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Title: Patients with established cancer cachexia lack the motivation and self-efficacy to undertake regular structured exercise.

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Compliance with Ethical Standards

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Conflict of interest

The authors have full control over primary data and allow the journal to review this if requested.

Ethical Statement

The study received ethical approval from the South East Wales Ethics Committee (REC Ref 11/WA/0178) and was sponsored by Cardiff University (Ref: SPON969-11). Informed consent was obtained from all individual participants included in the study.

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1 **Objectives**

2 Patients with advanced cancer frequently suffer a decline in activities associated with
3 involuntary loss of weight and muscle mass (cachexia). This **can profoundly affect** function
4 and quality of life. Although exercise participation can maintain physical and psychological
5 function in patients with cancer, uptake is low in cachectic patients who are underrepresented
6 in exercise studies. To understand how such patients' experiences **are associated with**
7 exercise participation we investigated exercise history, self-confidence and exercise
8 motivations in patients with established cancer cachexia, and relationships between relevant
9 variables.

10 **Methods**

11 Lung and gastrointestinal cancer outpatients with established cancer cachexia (n=196)
12 completed a questionnaire exploring exercise history and key constructs of the Theory of
13 Planned Behaviour relating to perceived control, psychological adjustment and motivational
14 attitudes.

15 **Results**

16 Patients reported low physical activity levels and few undertook regular structured exercise.
17 Exercise self-efficacy was very low with concerns it could worsen symptoms and cause harm.
18 Patients showed poor perceived control and a strong need for approval but received little
19 advice from healthcare professionals. Preferences were for low intensity activities, on their
20 own, in the home setting. Regression analysis revealed no significant factors related to the
21 independent variables.

22 **Conclusions**

23 Frequently employed higher intensity, group exercise models do not address the motivational
24 and behavioural concerns of cachectic cancer patients in this study. Developing exercise
25 interventions which match perceived abilities and skills are required to address challenges of
26 self-efficacy and perceived control identified. Greater engagement of health professionals with
27 this group is required to explore potential benefits of exercise.

28

29 **Background**

30 Patients with cancer frequently suffer a decline in daily activities, associated with involuntary
31 weight loss (in particular loss of muscle mass) and loss of appetite [1]. This syndrome of
32 cancer-related cachexia has profound effects on quality of life (QoL) for both patients and their
33 carers. The role of structured exercise in maintaining physical and psychological function has
34 been explored, with improved outcomes in cachectic patients with conditions such as chronic
35 lung disease [2], and in cancer patients undergoing active treatment [3]. There is growing
36 evidence of its importance in cancer survivors, with ongoing research exploring the impact of
37 exercise on cancer re-occurrence [4-6]. This data underpins the potential of exercise to reduce
38 the rate of decline in function in more advanced disease. The non-linear relationship between
39 muscle mass and function suggests that targeted intervention may be viable even in those
40 with established cancer cachexia.

41 Nonetheless there is evidence that patients with advanced cancer engage in very low levels
42 of physical activity [7]. To date, studies exploring the role of exercise in the advanced setting
43 have also been small and most often in patients well enough to attend centres for group
44 interventions. Payne's systematic review highlighted issues of attrition and poor adherence
45 [8]. Oldervoll et al. in a randomised controlled trial of supervised exercise found that patients
46 with incurable cancer reported high attrition particularly in those with less than one year
47 survival, and adherence of less than 70% [9]. A pilot study of neuromuscular electrical
48 stimulation in lung cancer patients undergoing palliative chemotherapy similarly identified
49 adherence problems [10]. Critically, patients with established cachexia represent a minority of
50 the participants in these studies and a Cochrane review of exercise for cancer cachexia
51 concludes that there is insufficient evidence to determine the safety and efficacy of exercise
52 in this patient group [11]. Studies of sufficient size and methodological quality are therefore
53 required to formally evaluate the role of exercise in sustaining daily activities in patients with
54 established cancer cachexia.

