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An ecological momentary assessment of self-management in prostate cancer survivors.

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Abstract

Purpose: To assess the "real time" self-management strategies employed by prostate cancer survivors to inform personalised supportive care interventions in the future.

Method: A purposive sampling framework was used to recruit men with different stages of cancer and treatment to an ecological momentary assessment (capturing experiences in real time) study. Each participant was prompted by an audio alert to complete self-report questionnaires 3 times per day (93 data entries in total) for a total duration of 31 days. A personal digital assistant (PDA) and pocket interview software was used.

Results: Prostate cancer survivors experienced a wide range of after-effects of therapy for which they used various self-management strategies. Many of the men experienced sexual dysfunction but did not perform any self-management.

Conclusion: Our findings reinforce the importance of having access to tailored, timely and person-centred supported self-management care plans. Real time monitoring data can provide helpful information to facilitate tailored recommendations for self-management.

Implications for Cancer Survivors:

Prostate cancer survivors can experience unmet supportive care needs which may increase men's demands to perform self-management of their condition. Future clinical intervention studies aimed at utilising the remote exchange of real time data serves to optimise tailored supported self-management.

Key words: Prostate cancer; self-management; mobile technology; real time; supportive care; ecological momentary assessment.

Introduction

Prostate carcinoma is the most prevalent type of cancer in men [1]. Improved diagnostic techniques and treatments have dramatically improved survival rates [2]. However, men affected prostate cancer can experience profound decrements in quality of life, debilitating and challenging symptoms with psychosocial concerns. Distress can be related to sexual, urinary and bowel dysfunction, emotional difficulties and changes in perceptions of masculinity [3]. Prostate cancer is a long-term condition with numerous healthcare challenges. Prostate cancer survivors can experience unmet supportive care needs [4-14] in routine service delivery, which may exacerbate their own individual demands to perform self-management of their condition. Men continue to report a lack of self-management advice in contemporary healthcare [4-14].

Self-management is a concept which specifically relates to an individual's skill and capability to manage symptoms, physical and psychosocial after-effects of therapy, and adopting lifestyle modifications [15]. Clinical management of millions of prostate cancer survivors [16] in a stressed healthcare system imposes effective self-management strategies on individuals [15, 17]. Generally, most men will have to adopt various self-manage strategies unsupervised from healthcare professionals in the community setting [4].

Two systematic reviews [18, 19] classified self-management in prostate cancer survivors. On critical analysis both systematic reviews have limitations worthy of comment. Firstly, the existing evidence base does not explore the influence of clinical and demographic factors which may influence self-management capabilities. For example, employment status, cancer stage, treatments, marital status, level of education or multiple co-morbidities. Secondly, existing studies in this area do not assess how self-management behaviours performed by men change over time. Thirdly, all existing studies in this area are subject to retrospective memory recall bias and cross-sectional designs.

Ecological momentary assessment (EMA) encompasses real time self-report assessment methods in the individual's naturalistic environment [20, 21]. Participants are audio prompted using mobile technology, such as a smart phone or personal digital assistant, at various times daily to self-report on their current state of mood, symptoms, or behaviours. This novel approach to real time data collection reduces concerns over data fabrication and retrospective memory recall bias. Therefore, studies which incorporate a novel design embedded in eHealth strategies [22, 23] and real time methodology [20] are needed to identify gaps in self-management experiences to develop personalised supportive care interventions moving forward. The assessment of real time self-

management strategies may provide useful understandings about how healthcare professionals can enhance shared self-management care plans and identify potential barriers encountered while self-managing.

Research questions

I. What patient characteristics (clinical and demographic) influence agreement to participate in an EMA study?

II. What self-management strategies are used, and do they change over time?

Methods

This study had National Health Service (NHS) ethical approval (10/S1402/7). The setting was two large cancer hospitals in Scotland. Inclusion criteria: capable to provide written informed consent, multidisciplinary team sanctioned diagnosis of prostate cancer irrespective of cancer stage or therapies, over 18 years of age, and self-assessed proficiency in ability to read and write English. Clinicians who considered patients to be psychologically or physically unfit were excluded from the study. Written informed consent was obtained for each participant. The current study formed part of a larger project [24, 25] and here we report the results of the EMA of the real time self-management behaviours.

