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A pilot randomised controlled trial of a multimodal supportive care (ThriverCare) intervention for managing unmet supportive care needs in men with metastatic prostate cancer on hormonal treatment and their partner/caregivers

Original Research

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Running Head: A multimodal supportive care intervention

Key words: Supportive Care; Patient Reported Outcomes; Metastatic Prostate Cancer; Intervention; Randomised Controlled Trial; Unmet Needs, Partner/Caregivers

Abstract

Purpose: Men with metastatic prostate cancer experience high levels of unmet supportive care needs in current healthcare delivery. We set out to determine the effectiveness of a multimodality supportive care (ThriverCare) intervention on the prevalence of unmet supportive care needs for men and their partner/caregivers.

Methods: A prospective parallel group, pilot randomised controlled pilot trial in 4 hospitals in Scotland. 38 participants with radiologically proven metastatic prostate cancer disease and 10 partners/caregivers were recruited into the study. A two arm 1:1 study design compared the usual standard of care (SC) approach to SC plus ThriverCare intervention. The primary outcome was the Supportive Care Needs Survey at 3 months of intervention.

Results: There was no statistical significant difference in the prevalence of unmet supportive care needs between the intervention group and the usual SC group at baseline p=0.112, however a statistically significant difference was observed at 3 months, indicating that the prevalence of unmet supportive care needs were less in the intervention group (1.13, SD 2.5) compared to the usual SC (6.17, SD 7.05), p=0.002.

Conclusion: ThriverCare appears to improve the supportive care experience of men with metastatic prostate cancer on hormonal treatment and their partner/caregivers. Our results accentuate that no longer one size of care delivery fits all, care must be responsive and adaptable to meet the individual needs of people affected by cancer to thrive.

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Introduction

Androgen deprivation therapy (ADT) for metastatic prostate cancer remains the mainstay of treatment and has been proven to be effective in controlling disease (Sternberg et al., 2013). The majority of men face a range of physical and psychological problems that can have a profound decrement on quality of life and exacerbate the need for supportive care (Cockle-Hearne et al., 2013; King et al., 2015; Paterson et al., 2017; Watson et al., 2016). The treatment specific side effects include hot flushes, osteoporosis, fatigue, sexual dysfunction, changes in muscle mass, adiposity, and psychological effects such as, mood disturbance, cognitive impairment, difficulties with self-image and masculinities (Fitzpatrick et al., 2014). Men affected by metastatic prostate cancer are likely to have a long illness pathway, as well as the individual burden to patients and their partner/caregivers with the associated side-effects, and this represents a burden on healthcare resources internationally (Carter et al., 2011; Chambers et al., 2018; Paterson et al., 2015a; Paterson et al., 2017).

Systematic reviews in the area of unmet supportive care needs in men affected by prostate cancer underscore that many can experience on-going and unresolved concerns related to psychological needs, managing physical side-effects and a lack of information and support (Chambers et al., 2018; King et al., 2015; Paterson et al., 2015b). Moreover, recent evidence acknowledges that current delivery of care is failing to provide a person-centred model of supportive care for men and their partner/caregivers affected by metastatic prostate cancer (Chambers et al., 2018; Paterson et al., 2017). National and international cancer reforms (McCabe et al., 2013) recognise that men affected by metastatic prostate cancer continue to experience a range of complex unmet supportive care needs even in twenty-first century healthcare (Carter et al., 2011; Chambers et al., 2018; Paterson et al., 2017).

Supportive care needs are defined as requirements for care arising during treatment and illness to manage symptoms and side-effects, enable adaption and coping, optimise understanding and informed decision-making, and minimise decrements in functioning (Hui, 2014). Supportive care is a person-centred approach to the provision of the necessary services for those living with or affected by cancer to meet their informational, spiritual, emotional, social, or physical needs during diagnosis, treatment, follow-up and into survivorship (Hui, 2014). One approach to quality of life evaluation that assesses supportive care requirements is needs assessment (Bonevski et al., 2000). A large body of evidence now exists which focusses on the prevalence of unmet supportive care needs in men with prostate cancer (Cockle-Hearne et al., 2013; King et al., 2015; Paterson et al., 2017; Primeau et al., 2017; Watson et al.,

2016), including those with metastases on ADT (Chambers et al., 2018; Paterson et al., 2017; Primeau et al., 2017) but little or no evidence has been reported to address possible interventions (McCabe et al., 2013; Watson et al., 2016). An innovative pilot multimodal supportive care intervention, called ThriverCare (Paterson et al., 2017; Primeau et al., 2017) was designed in the present study and tested through a pilot randomised controlled trial. Thrivercare was informed by the Prostate Cancer Model of Consultation as the underpinning theoretical study model (Paterson and Nabi, 2016). ThriverCare was developed to address unmet care need concerns, normalise follow-up treatment experience, and move beyond prostate cancer survivorship to cancer thrivership (Weiner et al., 2005). This pilot randomised controlled study aimed to provide supporting evidence for the acceptability and usefulness of the ThriverCare intervention for patients and their partners/caregivers affected by metastatic prostate cancer compared to the usual standard of care.

Hypothesis

We tested the hypothesis that the ThriverCare intervention would improve 1) supportive care needs, 2) psychological outcome, 3) health-related quality of life and 4) self-efficacy in comparison to patients and their partner/caregivers receiving the usual standard of care.

Patients and Methods

Design

This was a pilot parallel randomised controlled trial conducted according to the Consolidated Standards of Reporting Trials (CONSORT) statement guidelines (Schulz et al., 2010).

Participants

Eligible participants were diagnosed with metastatic prostate cancer on primary androgen deprivation therapy (ADT), aged 18 years or over, self-assessed written and verbal English proficiency and, able to provide written informed consent. Radionuclide bone scan/computed tomography (CT) scan or magnetic resonance imaging (MRI) confirmed metastatic disease in all the participants.

Exclusion criteria were: men lacking inclusion criteria, men with dual cancer and those on chemotherapy or following relapse of disease.

Setting

The study was undertaken at four hospitals in Scotland from March 2016 to April 2017. The healthcare provision serves a geographical area which consists of a predominantly rural and urban population of white ethnicity (405,721) published by the General Register Office for Scotland. The study had NHS Ethical approval (16/ES/0024).

Sample Size

The consortium design of study is shown in **Figure 1**. As pilot trials do not have the same objectives as a main trial, setting the sample size in the same way by utilising a formal power calculation is not appropriate (Whitehead et al., 2016). However, we carefully considered the optimum sample size justification for the pilot study using guidance from (Billingham et al., 2013; Whitehead et al., 2016). For the main trial designed with 90% power and two-sided 5% significance, we followed a pilot trial sample size of 25 per treatment arm for a standardised small effect size (0.2).

Recruitment Process

Patients were randomly assigned 1:1 to either usual standard of care (SC) or SC plus ThriverCare, see **Figure 2**. Block randomization was used to reduce bias and was generated in a permuted block design (Kang et al., 2008). Participants were randomly assigned and notified of allocation after completion of consent and baseline study questionnaires. As active patient participation is required as part of the intervention, a traditional single-blind (i.e. patient level) or double-blind RCT (i.e. patient and investigator level) was not deemed feasible in the context of this pilot study. To mitigate the adverse effects of blinding bias, the patient information sheets were designed to avoid any reference to the 'intervention group' or 'control group'. Patients were only informed that they were randomly allocated to one of two different methods of supportive care delivery.

Intervention Group: ThriverCare

The intervention was developed using the Medical Research Council Framework for complex interventions (Craig et al., 2008) and the six steps in quality intervention development (6SQuID) (Wight et al., 2015). The intervention was informed by the Prostate Cancer Model of Consultation (Paterson and Nabi, 2016) and comprised four main components: 1) informational materials, 2) holistic needs assessment, 3) individualised self-management care plans, and 4) group-based seminar. The

intervention and associated materials were developed in consultation with multidisciplinary healthcare experts involved in prostate cancer and patient's representatives.

Informational materials

Participants were provided with a custom-made evidence-based self-management booklet entitled "*A Prostate Cancer Guide to Thrivership: Men it is time to Thrive*" (Supplementary Information). The information booklet covered the following general topics: how to self-care, managing side-effects of ADT, nutrition and exercise, relationships and sexual well-being, healthy lifestyle approaches and community-based support resources.

Holistic Needs Assessment

An individualised, nurse-led face-to-face session was conducted across the four hospitals at baseline and at three months. Patients and their partners/caregivers completed the Macmillan's Holistic Needs Assessment (HNA) questionnaire (Doyle and Henry, 2014) ten minutes before the nurse-led session, at baseline and at three months. The HNA questionnaire information was then directly used in the consultation to tailor individualised self-management care plans of each patient and their partner/caregiver. The consultation included the discussion of concerns/problems, determining an individualised strategy with realistic goals and expectations which could be incorporated into daily life. Consultation sessions were concluded by summarising the main issues, making necessary referrals and appointments for follow-up including open door access using emails.

Self-management care plans

Self-management care plans were formatted as written documents provided to the participants at the end of the discussion of the HNA in the nurse-led session. Further copies of the care plans were provided to the General Practitioner and filed in the patients' medical case notes, for quality assurance. The Prostate Cancer Model of Consultation (Paterson and Nabi, 2016) and evidence based guidelines for nurse-led survivorship care (Paterson et al., 2015a) were used to support the development of shared self-management care plans. The prostate cancer care model (Paterson et al., 2015a; Paterson and Nabi, 2016) enabled standardization of evidence-based self-management interventions for precise intervention content. The nurse-led session took place in an out-patient hospital clinic room and lasted approximately 30 minutes.

Group-based seminar

The self-management seminar included the following topics: 1) introduction to ADT and potential side-effects, 2) self-managing side-effects, 3) managing emotions and mind changes, 4) erectile dysfunction and relationships, 5) nutrition and exercise, 6) finance and benefits, 7) relaxation and stress management, and 8) sign-posting to community-based services and open question session (**Figure 3**). The seminar was led by a senior prostate cancer specialist nurse, physical activity instructor and a trained counsellor.