55 Successful completion of a pragmatic exercise intervention in patients with established cancer
56 cachexia is likely to depend on the practicality, acceptability and perceived benefits of the
57 exercise intervention [12]. The reasons for lack of engagement with physical activity in
58 cachectic patients are not well defined, nor is it clear whether they receive any advice on
59 exercise from their healthcare professionals. To overcome previous shortcomings and
60 develop sustainable and clinically meaningful interventions, better understanding is therefore
61 required of cachectic patients' beliefs around physical activity and their motivational
62 influences.

63 The Theory of Planned Behaviour (TPB) proposes that patient motivation to undertake an
64 intervention will be influenced by beliefs around expected benefit or harm (instrumental

65 attitudes), potential for enjoyment (affective attitudes) as well as attitudes relating to
66 anticipated difficulty (perceived control), and sense of support and approval of others
67 (subjective norm) [13]. There is a growing literature supporting the use of the TPB to explore
68 exercise behaviours in cancer patients [14, 15], and encourage the promotion and
69 sustainability of recovery in cancer survivors [16]. Although the TPB has been used to explore
70 physical activity behaviours in a small sample of palliative cancer patients [17] it has not been
71 formally used to explore wider patient behaviours in response to cancer related anorexia and
72 cachexia. Nonetheless affective attitude, perceived behavioural control and subjective norm
73 as social-cognitive constructs would appear highly relevant in examining the impact of the
74 cancer cachexia-anorexia syndrome (CACS) on individual behaviours. The psychosocial
75 impact of CACS is well described [17] where weight loss and change in physical appearance
76 can prompt feelings of stigmatization and of loss of control and self-efficacy [18]. The negative
77 impact on perceived control may be compounded by a sense of isolation [19] and conflict with
78 the perceived expectations of family [20] and healthcare professionals [21] in relation to eating
79 and physical activity. Use of the TPB model in a cancer cachexia population therefore offers
80 opportunity to examine social-cognitive correlates which may have wider applicability than
81 physical activity behaviours alone.

82 We have used these constructs as the basis of a study to examine how exercise history,
83 perceived self-efficacy and attitudinal factors interact in the context of established cancer
84 cachexia. We also wished to explore the effects of adjustment to illness and subjective norms
85 on preferences and potential barriers to exercise, specifically in those with primary
86 intrathoracic and gastrointestinal (GI) cancers which have a high incidence of advanced
87 presentation and weight loss.

88

89 **Methods**

90 **Participants**

91 Between September 2011 and December 2013, 200 patients were recruited from lung cancer,
92 GI cancer or palliative care clinics across Wales including South East, South West, Mid and
93 North regions. Adults with lung and GI cancer with a self-reported or recorded unintentional
94 weight loss of >5% or a BMI of <20 and any weight loss in the preceding six months were
95 recruited from an outpatient setting. Patients fulfilling these criteria at any stage of their
96 treatment plan were eligible. The study was approved by the South East Wales Ethics
97 committee, and all participants gave written informed consent.

98 **Questionnaire**

99 The questionnaire was developed by the co-investigators and utilised items from established,
100 validated questionnaires selected for their relevance to components of the TPB, patient health
101 status and physical activity. Patient functional impairment was assessed using the Karnofsky
102 Performance Status (KPS) scale which was adapted to be rated by the patients themselves
103 [22]. The KPS is widely used in oncology and palliative care settings to quantify cancer
104 patients' function in relation to daily activities, with a score from 100 to 0, where 100 reflects
105 normal functioning and health. Perceived Control as a construct influences lifestyle behaviours
106 including physical activity, exercise and health status factors [23]. This was assessed using
107 the Thompson's nine item scale that combines Likert scales with open questions to identify
108 any control strategies employed and their efficacy (Cronbach's α 0.69-0.88) [24, 25]. Higher
109 values indicate more use of and efficacy of control strategies. Psychological maladjustment
110 was assessed using the 20-point self-report scale (CES-D scale) originally developed by
111 Radloff and widely used [26]. Irrational Beliefs, indicative of the TPB themes, were measured
112 using the scale of Malouff and Schutte [27]. The 20-item instrument measures irrational beliefs
113 independent of emotional reactions that might be related to those beliefs with higher values
114 reflecting stronger perceived beliefs. The following subscales are included: Need for Approval;
115 Need For Achievement; Demands About Others/Other Rating; Awfulizing; Emotions Are
116 Externally Caused; Usefulness Of Being Concerned; Problem Avoidance; Importance of the
117 Past; Demands About Life; Discomfort Anxiety. Previous work has reported good internal
118 consistency (Cronbach's α =.80) [27].