Ecological Momentary Assessment (EMA)

We conducted an EMA study in prostate cancer survivors [26] according to the Checklist for Reporting EMA Studies (CREMAS) [27]. The study was informed by the theoretical model of social support [28, 29]. A total of n74 consented to participate in the prospective longitudinal survey (reported elsewhere), and of which, n62 of these participants also consented to take part in the EMA study. Of the n62 who consented to the EMA study, n12 participants were purposively sampled.

Sampling Framework

A purposive sampling framework defined by: level of social support (as measured by the Berlin Social Support Scale [BSSS]) [30] at baseline recruitment as part of the prospective longitudinal survey [24], having a partner or not, and cancer stage. The BSSS has good reliability >.80 and validity (31-35). Previously reported data on the mean and standard deviation (SD) of social support scores (BSSS) for prostate cancer survivors was used to guide

the sampling framework [31-35]. The next step, was to calculate the means and SDs for the study participants in the prospective longitudinal survey [24] at baseline. The mean was identified as 3.2 (SD 0.6, [range 2.2 to 4.0]). Twelve participants were purposively sampled by applying 1 SD (2.6) below the mean and 1 SD (3.8) above the mean to designate high and low social support, see **Table 1**.

The sampling framework was important for several clinical reasons. Firstly, it facilitated an exploration of the influence of support on self-management strategies and evaluated self-management across different stages of prostate cancer.

Electronic Behavioural Diary

A small digital personal assistant (Dell Axim X51) with Pocket Interview software was used. Twelve participants is a recommended sample size for this type of study design [36]. The digital personal assistant hosted Pocket Interview software [37] and used a RC4 cipter. Prior to the EMA study pilot work was carried out and a steering group convened. The steering group panel consisted of researchers, prostate cancer survivors and clinicians. The pilot work ensured patient involvement in the co-design [38] and provided an essential opportunity to address any technical issues and explored considerations of acceptability and face validity. The pilot study specifically was conducted in two distinct phases. The first part involved 11 pilots with colleagues and acquaintances, and the second part, comprised of three pilots with prostate cancer survivors. This work resolved technical problems and collated essential information on the scheduling and contents of the EMA study.

Data Collection

The schedule of the EMA data collection were informed by prostate cancer survivors and clinicians (see **Table 2**). Data collection was signal contingent (alerted by an audio signal) at fixed time points throughout each day (although the timings differed from participant to participant) using the electronic behavioural diary. We also included an event contingent data collection which enabled the capture of experiences as they randomly occurred in the real world [20]. Signal contingent data collection was completed at 3 pre-determined intervals per day for a total of 1 month (totalling 93 data points). The individual timings were tailored by factors such as employment commitments, lifestyle, sleeping and waking times, etc. Signal contingent data collection were at intervals equally spaced (i.e. 8am, 2pm, and 8pm). The “snooze function” enabled a delay in the participant completing the electronic questionnaire from 5 to 60 minutes if the timing was inconvenient. The participants were provided with

written and verbal instruction on how to complete the data collection. The twelve participants were provided with a curtesy telephone conversation on the second day of their data collection answer any questions and resolve any technical problems. After the one month of data collection the electronic device was retrieved from the participant and the data safely downloaded to a secure database.

Outcome Variables

SELF-MANAGEMENT STRATEGIES: Questionnaire items were informed by self-management diary research within cancer care [19, 39-41] and involvement from prostate cancer survivors and clinicians. The questions were structured to address: 1) symptom, 2) strategies/behaviours performed, and 3) the outcome of the action. Self-management item questions were asked in relation to bowel, urinary, and sexual function (see **Figure 1** for example of the electronic diary and the sexual function self-management options). To assess other symptoms or problems for which self-management was performed we asked, *"Did you use any other self-care activities (not already mentioned) to help alleviate your symptoms/problems today?"* and participants responded by "tapping" a box on the PDA screen to indicate *"yes or no"*. If *"yes"* was selected, *"Please describe the problem/symptom for which you carried out your self-care"*, *"Please describe the self-care tasks"* was automatically prompted. The questions were answered by digitally typing letters with a stylus to form words on the PDA screen. To evaluate the perceived effectiveness of the various self-management strategies, *"Generally, did your self-care actions relieve this problem?"* was anchored by *"not at all/completely"* (scale anchor 0-100).