Standard of care/control group: Patients in the control group received the usual standard of care as was offered at the hospitals or by their usual clinicians. This involved baseline and three monthly outpatient clinic review and does not include any elements of the ThriverCare intervention.

Data collection

All participants completed the baseline questionnaires on the day of randomization and one further questionnaire three months later. The outcomes measures at baseline and at three months were administered by a research assistant not involved in the intervention delivery. Thirty-three semi-structured interviews were conducted to explore their experience of supportive care and these data have been published elsewhere (Primeau et al., 2017).

Clinical and demographic data

Demographic and clinical data were collected at the start of the study and included: age, marital status, socio-economic (Scottish Index of Multiple Deprivation), employment status, diagnosis, stage of disease, prostate specific antigen (PSA), Gleason score, length of time since diagnosis, treatment, and existing co-morbidities. Only demographic data was collected from partners/caregivers.

Outcome measures

All self-report standardized outcome measures were psychometrically validated, responsive, acceptable, and have been used in this patient population.

Primary outcome

Unmet supportive care needs

Supportive Care Needs Survey (SCNS-SF34) is a multidimensional self-report questionnaire that evaluates 34 patient needs that fall under the following five domains: health system and information, psychological, physical and daily living, patient care and support, and sexuality.

Secondary outcomes

Self-efficacy

Self-management Self-Efficacy Scale (SE Scale) provides an assessment of participant's belief and confidence to perform their self-management. Self-efficacy is a general term used to describe the belief that one can perform a novel or a difficult task, or cope with adversity in various domains of human functioning.

Health-related quality of life

EORTC Quality of Life (QLQ C30) *and* (PR25) is an integrated measurement system for quality of life in cancer participants.

Psychological outcome

Hospital Anxiety and Depression Scale (HADS) assesses anxiety and depression in non-psychiatric patients.

Statistical approach

All analyses were conducted in SPSS Statistics for Windows version 21.0 (IBM Corp., http://www-03.ibm.com/software/products/en/spss-statistics). Descriptive statistics were used to summarize outcome measures, baseline demographic and clinical characteristics of patients randomized to each study arm. Prior to the analysis, variables were examined for accuracy of data entry, missing values and the assumptions of the proposed analysis. Basic exploratory statistical analysis of *indicative findings* was undertaken to characterise the cohort (Tabachnick and Fidell, 2007).

Results

Of the 73 patients approached to take part in the study, 25 declined participation. There was a statistically significant difference in age between the consented group 75 years (SD 5.9) and non-consented group 84 years (SD 6.6) $p<0.01$. Moreover, we did not observe any statistically significant difference in the duration of ADT or time since diagnosis between the two groups $p>0.05$. The reasons for declining participation included: a lack of time due to being a main carer, dislike of completing questionnaires, patients reported that they felt too old, and too much going on with treatment, see **Figure 1** for Consort diagram.

There were no statistically significant differences in age, employment, Gleason score, number of co-morbidities, PSA levels between the intervention and standard of care groups, see **Table 1.** We observed a statistically significant difference in socio-economic ($p=0.048$) and marital status ($p=0.005$) between the intervention and control groups, but overall the characteristics were well-balanced between the two groups. Time since diagnosis ranged from seven to 56 months.

Primary outcomes

There was no statistically significant difference in the prevalence of unmet supportive care needs between the intervention group and usual SC group at baseline ($p=0.112$). A statistically significant difference was observed at three months, indicating that the prevalence of unmet supportive care needs were less in the intervention group (1.13, SD 2.5) than compared to usual SC (6.17, ± 7.05) $p=0.002$ shown in **Figure 4**. The most common unmet supportive care needs identified through baseline evaluation included physical symptoms such as fatigue (18.8%), pain (16.7%), fear of the cancer spreading (27.1%), uncertainty of the future (29.2%), anxiety of death and dying (18.8%), changes in sexual feelings (23.0%), worries and concerns of those closest to you (29.9%), more choice about which cancer specialist you would like to see (25.1%), lack of self-management advice (23.0%), unmet informational needs (18.8%) and not being informed of test results (22.9%).

We observed the greatest improvements in the following domains of unmet needs following the ThriverCare Intervention at three months (**Table 2**): physical symptoms (pain 0%, fatigue 7.7%), fear of the cancer spreading (7.7%), fear of death and dying (0%), changes in sexual feelings (7.7%), concerns of those closest to you (7.7%), more choice about which cancer specialist you see (0%), informational

needs (0%), self-management advice (0%), and being informed of test results as soon as is feasible (7.7%). In the control group 205 unmet supportive care needs were reported, and 14 unmet needs in the intervention group at three months, noteworthy all the unmet needs in the intervention group were scored as "low unmet need" (**Table 2**).

Secondary outcomes

No statistically significant differences were observed between the two groups with regards to, or within group score changes on self-efficacy (p=.212), anxiety (p=.101), depression (p=.489) and health related quality of life (p=.886) over time (**Table 1**).

Discussion

A significant proportion of men affected by metastatic prostate cancer encounter a broad scope of concerns and unmet needs, despite ongoing follow-up care in a range of international counties which include Australia, UK, and Canada (Carter et al., 2011; Chambers et al., 2018; Paterson et al., 2017; Paterson et al., 2015b). To our knowledge, this is the first pilot RCT study that compared a multimodal supportive care (called ThriverCare) intervention for men and their partners/caregivers and compared this to the usual SC. We hypothesized that the intervention would reduce unmet supportive care needs, improve quality of life, reduce anxiety and depression and improve self-efficacy. Our primary outcome was supportive care needs. We observed a statistically significant main group effect on the prevalence of unmet supportive care needs over time, in favour of the ThriverCare intervention. Integrating the evidence-based seminar with the use of Holistic Needs Assessment (HNA) questionnaires in clinical practice permitted a tailored, personalised model of care and targeted self-management plans. Areas of supportive care which demonstrated the most improvement included physical symptoms, existential concerns (fear of death), choice of which cancer specialist patients see, informational needs and self-management advice was observed at three months in the intervention group. Supportive interventions which incorporate direct interaction with specialist healthcare professionals and feature individually tailored self-management have shown promise in improving patient outcomes elsewhere (Bourke et al., 2012; Menichetti et al., 2016; Parahoo et al., 2015) but our study is the first to demonstrate a direct improvement on the prevalence on unmet supportive care needs in patients with metastatic prostate cancer.

The intervention did not have any impact on secondary outcomes which included, health-related quality of life, anxiety and depression, or self-efficacy over time. While self-efficacy is a prevalent construct used in existing intervention studies, it has inconsistent outcomes (Hofman, 2013). Very few studies (Moore et al., 2015) that have incorporated self-efficacy reported that self-efficacy was not affected by, or could explain the intervention effect; similar to the indicative findings in the current study. Moreover, our results are in keeping with other supportive care interventions in prostate cancer populations, in so far that they also did not demonstrate any changes in health-related quality of life or psychological outcome scores (Carmack Taylor et al., 2004; Northouse et al., 2007). Reasons for no statistically significant improvements in these outcomes remains unknown and may need further exploratory studies in this area (Primeau et al., 2017).

Patients are increasingly completing standardised patient reported outcome (PRO) questionnaires about their symptoms, functioning, well-being, supportive care needs and these PRO data are being used along with other clinical information to screen for conditions, monitor progress, and inform patient management (Greenhalgh, 2009; Jensen et al., 2014). Unmet needs of people affected by cancer often mediate a poorer quality of life, including greater physical impairment and symptom burden, anxiety and depression, and persistent supportive care requirements over time (King et al., 2015). These consequences may be under-recognized and under-treated in oncology practice and this was evident in the standard of care group in the present study. Globally, cancer organizations have published supporting recommendations about the pilot and beneficial effects of using PROs in routine clinical practice (Abernethy et al., 2010) which underpinned our intervention design.

A number of studies have examined the clinical utility of PRO holistic needs assessment (Bonevski et al., 2000). To the best of our knowledge, this is the first pilot RCT to demonstrate an improvement in supportive care experience for men affected by metastatic prostate cancer through the use of PRO HNA's in clinical practice, elsewhere studies are currently on-going (Snowden et al., 2015; Stanciu et al., 2015) . As a strengthen to our study, we implemented the Prostate Cancer Model of Consultation as part of the HNA process (Paterson and Nabi, 2016) which enabled precise standardization of evidence-based self-management interventions tailored to the individual area of need. Arguably, the completion of HNAs questionnaires in clinical practice alone, are of no benefit or can worsen unmet supportive care needs experience, if the clinician does not discuss the unmet needs information documented in the consultation, or if the clinician does not have access to precise evidence-based self-management

interventions to support or advice the patient appropriately. A methodological limitation of studies elsewhere (Snowden et al., 2015; Stanciu et al., 2015) is that they do not clearly evidence the standardization of the intervention content following the completion of the HNA. Inevitably, this will create the opportunity for bias because healthcare professionals vary in experience, knowledge and expertise in their ability to develop shared self-management plans to address unmet physical, emotional, spiritual, environmental, social, sexual, financial and cultural needs.

A statistically significant difference was observed for marital status and socio-economic status between the intervention and control group, which may have affected supportive care, for example, the informal care provided by the spouse. However, this seems unlikely as there was no statistically significant difference in the prevalence of unmet supportive care needs between the intervention and control group at baseline. Furthermore, there was no statistically significant difference in co-morbidities between the two groups, as we recognise multiple health conditions might increase the need and provision for supportive care (Holm et al., 2014). Regardless of the clinical characteristics and time since treatment, we observed men with metastatic prostate cancer in the control group continued to experience a range of unmet supportive care needs at a follow-up of three months related to, physical and psychological problems, fear of cancer spreading, uncertainty of the future, intimacy and sexual needs, and a lack of personalised holistic care, in keeping with the existing evidence base (Carter et al., 2011; Chambers et al., 2018; King et al., 2015; Paterson et al., 2015b).

