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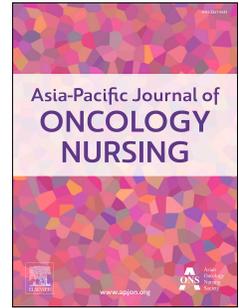
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The role of the nurse in meeting the educational needs for self-care in cachectic cancer patients and their family caregivers: a scoping review

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Ethics statement

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Data availability statement

The data that support the findings of this study are available from the corresponding author, JBH, upon reasonable request.

1 **Review Article**

2 **Title**

3 **The role of the nurse in meeting the educational needs for self-care in cachectic cancer patients**
4 **and their family caregivers: a scoping review**

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1 **ABSTRACT**

2

3 Purpose

4 To give an overview of what is known about the nurse contribution to education in self-care
5 by people with cancer cachexia and their family caregivers.

6

7 Background

8 Nurse-led patient education can help patients and their family caregivers to manage cancer
9 symptoms, cancer treatments and treatment side effects.

10

11 Methods

12 This scoping review explored the extent to which nurse-led education has become part of the
13 multimodal management of cancer cachexia. It is based on a systematic search of Medline,
14 Embase, CINAHL, APA PsycINFO, and the Cochrane Library. Search limits were English
15 language, date range January 2015 to March 2023, and adults 18 years and older.

16

17 Results

18 A total of 6,370 titles were screened, 127 papers and conference abstracts selected for full
19 text examination and 9 publications included in the review. The analysis found the nurse
20 within the multidisciplinary cancer cachexia care team can:

- 21 • raise awareness of cancer cachexia syndrome and its causes,
- 22 • share knowledge of symptoms and related problems, which can aid patient
23 understanding to support adherence to interventions and to support emotional coping,
- 24 • offer dietary information and advice to mitigate risk of malnutrition,
- 25 • teach skills in the self-management of nutritional impact symptoms,

- 26 • adjust information, advice and skills training to cultural and social context and
27 • offer and signpost educational resources about the management of cancer cachexia.

28 Nurses, like other healthcare professionals, do not have a shared understanding of cancer
29 cachexia and its management. For nurses to be confident and competent in the provision of
30 nurse-led cachexia education, they themselves need evidence-based education in cachexia
31 care and how to tailor education according to cachexia stage, symptoms, emotional response
32 and social circumstance.

33

34 Conclusion

35 Nurses with the knowledge and confidence to provide cancer cachexia education for their
36 patients can potentially play an important role in the management of cancer cachexia and
37 mitigation of cachexia-related problems.

38

39 **Keywords:** cachexia, cancer, self-care, nursing, education, scoping review

40

41

42 1.0 Introduction

43 Patients with cancer cachexia experience involuntary weight loss, poor appetite, fatigue,
44 declining physical function and other troubling symptoms and problems (1).

45

46 Clinical guidelines for the management of cancer cachexia recommend a multimodal approach
47 that combines disease treatment, intervention to arrest the metabolic and inflammatory
48 processes causing cachexia, and the management of associated physical problems (e.g. physical
49 decline), emotional problems (e.g. distress), and social problems (e.g. conflict with family
50 members over food) (1, 2). Education provided by a multidisciplinary team is important if
51 patients are to successfully self-manage cachexia-related problems (3). Two of the nine
52 domains of multimodal care for cancer cachexia focus on education: i) the provision of
53 evidence-based information and ii) education about cancer cachexia for patients and their
54 family caregivers (4). There is potential for education to enable self-care that i) mitigates
55 malnutrition and malnutrition risk and ii) mitigates cachexia-related distress with benefit to
56 quality of life (5).

57

58 Most effective interventions initiated by nurses, nurse-led, interventions for cancer symptoms
59 include educational and psychological components (6). However, in 2015 a scoping review
60 with focus on nutritional care, nurses were found to lack sufficient knowledge and confidence
61 to deliver nutritional care in cancer cachexia (7). The review concludes that nurses have an
62 unmet need for education if they are to fulfil an important nutritional care role in cancer
63 cachexia.

64

65 Nurses need education in cancer cachexia

66 Nurses may be educating patients and their family members in cancer cachexia and its
67 management but, with their contribution unstudied and therefore not reported. Yet surveys of
68 cancer and palliative care clinician knowledge and practice of guideline recommended
69 cachexia care have found a lack of formal education and know-how (8-12) (see Table 1.).

70

71 For nurses, undergraduate and postgraduate education rarely includes preparation for the
72 management of either cachexia or nutrition in cancer. More than 75% of nurses report no formal
73 education in cachexia, with authors concluding this contributes to inconsistent management of
74 the complex needs of a patient with cancer cachexia (13), as nurses do not have sufficient
75 awareness of the risk, problems, appropriate assessment and management (13,14). Nearly half
76 (43%) of 355 oncology nurses in the Netherlands reported insufficient knowledge to provide
77 advice on nutrition (15). Education of oncology nurses has been shown to increase their
78 knowledge, self-confidence, and self-efficacy to deliver nutritional care to cancer patients (16).
79 If nurses are to raise awareness of cancer cachexia, its causes and management in their work
80 with patients, then they need cachexia education themselves.

81

82 To address the educational need of nurses in cancer cachexia, it is first necessary to identify
83 what they need to know. An important part of what cancer nurses do is to educate patients in
84 self-care (6). This scoping review examines the extent that patient education by nurses has
85 become part of the multimodal management of cancer cachexia by asking the following
86 question.

87

88 **2.0 Review Question**

89 What is known about the role of the nurse in meeting the educational needs of self-care in
90 cachectic cancer patients and family caregivers?