SELF-MANAGEMENT DEMAND AND CONTROL: Questions included: *"How demanding has self-care been for you?"*, *"how much control have you had over your self-care?"* answered by *"not at all/completely"* (scale anchor 0-100). Finally, participants were asked *"What was your most demanding self-care task that you had to do today"?*

HEALTH-RELATED QUALITY OF LIFE: Question items were constructed by the EORTC C30 and PR25 questionnaires [42, 43]. *"How would you rate your quality of life today?"* answered by *"very poor/excellent"* (scale anchor 0-100), and *"To what extent have you experienced the following symptoms today? (blood in the urine, constipation, diarrhoea, nausea, pain, tiredness, unable to sleep, urgency to pass urine, urinate frequently day, urinate frequently night, vomiting, erectile dysfunction)"* answered *"not at all/always"* (scale anchor 0-100).

Results

No statistically significant differences were observed employment, marital status, co-morbidity and gleason score variables between those who consented to the EMA study and those who did not (see **Table 3,** Fisher's exact test P>0.05, 2-tailed). It was not possible to explore the relationship with education, socio-economic, and treatment using Chi²-test as the assumptions were not met. We observed a statistically significant association between participation in the EMA study and cancer stage: χ^2 (2)=12.765, p=0.002. Men with metastatic prostate cancer were less likely to consent to the EMA study, but due to the small numbers caution should be taken in the interpretation.

Four participants had localised prostate cancer, five participants had locally advanced prostate cancer, and three men had metastatic cancer. Regrettably, Mr L's data was unable to be retrieved from the PDA. Mr L articulated excellent compliance with the EMA study, but forgot to tap the finish key at each entry. Overall, response rates were very high to the EMA study, >90%.

Prostate cancer survivors' self-management

Men experienced a wide range of after-effects after treatment. Generally, self-management strategies were used to relieve urinary, bowel and sexual dysfunction. However, men also reported other symptoms which included: infected wound, severe rectal pain, poor sleeping, morning sickness, radiation burns to penis and problems with relaxation for which participants implemented self-management strategies, see **Table 4.** The frequency of self-management activity varied over time, see **Table 5**. The two men who were receiving androgen deprivation therapy for their metastatic prostate cancer did not report any self-management strategies at all, despite experiencing a range of problematic symptoms.

Self-management strategies demonstrated variation across the participants so did the self-management relief over time. The real time series data across all the participants demonstrated the unique variation in symptom experience and self-management experience that traditional research methodologies are unable to measure (see **Figure 2,** for exemplar). Sexual well-being self-management was infrequently performed across the 11 prostate cancer survivors and the reasons for this are unclear. A commonality for Mr B, Mr G, Mr I, was identified in that they reported to have low social support and collectively, they all stated that they experienced inadequate symptom relief from their self-management strategies.

Discussion

This innovative EMA study sought to identify the real time self-management behaviours of prostate cancer survivors over time. We also investigated potential sources of bias in relation to participation in this ecological momentary assessment study. Overall, acceptability to participate in this unique study was high (83.8%) with high data collection responses rates (<90%). This study has demonstrated that future digitalised real time assessments in this older patient group are acceptable, and refutes the widely accepted perceptions of the barriers to engaging an aging population in future eHealth studies [44]. The acceptability of this innovative study for participants was enhanced by the co-design with service users and prostate cancer clinicians.

We did not identify any statistically significant differences between those who agreed to participate in the EMA study across a range of clinical and demographic variables. However, men with metastatic prostate cancer were less likely to agree to take part in an EMA study, but due to the small participant numbers caution should be taken. One explanation, which might be offered is in relation to the burden of metastatic prostate cancer on quality of life [6, 45], which might have influenced their decision to participate. Ultimately, this will remain unknown.

Self-management strategies varied in relation to prostate cancer specific domains of health-related-quality-of-life, specifically, urinary, bowel and sexual dysfunction over time. Men who received radical therapy (radiotherapy and surgery) performed self-management more often compared to men on active surveillance. However, men affected by incurable metastatic prostate cancer receiving androgen deprivation therapy did not report any self-management despite the frequency of their reported symptoms. The reasons why they did not perform any self-management is unknown, but several explanations are offered. Clinically, metastatic prostate cancer can result in physical and psychological sequalae which can include: body feminization (gynecomastia, hot flushes, genital shrinkage, loss of muscle mass), sexual dysfunction and lack of libido, relationship changes, cognitive and affective symptoms, and sleep disturbance, depression and fatigue [46-52] which could afford various self-management strategies. However, a considerable body of evidence now exists that prostate cancer survivors can experience distressing unmet supportive care needs and a lack of self-management advice [5, 7, 9, 12, 14, 53-56], in particular men diagnosed with metastatic prostate cancer [5, 47, 57-59] . Therefore, future research should be prioritised to investigate the potential association between self-management strategies and the experience of unmet supportive care needs specifically for men affected by metastatic prostate cancer [6, 45].

