneficial to sustain a healthy behaviour. | Content of dietary information Sustaining dietary change |
| Rozmovits | Face-to-face interviews | Respondents reported being given little or no advice after surgery. Some had severe difficulties readjusting their eating and bowel habits. Patients described needs for realistic and non-contradictory information about diet, as they reported receiving contradictory and even inappropriate advice to eat "a high fibre diet". There is confusion on what constitutes an appropriate diet post-surgery to manage bowel function and no one had such knowledge. | Content of dietary information |
| Samuelsson | Face-to-face interviews | Older patients expressed concerns related to diet and nutrition during recovery and follow up. Most of them perceived nutritional support during recovery from surgery as inadequate to match their individual requirements. They also reported not being given guidance on how to manage side effects. On follow up, a lot of participants experienced difficulty regaining weight after surgery but very few received dietetic support. Older people ask for individually tailored information throughout the entire process (diagnosis to follow up). | Content of dietary information Sustaining dietary change |
| Beaver | Questionnaire | Most (59%) respondents stated they received all information they needed about diet in relation to their disease and 56% were satisfied. Those who didn't receive information expressed a need of getting advice on the role of diet and how diet could help from now on. | Content of dietary information |
| Cha | Questionnaire | 43% of the participants reported that they had received dietary information after surgery. 50% of participants suggested that they would like to have had more information provided to them. | Content of dietary information |

| Study first author | Tool used | Description of provision (or lack of) of information and identification of needs | Themes |
|--------------------|---|---|--|
| Nikoletti | Questionnaire | 53% of respondents expressed a need to receive dietary information to manage bowel function and this was rated as important. Most participants who did receive advice perceived it as inadequate. Respondents expressed a particular need for information on what foods to eat when they dine out to avoid bowel problems (28%). | Content of dietary information |
| Perl | Questionnaire | As part of an overall needs assessment, 70% respondents expressed a need for nutritional counselling after diagnosis and it was highlighted significantly more by women rather than men. | Content of dietary information |
| Pullar | Questionnaire | 33% of respondents received advice on dietary change. Most of them felt they had not received enough information in relation to their condition. Half of the respondents received advice in relation to survivorship (reducing red/processed meat and increasing fruit and vegetables) and half in relation to their treatment (formation of a stoma, future weight gain and managing low appetite). No participant classified as obese reported any discussions around diet and nutrition. They would be interested in getting more information and would more likely consider changing habits, particularly people with a higher Body Mass Index. | Content of dietary information |
| Hoedjes | Questionnaire and focus groups | 17% reported the need for dietary support, which was significantly higher in participants classified as overweight or obese. Focus groups highlighted that individuals with treatment-related complaints expressed a need for advice for appropriate nutrition to reduce side effects, such as lack of strength and energy, stoma-related problems and bowel changes. Some participants needed information and individually-tailored advice on lifestyle-related issues, such as appropriate nutrition and use of dietary supplements, in order to make an informed, autonomous decision on adapting their lifestyle or not. Some wanted feedback on their lifestyle and how healthy or unhealthy it is and what areas may need improvement. A gastrointestinal oncology nurse, an oncology dietitian and a stoma nurse specialist were regarded the most appropriate providers for dietary advice and support. | Content of dietary information Sustaining dietary change |
| Avery | Face-to-face and telephone interviews and a focus group | Irrespective of whether they made changes, most men expressed confusion and dissatisfaction with available dietary information and/or its contradictory nature. Some men described unreliable information as a barrier to making dietary changes. Men said they would welcome scientific and evidence-based dietary advice from authoritative sources (primary care physician, consultant or nurse) but information needs varied according to treatment success and disease status. | Content of dietary information Views on the role of diet in survivorship |
| Er | Face-to-face interviews | Participants reported mistrust of dietary messages from media, because they were conflicting. They preferred receiving information from HPs who they regarded as experts and a trusted source of health information and that had a positive influence on their health behaviour. A small amount of men were sceptical about the role of diet in cancer progression, especially if treatment was effective. | Content of dietary information Views on the role of diet in survivorship |
| Kassianos | Telephone interviews | Participants had high expectations but felt health professionals' did not have sufficient knowledge on diet and nutrition support for future health. They felt that lack of/conflicting information could lead them to get wrong messages and inappropriate action. Credible, evidence-based information was considered important for the management of their condition and for reducing the risk of recurrence. Some participants expressed uncertainty about the nature of the relationship between dietary change and recurrence. The health professionals' advice was an important trigger for dietary change and health action. | Content of dietary information Sustaining dietary change Views on the role of diet in survivorship |
| Lee (2017) | Focus groups and one interview | Patients wanted information on diet and supplements tailored to their disease, in order to prevent recurrence and improve overall health. The advice they got about healthy eating was perceived as generic and therefore not helpful to prevent recurrence. | Content of dietary information |
| Sutton | Face-to-face and telephone interviews | Men (who did not participate in a Lifestyle coaching program) did not recall any discussions about diet with health professionals. They would have valued an assessment of their diet or evidence-based advice that could be beneficial long term. Few patients believed that dietary changes would not be necessary successful removal of the prostate. A trusted healthcare professional, regardless of the role, was viewed as a credible source of information. Some men were given leaflets which were hard to read. | Content of dietary information Sustaining dietary change Views on the role of diet in survivorship |