91

92 **3.0 Design and Methods**

93 The scoping review was to identify gaps in the knowledge base with development of the
94 question guided by population, concept and context (17). The search was of Medline, Embase,
95 CINAHL, APA PsycINFO, and the Cochrane Library for publications about nurses and
96 education for people with cancer cachexia or its defining characteristic, involuntary weight
97 loss. Limits were the English language, January 2015 (the year of an earlier scoping review by
98 the author about the nurse contribution to nutritional care in cancer cachexia) to March 2023,
99 and human subjects. The search strategy was developed for Medline by the author, discussed
100 with a librarian, and then translated into other databases.

101

102 The search combined selected MeSH terms and free text terms seeking hits for (nurse) AND
103 (nutrition) AND (education), (nurse) AND (cachexia) AND (education). These searches were
104 cross-checked by reruns from January 2015 to March 2023 of the search strategies for already
105 published reviews about nurse nutritional care offered by nurses for cachexia (7) and
106 multimodal interventions for cachexia with a psychosocial component (18) (see Figure 1.).

107 All hits were screened by the author for relevance to this scoping review.

108

109 The review comprised multiple searches because it was a scoping review to map breadth and
110 depth of literature (19) [see Appendix 1 for an example search in MEDLINE]. The eligibility
111 criteria were broad, allowing inclusion irrespective of study design, methodology, or method.
112 Inclusion criteria were, peer reviewed publication (conference abstract or full paper), cancer
113 cachexia, adults (18 years of older), nurse-led education, primary or secondary care setting,
114 English language, date range January 2015 to March 2023. Data that related to nurse-led
115 education for people with cancer cachexia and their family caregivers was extracted from

116 selected publications. The reference lists of included publications were screened (backward
117 chaining) and articles citing the selected publications sought (forward chaining) with one
118 additional publication identified and included.

119

120 The data extraction was of any report of nurse-led cachexia education for a patient with cancer
121 or their family caregiver. The extracted data was entered into a thematic conceptual matrix
122 (20). The initial thematic structure was derived a priori using the research question and
123 literature leading to the question. The conceptual matrix was further developed during data
124 extraction to accommodate newly emergent themes, such as, caregiver educational need.

125

126 For the review, nurses were considered to be providing cachexia education if reported to give
127 information/advice, offer guidance, or to educate in the causes, symptoms and other associated
128 problems, and/or management of cancer cachexia or involuntary weight loss in cancer. The
129 scoping review is reported according to the PRISMA-ScR Checklist (21).

130

131 **Results**

132 A total of 6,370 titles were screened and 126 papers and conference abstracts selected for full
133 text examination (see Figure 1.). Eight documents were selected and a ninth was added after
134 searching and screening citations of these eight publications. Table 2. gives details of the nine
135 publications. They included three empirical studies (four publications) (13, 22-24), three
136 literature reviews (25-27), one service improvement project (28), and one publication based on
137 expert opinion (14). The studies were conducted in Europe, UK, Japan, China, Mexico, and
138 USA.

139

140 The findings of this review are reported under the subheadings, patient educational need
141 addressed by nurses, family caregiver educational need addressed by nurses, nurse educational
142 role in multimodal management, nurse-led education, and the impact of nurse-led education.
143 Collectively, these themes comprise the component parts that can be deduced from the
144 literature of the nurse role in the education of patients with cancer cachexia and their family
145 caregiver.

146

147

148 **Patient educational need addressed by nurses**

149 Patients were thought to need nurse-led education in cachexia to help them cope with poor
150 appetite and involuntary weight loss (22, 23, 26, 27) and to manage interpersonal relationships
151 disrupted by the symptoms of the syndrome (22, 23, 24) and other cachexia-related
152 psychosocial problems causing distress (24, 26). Education was also reported as necessary for
153 patients to learn skills in symptom management, such as energy conservation techniques to
154 manage life with fatigue (25, 27). One publication recommended that the education provision
155 should extend beyond the specialist clinic to help patients manage cancer cachexia cared for in
156 any setting , hospital or community (14).

157

158 **Family caregiver educational need addressed by nurses**

159 Family caregivers were thought to need nurse-led education in cachexia to help them cope with
160 the patient's poor appetite and involuntary weight loss (22, 23, 24, 28) and to manage
161 interpersonal relationships disrupted by the symptoms of the syndrome (22, 23, 24) and other
162 cachexia-related psychosocial problems causing distress (22, 23, 24, 26). Carers had been
163 found to take on a nourishing role of patients with advancing cancer and involuntary weight
164 loss and thus needed guidance on how to best help the patient (24). A particular need was

165 identified for education in nutrition and hydration as the patient approached end of life, for
166 example talking about reasons for loss of appetite as end-of-life approaches to reduce the
167 likelihood of inappropriate feeding (27).

168

169 **Nurse educational role in multimodal management**

170 Multimodal management of cachexia was offered by a multidisciplinary team with nursing a
171 core role. Other core roles were dietitian, physiotherapist, and doctor (14). Nurses provided
172 psychoeducation (practical examples of how to manage cachexia-related problems and
173 emotional response tailored to the experience of patient and family caregiver), along with an
174 information booklet about coping with cachexia to encourage self-care of cancer cachexia-
175 related problems thus influencing coping and self-confidence (22, 23). Nurses were described
176 as encouraging and motivating patients to take part in interventions (26) and educating them in
177 symptom management (27).