119 Current confidence to exercise was assessed in three sections, firstly confidence linked
120 directly to the illness – i.e. 'I feel confident I can exercise without making symptoms worse'. In
121 the second and third sections, aerobic exercise (with a follow-up on intensity) and gentle
122 resistance exercise were assessed using self-efficacy scales [28]. Current exercise behaviour
123 was measured using two questions from the seven-day recall and lifespan exercise. These
124 were: On how many of the last SEVEN DAYS did you participate... a) in at least 10 minutes of
125 physical activity (e.g. gardening, cooking and walking)? b) a specific exercise session (e.g.
126 swimming, walking, and cycling) other than what you do around the house or as part of your work?
127 [28]. Advice from the patients' health care team was measured using a multiple response
128 question with, for example 'Get low level exercise (such as gardening, housework) on a daily
129 basis', available, and a free text option to describe any other exercise related advice. The
130 perceived benefit of exercise on their condition was assessed with an 8-item scale of known
131 links between exercise and patients with cancer. The list was derived from the ASCM literature
132 [29] on the effects of exercise cancer and item inclusion was based on expert opinions of four
133 of the research team. Preferences of with whom and where they would be willing to exercise
134 were examined. Barriers to exercise were assessed using ten items specific to their condition

135 obtained from Sechrist, Walker [30] Examples of the items used include 'too tired', 'fear' and
136 'breathlessness'.

137 Pilot testing of the questionnaire was conducted on 15 patients with cancer. Patients in the
138 pilot met the following criteria: clinically diagnosed with cancer, at least 18 years old, able to
139 read, understand and give informed consent. Where appropriate revisions to the structure,
140 response recording and administration were made. For the full study, all research nurses
141 involved in the administration and distribution of the questionnaires were trained by one of the
142 authors. Patients were approached in the outpatient setting. Following consent, they were
143 given the opportunity to complete the questionnaire in the outpatient clinic or at home. **The**
144 **research nurses did not record all patients approached who did not wish to take part,**
145 **therefore it is not possible to report the response rate.** All questionnaires were interviewer
146 administered with participants requesting variable degrees of support, with the duration for
147 completion lasting up to one hour. Considering patient condition and the length of the
148 questionnaire battery, respondents were provided the opportunity to complete it over two
149 periods. **There were no cases of patients taking this option.**

150 **Statistical Analysis**

151 Descriptive results are presented as means \pm standard deviation (SD), median, mode and
152 min/max values. Analysis of data showed that the data were not normally distributed; therefore
153 non-parametric summary data were reported. **Linear and** Logistical regression analysis **as**
154 **required by the nature of the independent variable** were conducted **on the** independent
155 variables: duration of cancer, total other conditions, **age, sex** and living alone. **These**
156 **independent variables were considered for their importance in the context of cancer**
157 **cachexia and relevance to exercise behaviours in other settings [14, 15, 32].** The
158 dependent variables were general perceived control, psychological maladjustment, irrational
159 beliefs, total barriers to exercise, total benefits of exercise and physical function.

160 **Results**

161 For the purposes of analysis, four participants were removed from the study due to significant
162 levels of incomplete data. The remaining questionnaires were completed by 93 patients with
163 GI cancer and 103 patients with lung cancer. Sample size in the analysis sections varied
164 where items were left blank. The range is from 182 to 196 when incomplete data was present.

165 General participant characteristics:

166 The mean \pm SD age of participants was 67 \pm 7 years with a 2:1 ratio of male to female
167 respondents of whom **79% cohabited.** More than half of participants (54%) reported at least
168 one other co-morbid condition of whom **34 had a joint related condition, 27 undergoing**
169 **treatment for a heart condition, 19 had hypertension, 15 diabetes and 12 had recent**

170 **surgery. The mean duration since diagnosis was 12.5 ±14.8 months and the distribution**
 171 **was positively skewed.** The most commonly self-reported performance score equated to
 172 Karnofsky of 70, reflecting an inability to work, but able to live at home with no or occasional
 173 support.