Implications for practice

This EMA study provides the first real time assessment of the strategies that prostate cancer survivors used to cope and reduce their symptoms. This methodology can provide a clinical tool for healthcare providers to assess the diverse strategies patients use and to support and tailor the most effective self-management techniques to alleviate their symptoms. We observed that all participants experienced a range of symptoms. Noteworthy, few men reported self-management strategies to alleviate erectile dysfunction (ED) across the case series. The reasons for this are unknown. Healthcare professionals should offer a proactive approach to evidence-based interventions for ED in routine clinical consultation [60] including prehabiliation self-management support [61]. Healthcare professionals must elicit an understand about the connection between symptom experience (bother, frequency and severity) and its relationship with self-management strategies to further advance new knowledge and understanding over the cancer care continuum [62]. Prostate cancer survivors performed diverse self-management strategies to improve their overall quality of life. Three men described ineffective outcomes from their self-management strategies on their symptoms and had low social support. In keeping with social support theory, these men may not have had access to informational, practical and emotional support to help them alleviate and cope with their symptoms [4].

The symptom experience is complex and multidimensional. Healthcare professionals need to elicit prostate cancer survivors interpretations of various symptoms [41]. This study has demonstrated that prostate cancer survivors evaluate their symptoms daily. Men will make decisions about the cause, severity, treatability, and impact of the symptoms on their quality of life. Healthcare professionals need to elicit this information accurately to tailor supported-self-management care plans which are customised to each patient's needs [41, 62]. An understanding of fundamental factors such as: timing (frequency of occurrence), symptom intensity (severity), level of perceived distress (bother), and perceived self-efficacy [63] are needed to support men in their recovery and tailored self-management care plans.

Limitations

We evaluated self-management strategies used by men with different levels of social support and clinical characteristics, enabling some replication. However, this study was at risk of habituation and reactivity due to

repeated exposure to the electronic diary questions over time. Several symptoms were not explicitly assessed as a potential limitation; however, participants could report on any symptoms using "free text". Moreover, as real time methodologies in cancer care is an emerging science there are no existing standardised questionnaires available with demonstrated reliability or validity. Future studies should focus efforts on developing robust standardised tools for eventual use by researchers and clinical teams.

Conclusion

This study was designed move beyond traditional studies which are plagued with retrospective memory recall bias. We aimed to advance science in the understanding of real time symptom experience and the self-management strategies used across different stages of cancer, treatment modalities and level of support. This real time approach to capturing prostate cancer survivors experience serves as the basis for future intervention studies aimed at utilising the remote exchange of data and communication between patients and health care professionals. Our findings reinforce the clinical need that healthcare professionals must recognise the support needs and symptom-related-distress to provide timely and person-centred supported self-management plans.

Compliance with Ethical standards

Funding: This study was funded by the University of Dundee.

Conflict of Interest: The author has no conflict of interest.

Ethical approval: This study was conducted in accordance with the ethical standards of the national research committee and with the 1964 Helsinki declaration and its later amendments.

Informed Consent: Written informed consent was obtained from all individual participants included in the study.

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Q3 What types of self-care have you used today to help with your sexual function?