178

179 **Nurse-led education**

180 Nurses provided patients and family caregivers with nutritional information and guidance (13,
181 22-25, 27, 28). For example, they offered advice on safe feeding, diet management, and
182 unproven diets (25). They also provided education to help the patient and family caregiver to
183 understand the physical and psychosocial problems that can accompany cachexia (22, 23, 24,
184 26) and to make them aware of successful coping strategies (22, 23, 26, 27). In addition to
185 talking about nutrition and providing psychosocial support, they taught skills in symptom
186 management, such as the modification of food texture to mitigate the pain of mucositis (27).
187 One study described a nurse navigator educating to facilitate acceptance of screening for risk
188 of cachexia-related problems, intervention, and follow-up care (14). Other authors also noted
189 the potential for psychosocial support to improve adherence to interventions (14, 27). Booklets,

190 posters, health education prescriptions, and online videos uploaded to public websites, were
191 used to support the cachexia education provided (22, 28). A method of education described
192 was the use of open questions and a non-judgmental approach to establish change in the
193 patient's eating habits across the course of their cancer. This patient experience was then used
194 to tailor information to raise awareness of common emotional responses to changing eating
195 habits. A booklet was offered giving practical examples of how patients and family caregiver
196 can manage eating problems (22). A second study drew attention to the needs for cachexia
197 education of family caregiver who might be uncertain of how best to manage the patient's loss
198 of appetite or changing eating habits or be at risk of malnutrition themselves if aligning their
199 food intake to the patient's (24).

200

201 **The impact of nurse-led education.**

202 Psychoeducational sessions are feasible for nurses to deliver, with more than 80% of patients
203 and their family caregivers attending at least 2/3 sessions and expressing appreciation of the
204 opportunity to talk about cachexia (22). The sessions were perceived to set out a positive role
205 for family caregivers who were found to experience less caregiver burden at 4 weeks from
206 baseline (pre-sessions) (22). The patient and family caregivers also reported benefit for their
207 relationship through improved interactions relating to food and eating (22, 23, 24). Proactive
208 psychosocial intervention is proposed to be most likely of benefit when there is a mismatch
209 between patient and family caregiver nutritional goals (24).

210

211 Nurse-led education has also been reported to support improved nutritional intake of patients
212 with cancer cachexia (24, 25, 27). Nurses are familiar with the culture and health habits of the
213 patients they care for and can use this knowledge to adjust their education to help patients
214 adapt to life with cachexia (27). A large number of potential nurse-led interventions for

215 symptoms are reported, for example, for dry mouth (23, 25, 27). However, the nurse
216 contribution to cachexia education is, in the main, overlooked in the literature and the nature
217 and methods of education with benefit are not well described. There are calls for a practical
218 guide to aid the communication and education component of nurse-led cachexia care (14, 26).

219

220 **Discussion**

221 The scoping review found only 9 publications (13, 14, 22-28) that included description of the
222 nurse role in cachexia education for patients and their family caregivers. Of these, only 3 were
223 empirical research (13, 22-24) and just one testing a nurse-led intervention (22). The
224 contribution of nurses to the multimodal management of cancer cachexia through the offer of
225 patient and family caregiver education has received little attention in the literature. All cancer
226 patients meet nurses and patient education in the management of disease and symptoms is a
227 recognized important therapeutic activity within the cancer nursing role (6).

228

229 This review found that the educational role of the nurse in meeting the needs of a patient with
230 cancer cachexia and their family caregiver can be to:

- 231 • raise awareness of cancer cachexia syndrome and its causes,
- 232 • share knowledge of symptoms and related problems, which can aid patient
233 understanding to support adherence to interventions and to support emotional coping,
- 234 • offer dietary information and advice to mitigate risk of malnutrition,
- 235 • teach skills in the self-management of nutritional impact symptoms,
- 236 • adjust information, advice and skill training to cultural and social context and
- 237 • offer and signpost educational resources about management of cancer cachexia.

238 The review supports an argument that this educational offer should be tailored according to
239 stage of cachexia, symptoms, emotional response and social circumstance – it should be

240 personalised (1). This personalization might include, adjusting advice and goals negotiated
241 with patients and families according to stage of cachexia, with focus on screening and
242 addressing risk of malnutrition in the pre- and early stages of cachexia (14, 25), focus on
243 maintenance of muscle mass and optimal nutritional status during active or palliative
244 treatment (25-27), and negotiating goals that focus on quality of life with patients who are
245 approaching end of life with refractory cachexia (22, 24, 27).

246

247

248 **Nurse cancer cachexia education with impact**

249 The review has found interaction between patient, family caregiver and nurse a central
250 feature of nurse-led patient education in cachexia (13, 22, 24, 26-28). Cancer cachexia and its
251 symptoms can be a sensitive topic of conversation with patients and their family caregiver.

252 The methods for initiating discussion, sharing information, and promoting self-management
253 are an important consideration (5). Knowledge of health behaviour change can be applied to
254 an evidence-based approach for engaging patients and their family caregivers in conversation
255 and for supporting uptake and adherence to advice for self-care (5). Nurses have been found
256 able to offer dietary advice with beneficial effect in other contexts, such as the management
257 of diabetes (29, 30). If nurses offer dietary advice to patients with cancer cachexia, they can
258 contribute to the management of malnutrition risk. They can teach self-care for nutritional
259 impact symptoms, to include teaching skill in modifying foods to increase protein intake for
260 those with poor appetite and involuntary weight loss (31). Feedback that evokes positive
261 emotion (positive sense of self) may be important for cachexia education with health benefit
262 for the patient and for positive impact on quality of life for the family caregiver (32). Audit
263 using clinical practice guidelines for cancer cachexia (1,2) to set a standard of best practice,
264 can have a role to play in feedback to support service improvement in the management of

265 cachexia, to include feedback on the patient education and patient/family caregiver adoption
266 of advocated self-care practices (28).

267

268 Patient education in self-care, which adopts methods known to support behaviour change
269 such as goal setting (33, 34) cannot stand alone from a knowledge of the causes of cachexia,
270 its symptoms and natural progression (35). Nurses work with people on the boundary of
271 treatment for disease and support of their everyday life. They help with adjustment to disease
272 symptoms and treatment for best possible health and well-being outcome. This involves
273 working in a biopsychosocial space requiring understanding of disease process and emotional
274 coping to include influence of social context on adaptation (18). Nursing knowledge spans
275 disease, treatment, emotional adaptation and coping. The how, when and what of sharing this
276 knowledge and understanding with patients and family caregivers affected by cancer cachexia
277 – the nurse educational role in cachexia – has been little studied, as shown by the dearth of
278 literature identified for this review. Exploratory and pilot trials of multimodal interventions
279 for people with advanced cancer and symptoms of cachexia that include an educational
280 component delivered by a dietitian or physiotherapist, have been found acceptable to patients
281 and their family caregivers. Benefits have been found to include improved emotional well-
282 being and improved nutritional intake (32, 36, 37). The potential contribution of the nurse
283 educational role in cachexia has been, in the main, overlooked and is thus little studied.
284 Nurses need to know how to deliver patient education in cachexia for positive effect on
285 patient and family caregiver health and well-being.