174 Exercise history:

175 The majority of the study population were inactive. Historically, the level of exercise
 176 participation decreased over time as would be expected, from the first decade of adult life from
 177 a mode of 'often' (16-25; mean activity = 4.3 ±1.17 on a 5 point Likert scale) with a taper of
 178 between 0.3 and 0.5 per decade over the lifespan. Typical involvement in the last decade was
 179 rated as 'seldom' (2.5 ±1.31) in the 112 participants with complete data between the age 16
 180 and 75.

181 Self-efficacy and perceived behavioural control:

182 General exercise over 10 minutes in duration was reported most frequently and appeared to
 183 be related to activities of daily living (ADL) rather than planned, structured exercise. Patients
 184 typically reported very low levels of self-efficacy in terms of ability to undertake either aerobic
 185 or resistance type of structured exercises with a score of 16% where 100% represents
 186 complete self-efficacy. Distributions in response to questions in relation to confidence in
 187 exercising were skewed. The median and mode values are reported (Table 1) as they reflect
 188 important information on the perceived confidence of participants. While the average response
 189 to being 'unable to exercise unless feeling like it' tends towards the middle of the scale, the
 190 mode indicated most respondents were strongly in agreement with this statement. The same
 191 pattern was observed in the question about confidence to 'exercise several times a week'.

192 Table 1: Confidence to exercise and amount of exercise reported

	N	Mean	SD	median	mode	Min	Max
Cannot exercise unless I feel like exercise*	196	3.90	2.00	4	6	1	6
I can exercise several times a week*	196	3.41	2.06	3	1	1	6
I feel confident I can exercise without making symptoms worse*	196	3.42	2.02	4	1	1	6
Number of days with at least 10 minutes of general exercise	192	5.02	2.76	7	7	0	7
Number of days with a specific exercise session	192	1.97	2.73	0	0	0	7

193 Notes: * range of response 1 (strongly disagree) - 6 (strongly agree)
 194

195 There was also a trend in relation to anticipated difficulty of exercise where the majority (64%)
 196 only felt able to undertake 'light' activity rather than moderate (slightly out of breath) – 31%) -

197 or high (very out of breath and sweating) levels. This perception is markedly out of keeping
 198 with the moderate to high intensity levels prescribed in many current exercise studies.
 199 More generally, the median score for perceived control over emotional and physical symptoms
 200 and relationships was 4.5 out of a maximum of 6 indicating reasonable control, although
 201 control over medical care and progression of the disease was lower (Table 2). **Linear and**
 202 **logistical regression analysis** revealed no significant factors related to the independent
 203 variables.

204 Table 2: Descriptive data of the key factors

Factor	N	Mean	SD	Median	Min	Max
Karnovsky*	200	66.8	10.5	70	20	80
Perceived control #						
- General Perceived control	196	4.06	1.99	4.50	0.00	6.00
- Emotional and physical symptoms	196	4.37	1.92	4.50	0.00	6.00
- Relationships	196	3.98	1.96	4.50	0.00	6.00
- Medical care	196	3.64	1.88	3.75	0.00	6.00
- Progression	196	2.25	2.15	1.75	0.00	6.00
Total Perceived control of emotional and physical symptoms ^f	196	14.24	5.57	14.08	0.00	24.00
Psychological Maladjustment ^{ff}	196	14.88	10.50	13.00	0.00	52.00
Irrational beliefs – Total [¥]	186	57.82	16.01	57.50	23.00	94.00
- Need for approval ^{¥¥}	195	6.48	2.61	6.00	2.00	10.00
- Need for achievement	195	5.77	2.72	6.00	2.00	10.00
- Demands about others	188	4.20	2.61	3.00	2.00	10.00
- Awfulizing	195	5.07	2.49	5.00	2.00	10.00
- Emotions are externally caused	194	5.37	2.38	5.00	2.00	10.00
- Usefulness of being concerned	195	7.10	2.37	8.00	2.00	10.00
- Problem avoidance	195	4.56	2.19	5.00	2.00	10.00
- Importance of the past	195	6.27	2.70	6.00	2.00	10.00
- Demands about life	194	6.20	2.72	6.00	2.00	10.00
- Discomfort anxiety	194	6.67	2.70	7.00	2.00	10.00