None ☐ (if ticked Q4)

- ☐ Took Medication
- ☐ Found out information
- ☐ Tried to lose weight (if overweight)
- ☐ Limited alcohol intake
- ☐ Stopped smoking (if smoke)
- ☐ Used a penis pump
- ☐ Took exercise
- ☐ Found ways to reduce stress
- ☐ Shared my feelings

☐ Other

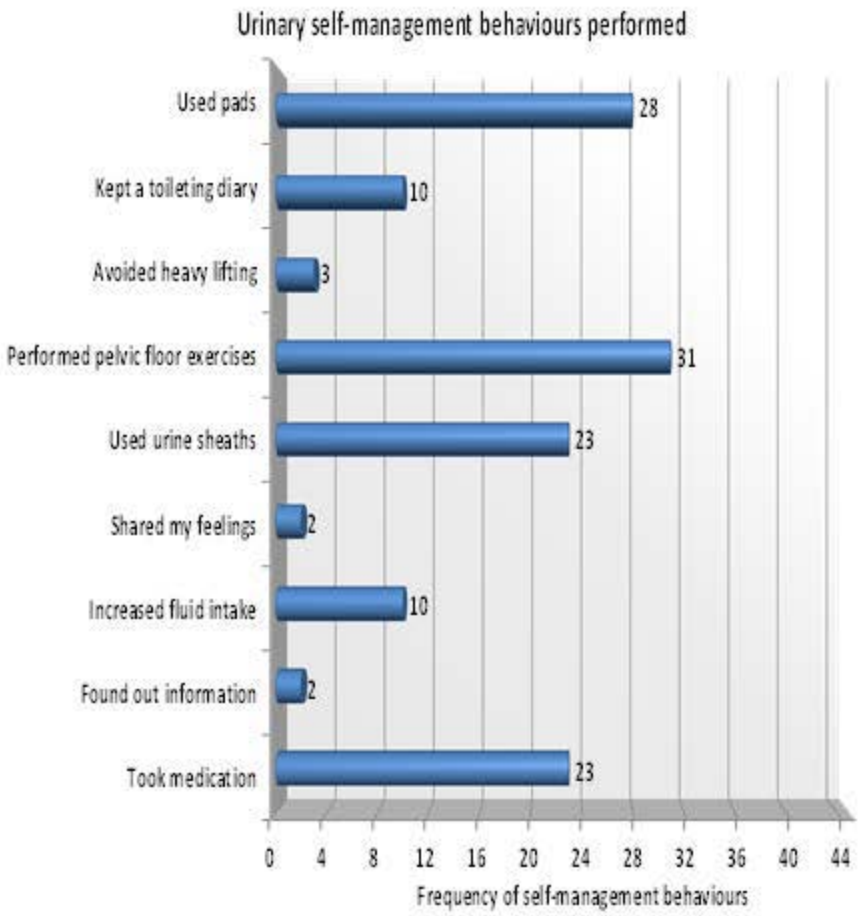
Please describe

Generally, did your self-care actions relieve the problem?

Not at all_____Completely

Figure 1. Example of the electronic diary and erectile dysfunction self-management question

Exemplar of case study self-management and change over time (Mr C)