286

287 **Cancer cachexia care must be multidisciplinary if it is multimodal**

288 Publications have called for guidelines and presented models for nurse-led cachexia care (26,
289 31). However, all nine publications included in this review positioned the nurse as being a

290 member of a multidisciplinary team supporting patients with cancer cachexia. Multimodal
291 cachexia care is delivered by a team of people with complementary expertise. Whilst the
292 contribution of some team members is clearly defined, for example the physiotherapist supports
293 physical activity/exercise, the role of the nurse has not been clearly differentiated. It has been
294 reported that it can include screening patients for risk of cachexia and initial assessment (38-
295 41) and coordination of cachexia care (42). This review draws attention to the important patient
296 and family caregiver educational component of the nursing role within the multidisciplinary
297 team. What is perhaps needed is not a model for nurse-led cachexia care but a wider model for
298 cachexia care with clearly defined embedded roles to include a nursing role with patient
299 education component. The reported patient and family caregiver acceptance of booklets,
300 videos, and posters to support nurse-led cachexia education (22, 23, 28) suggests they are
301 needed to support the multidisciplinary team offer of cachexia care. They can act as boundary
302 objects facilitating talk about technical and sensitive topics (43) such as involuntary weight
303 loss and conflict in the home over food. Investigation is needed of how to tailor electronic and
304 hard copy educational resources to meet the needs of people from different cultures and
305 socioeconomic backgrounds thus accommodating variability in the meanings of food, eating,
306 diet and weight (44).

307

308 **Limitations**

309 A single nurse researcher conducted this rapid scoping review with implications for the
310 reliability of selection and data extraction. The risk of error through omission of relevant papers
311 was addressed in three ways. First, by running multiple parallel searches (multiple databases
312 and multiple searches within each database). Second, by screening the reference lists and
313 searching for citations of included publications. Finally, by cross-checking with reruns January
314 2015 to February 2023 of related published peer reviewed searches by the author (7, 18)

315 The review focused on a nursing contribution to cancer cachexia care, namely the education
316 that can be provided by nurses for patients with cancer cachexia and their family members.
317 Whilst the multifaceted problems associated with cachexia require a multimodal approach
318 delivered by a team with diverse expertise, the expert contribution of the nurse can be difficult
319 to delineate. The nursing role in the management of cachexia has been reported to screen
320 patients, identify cachexia and related problems, then coordinate interventions delivered by
321 other team members (1, 38). Whilst these are valuable tasks completed by nurses within
322 multidisciplinary cancer care teams, nurses can make other contributions to holistic cachexia
323 care (27, 45). Education in cachexia for the support of self-care is one. The focus on this topic
324 has detracted from other possible learning from the review and is a bias arising from the
325 professional background and clinical experience of the author. A second reviewer, with
326 different history and experience, or consultation with patients, caregivers and clinicians, may
327 have enabled additional insights.

328

329

330 **Conclusion**

331 Nurse-led education may be important for any successful multimodal intervention in cancer
332 cachexia. However, little attention has yet been paid to this potential mechanism of successful
333 intervention. Understanding the teaching content and methods that can be used by nurses to
334 provide effective education in self-care by people with cancer cachexia could make an
335 important contribution to improvement in clinical outcomes and quality of life of patients and
336 their family caregivers.

337

338 **Appendix A. Supplemental data: MEDLINE searches**

339

340 **SEARCH EXAMPLE**

341

342 Database: Ovid MEDLINE(R) ALL <1946 to February 22, 2023>

343 Search Strategy:

344 -----

345 1 (nutrition* or dietary counselling or dietary advice or nutritional counselling).mp.

346 [mp=title, book title,

347 abstract, original title, name of substance word, subject heading word, floating sub-heading

348 word, keyword heading word,

349 organism supplementary concept word, protocol supplementary concept word, rare disease

350 supplementary concept word,

351 unique identifier, synonyms, population supplementary concept word, anatomy

352 supplementary concept word] (459802)

353 2 (education or teaching or training).mp. [mp=title, book title, abstract, original title, name

354 of substance word,

355 subject heading word, floating sub-heading word, keyword heading word, organism

356 supplementary concept word, protocol

357 supplementary concept word, rare disease supplementary concept word, unique identifier,

358 synonyms, population

359 supplementary concept word, anatomy supplementary concept word] (1505433)

360 3 Nurses/ (45017)

361 4 nurs*.mp. [mp=title, book title, abstract, original title, name of substance word, subject

362 heading word, floating

363 sub-heading word, keyword heading word, organism supplementary concept word, protocol

364 supplementary concept word, rare

- 365 disease supplementary concept word, unique identifier, synonyms, population supplementary
366 concept word, anatomy
367 supplementary concept word] (801905)
368 5 3 or 4 (801905)
369 6 1 and 2 and 5 (4450)
370 7 limit 6 to (english language and humans and yr="2015 -Current") *(1073)
371 8 cachexia.mp. or Cachexia/ (11168)
372 9 weight loss.mp. or Weight Loss/ (117877)
373 10 Wasting Syndrome/ or Wasting Disease, Chronic/ (1983)
374 11 8 or 9 or 10 (128370)
375 12 7 and 11 *(40)
376 13 2 and 5 (225070)
377 14 11 and 13 (458)
378 15 limit 14 to (english language and humans and yr="2015 -Current") *(133)