One of major findings of this pilot RCT study is that through targeting self-management plans to individual needs is one of the most important issues to be considered. Broad targeting interventions are at risk of including men with dissimilar needs, which can affect intervention adherence, study attrition and dilute effect. Men's needs will inevitably differ across the disease, with emotional distress and uncertainty of the future being most salient around the time of diagnosis, and symptom problems and self-management critical during treatment. We argue, optimising supportive care can be achieved by tailoring interventions informed by the ThriverCare to identify individual needs/concerns and address each patients requirements individually (Paterson and Nabi, 2016). Individual needs and concerns will differ in terms of social support, education, economic status, religion, and ethnicity, and such factors should also be taken into account explicitly in targeting and evaluating outcomes (Paterson and Nabi, 2016).

The participation rate into the trial was 67% and similar to other studies in this patient group. However, we observed a statistically significant difference in age between the consent and non-consents groups. Typically, clinical trials conducted in the adult population include patients between the ages of 18 and 65 years, and often elderly patients over >65 years are poorly represented. Our study highlights some of the issues which elderly people with metastatic disease expressed as reasons for non-participation into the trial. Time restraints, social circumstances, age and physical activities were important barriers to the participation in the present study.

Several limitations are worth noting. First, the study had a small sample size and limited follow-up. Second, we lacked information on the actual self-management behaviours performed by participants and how this impacted upon their experience of supportive care. Third, this study was biased in favour of white participants and as a result, some caution should be taken in the interpretation of these findings and requires the study to be replicated with a larger multi-centre sample, and men from minority groups to be equally represented.

Conclusion

This study has demonstrated that the novel ThriverCare intervention for men and their partners/caregivers affected by metastatic prostate cancer improves the prevalence of unmet supportive care needs over time. This should inform management and care planning of men with metastatic disease on androgen deprivation therapy. Future studies in other tumour groups should carefully consider targeting individuals with significant issues or unmet needs to strive to deliver a model of care that is individualised and flexible. Our results accentuate that no longer one size of care delivery fits all, care must be responsive and adaptable to meet the individual needs of people affected by cancer to thrive.

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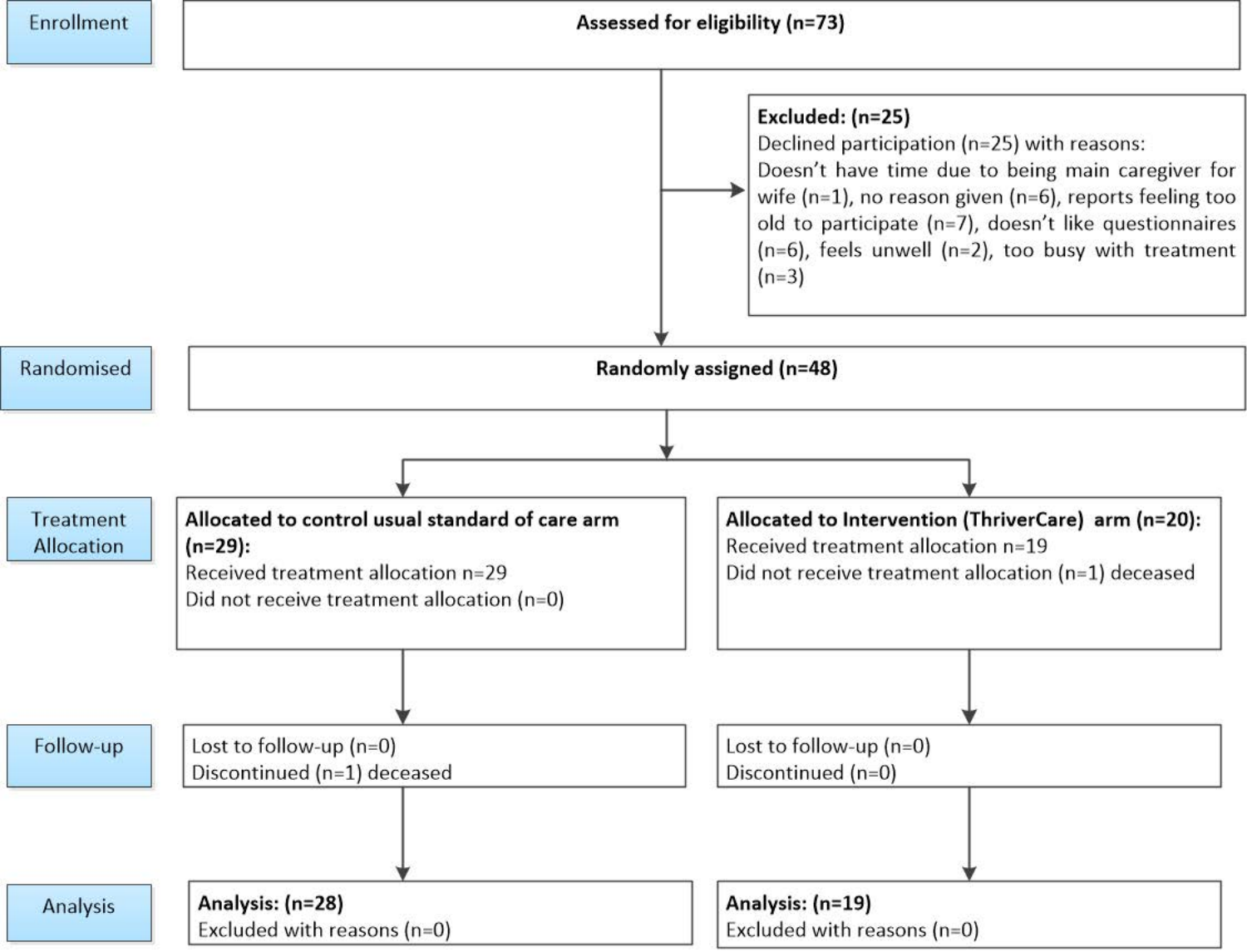


Figure 1. Flow diagram of the progress through the phases of a parallel randomised trial of two groups (that is, enrolment, intervention allocation, follow-up, and data analysis)