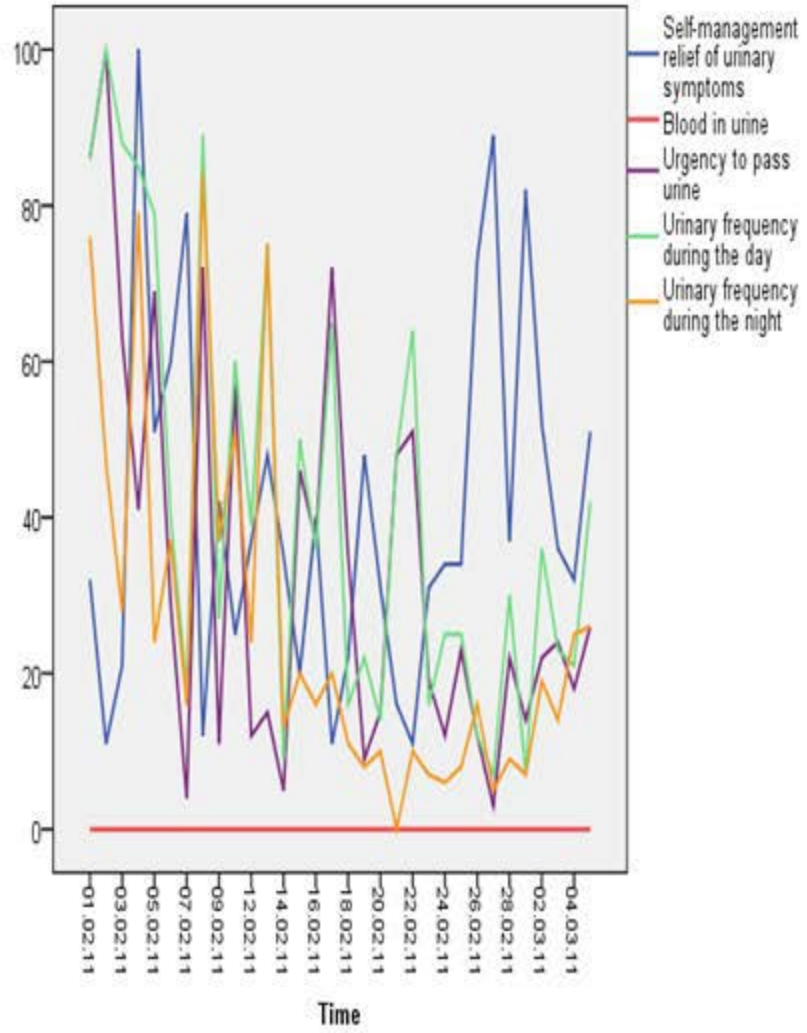


Figure 2. Real time data

Table 1. Sampling framework

	Localised prostate cancer	Locally advanced prostate cancer	Metastatic prostate cancer
Partner	high social support 3.8 ≥ low social support 2.6 ≤	high social support 3.8 ≥ low social support 2.6 ≤	high social support 3.8 ≥ low social support 2.6 ≤
No partner	high social support 3.8 ≥ low social support 2.6 ≤	high social support 3.8 ≥ low social support 2.6 ≤	high social support 3.8 ≥ low social support 2.6 ≤
Total = 12 ecological momentary assessment studies.			

Table 2. Data collection timings

Treatment	**Timing of data collection**
Radical Prostatectomy (RP)	1 month after RP
External Beam Radiotherapy (EBRT)	1 month after EBRT
Androgen deprivation therapy	No timing restrictions
Active surveillance (AS)	No timing restrictions
Brachytherapy (BT)	1 month after BT

Table 3 Comparisons between those who consented to EMA and those who did not

Variables	Consented to complete the electronic diary (n=62, 83.8%)	Did not consent to completing the electronic diary (n=12, 16.2%)	Comparisons
Age (years) at study consent	69.7 (SD 7.8)	72.0 (SD 9.4)	t(72)=0.914, p=0.361
Education			
High school	9.7% (n=6)	8.3% (n=1)	The assumption for 'minimum expected cell frequency' was not met for the Chi² -test.
Further education	22.6% (n=14)	8.3% (n=1)	
Higher education	22.6% (n=14)	33.3% (n=4)	
Trade qualification	40.3%(n=25)	16.8% (n=2)	
No qualifications	4.8% (n=3)	33.3% (n=4)	
School leaving age (years)	16.2 (SD 1.4)	15.9 (SD 1.5)	t(72)=-1.232, p=0.221
Employment			
Unemployed	3.2% (n2)	0% (n0)	The Chi²-test was performed with employed and retired categories only, because the participants in the unemployed categories (n=2) were very small for the entire study sample. χ^2 (1)=0.626, p=0.431 Fisher's Exact Test p=0.502, (2-tailed).
Employed	29.0% (n18)	41.7% (n5)	
Retired	67.7% (n42)	58.3% (n7)	
Socio-economic (SIMD)			
1 most deprived	3.2% (n2)	16.7% (n2)	The assumption for 'minimum expected cell frequency' was not met for the Chi²-test.
2	6.5% (n4)	16.7% (n2)	
3	16.1% (n10)	25.0% (n3)	
4	48.4% (n30)	25.0% (n3)	
5 Least deprived	25.8% (n16)	16.7% (n2)	
Martial			
Partner	80.6% (n50)	83.3% (n10)	χ^2 (1)=0.047, p=0.833. Fisher's Exact Test p=1.0 (2-tailed)
No partner	19.4% (n12)	16.7% (n2)	
Cancer stage			
Localised	43.5% (n27)	41.7% (n5)	χ^2(2)=12.765, p=0.002, Cramer's V statistic =0.415, p=0.002.**
Locally advanced	50.0% (n31)	16.7% (n2)	
Metastatic	6.5% (n4)	41.7% (n5)	
Cancer treatment			
Watchful waiting	4.8% (n3)	0% (n0)	The assumption for 'minimum expected cell frequency' was not met for the Chi²-test.
RRP	1.6% (n1)	0% (n0)	
LRP	11.3% (n7)	8.3% (n1)	
EBRT	9.7% (n6)	0% (n0)	
Hormone therapy	14.5% (n9)	41.7% (n5)	
Active surveillance	11.3% (n7)	16.7% (n2)	
Hormone therapy and EBRT	46.8% (n29)	33.3% (n4)	
PSA	26.1 (SD 31.8)	56.6 (SD 86.6)	t(11.6)=1.205, p= 0.253
Gleason			
Low grade (2-4)	0 % (n0)	0% (n0)	χ^2 (1)=1.244, p=0.262. Fisher's Exact Test p=0.303, 2-tailed)
Intermediate grade (5-7)	74.2% (n46)	58.3% (n7)	
High grade (8-10)	25.8% (n16)	41.7% (n5)	
Existing co-morbidity (yes)	*71.0% (n44)*	*58.3% (n7)*	χ^2 (1)=0.749, p=0.384 Fisher's Exact Test p=0.498, (2-tailed)