379

380 * = abstracts screened

381

382

383 **References**

- 384 1. ESMO Clinical Practice Guidelines. Arends J, F Strasser F, Gonella S, et al. Cancer
385 cachexia in adult patients. ESMO Guidelines Committee. ESMO Open. 2021; 6(3):
386 100092.
- 387 2. ASCO Guideline. Roeland EJ, Bohlke K, Baracos VE, et al. Management of
388 Cancer Cachexia. Journal of Clinical Oncology. 2021; 38(21): 2438-53.
389 <https://doi.org/10.1200/JCO.20.006111>].
- 390 3. Garcia JM, Dunn RF, Santiago K et al. Addressing unmet needs for people with
391 cancer cachexia: recommendations from a multistakeholder workshop. J Cachexia
392 Sarcopenia Muscle. 2022;13: 1418–1425.
- 393 4. Amano K, Hopkinson J, Baracos V et al. Psychological symptoms of illness and
394 emotional distress in advanced cancer cachexia. Current Opinion in Nutrition and
395 Metabolism. 2022; 1; 25(3):167-172. doi: 10.1097/MCO.0000000000000815.
- 396 5. Hopkinson JB. Educational needs of self-care in cachectic cancer patients and their
397 family caregivers. Current Opinion in Oncology. 1;35(4):254-260.
398 doi:10.1097/CCO.0000000000000948.
- 399 6. Kelly D, Campbell P, Torrens C et al. The effectiveness of nurse-led interventions
400 for cancer symptom management 2000–2018: A systematic review and meta-analysis.
401 Health Sciences Review. 2022; 4(2022): 100052.
- 402 7. Hopkinson J. The nursing contribution to the nutritional care of people with cancer
403 cachexia. Proceedings of the Nutrition Society. 2015; 74(4): 413-8. doi:
404 10.1017/S0029665115002384.
- 405 8. Baracos V, Coats AJ, Anker SD, et al. on behalf of the International Advisory
406 Board, and Regional Advisory Boards for North America, Europe, and Japan.
407 Identification and management of cancer cachexia in patients: Assessment of

- 408 healthcare providers' knowledge and practice gaps. *Journal of Cachexia, Sarcopenia*
409 *and Muscle*. 2022; DOI: 10.1002/jcsm.13105
- 410 9. Amano K, Koshimoto S, Hopkinson J et al. Perspectives of health care
411 professionals on multimodal interventions for cancer cachexia. *Palliative Medicine*
412 *Reports*. 2022; 3(1). DOI: 10.1089/PMR.2022.0045
- 413 10. Murphy JL, Munir F, Daveys F, et al. The provision of nutritional advice and care
414 for cancer patients: a UK national survey of healthcare professionals. *Supportive Care*
415 *in Cancer*. 2021; 29:2435–2442.
- 416 11. Muscaritoli M, Corsaro E and Molfino A. Awareness of Cancer-Related
417 Malnutrition and Its Management: Analysis of the Results From a Survey Conducted
418 Among Medical Oncologists. *Front. Oncol*. 2021; 11:682999. doi:
419 10.3389/fonc.2021.682999
- 420 12. Ellis J, Petersen M, Chang S, et al. Health care professionals' experiences of
421 dealing with cancer cachexia. *International Journal of Clinical Oncology*. 2023;
422 28:592–602. doi.org/10.1007/s10147-023-02300-6
- 423 13. Socratous G, Cloconi C, Tsatsou I, Charalambou A. Nurses' Knowledge in
424 Relation to the Anorexia–Cachexia Syndrome in Cancer Patients: A Cross-National
425 Comparison in Two European Countries. *SAGE Open Nursing*. 2021: 1-13.
- 426 14. Granda-Cameron C, Lynch MP. Clinical Framework for Quality Improvement of
427 Cancer Cachexia. *Asia Pac J Oncol Nurs*. 2018; 5: 369-76.
- 428 15. van Veen MR, Hoedjes M, Versteegen JJ et al. Improving Oncology Nurses'
429 Knowledge About Nutrition and Physical Activity for Cancer Survivors. *Oncol Nurs*
430 *Forum*. 2017; 44(4): 488-496. doi: 10.1188/17.ONF.488-496.

- 431 16. Sharour LA. Improving oncology nurses' knowledge, self-confidence, and self-
432 efficacy in nutritional assessment and counseling for patients with cancer: A quasi-
433 experimental design. *Nutrition*. 2019; 62:131-134.
- 434 17. Munn Z, Peters MDJ, Stern C, et al. Systematic review or scoping review?
435 Guidance for authors when choosing between a systematic or scoping review
436 approach. *BMC Medical Research Methodology*. 2018; 18: 143.
437 doi.org/10.1186/s12874-018-0611-x
- 438 18. Hopkinson JB. The psychosocial components of multimodal interventions offered
439 to people with cancer cachexia: a scoping review. *Asian Pacific Journal of Nursing*.
440 2021; 8: 450-61.
- 441 19. Arksey H, O'Mally L. Scoping studies: Towards a methodological framework. *Int*
442 *J Soc Res Methodol*. 2005; 8:19-32.
- 443 20. Miles MB, Huberman AM. Within-case displays: Exploring and describing. In:
444 Miles MB, Huberman AM. *Qualitative data analysis*. 2nd Ed. SAGE. London. 1994;
445 131.
- 446 21. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews
447 (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169(7):467-473.
448 doi: 10.7326/M18-0850.
- 449 22. Buonaccorso L, Fugazzaro S, Autelitano C et al. Psycho-educational and
450 rehabilitative intervention to manage cancer cachexia (PRICC) for advanced patients
451 and their caregivers: Lessons learned from a single-arm feasibility trial. *Cancer*. 2323;
452 15: 2063. doi.org/10.3390/cancers15072063
- 453 23. Buonaccorso L, Bertocchi E, Autelitano C et al. Psychoeducational and
454 Rehabilitative Intervention to Manage Cancer Cachexia for Patients and Their
455 Caregivers: Single-Arm Feasibility Trial. *Palliative Medicine*. Conference: 12th