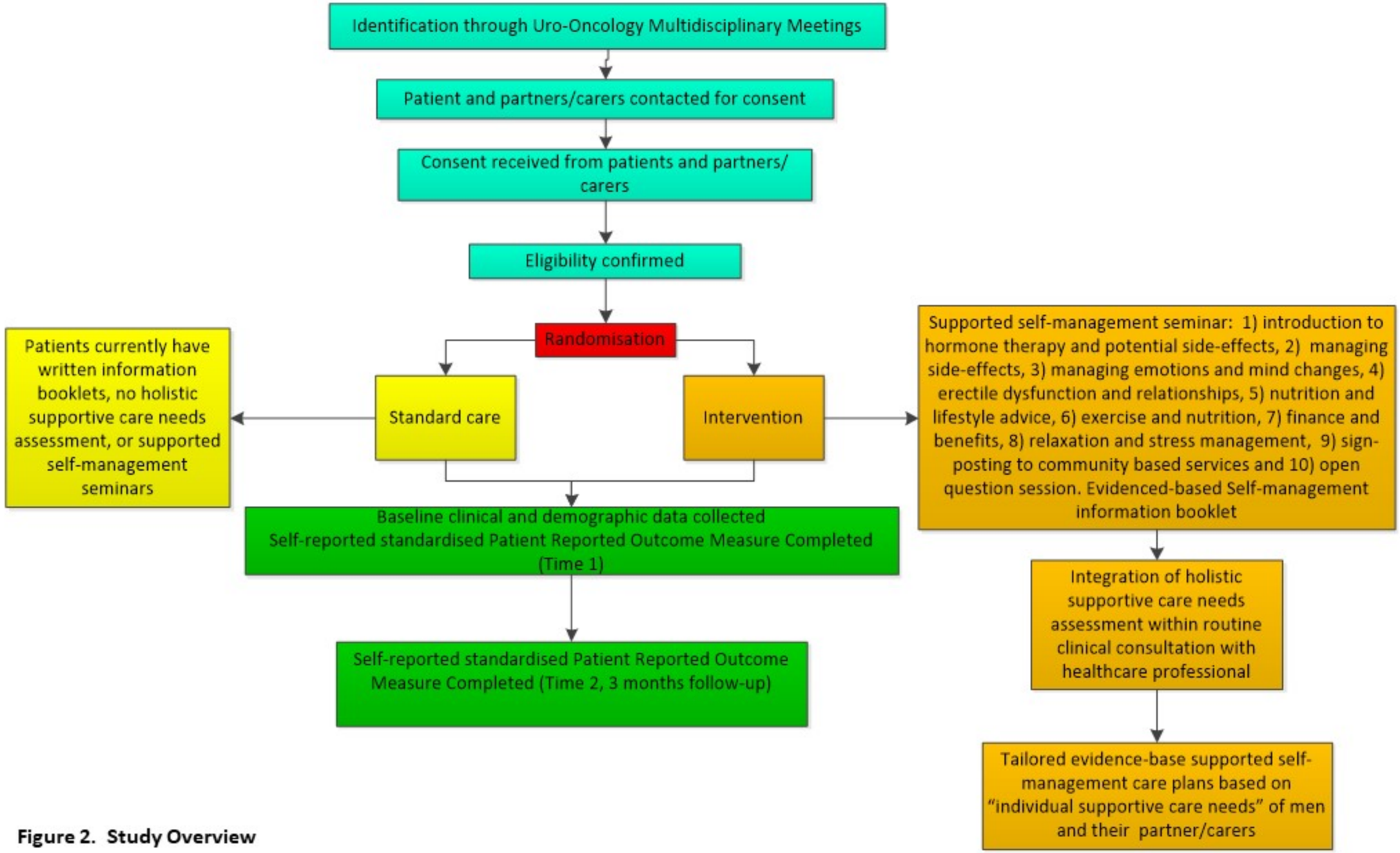


Figure 2. Study Overview

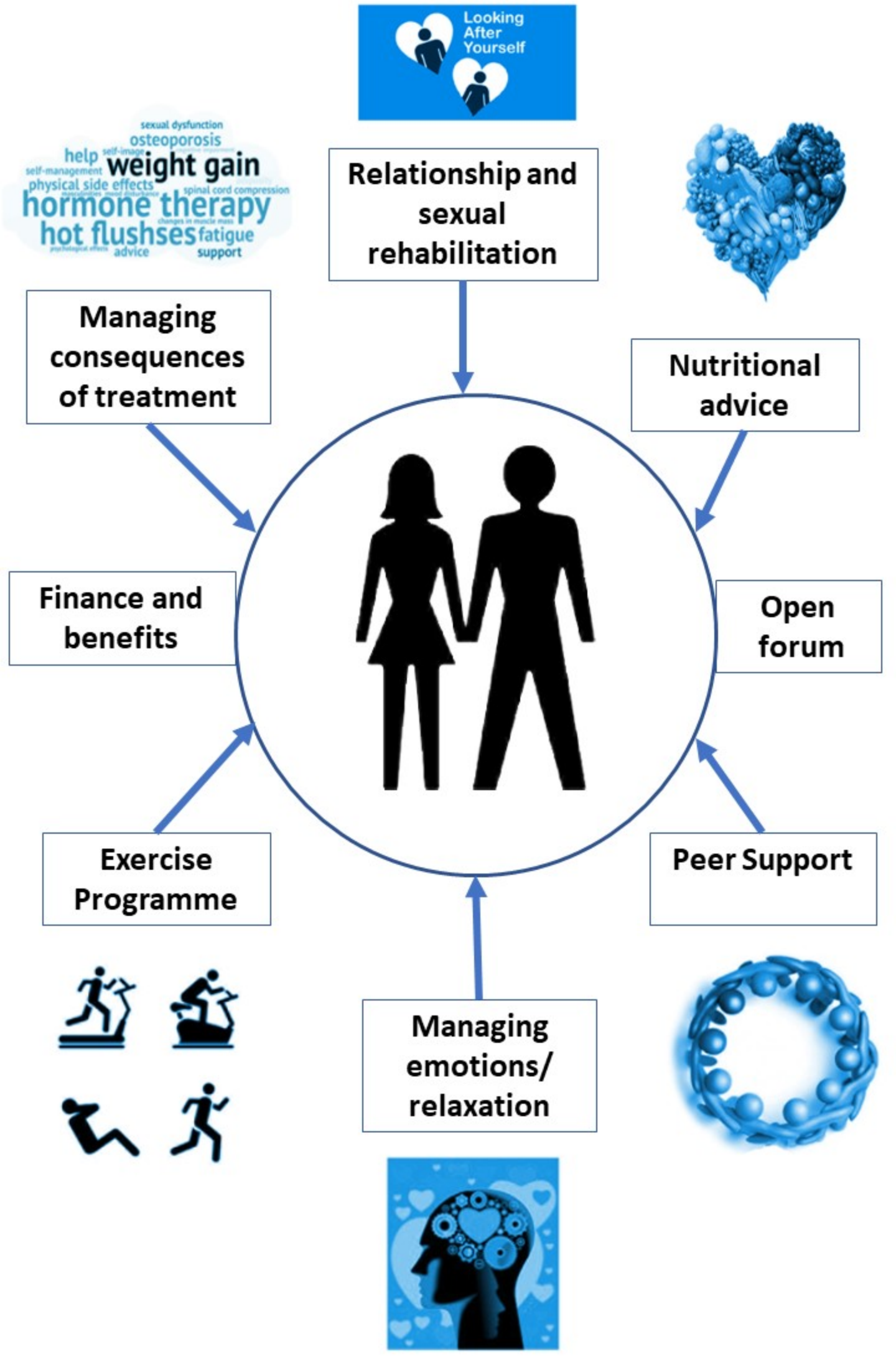


Figure 3. Thematic Content of Group-Base Seminar

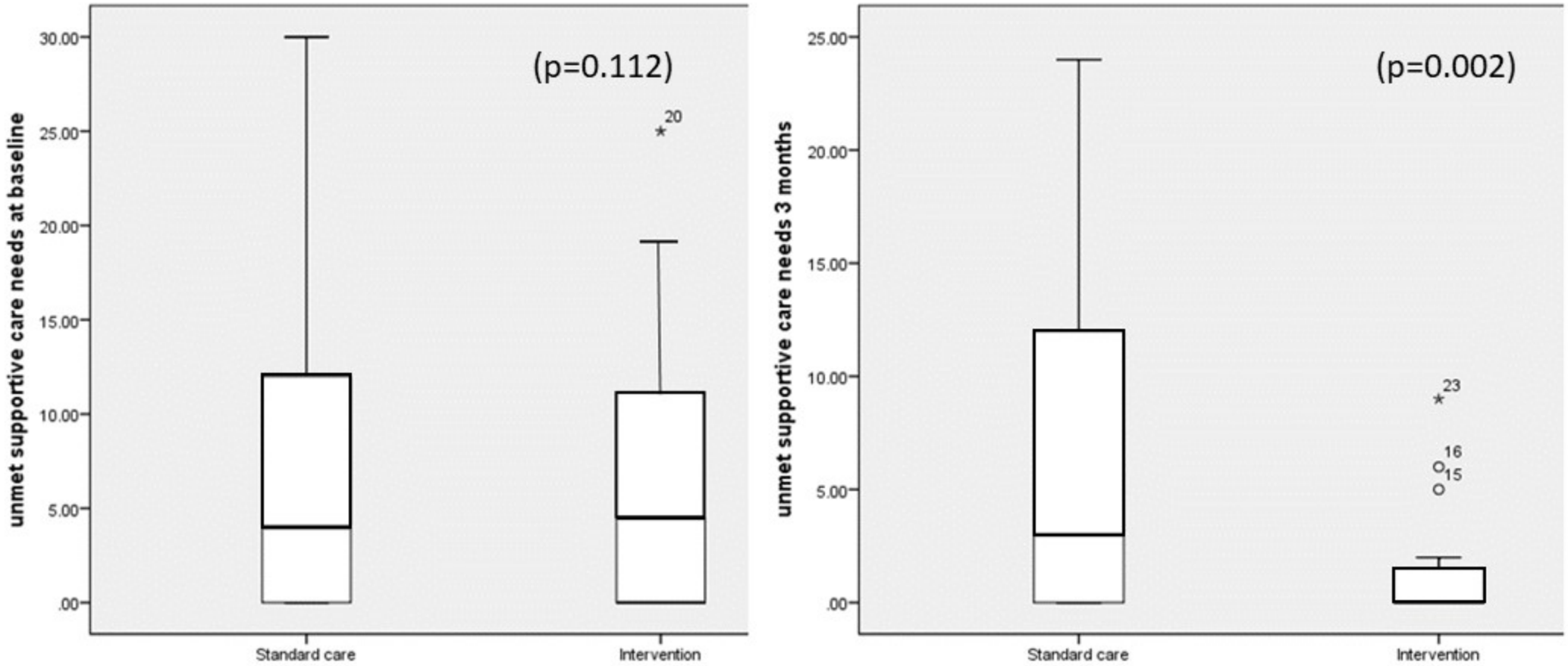


Figure 4. Prevalence of unmet supportive care needs at baseline and 3 months

Table 1 Clinical and Demographic Characteristics

	Standard care group (n29)	Intervention group (n19)	p Value
Age	77.5 (SD 6.2, min 66 – 93) years	74.9 (SD 8.2, min 60 – 86) years	.177
SIMD*			
Most deprived	3 (10.3%)	0 (0%)	.048*
2	2 (6.9%)	5 (26.3%)	
3	6 (20.7%)	3 (15.8%)	
4	15 (51.7%)	5 (26.3%)	
Least Deprived	3 (10.3%)	6 (31.6%)	
Marital status	Widowed 11 (37.9%) Married 18 (62.1%)	Single 1 (5.3%) Widowed 3 (15.8%) Married 15 (78.9%)	.005*
Employment status	Retired 29 (100%)	Retired 19 (100%)	.203
Number of co-morbidities	2.4 (SD 2.8)	2.7 (SD 2.6)	.377
Gleason Score			.202
6	0 (0%)	0 (0%)	
7	2 (6.9%)	6 (31.6%)	
8-10	2 (6.9%)	0 (0%)	
No pathology	21 (86.2%)	7 (68.4%)	
PSA diagnosis	131.2 (SD 208.2)	319.2 (SD 380.6)	.052
PSA Recent	12.9 (SD 23.4)	20.7 (29.5)	.363
Psycho-social constructs			
Anxiety baseline	2.9 (SD 3.4)	2.3 (SD 3.8)	.686
Anxiety 3M	2.1 (SD 1.9)	2.4 (SD 4.6)	.102
Depression baseline	3.6 (SD 3.6)	3.6 (SD 3.1)	.760
Depression 3M	4.1 (SD 4.4)	3.6 (SD 3.6)	.489
Self-efficacy	3.5 SD .8)	3.7 (SD.37)	.364
Self-efficacy 3M	3.6 (SD .6)	3.7 (SD .12)	.212
Health Related Quality of Life			
Global QoL	73.5 (SD 22.2)	76.4 (SD 23.4)	.788
Global QoL 3M	79.6 (SD 23.9)	81.9 (SD 19.6)	.866
Physical function	77.8 (SD 24.9)	81.9 (SD 19.9)	.536
Physical function 3M	82.8 (SD 20.7)	83.9 (SD 20.9)	.451
Role Function	78.4 (SD 29.5)	81.4 (SD 29.4)	.521
Role Function 3M	88.1 (SD 31.4)	80.2 (SD 28.0)	.316
Emotional Function	87.5 (SD 15.6)	82.4 (SD 15.7)	.421
Emotional Function 3M	84.1 (SD 12.4)	81.8 (SD 17.1)	.071
Cognitive function	82.7 (SD 16.0)	85.2 (SD13.0)	.582
Cognitive function 3M	84.1 (SD 12.6)	84.3 (SD 18.1)	.586
Social Function	85.7 (SD 19.1)	86.3 (SD 25.8)	.452
Social function 3M	80.5 (SD 26.7)	85.4 (SD 26.4)	.321
Fatigue	19.7 (SD .5)	19.7 (SD .8)	.521
Fatigue 3M	19.8 (SD .9)	16.7 (SD .8)	.564
Nausea and vomiting	1.7 (SD 6.9)	2.9 (SD 6.5)	.423
Nausea and vomiting 3M	2.3 (SD 6.2)	2.8 (SD 6.1)	.361
Pain	11.1 (SD 18.4)	5.8 (SD 26.3)	.502
Pain 3M	12.3 (SD 6.2)	4.7 (SD 26.7)	.191
Dyspnoea	12.5 (SD 19.9)	13.7 (SD 20.6)	.501
Dyspnoea 3M	19.0 (SD 17.8)	13.7 (SD 16.9)	.491