205 Notes: * = range 20 (limited daily living function) to 80 (high daily living function); # = range 0 (no control and not effective) – 6
 206 (high control and effective); ^f = range 0 (no control and not effective) – 24 (high control and effective); ^{ff} = range 0 (low
 207 maladjustment) – 52 (high maladjustment); [¥] = range 23 (low) – 94 (high);; ^{¥¥} = range 2 (strongly disagree) – 10 (strongly agree).

208 Expected benefits, perceived barriers and approval of others:

209 Participants were asked several questions in relation to the perceived effects of exercise on
 210 their cancer and symptoms. They expressed strong reservations about the statement relating
 211 to ‘exercise not making symptoms worse’. In keeping with concerns that exercise might
 212 negatively affect symptoms, only a minority of patients felt that structured exercise would
 213 reduce the effects of their cancer. This resonates with their low perceived control over their
 214 illness. The most common perceived benefits of exercise related to improvements in mood,
 215 appetite and cognition (Table 3). Although participants identified a strong need for approval,

216 they reported receiving very limited exercise advice from healthcare professionals, with 69%
 217 of patients reporting receiving no advice at all. Those who did get advice were typically told to
 218 do low intensity exercise.

219 In keeping with participant concerns of negative effects on symptoms and perceived difficulty,
 220 the most commonly perceived barriers to exercising were symptoms of fatigue (n=99, 51%),
 221 breathlessness (n=76, 39%) and the presence of other health conditions.

222 Table 3 summarises preferences for place of exercise, and with whom participants would like
 223 to undertake structured activity. In keeping with previous reports[31], the majority wished to
 224 undertake exercise at home rather than in institutional settings or with other patients. Although
 225 31% of participants would be happy to exercise with partners or friends, the preferred option
 226 was to exercise alone, despite concerns over symptoms and their low perceived self-efficacy
 227 with all exercise types.

228 Table 3: Perceived benefits and location and social factors of exercise preferences

Factor	Item	No	Yes	% Yes
Benefit of PA*	Limit the effect of cancer	141	55	28
	Think better	72	124	63
	Stay more alert	67	129	66
	Improve mood	66	130	66
	Help socialize	92	104	53
	Improve appetite	67	129	66
	Help me do/maintain tasks	59	137	70
Location Preference*	At home	44	152	78
	Fitness centre	170	26	13
	Hospital	170	26	13
	Day centre	173	24	12
	Community Hall	176	20	10
With Whom*	Other patients	155	41	21
	Friends	134	62	32
	On my own	75	121	62
Barriers#	No point	183	12	6
	Family concern	176	19	10
	Afraid	168	27	14
	Would be tiring	96	99	51
	Too expensive	184	11	6
	Too much pain	144	51	26
	Too tired	99	96	49
	Out of breath	119	76	39
	Don't know where to	186	9	5
	No transport	186	9	5
Don't like	174	21	11	

229 Note: * n = 196; # n = 195

230

231 **Discussion**

232 This questionnaire study uniquely captures information on the attitudes and perceived control
233 which influence motivation to exercise in a large cohort with established cancer cachexia. The
234 importance of instrumental and affective attitudes on exercise participation has previously
235 been described in cancer patients [32], but their nature and strength in the cachectic
236 population has not previously been explored in detail.

237 Our study was undertaken with 200 lung and upper GI patients. Despite the presence of
238 cachexia they described themselves as largely independent and able to self-care. Yet as a
239 group they are significantly under-represented in published studies, and even in palliative
240 contexts interventions are being increasingly targeted at earlier stages of the patient pathway
241 [9]. Understanding the desirability of physical activity, and what influences the strength of
242 patients' intention to undertake exercise, will guide clinical practice in helping to maintain
243 independence and inform the design of future studies in this patient group.

244 Our results demonstrate a lack of self confidence in the ability to undertake exercise and a
245 strong belief that even moderate intensity exercise would be too difficult. This is reflected in
246 an exercise history which declines consistently from the first adult decade to a point where the
247 majority describe only low levels of informal activity.