- 456 World Research Congress of the European Association for Palliative Care, EAPC
457 2022. 2022; 36(1): 70.
- 458 24. Hopkinson JB. The Nourishing Role: Exploratory Qualitative Research Revealing
459 Unmet Support Needs in Family Carers of Patients With Advanced Cancer and Eating
460 Problems. *Cancer Nursing*. 2018; 41(2): 131-138.
- 461 25. Oakvik J, Ready D. Updates in Cancer-Related Symptom Management of
462 Anorexia and Cachexia Syndrome. *Seminars in oncology nursing*. 2022; 38(1):
463 151254.
- 464 26. Sato R, Tateaki N, Hayashi N. Barriers in Nursing Practice in Cancer Cachexia: A
465 Scoping Review. *Asia-Pacific Journal of Oncology Nursing*. 2021;8(5): 498-507.
- 466 27. Zhao Y, Pang D, Lu Y. The Role of Nurse in the Multidisciplinary Management
467 of Cancer Cachexia. 2021; 8(5): 487-497.
- 468 28. Zhang L, Zhou C, Wu Y, et al. Assessment and nonpharmacological management
469 for patients with cancer anorexia–cachexia syndrome: a best practice implementation
470 project. *JBIEvid Implement* 2022; 20: 334–343.
- 471 29. Wilson M, Chen H-S, Wood M. Impact of nurse champion on quality of care and
472 outcomes in type 2 diabetes patients. *Int J Evid Based Healthc*. 2019; 17(1): 3-13. doi:
473 10.1097/XEB.0000000000000156.
- 474 30. Azami G, Soh KL, Sazlina SG, et al. Effect of a Nurse-Led Diabetes Self-
475 Management Education Program on Glycosylated Hemoglobin among Adults with
476 Type 2 Diabetes. *J Diabetes Res*. 2018; 8:4930157. doi: 10.1155/2018/4930157.
- 477 31. Hopkinson J, Fenlon D, Wright D et al. The deliverability, acceptability and
478 perceived effect of the Macmillan Approach to Weight loss and Eating difficulties
479 (MAWE): Phase II cluster randomised exploratory trial of a psychosocial intervention

- 480 for weight- and eating-related distress in people with advanced cancer. *J Pain*
481 *Symptom Manage.* 2010; 40: 684–695.
- 482 32. Hall CC, Skipworth R, Blackwood et al. A randomised, feasibility trial of an
483 Exercise and Nutrition-based Rehabilitation programme (ENeRgy) versus standard
484 care in people with cancer. *Journal of Cachexia, Sarcopenia and Muscle.* 2021; 12(6):
485 2034–2044.
- 486 33. Michie S, van Stralen MM, and West R. The behaviour change wheel: A new
487 method for characterising and designing behaviour change interventions.
488 *Implementation Sci.* 2011; 6, 42. <https://doi.org/10.1186/1748-5908-6-42>
- 489 34. Social Change UK. A guide on the COM-B Model of Behaviour. Available at:
490 https://social-change.co.uk/files/02.09.19_COM-B_and_changing_behaviour_.pdf
491 Accessed 8.5.2023
- 492 35. Hopkinson J, Amano K, Baracos V. Eating Issues in Palliative Cancer Patients: a
493 source of cachexia-related distress. In, Chochinov H, Schulman L (Eds) 3rd Edition of
494 the Handbook of Psychiatry in Palliative Medicine: Psychosocial Care of the
495 Terminally Ill. Oxford University Press. 2022.
- 496 36. Molassiotis A, Brown T, Cheng HL et al. The effects of a family-centered
497 psychosocial-based nutrition intervention in patients with advanced cancer: the
498 PiCNIC2 pilot randomised controlled trial. *Nutrition Journal.* 2021; 20(1): 2.
- 499 37. Solheim TS, Laird BJA, Balstad TR, *et al.* A randomized phase II feasibility trial
500 of a multimodal intervention for the management of cachexia in lung and pancreatic
501 cancer. *J Cachexia Sarcopenia Muscle.* 2017; 8:778-88.
- 502 38. Berry DL, Blonquist T, Nayak MM, et al. Cancer anorexia and cachexia:
503 Screening in an ambulatory infusion service and nutrition consultation. *Clinical*
504 *Journal of Oncology Nursing.* 2018; 22(1): 64-68.

- 505 39. Del Fabbro E, Jatoi A, Davis M, Fearon K, Di Tomasso J, Vigano A. Health
506 professionals' attitudes toward the detection and management of cancer-related
507 anorexia-cachexia syndrome, and a proposal for standardized assessment. *Journal of*
508 *Community and Supportive Oncology*. 2015; 13(5): 181-187.
- 509 40. Baba MR, Buch SA. Revisiting Cancer Cachexia: Pathogenesis, Diagnosis, and
510 Current Treatment Approaches. *Asia Pac J Oncol Nurs*. 2021; 8(5): 508–518.
511 doi: [10.4103/apjon.apjon-2126](https://doi.org/10.4103/apjon.apjon-2126)
- 512 41. Hertel C, Harandi A, Connery CP, Papadopoulos D. Nutritional intervention in
513 high-risk patients receiving radiation for a broad spectrum of tumor types. *Journal of*
514 *Clinical Oncology*. Conference: 2017 ASCO Quality Care Symposium. Orlando, FL
515 United States. 2017; 35(8 S1).
- 516 42. Vaughan VC, Farrell H, Lewandowski PA, McCoombe SG, Martin P. Defining a
517 new model of interdisciplinary cancer cachexia care in regional Victoria, Australia.
518 *Supportive Care in Cancer*. 2020; 28(7): 3041-3049.
- 519 43. Kertcher, Z.; Coslor, E. Boundary Objects and the Technical Culture Divide:
520 Successful Practices for Voluntary Innovation Teams Crossing Scientific and
521 Professional Fields. *Journal of Management Inquiry*. 2020; 29(1):76-91.
- 522 44. Dovey TM. Chapter 6. The effect of others. In: Dovey TM. *Eating behaviour*.
523 Open University Press. Maidenhead, England. 2010.
- 524 45. Del Fabbro E, Orr T, Stella S. Practical approaches to managing cancer patients
525 with weight loss. *Curr Opin Support Palliat Care*. 2017; 11(4):272–277.
526 DOI:10.1097/SPC.0000000000000300
- 527