Insomnia	6.2 (SD 24.7)	4.6 (SD 23.9)	.224
Insomnia 3M	9.2 (SD 16.2)	5.6 (SD 20.6)	.236
Appetite loss	7.1 (SD 13.9)	7.8 (SD 18.6)	.267
Appetite loss 3M	9.5 (SD 25.1)	7.8 (SD 18.7)	.354
Constipation	15.4 (SD 24.8)	13.7 (SD 20.6)	.356
Constipation 3M	19.0 (SD 32.5)	21.6 (SD 28.7)	.451
Diarrhoea	9.2 (SD 23.0)	7.8 (SD 14.6)	.267
Diarrhoea 3M	8.2 (SD 23.1)	7.6 (SD 14.9)	.312
Financial Difficulties	2.3 (SD 8.7)	1.9 (SD 8.0)	.326
Financial Difficulties 3M	0 (SD .0)	1.9 (SD 8.0)	.412
Urinary symptoms	17.6 (SD 14.6)	17.6 (SD 14.6)	.312
Urinary symptoms 3M	23.6 (SD 9.6)	20.4 (SD 13.9)	.545
Bowel symptoms	5.5 (SD 8.7)	6.5 (SD 3.7)	.599
Bowel symptoms 3M	2.8 (SD 4.1)	4.1 (SD 7.1)	.512
Treatment symptoms	12.7 (SD 9.9)	9.7 (SD 11.6)	.170
Treatment symptoms 3M	20.8 (SD 9.5)	12.1 (SD 10.4)	.123
Sexual activity	13.1 (SD 21.9)	11.6 (13.7)	.830
Sexual activity 3M	12.5 (SD 15.9)	12.5 (SD 18.9)	.631
Sexual function	1.0 (SD .3)	0.8 (SD .2)	.859
Sexual function 3M	0 (SD .0)	0 (SD 0)	.696

*Scottish Index of Multiple Deprivation (1 most deprived – 5 least deprived)

Table 2. Prevalence of Unmet Supportive Care Needs at 3 Months

Domains of unmet supportive care needs		Low unmet need. I had little need for additional help. N (%)	Moderate unmet need. I had some need for additional help. N (%)	High unmet need. I had strong need for additional help. N (%)
Pain	(standard) (Intervention)	2 (8.0%) 0 (0%)	4 (16%) 0 (0%)	0 (0%) 0 (0%)
Lack of energy/tiredness	(standard) (Intervention)	5 (20.0%) 1 (7.7%)	1 (4.0%) 0 (0%)	1 (4.0%) 0 (0%)
Feeling unwell a lot of the time	(standard) (intervention)	1 (4%) 0 (0%)	1 (4%) 0 (0%)	0 (0%) 0 (0%)
Work around home	(standard) (intervention)	1 (4%) 0 (0%)	0 (0%) 0 (0%)	0 (0%) 0 (0%)
Not being able to do the things that you used to do	(standard) (intervention)	5 (20%) 2 (15.4%)	1 (4%) 0 (0%)	0 (0%) 0 (0%)
Anxiety	(standard) (intervention)	3 (12%) 0 (0%)	0 (0%) 0 (0%)	0 (0%) 0 (0%)
Feeling down or depressed	(standard) (intervention)	3 (12%) 2 (15.4%)	1 (4%) 0 (0%)	0 (0%) 0 (0%)
Feelings of sadness	(standard) (intervention)	3 (12%) 1 (7.7%)	0 (0%) 0 (0%)	1 (4%) 0 (0%)
Fear about the cancer spreading	(standard) (intervention)	6 (24%) 1 (7.7%)	4 (16%) 0 (0%)	0 (0%) 0 (0%)
Worry that the results of treatment are beyond your control	(standard) (intervention)	6 (24%) 1 (7.7%)	2 (8%) 0 (0%)	0 (0%) 0 (0%)
Uncertainty about the future	(standard) (intervention)	9 (36%) 1 (7.7%)	0 (0%) 0 (0%)	1 (4%) 0 (0%)
Learning to feel in control of your situation	(standard) (intervention)	7 (28%) 1 (7.7%)	0 (0%) 0 (0%)	1 (4%) 0 (0%)
Keeping a positive outlook situation	(standard) (intervention)	3 (12%) 0 (0%)	0 (0%) 0 (0%)	0 (0%) 0 (0%)
Fear about death and dying	(standard) (intervention)	4 (16%) 0 (0%)	1 (4%) 0 (0%)	1 (4%) 0 (0%)
Changes in sexual feelings	(standard) (intervention)	5 (20%) 1 (7.7%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Changes in sexual relationships	(standard) (intervention)	5 (20%) 1 (7.7%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Concerns about the worries of those close to you	(standard) (intervention)	5 (20%) 1 (7.7%)	2 (8%) 0 (0%)	2 (8%) 0 (0%)
More choice about which cancer specialist to see	(standard) (intervention)	6 (24%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
More choice about which hospital you attend	(standard) (intervention)	0 (0%) 0 (0%)	0 (0%) 0 (0%)	1(4%) 0 (0%)
Reassurance by medical staff that the way you feel is normal	(standard) (intervention)	2 (8%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)

Hospital staff attending promptly to your physical needs	(standard) (intervention)	0 (0%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Hospital staff acknowledging, and showing sensitivities to your emotional needs	(standard) (intervention)	0 (0%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Being given written information about the important aspects of your care needs	(standard) (intervention)	4 (16%) 0 (0%)	3 (12%) 0 (0%)	1 (4%) 0 (0%)
Being given information (written diagrams, drawings) about managing your illness and side-effects at home	(standard) (intervention)	6 (24%) 0 (0%)	1 (4%) 0 (0%)	1 (4%) 0 (0%)
Being given explanations for those test for which you would like explanations	(standard) (intervention)	7 (28%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Being adequately informed about the benefits and side-effects of treatment before you choice to have them	(standard) (intervention)	4 (16%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Being informed about test results as soon as feasible	(standard) (intervention)	3 (12%) 1 (7.7%)	5 (20%) 0 (0%)	1 (4%) 0 (0%)
Being informed about cancer that is under control or diminishing	(standard) (intervention)	5 (20%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Being informed about the things that you can do to get well	(standard) (intervention)	4 (16%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Having access to professional counselling	(standard) (intervention)	3 (12%) 0 (0%)	1 (4%) 0 (0%)	1 (4%) 0 (0%)
Being given information about sexual relationships	(standard) (intervention)	3 (12%) 0 (0%)	1 (4%) 0 (0%)	1 (4%) 0 (0%)
Being treated like a person not just another case	(standard) (intervention)	2 (8%) 0 (0%)	1 (4%) 0 (0%)	1 (4%) 0 (0%)
Being treated in a hospital or clinic that is physically pleasant as possible case	(standard) (intervention)	0 (0%) 0 (0%)	2 (8%) 0 (0%)	1 (4%) 0 (0%)
Having one member of hospital staff with whom you can talk to	(standard) (intervention)	5 (20%) 0 (0%)	0 (0%) 0 (0%)	2 (8%) 0 (0%)

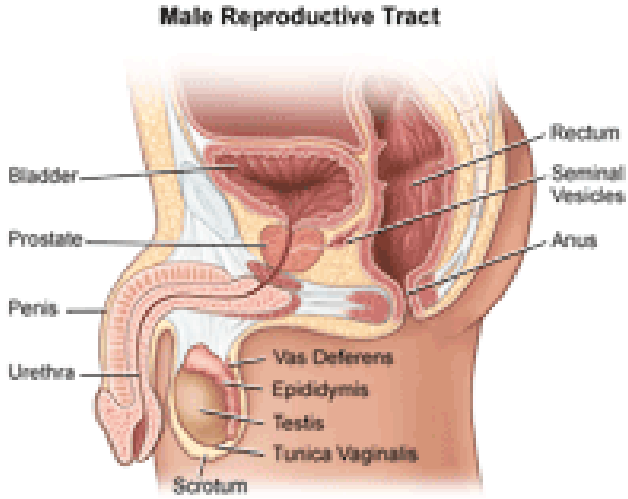
A Prostate Cancer Guide to Thrivership:
Men, it's time to thrive

Contents

What is the prostate?

Only men have a prostate gland. The prostate is usually the size and shape of a walnut and naturally grows bigger as you get older. The normal size of a prostate is around 40g. It sits underneath the bladder and surrounds the urethra – the tube men urinate and ejaculate through.