248 The lack of perceived control is compounded by concerns that regular exercise could make
249 symptoms worse and a lack of belief that it would positively influence the course of their
250 cancer. Although approval of others also appears to be an important concept for this patient
251 group, the majority would prefer to undertake exercise at home and alone. All of this contrasts
252 with common intervention designs in cancer studies, which tend towards group based and at
253 least moderate intensity interventions [9, 33] and underscores the challenges for tailoring
254 regimens to the individual, as advised in American College of Sports Medicine Guidelines [34].

255 **Clinical implications**

256 Our results highlight key elements which need to be addressed to improve participation in
257 exercise activities as part of clinical care, with important lessons also for the design of studies
258 involving this particular patient group. Firstly, the perceived lack of benefit of exercise and
259 concerns regarding harm require engagement from healthcare professionals. Tellingly, most
260 participants (69%) reported receiving no advice on exercise from their clinicians. In a UK study
261 Williams et al. surveyed 460 multi-professional cancer clinicians and found that they offered
262 lifestyle advice to less than 50% of their patients [35]. Puhlinger et al. identified several barriers
263 for clinicians including lack of expertise, time and support infrastructure [21]. Although lack of
264 robust data supporting benefits of exercise in the cachectic cancer patient is likely to impact
265 on clinician behaviours, focused education on the wider potential of planned exercise activities

266 to improve outcomes [36, 37], and on identifying the specific concerns of this patient group,
267 may help empower individual patients to engage [38].

268 Secondly, self-efficacy has been shown to be a stronger predictor of physical activity in cancer
269 patients [39]. Direct involvement of patients in co-production of planned, structured exercise
270 activities is required to address the attitudinal and self-efficacy challenges described. Studies
271 in other conditions have suggested that patients are more likely to engage in interventions
272 which match their previous skills and abilities and minimise disruption to daily life [40]. Our
273 patient group indicated a preference for low intensity activity which may explain poor
274 adherence to institutionally based, moderate intensity, group exercise [9]. Identifying
275 interventions of lower intensity, which relate more to activities of daily living and build on
276 previous abilities would positively impact on perceived control, associated with a greater
277 chance of achieving behaviour change [41]. This may inform the goals and outcome measures
278 which are of most relevance to participants. Thirdly, more understanding is required of the
279 type of supervision most likely to support adherence in clinical and research contexts.
280 Identifying the type of instructional content and feedback that would enable, strengthen and/or
281 maintain exercise intent is required, balanced against the desire for privacy and home based
282 approaches. Fourthly, our results highlight the importance of prior understanding of the beliefs
283 influencing exercise preferences in cancer cachexia in allowing comparison between
284 randomised groups within research studies. This may help minimise bias as previously
285 described in other settings [32].

286 **Limitations**

287 The strengths of our study include the recruitment of a large participant group with established
288 unintended weight loss across different geographical settings, and the use of validated
289 questionnaires reflecting a validated theoretical model of understanding patient preferences.
290 The limitations of the study include the cross-sectional nature with the inclusion of patients at
291 varied stages of treatment, using responses based on patient recall, and use of a researcher-
292 administered questionnaire set which might influence responses.

293 **Conclusion**

294 In summary, this study of 196 evaluable patients with cancer cachexia demonstrates the
295 significant concerns they have in relation to the impact of exercise on both symptoms and their
296 cancer, and their low levels of confidence and self-efficacy in relation to structured exercise.
297 Compounding this is a lack of advice and empowerment from their healthcare providers. This
298 may help explain why patients with established cancer cachexia are under-represented in
299 studies of exercise interventions, frustrating attempts to address clinical uncertainty on their
300 effects in this patient group. These findings have important implications for clinical practice

301 and for future research designs, making common models of exercise in group settings difficult
302 to realise in this population group. We suggest a more consistent approach to involving
303 patients with established cachexia in exercise studies, with a greater emphasis for that
304 subgroup on patient designed, structured activity models which address the specific attitudinal
305 and self-efficacy concerns highlighted here.

306

307

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