*p<0.05, **p<0.01

Table 4. Self-management

	Symptoms	Self-management
Urinary dysfunction	Urinary incontinence Urinary frequency (during day) Urinary frequency (during the night) Urinary urgency Blood in the urine	Found out more information Used continence pads Took medication (anticholinergics, ie. Tolterodine) Increased oral fluid intake Used catheter sheaths Avoided heavy lifting of objects Reduced caffeine intake (switched to decaffeinated alternatives) Shared thoughts and feelings with friends and family Drank cranberry juice Kept a toileting diary (urinary and bowel patterns) Reduced alcohol intake Washed incontinence pads (re-usable ones) Mind over matter strategies
Bowel dysfunction	Diarrhoea Constipation Bleeding from anus Rectal pain	Took medication Took a high fibre diet Took califig/fybogel Changed fluid intake Applied anusol Used continence pads Shared my thoughts and feelings with friends and loved ones Changed and modified diet Kept a toileting diary Took physical exercise
Sexual dysfunction	Impotence	Used a penis pump Found out information Shared thoughts and feelings with friends and family Took medication (Viagra) Limited alcohol intake Found ways to reduced stress
Other	Ankle oedema	Took furosamide pill Went for a walk regularly Elevated feet when sitting down
Other	Infected surgical wound	Sought help from nurse and doctor

		Dressed wound Changed and emptied wound drainage bag Took antibiotic tablets
Other	Poor sleeping patterns/problems with relaxation	Took a large whisky before bed Increased amitriptyline dosage
Other	Morning sickness	Took anti-sickness tablets
Other	Radiation burns to abdomen and penis	Applied savlon and aqueous cream Applied gel medication Wiped tip of penis after urinating

Table 5 The number of days that self-management was performed

	Social support	Clinical details	Self-management of urinary symptoms	Self-management of bowel symptoms	Self-management of sexual function symptoms
Mr A, 73 years old, retired	Partner high support	Localised cancer AS Comorbidity: None	5 days	None	None
Mr B, 61 years old, employed	Partner low support	Localised cancer AS Comorbidity: None	29 days	None	None
Mr C, 51 years old, employed	Partner high support	Localised cancer LRP Comorbidity: None	31 days	8 days	1 day
Mr D, 59 years old, retired	Partner high support	Localised cancer LRP Comorbidity: None	30 days	None	None
Mr E, 65 years old, retired	Partner high support	Locally advanced cancer ADT and EBRT Comorbidity: None	None	3 days	None
Mr F, 57 years old, employed	Partner high support	Locally advanced cancer ADT and EBRT Comorbidity: None	25 days	3 days	None
Mr G, 64 years, retired	Partner low support	Locally advanced cancer ADT and EBRT. Comorbidity: Asthma, Hypertension, Depression	31 days	31 days	None
Mr H, 73 years old, employed	No partner high support	Locally advanced cancer ADT and EBRT Comorbidity: None	12 days	13 days	11 days
Mr I, 73 years old, retired	No partner low support	Locally advanced cancer ADT and EBRT Comorbidity: Asthma, Hypertension	30 days	30 days	1 day
Mr J, 73 years old, retired	Partner low support	Metastatic cancer ADT Comorbidity: None	None	None	None

Mr K, 72 years old, retired	Partner high support	Metastatic cancer ADT Comorbidity: None	None	None	None