It's main job is to help make semen – the fluid that carries sperm.



Facts and figures

Below are some of the very basic facts and figures about prostate cancer.

Across the UK

- Prostate cancer is the most common cancer in men.
- Over 47,000 men are diagnosed with prostate cancer every year – that's 130 men every day.
- Every hour one man dies from prostate cancer – that's more than 10,800 men every year.
- 1 in 8 men will get prostate cancer in their lifetime.
- Over 330,000 men are living with and after prostate cancer.

In Scotland

- More than 3,000 men are diagnosed with prostate cancer every year in Scotland.
- More than 850 men die from prostate cancer every year in Scotland.

In England

- Almost 40,000 men are diagnosed with prostate cancer every year in England.
- More than 9,500 men die from prostate cancer every year in England.

In Wales

- More than 2,500 men are diagnosed with prostate cancer every year in Wales.
- More than 600 men die every year from prostate cancer in Wales.

In Northern Ireland

- More than 1,000 men are diagnosed with prostate cancer every year in Northern Ireland.
- More than 250 men die every year from prostate cancer in Northern Ireland.

How can I help myself?

Everyone has their own way of dealing with prostate cancer, but you may find some of the following suggestions helpful.

Look into your treatment options

Find out about the different types of treatment available to you. Bring a list of questions to your doctor or nurse. And ask about any side effects so you know what to expect and how to manage them. This will help you decide what's right for you.

"Remember, your Prostate Cancer Care Team are here to help and support you."

Talk to someone

Unload what's going on in your head – find someone you can talk to. It could be someone close, or someone trained to listen, like a counsellor or your medical team. Your GP, nurse or other health professionals involved in your care should be able to answer any questions or concerns you might have.

Set yourself some goals

Set yourself goals and things to look forward to – even if they're just for the next few weeks or months. It might be doing more exercise, gardening or getting ready for a holiday.

Look after yourself

Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like listening to music or breathing exercises.

Eat a healthy, balanced diet

Eating well is good for your general health and lowers your risk of other health problems. There is also some evidence that certain foods may slow down the growth of prostate cancer or lower the risk of it coming back after treatment.

Be as active as you can

Keeping active can improve your physical strength and fitness, and can lift your mood. Research shows that physical activity can help to slow down the growth of prostate cancer. It can also help you stay a healthy weight, which may be important for lowering your risk of advanced prostate cancer. **Even if you don't feel able to do a lot of physical activity, a small amount will still help – take things at your own pace and don't overdo it.**

Who can help?

Your Specialist Prostate Cancer Nurses

Your Specialist Nurses can answer your questions and explain your diagnosis and treatment options. They've got time to listen to any concerns you or those close to you have in confidence.

Prostate Cancer Specialist Nurse Team, Ninewells Hospital:
01382 660111, extension 35138.

Your medical team

It could be useful to speak to your nurse, doctor, GP or anyone in your medical team. They can explain your diagnosis, treatment and side effects, listen to your concerns, and put you in touch with others who can help.

Trained counsellors

Counsellors are trained to listen and can help you to find your own ways to deal with things. Many hospitals have counsellors or psychologists who specialise in helping people with cancer. Your GP may also be able to refer you to a counsellor, or you can see a private counsellor. To find out more, contact the British association for Counselling & Psychotherapy.

http://www.bacp.co.uk/

Local support groups

You have local support groups both in Dundee and Perth, where men get together to share their experiences – you can ask questions, offload worries and know that someone understands what you're going through. Some groups have been set up by local health

professionals, others by men themselves. Many also welcome partners, friends and relatives.

Online community

Prostate Cancer UK online community is a place where you can talk about whatever's on your mind – your questions, your ups and your downs. Anyone can ask a question or share an experience. It's a place to deal with prostate cancer together.

http://community.prostatecanceruk.org/

Spiritual support

You might begin to think more about spiritual beliefs as a result of having prostate cancer. It's important that you get spiritual support if you need it. This could be from your friends or family, or from your religious leader or faith community.

Lifestyle and Nutrition

Studies have shown that lifestyle — especially nutrition and exercise — has a significant influence in prostate cancer prevention and treatment.

Treatment options for prostate cancer are more effective than ever before. **Yet, for many men, the diagnosis and treatment of cancer brings to their attention the need to change their diet and exercise behaviors**. Men are beginning to realise that a healthy diet and regular exercise can be an important step toward preventing other diseases that commonly occur with aging, including heart disease and diabetes.

Exciting new data suggest that this same approach may also slow prostate cancer growth.

You may have had prostate cancer, but now you are in charge of your life, adopting new healthy habits and enjoying each day to its fullest. As a prostate cancer thriver, you can use the latest knowledge about nutrition and exercise to improve your overall health and quality of life. Your diagnosis of prostate cancer can be the beginning of a healthier lifestyle.

Implementing a Plan for Success

It is critical to focus on the benefits of a healthy diet and regular exercise. We describe how a healthy diet and regular physical activity may help you manage the effects of prostate cancer and its treatment.

1 Making a commitment to change is a first step in successful thrivership
2 Effective change can only be accomplished in steps
3 Learn from mistakes made over time and use the gains to move forward
4 Reduce stress: live a balanced life and take care of yourself
5 Control your environment: plan ahead to eat healthy and minimize stress
6 Monitor your action: track your behaviours to help chart your progress
7 Establish a support system: maintain healthy relationships with people who understand what you are going through

We don't recommend any set diet or exercise programme. Instead, we suggest ways to improve your overall health, including some changes that might help with your prostate cancer.

1 Lose body fat: eat fewer calories per day than you burn
2 Maintain muscle mass: increase protein intake and exercise
3 Exercise every day: combine cardio-fitness and weight lifting
4 Eat fruits and vegetables: recommended nine servings a day

Building Strong Muscles

Increased protein intake at the upper end of the range recommended by the Institute of Medicine (10% to 35% of total calories) has been shown, in several clinical studies, to reduce hunger and improve lean body mass during weight loss. Exercising for durations of approximately one hour each day is an excellent strategy for weight maintenance, while progressive resistance training has been shown to build muscle, increase resting metabolism, improve glucose tolerance, increase strength, muscle function, and aerobic fitness, contribute to increased bone density, and improve quality of life.

Note also that *maintaining* muscle mass can have a positive impact on metabolism. A pound of muscle burns 14 calories for every 3 calories burned by a pound of fat. Thus, the number of calories burned per day is at least in part determined by the ratio of muscle to fat.

Avoiding the muscle loss common in aging, inactivity, and hormonal therapies and/or gaining muscle through increased protein intake and exercise can help you achieve and maintain a healthy body weight, giving you more energy and an ability to enjoy active sports more fully.

Restoring a Healthful Caloric Balance

Concentrating on fruits and vegetables can pay dividends immediately. The average vegetable serving is only 50 calories and the average fruit serving is only 70 calories, while the average serving of refined carbohydrates such as potatoes, rice, pasta, bread, bagels, or cakes is more than 200 calories. Considering that you have to run 3 miles in 30 minutes to burn off the calories in a medium potato and bicycle 8 miles in 30 minutes to burn off the calories in a donut,

minimizing your caloric intake from these types of refined carbohydrates can help you maximize the effects of regular exercise.

1 **Avoiding muscle loss and/or gaining muscle through increased protein intake and exercise can help in achieving and maintaining a healthy body weight.**
2 **Increase intake of fruits and vegetables and minimize caloric intake from refined carbohydrates.**

Adopting a Healthy Approach

It is a lot easier than you think to incorporate good nutrition and exercise into your everyday routine.

The key is to recognise that implementing dietary changes does not mean giving up things you love and that exercising does not mean spending additional time that you don't have. The key is to see your life in a new way — with a new set of lifestyle changes all designed to turn you from a prostate cancer survivor into a prostate cancer thriver.

Lose the body fat

Losing fat is a simple equation: eat fewer calories per day than you burn and increase your activity levels. This can be done by changing your dietary pattern away from high fat foods, sweets, fast foods, and savory snacks and eating more fruits and vegetables, low-fat proteins from poultry, fish, and seafood, and fewer refined carbohydrates.

Here are some practical examples of places you can cut calories:

- **replace** high-fat red meats for fish and white meat (turkey or chicken)
- **replace** rice, pasta, potato, and breads for fruits and vegetables
- **replace** ice creams, cakes, pastries for mixed berries and fruits
- **replace** cheese and full-fat dairy products for low-fat dairy and soy products
- **replace** soft drinks for water.

Maintain muscle mass

In order to maintain muscle mass as you age, it is important to take in adequate amounts of protein and to exercise muscles adequately to maintain them. As you age, the body's metabolism slows down due in large part to the decrease in muscle mass that is seen with inactivity. It is harder to build muscle as you age and it breaks down more quickly with inactivity than in younger individuals. However, it is possible to build and maintain muscle mass well into your 90s by simply eating adequate protein and doing muscle building exercises.

Also, building muscle mass is one of the most effective ways to change your metabolism: build 10 extra pounds of muscle, and you will burn an extra 140 calories per day. However, to maintain that muscle you need to do more than simply provide the extra 140 calories per 10 pounds; you must also supply the right amount of the right kinds of protein to nourish the muscles.

Your lean body mass determines how much protein you need each day. In fact, it's about twice what was recommended by government advisory groups until recently, when the Institute of Medicine broadened its recommendation to 10% to 35% of calorie intake. It

takes about 1 gram of protein per pound of lean body mass or 29% of resting energy expenditure, which is the number of calories you burn at rest to build and maintain muscle.

For example, a typical man with 150 pounds of lean body mass will burn 2100 calories at rest per day and will need about 150 grams of protein per day.