| Study first author | Tool used | Description of provision (or lack of) of information and identification of needs | Themes |
|--------------------|---------------------------------------|---|--|
| Demark-Wahnefried | Questionnaire | Few respondents reported discussions with HPs regarding increasing F&V or reducing fat. 48% of respondents were very or extremely interested for diet-related programs, particularly the younger ones. | Content of dietary information |
| Des Bordes | Questionnaire and interviews | Patients expressed a need for information on nutrition, particularly nutritional supplements, to maintain or improve bone health. Most of them didn't know the negative effects of salt and alcohol on bone health while few prostate cancer survivors knew the optimal calcium requirement in diet. | Content of dietary information |
| Hardcastle | Face-to-face interviews | Most participants do not recall receiving lifestyle advice, including dietary information. Oncologists are viewed as an authoritative and trustworthy source of information and they would feel obliged to follow their advice on healthy eating and weight loss. Apart from advice, regular monitoring was expressed as a need, because it motivates patients to stick to a healthier diet and a lower weight. | Content of dietary information Sustaining dietary change |
| Koutoukidis | Telephone interviews and focus groups | None of the participants received any lifestyle advice from a health professional post-treatment. Those who underwent radiotherapy received dietary advice for bowel symptom management during treatment, but there was no follow up. Participants prompted discussions with health professionals but received unsatisfactory advice. Health professionals were unaware of support groups or just advised to eat healthy. Participants searched for information on their own e.g. online, but it was difficult to find reliable information. They would welcome tailored advice regarding recovery, symptom management and healthy lifestyle overall. | Content of dietary information Sustaining dietary change Views on the role of diet in survivorship |
| Clark | Questionnaire | 52% reported weight loss counselling from a primary care physician and 35% from a gynae-oncologist. 47% reported dietary advice from a primary care physician and 25% from a gynae-oncologist. Receipt of weight loss counselling was significantly associated with attempting weight loss. Provider counselling and encouragement can help overcome motivation barriers. | Content of dietary information |
| Fitch (2000) | Questionnaire | Several respondents reported changes in diet (eating healthy foods and taking supplements, especially vitamins C & E). 79% of women rated diet and nutrition as important discussions in the survivorship phase. However, not all were satisfied with the information they received. | Content of dietary information |
| Fitch (2001) | Questionnaire | 66% of women rated diet and nutrition as important discussions in the survivorship phase. However, not all were satisfied with the information they received. | Content of dietary information |
| Lee (2016) | Questionnaire | Most respondents demanded nutritional care and education in a variety of topics; mainly foods to avoid, appropriate nutrition to prevent recurrence, information on how to improve nutritional status, healthy recipes, and nutritional guidance for the patient's family. | Content of dietary information |
| Tseng | Questionnaire | 50% of respondents reported weight management or lifestyle counselling, primarily from a gynaecologic oncologist or a primary cancer provider. Providers discussed the need for weight loss but did not make specific recommendations regarding how to achieve this. However, most found the counselling motivating to make a change. In terms of duration, of those who got support (50%), 28% had less than 1-minute discussions, 59% between 1 and 5 minutes and 14% more than 5 minutes. In terms of frequency, of those who got support (50%), 38% had discussions during one clinic visit, 28% in less than half visits, 11% in more than half visits and 24% in every visit. Of those who did not receive counselling, most believe would have been motivated to set goals and make positive lifestyle changes. Several of them expressed a desire to discuss weight and lifestyle during most clinic visits. Oncologists and nutritionists were the most preferable sources of information. | Content of dietary information Sustaining dietary change |
| Zaleta | Questionnaire | Most women have attempted weight loss thought diet restriction but only few under guidance and even fewer routinely. Although most agree that oncologists should discuss weight loss with the patients, only very few reported this sort of counselling, in contrast with counselling for smoking cessation. Most respondents believe that weight management counselling would prompt them to attempt weight loss. The oncologist was viewed the most reliable source for information. | Content of dietary information Sustaining dietary change |