Table 1. Nurse knowledge and confidence in cachexia care in cancer

Authors	Survey sample	Finding	Country
Ellis et al. (12) 2023	n=192, 90% doctors or nurses	56% neutral or not confident in managing cancer cachexia	Australia and New Zealand
Baracos et al. (8) 2022	n=2375, 33% doctors, 14% nurses, 28% dietitians, other health care professionals	32% confident in ability to provide care for patients with or at risk of cachexia	Japan, Europe, North America
Amano et al. (9) 2022	n=1320 HCPs (58.5% response rate) in 451 cancer designated hospitals	No profession reported adequate training and confidence in cancer cachexia management <50% used a clinical practice guideline for the management of cachexia.	Japan
Socratous et al. (13) 2021	n=197 cancer nurses	75% report no formal education in cachexia	Greece and Cyprus
Murphy et al. (10) 2021	n=610, 31% nurses, 25% dietitians, 31% doctors	20% completely confident in giving nutritional advice in cancer	UK
van Veen et al. (15) 2017	355 oncology nurses	43% reported insufficient knowledge to provide advice on nutrition	Netherlands

Table 2. The role of the nurse in meeting the educational needs of self-care in cachectic cancer patients and caregivers

Journal Pre-proof

EMPIRICAL RESEARCH							
Author Date Location	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Buonaccorso et al. (22) Italy 2023	Mixed-methods single arm feasibility and acceptability study conducted 2019 to 2021. 24 cancer patients with refractory cachexia/cachexia and their caregivers (12 (50%) patients died within 3 months of enrolment).	Psycho-educational intervention combined with a rehabilitative intervention for patient family carer dyads. Aim: to evaluate the feasibility of the intervention to treat cancer cachexia, assessed by completion rate.	Intervention delivered, in addition to standard care, by a nurse and a physiotherapist. The nursing role being to offer psychoeducation to help the patient and family carer cope with declining appetite and involuntary weight loss in the patient by strengthening individual and dyadic coping resources for the self-management of cancer cachexia. The physical activity component (not found feasible) facilitated enrolment to the nurse delivered psycho-educational intervention component.	Need for information, offered using a non-judgmental approach, to cope with involuntary weight loss and declining appetite.	Need for information, offered using a non-judgmental approach, to cope with involuntary weight loss and declining appetite in a family member.	During consultations once per week for three weeks, the trained nurse (n=3) i) used open questions to understand the viewpoints of patient and family carer of cancer cachexia, ii) mapped changing eating habits, iii) offered practical examples of different ways of managing food in the care of the patients, and iv) re-evaluated dyad's needs in the study period. The dyads were given an information booklet, which included a description of cancer cachexia and common emotional responses.	The psychoeducational sessions were evaluated to be feasible, as 20 dyads 83.3% (Confidence Interval 62.6% to 95.3%) received at least two sessions. For patients evaluated at 2 months follow-up (T3), there was no deterioration in patient quality of life or caregiver burden. Caregiver burden diminished between enrolment and T2 (4 weeks). Participants appreciated the booklet and the opportunity to talk about cancer cachexia, they were positive about a non-clinical intervention and considered it to offer a positive caregiver role, they also perceived a positive benefit for their relationship with respect to interactions over food.
Buonaccorso et al. (23) Italy 2022 (Conference abstract: Poster)	Mixed-methods single arm feasibility and acceptability study. 24 dyads: patients with cachexia and their caregivers (87.5% spouse)	Psycho-education combined with a rehabilitative intervention for patient family carer dyads. Aim: to evaluate i) the feasibility of, ii) acceptability of the intervention and, iii) quality of life.	Intervention delivered by a nurse and a physiotherapist. The nursing role being to offer psychoeducation to help the patient and family carer to cope with cancer cachexia by strengthening dyadic coping resources for the self-management of cancer cachexia.	Need for information to self-manage the complex relational experience of cachexia.	Need for information to self-manage the complex relational experience of cachexia	During consultations once per week for three weeks, the nurse i) explained cachexia, ii) taught patients how to recognize its effects (e.g., weight loss), iii) facilitated discussion of the patient and family's perspectives, feelings about diet, and made suggestions of how to support each other in managing weight-and eating-related problems.	12 (50%) completed the nurse-led intervention components (3 sessions). The dyads appreciated participation in a non-pharmacological cachexia study with their caregiver, with perceived positive impact on their relationship.
Socratous et al. 2021 (13) Greece and Cyprus	Survey in 2018 119 nurse attendees, 8th Nursing Oncology Conference in Cyprus and 78 nurse attendees,	Nurses' knowledge in relation to the Cancer Anorexia-Cachexia Syndrome (CACS) in cancer patients.	Participants named 23 different healthcare roles/people involved in management of CACS, which included nursing roles.	Not reported.	Not reported.	Discussion with the patient for his/her diet (n=1 participant). Psychological support (unspecified) (n=7 (4%) participants).	Not reported