Here is a list of some low-fat, high protein choices you can make:

- 7 egg whites: 25 g protein and 115 calories
- Chicken breast (4 oz): 25 g protein and 140 calories
- Ocean-caught fish (4 oz): 25 g protein and 140 calories
- Canned tuna in water ((3.5 oz): 25 g protein and 110 calories

Exercise every day

Regular exercise will help you lose fat, build muscle, and improve your outlook overall. A combination of cardio-fitness and weight lifting will not only help to round out the benefits, but the variety will help make it more interesting. This is key to sticking to a regular routine. Choose an exercise you like and/or one that you can do with friends to make it more enjoyable. For example, walk 30 minutes every day at a comfortable pace and lift weights three times each week, alternating different body parts and allowing a day of rest between weight-lifting days.

If you work on your chest muscles and triceps one day, switch to your back muscles and biceps on the next, followed by leg muscles and shoulders on the third day.

Most important, obtain professional instruction on how to perform exercises for each of these muscle groups and consult with your doctor before starting the exercise program to be sure it is safe for you. A certified fitness instructor, exercise physiologist, or physical therapist can provide exercise instruction and ensure that you are maximizing the benefit from your workouts.

Ask you Nurse/Doctor to refer MOVE MORE Program, to enable you to have your own personalised programme.

Eat fruits and vegetables

We recommend eating 9 servings of fruits and vegetables every day, equivalent to about one cup or 100 grams per serving. Why is this important? A typical serving of vegetables has about 50 calories and a typical serving of fruit has about 70 calories, making them some of the least calorie-dense food ounce per ounce. So by simply increasing the amount of fruits and vegetables you eat each day, you will be decreasing the number of calories per bite of food even while packing in high levels of nutrients. Also, fruits and vegetables are rich in fibre, so five servings of fruit and vegetables can easily get you to the recommended 25 grams of fibre per day.

Why is a healthy lifestyle important?

A healthy lifestyle can give you more control over your health and help you to improve it. Lots of things can affect your health, including:

- body weight
- diet
- physical activity
- alcohol
- smoking.

Alcohol

We don't know if alcohol has any specific effect on men with prostate cancer. But we do know that drinking too much alcohol can make you put on weight and causes health problems such as heart disease and some other cancers. The government suggests that men should not regularly drink more than three to four units of alcohol a day.

How many units of alcohol are in a drink?

- A pint of lager, beer or cider contains 2-3 units.
- A 175ml glass of wine contains about 2 units.
- A 25ml measure of 40 per cent single spirit with mixer contains 1 unit.

If you have urinary problems after treatment, try to drink less alcohol. Alcohol can irritate the bladder and make urinary problems worse.

Smoking

Smoking increases the risk of health problems such as heart disease, stroke and some other cancers. It may also be harmful for men with prostate cancer. Some studies suggest that smoking may increase the chance that prostate cancer will grow and spread to other parts of

the body (advanced prostate cancer). The more you smoke, the greater the risk. But if you stop smoking, your risk should start to drop – and after 10 years it could be as low as men who have never smoked.

Stopping smoking can also help to reduce the side effects of treatment for prostate cancer. For example, you may be less likely to get certain urinary problems after radiotherapy if you don't smoke. Smoking also increases your risk of bone thinning. If you're having hormone therapy for your prostate cancer you're already at risk of bone thinning, but stopping smoking will help reduce your overall risk.

Speak to your healthcare team about Smoking Cessation service.

Heart disease and diabetes

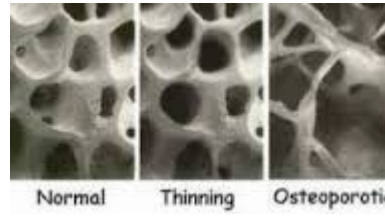
Hormone therapy may increase your risk of heart disease and diabetes. A healthy lifestyle, including a healthy diet and regular physical activity, can help reduce your risk of heart disease and diabetes.

Bone thinning

Long-term hormone therapy can cause your bones to gradually get thinner and weaker. Severe bone thinning can lead to a condition called osteoporosis, which increases your risk of broken bones (fractures). A number of lifestyle changes may help to reduce your risk of bone thinning.

Calcium and vitamin D are important for strong bones. You can get vitamin D from eating oily fish, such as salmon, mackerel and sardines, or foods with added vitamin D. But most of your vitamin D is made inside the body when your skin is exposed to sunlight. You may need to take calcium and vitamin D supplements to help reduce your risk of bone thinning.

Drinking lots of alcohol can increase your risk of osteoporosis, so try not to drink more than the recommended amount. Smoking can also increase the risk of bone thinning.



Hot flushes

Hot flushes are a common side effect of hormone therapy. Staying a healthy weight may help you manage hot flushes. Try to cut down on spicy foods, alcohol and drinks that contain caffeine, such as tea and coffee. Some men use herbal remedies, such as sage tea or supplements containing black cohosh, to help manage their hot flushes. But there is no scientific evidence that these are effective and

some, including black cohosh, may be harmful. Speak to your doctor before taking any herbal remedies.

Extreme tiredness (fatigue)

Some treatments for prostate cancer, including hormone therapy, radiotherapy and chemotherapy, can cause extreme tiredness. Light to moderate exercise, such as walking or swimming, can make you feel more awake. And doing this type of exercise along with strength training, such as lifting light weights, may be even more effective.

If your treatment is making you feel tired, you may find it difficult to be active. Try to plan activities at times when you usually have more energy. If you feel particularly tired, just do gentle exercise for a short time and take lots of breaks. You can even exercise from your chair or bed – for example, use a resistance band to help you lift and stretch your arms and legs.

How will prostate cancer affect my sex life?

Prostate cancer can affect your sex life in three overlapping ways - your mind, body and relationships. Finding out you have cancer can make you feel down or anxious, changing your feelings about sex. Treatment can damage the nerves and blood supply needed for erections. Hormone therapy can affect your desire for sex. Coping with cancer can change your close relationships, or your thoughts about starting one.

Some common worries

- You can't pass on cancer through sexual activity.
- Having sex will not affect your cancer or the success of your treatment.
- Having sex has no effect on the chances of your cancer coming back.
- Erections are still safe even if you have a catheter in.

What causes erection problems?

When you're sexually aroused your brain sends signals to the nerves in your penis. The nerves increase the blood flow to your penis, making it stiff and giving you an erection. Anything that interferes with your nerves, blood supply or your sexual desire (libido) can make it difficult to get or keep an erection. You may hear this called erectile dysfunction or impotence. Many men get problems with their erections and this is more likely to happen as men get older.

Treatments for prostate cancer

Some treatments for prostate cancer can damage the nerves and blood vessels that are needed for an erection. Treatments that can have this effect include surgery, external beam radiotherapy, brachytherapy, high intensity focused ultrasound and cryotherapy.

All types of hormone therapy can cause erection problems. Having less interest in sex can also play a part.

Treatments for erection problems

Many of the treatments for erection problems work by improving the flow of blood to the penis. There are a number of treatments available.

Tablets

A group of drugs called phosphodiesterase type 5 (PDE5) inhibitors can help men get erections. These include:

- sildenafil (generic sildenafil or Viagra®)
- tadalafil (Cialis®)
- vardenafil (Levitra®)
- avanafil (Spedra®)

PDE5 tablets don't cause spontaneous erections - they only work if you are sexually aroused. They normally take 30 minutes to an hour before they start to work.

Sildenafil, vardenafil and avanafil are taken when needed and will work for four to six hours. This means you'll be able to get an erection if you're sexually aroused in that time.

Tadalafil can work for up to 36 hours, so it allows you to have more spontaneous sexual activity. Your doctor may suggest you take a low-dose tablet (5mg) every day.

Don't take PDE5 tablets with nitrates: Nitrates are usually used to treat heart problems and are used in some recreational drugs (called poppers). If you have a heart problem or you're taking nitrates discuss other ways to treat your erection problems with your doctor or specialist.

Injections

Erection problems can also be treated with a drug called alprostadil (Caverject® or Viridal Duo®) injected into the side of your penis. An injection may sound alarming but many men find it isn't that bad and doesn't hurt. The first time you use the drug a nurse or doctor in the clinic will show you how to inject into your penis with a very fine needle.

The drug causes the penis to fill with blood and you'll get an erection within 5 to 10 minutes. The erection will normally last for 30 to 40 minutes.

Pellets or cream

The drug alprostadil is also available as a small pellet, called MUSE®, and as a cream called Vitaros®. These may not work as well as the injections but are a good alternative if you don't like the idea of an injection. You use an applicator to insert the pellet into the opening or 'eye' of the penis.

You or your partner can then massage your penis to help absorb the drug. You'll get an erection within 5 to 10 minutes, which will last between 30 and 60 minutes.

The cream may take a little longer to work. The cream is put onto the tip and 'eye' of the penis and gently rubbed in.

Vacuum pump

You use a pump and a plastic cylinder to create a vacuum, which makes blood flow into your penis to make it hard. You then slip a constriction ring from the end of the cylinder onto the base of your penis. This stops most of the blood escaping when you remove the vacuum pump. You shouldn't wear the ring for longer than 30 minutes at a time.

The vacuum pump may help men get an erection hard enough for penetration. It may also help maintain the length and thickness of the penis if used daily within four to eight weeks after surgery.

Implant

You have an operation to put an implant inside your penis. Implants are usually only recommended if other treatments haven't worked. There are two main types:

- Semi-rigid rods that keep your penis fairly firm all the time but allow it to be bent down when you don't want an erection.
- An inflatable implant in your penis and a pump in your scrotum. When you squeeze the pump the implant fills with fluid (saline) to make the penis hard. Your erection will last for as long as the implant is inflated.

Sex therapy

Because getting an erection also relies on your thoughts and feelings, tackling any worries or relationship issues as well as having medical treatment for erection problems, often works well.

Getting treatment and support

Speak to your GP or doctor or nurse at the hospital. Men with prostate cancer can get free medical treatment for erection problems or other sexual problems on the NHS. Your GP or doctor or nurse at the hospital can prescribe treatment if you want help getting erections for masturbation or sex.