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|------|------------------------------------|--|--------------------------------|
| Jang | Survey and face-to-face interviews | As part of the information needs assessment, 27% of participants requested information/education on diet in relation to metabolic syndrome and 14% information on weight management (survey data). Requests on dietary information were also expressed in interviews. Participants consider diet management as an important self-management tool for controlling metabolic syndrome. | Content of dietary information |
|------|------------------------------------|--|--------------------------------|

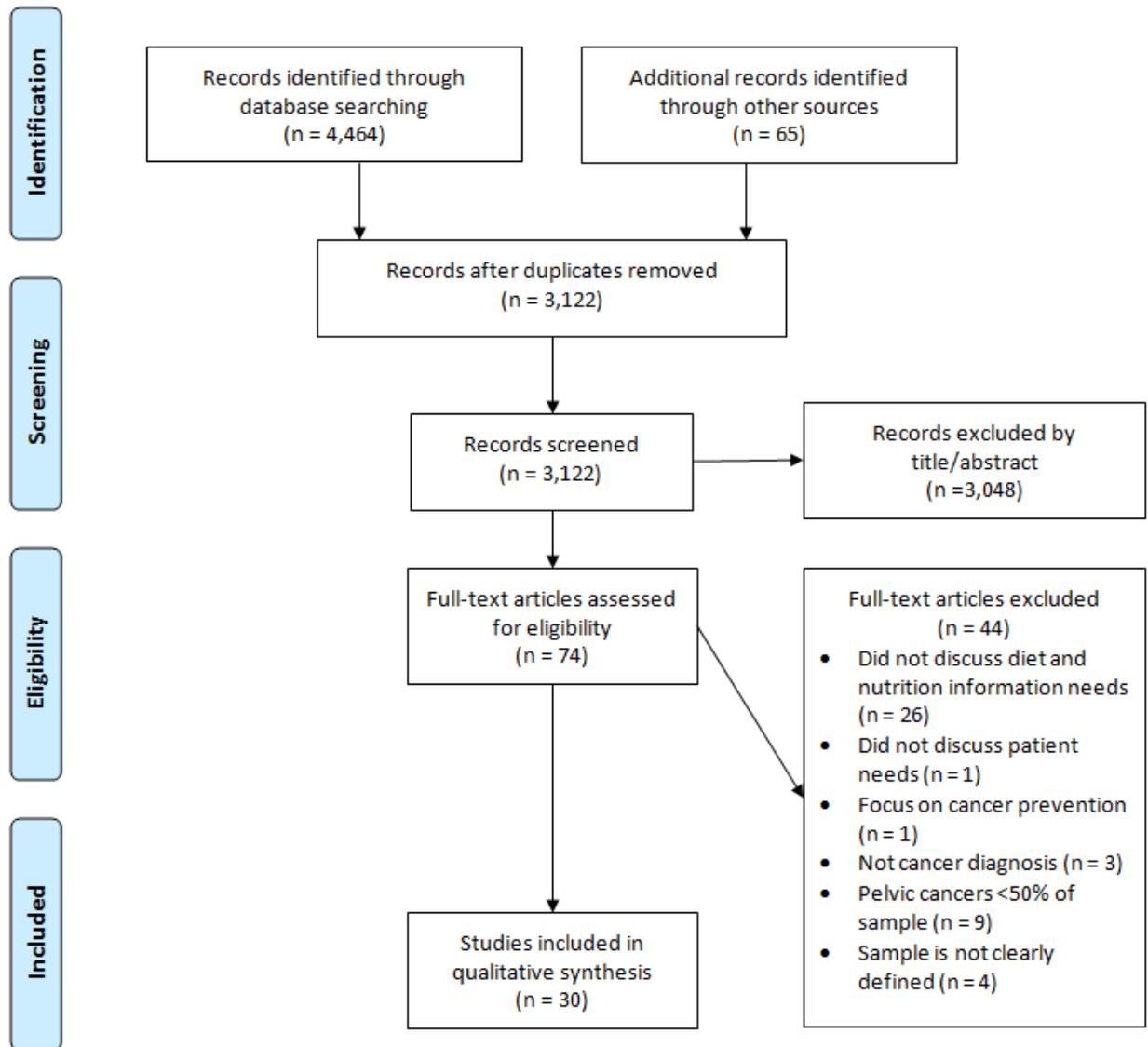


Figure 1: PRISMA flow diagram (Moher, Liberati, Tetzlaff, & Altman, 2009).