	5th Symposium of Nursing Oncology in Greece.	Aim: to conduct a comparison of two European countries.					
Hopkinson (24) 2018 UK	Exploratory secondary analysis of qualitative interviews. 31 partner/spouse family carers of patients with advanced cancer and involuntary weight loss.	The nourishing role of family carers of patients with advanced cancer who have weight loss and eating problems. Aim: to explore unmet support needs.	Member of homecare multidisciplinary palliative care team.	Not reported.	Need for guidance in their nutritional care responsibilities as family carers, which included helping the patient to manage changing weight and fickle eating habits.	Education in the nourishing role to address food and eating-related uncertainties that are causing anxiety, distress and/or conflict in the home and to help the family carer to know when they are offering appropriate food and fluid. Advice on eating well as a family carer, as their own eating habits can change when in the nourishing role putting them at nutritional risk.	Proposition that proactive education is most likely to be helpful when there is a mismatch in patient and family carer nutritional goals.
REVIEWS							
Author Date Location	Study design	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Oakvik et al. (25) Mexico 2022	Narrative review.	Cancer Anorexia-Cachexia Syndrome (CACS). Aim: to provide current evidence and updates in management.	CACS care is provided by an interdisciplinary team of nurses, dietary specialists, physicians, pharmacists, social workers, and specialists in pain and symptom management.	Not reported.	Not reported.	Nurses can provide nutritional education alongside dietitians. They can provide patients and caregivers with practical and safe advice for feeding, education on dietary management and advice against fad diets and other unproven or extreme diets.	Education provided by nurses can contribute to achieving optimal nutritional care for patients with cancer cachexia.
Sato et al. (26) 2021 Japan	Scoping review	Cancer cachexia management. Aim: to identification of barriers to nursing practice in cancer cachexia	In multidisciplinary interventions for cancer cachexia, nurses play an essential role in supporting self-care by encouraging and motivating their patients to engage in interventions.	Communication of information about cachexia and its associated physical and psychosocial problems that can cause distress.	Communication of information about cachexia and its associated physical and psychosocial problems that can cause distress.	Nurses (and other healthcare professionals) can provide patients and caregivers with the necessary Information i) to understand the physical and psychosocial distress associated with cancer cachexia and, ii) to be aware of effective coping strategies.	The methodology of communication and educational interventions concerning cancer cachexia is not well developed. A practical guide is needed for aiding nursing management of cancer cachexia.
Zhao et al. (27) 2021 China	Narrative review.	Cancer cachexia management. Aim: to describe the nature, cause, manifestations, treatment and the role of nurse in the multidisciplinary	Interdisciplinary team, which includes nurses, is essential for cancer cachexia management. The nursing role includes, nutritional management, symptom-control, and metabolic management.	Education to teach patients skills for symptom management.	Education in nutrition and hydration as end-of-life approaches.	Nurses have the knowledge and expertise to talk with patients and families about nutrition and exercise. They can also provide psychosocial support to facilitate compliance. Nurses can teach skills for symptom management, such as,	Education as an important nursing role in the management of cachexia. Nurses are familiar with the health habits, socioeconomic statuses, and cultural mores of the patients they treat, which helps them to facilitate efficient communication that can help patients and their family carers to

		management of cancer cachexia.				<p>i) modification of food texture to mitigate the pain of oral mucositis,</p> <p>ii) energy conservation techniques to help with cachexia-related fatigue</p> <p>iii) offering e-counselling to facilitate skills in coping with symptoms of cancer cachexia.</p>	adapt to changes that accompany cancer cachexia.
IMPROVEMENT PROJECTS							
Author Date Location	Study design and sample	Study focus and aim	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Zhang et al. (28) China 2022	<p>Audit and feedback.</p> <p>30 patients pre and 30 patients post service improvement.</p>	<p>Cancer Anorexia–Cachexia Syndrome (CACS) management.</p> <p>.Aim: to implement an evidence-based practice in assessing and managing patients with</p>	<p>CACS care was provided by a multidisciplinary team who included, the department head nurse, clinical doctor, clinical nurse, nutrition nurse, pharmacist, psychologist, physiotherapist, senior dietitian, and social worker, who used a standardized CACS screening and assessment process.</p>	<p>Patients need to understand CACS and pre-improvement believed the information provided insufficient to help them better deal with cancer-related anorexia and weight loss.</p>	<p>Carers need to understand CACS and pre-improvement believed the information provided insufficient to help them better deal with cancer-related anorexia and weight loss.</p>	<p>The nutrition nurse, specialist nurse (and other team members) educated patients. The patient education programs, included strategies to be used for managing cachexia, health education, and home care of anorexia-cachexia. One-to-one bedside health education was supported by posters, health education prescriptions, and online videos uploaded to public websites.</p>	Not reported.
EXPERT OPINION							
Author Date Location	Source	Focus	Nurse role in multimodal management	Patient educational need	Carer educational need	Nurse-led education	Effect and/or author interpretation of impact from the nurse-led education
Granda-Cameron et al. (14) 2018 USA	Clinical experience.	<p>Clinical framework for quality improvement of cancer cachexia.</p> <p>Aim: to report a Cachexia Care Framework, based on experience of a cancer cachexia clinic over 10 years</p>	<p>Interdisciplinary model to assess and manage cancer patients at risk or with cachexia. Core team comprised physician, nurse practitioner, nutritionist, physical therapist, speech pathologist, and clinic assistant with support available from social worker, chaplain, and psychologist.</p>	<p>Team approach and holistic care for cachexia extending beyond the Cancer Appetite and Rehabilitation (CARE) Clinic.</p>	Not reported.	<p>A master's prepared Oncology Nurse Navigator role includes patient and carer education to overcome barriers to screening, intervention, and follow-up care for cachexia.</p>	<p>Cachexia Care Framework helps nurses to recognise, organise, and decrease barriers to cachexia care across its stages, to include the education needed by patients and carers. (Although the education role is acknowledged as important, it is not detailed.)</p>

FIGURE 1. FLOW OF INFORMATION THROUGH THE PHASES OF THE SEARCH