Talking about sex

It can be tricky talking about sex, but talking to your doctor or nurse will mean you can get treatment and support. It can also help you feel better and more in control.

Changes in penis size

Some men find that their penis is shorter after surgery (radical prostatectomy). This happens because of changes to the tissue inside the penis. Other treatment such as hormone therapy with radiotherapy may also cause changes to the size of your penis.

Encouraging blood flow to the penis after surgery may improve erections and prevent your penis becoming smaller. In particular, using a vacuum pump on its own or with PDE5 tablets may help maintain your penis size and improve erections.

Changes to orgasm and ejaculation

After prostate cancer treatment you will still have feeling in your penis and you should still be able to have an orgasm, but this may feel different from before.

After surgery you will no longer ejaculate when you orgasm, as the prostate and seminal vesicles, which make some of the fluid in the semen, are removed during the operation. Instead you may have a 'dry orgasm' where you feel the sensation of orgasm but don't ejaculate any semen. Occasionally, you might release a small amount of liquid from the tip of your penis during orgasm, which may be fluid from glands lining the urethra.

If you've had other treatments, you may produce less semen during and after treatment. Some men on hormone therapy say their orgasms feel less intense.

If you've had surgery for an enlarged prostate called a called TURP (transurethral resection of the prostate) or radiotherapy you may get retrograde ejaculation. This is when you orgasm and the semen doesn't come out straightaway, but is passed out of the body when you next urinate. It isn't harmful and shouldn't affect your enjoyment of sex but it may feel quite different to the orgasms you're used to.

Some men leak urine when they orgasm, or feel pain. Others find they don't last as long during sex and reach orgasm quite quickly.

Your thoughts and feelings

If your ability to get erections and your experience of sex have changed then this can have a big impact on you. You may feel worried, unsatisfied, angry and as if you've lost a part of yourself. But there are ways to tackle these issues and find solutions that work for you (see the section on help).

Some couples find it useful to see a relationship counsellor. Help is available through Relate:

https://www.relate.org.uk/

Sex therapy is available on the NHS or privately.

Sex when you're single

Being sexually active and feeling attractive can be just as important if you are a single man. All the treatments described here are available to you if you're single - whether you want to be able to masturbate, have sex, or want to start a new relationship.

Some men worry that having problems with erections will affect their chances of having a new relationship. Fear of rejection is natural, and everyone has their own hang-ups whether they have had cancer or not. If you're single, you may want time to come to terms with any changes prostate cancer has caused for you, before you start having sex or dating.

Try talking over your worries with someone you feel comfortable with, such as a friend. Counselling or sex therapy may also help if you would prefer to talk to someone you don't know.

What can I do to help myself if I have urinary symptoms?

Sometimes men can experience the following symptoms, before, during or after treatment, including:

- bladder irritation
- needing to urinate more often (urinary frequency)
- a sudden urge to urinate (urinary urgency)
- difficulty urinating
- Some men can also leak urine

Lifestyle changes

Urinary problems can affect your self-esteem and independence, as well as your work, social and sex life.

Making some changes to your lifestyle can help, and there are some practical steps that can make things easier.

- Try to drink plenty of fluids, but cut down on fizzy drinks, alcohol, tea and coffee as these may irritate the bladder
- Do regular pelvic floor muscle exercises can help strengthen the muscles that control when you urinate.
- Try to stay a healthy weight. Being overweight can put pressure on your bladder and pelvic floor muscles.
- If you smoke, try to stop. Smoking can cause coughing which puts pressure on your pelvic floor muscles. See smoking

cessation service for more information about stopping smoking

- Plan ahead when you go out. For example, find out where there are public toilets before leaving home.
- Pack a bag with extra pads, underwear and wet wipes. Some men also find it useful to carry a screw-top container in case they can't find a toilet.

- Get an Urgent Toliet Card to help make it easier to ask for urgent access to a toilet.
- Disability Rights UK runs a National Key Scheme for anyone who needs access to locked public toilets across the UK because of a disability or health condition.
- If you often need to use the toilet at night, leave a light on in case you're in a hurry, or keep a container near your bed.
- Drink plenty of fluids (1.5-2 litres, or 3-4 pints a day), but try to avoid fizzy drinks, drinks containing caffeine – such as tea,

coffee and cola – and alcohol, as these can irritate the bladder.

- Some men find that drinking cranberry juice helps. But you should avoid cranberry juice if you're taking warfarin to thin your blood.
- Drugs called anti-cholinergics can help to reduce frequency, urgency and leaks.
- You may also need to urinate more often at night (nocturia). If this happens, it might help to drink less in the two hours before you go to bed.

Urine retention

Some men can still urinate a little, but can't empty their bladder fully – this is known as urine retention. The first signs often include:

- leaking urine at night
- feeling that your abdomen (stomach area) is swollen
- feeling that you're not emptying your bladder fully
- a weak flow when you urinate.

Tell your doctor or nurse if you get any of these symptoms. Urine retention is usually painless, but the pressure of the urine can cause the bladder muscles to slowly stretch and become weaker. Treatments for chronic urine retention include: a catheter to drain urine from the bladder, drugs (alpha blockers or 5-alpha-reductase inhibitors), surgery to widen the urethra or the opening of the bladder.

What can I do to help myself if I have bowel symptoms?

Some prostate cancer treatments can cause bowel symptoms in men (in particular radiotherapy). Such symptoms can include:

- loose and watery bowel movements (diarrhoea)
- passing more wind than usual
- needing to go to the toilet more often, or having to rush to the toilet
- feeling an urge to have a bowel movement, but then not being able to go
- a feeling that your bowels haven't emptied properly
- pain in the stomach area (abdomen) or back passage bleeding from the back passage – this is rare.

If you are experiencing new bowel symptoms it is important for you to tell your doctor or nurse. There are a number of practical life styles changes that can help if you are experiencing bowel symptoms:

- Drink plenty of liquid up to 1.5 to 2 litres a day to replace lost fluid.
- Avoid coffee and citrus fruits (if you have loose stool)
- Skin care at back passage: use unscented baby wipes instead of toilet paper to wipe yourself after you've been to the toilet, advice to have a warm bath to help soothe pain and help with healing, pat the area dry with a soft towel after a shower or bath – don't rub.
- Applying Vaseline around the back passage can help.
- Avoid wearing tight trousers or underwear. Cotton underwear will help to keep the area ventilated.

- Advice on gentle exercise (if able, brisk walking for at least 30 minutes, three times per week), is conducive to a more normal bowel routine.
- Eat food rich in fibre such as: fruit, vegetables, nuts, seeds, pulses, and wholemeal bread (to avoid constipation).

How will hormone therapy affect me?

Hot flushes are a common side effect of hormone therapy. They can be similar to the hot flushes women get when they're going through the menopause. They may happen suddenly without warning or they may be triggered by stress, a hot drink or a change in the temperature around you.

Hot flushes can vary from a few seconds of feeling overheated to a few hours of sweating that can stop you from sleeping or cause discomfort. Some men may not be worried by them, but others find them very disruptive and difficult to deal with. If your hot flushes are affecting your everyday life, speak to your doctor or nurse.

Breast swelling and tenderness

Hormone therapy may cause swelling (gynaecomastia) and tenderness in the chest area. The amount of swelling can vary from a small amount of swelling to a more noticeably enlarged breast. Tenderness can affect one or both sides of the chest and can range from mild sensitivity to ongoing pain.

Breast swelling and tenderness are more common if you take anti-androgen tablets such as bicalutamide on their own. If you take oestrogen tablets, you may also get breast swelling.

Breast swelling and tenderness can make some men feel uncomfortable or embarrassed about their bodies. But there are treatments available which can help prevent or reduce these side effects.

These include:

- treating the breast area with a single dose of radiotherapy
- tablets called tamoxifen
- surgery to remove some of the breast tissue.

Risk of heart disease and diabetes

Hormone therapy may increase your risk of heart disease and diabetes. You may be able to help reduce your risk by:

- eating a healthy diet
- being physically active
- limiting the amount of salt you eat
- avoiding smoking
- cutting down on alcohol.

Memory and Concentration

Testosterone may be linked to men's memory and concentration. Some studies have suggested that hormone therapy could affect this. But we don't know for sure whether any changes are caused by the hormone therapy or by something else. For example, feeling tired, stressed or anxious can all affect your memory or ability to concentrate. And these problems can happen as you get older.

Whatever the cause, you may find problems with memory or concentration very frustrating. There are things you can do which might help.

Further support and information

Prostate Cancer Specialist Nurses
NHS Tayside
Ninewells
Dundee
Telephone: 01382 660111, Extension 35138

Prostate Cancer UK
http://prostatecanceruk.org/get-support/our-specialist-nurses
Support Nurses
Telephone: 0800 074 8383

Healthy Working Lives, Fit for Work
Support for returning to work after Cancer (including self-employed advice)
Telephone: 0800 019 2211

Move More Programme (Macmillan Cancer Support)
Macmillan Development Office
Telephone: 01382 432407

Macmillan Cancer Support
www.macmillan.org.uk
Telephone: 0808 808 0000

Sexual Advice Association
www.sda.uk.net
Telephone: 020 7486 7262

QUIT (support to stop smoking)
www.quit.org.uk
Telephone: 0800 00 22 00

Mind (information to support psychological well-being, issue such as anxiety or depression)
www.mind.org.uk
Telephone: 0300 123 3393

Relate (information, advice on relationships and sex therapy)
www.relate.org.uk
Telephone: 0300 100 1234

Samaritans (non-judgemental emotional support 24 hours per day)
www.samaritans.org.uk
Helpline: 0845 790 9090

Maggie's Centre Dundee
https://www.maggiescentres.org/our-centres/maggies-dundee/
Telephone: 01382 632999

NHS 24
www.nhs24.com
Telephone: 08454 242424

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