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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 cipher. 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 courtesy 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 Chi<sup>2</sup>-test as the assumptions were not met. We observed a statistically significant association between participation in the EMA study and cancer stage:  $\chi^2(2)=12.765$ ,  $p=0.002$ . 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 sequelae 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 prehabilitation 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.

## References

1. Torre, L.A., et al., *Global cancer statistics*. CA: A Cancer Journal for Clinicians, 2015. **65**(2): p. 87-108.
2. Pompe, R.S., et al., *Tumor characteristics, treatments, and oncological outcomes of prostate cancer in men aged ≤50 years: a population-based study*. Prostate Cancer and Prostatic Diseases, 2018. **21**(1): p. 71-77.
3. Eeva, H., et al., *Marital relationship and health-related quality of life of patients with prostate cancer and their spouses: A longitudinal clinical study*. Journal of Clinical Nursing, 2018. **0**(0).
4. Paterson, C., et al., *Identifying the unmet supportive care needs of men living with and beyond prostate cancer: A systematic review*. European Journal of Oncology Nursing, 2015. **19**(4): p. 405-418.
5. Paterson, C., et al., *Unmet supportive care needs of men with locally advanced and metastatic prostate cancer on hormonal treatment: A mixed methods study*. Cancer Nursing: An International Journal for Cancer Care, 2017. **40**(6): p. 497-507.
6. Primeau, C., Paterson, C, Nabi, G, *A qualitative study exploring models of supportive care in men and their partners/caregivers affected by metastatic prostate cancer* Oncology Nursing Forum, 2017. **1;44**(6): p. E241-E249.
7. Boberg, E.W., et al., *Assessing the unmet information, support and care delivery needs of men with prostate cancer*. Patient Education And Counseling, 2003. **49**(3): p. 233-242.
8. Carey, M., et al., *The unfulfilled promise: a systematic review of interventions to reduce the unmet supportive care needs of cancer patients*. Support Care Cancer, 2012. **20**(2): p. 207-19.
9. Jakobsson, L., I.R. Hallberg, and L. Loven, *Met and unmet nursing care needs in men with prostate cancer. An explorative study. Part II*. European Journal of Cancer Care, 1997. **6**(2): p. 117-123.
10. Jakobsson, L., I.R. Hallberg, and L. Lovén, *Met and unmet nursing care needs in men with prostate cancer. An explorative study. Part II*. European Journal of Cancer Care, 1997. **6**(2): p. 117-123.
11. Kattan, M.W., *Measuring hot flashes in men treated with hormone ablation therapy: an unmet need*. Urologic Nursing, 2006. **26**(1): p. 13-18.
12. King, A.J.L., et al., *Prostate cancer and supportive care: a systematic review and qualitative synthesis of men's experiences and unmet needs*. European Journal of Cancer Care, 2015. **24**(5): p. 618-634.
13. O'Brien, R., et al., *"I wish I'd told them": a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment*. Patient Education & Counseling, 2011. **84**(2): p. 200-207.
14. Watson, E., et al., *Symptoms, unmet needs, psychological well-being and health status in survivors of prostate cancer: implications for redesigning follow-up*. BJU Int, 2016. **117**(6B): p. E10-9.
15. McCorkle, R., et al., *Self-Management: Enabling and empowering patients living with cancer as a chronic illness*. CA: a cancer journal for clinicians, 2011. **61**(1): p. 50-62.
16. Wong, M.C.S., et al., *Global Incidence and Mortality for Prostate Cancer: Analysis of Temporal Patterns and Trends in 36 Countries*. European Urology, 2016. **70**(5): p. 862-874.
17. Hammer, M.J., et al., *Self-management for adult patients with cancer: an integrative review*. Cancer Nurs, 2015. **38**(2): p. E10-26.
18. Spindelov, J.S., et al., *Coping and adjustment in men with prostate cancer: a systematic review of qualitative studies*. Journal of Cancer Survivorship, 2018. **12**(2): p. 155-168.

19. Paterson, C., et al., *Identifying the self-management behaviours performed by prostate cancer survivors: a systematic review of the evidence*. Journal of Research in Nursing, 2014. **20**(2): p. 96-111
20. Bolger, N., A. Davis, and E. Rafaeli, *Diary methods: Capturing life as it is lived*. Annual review of psychology, 2003. **54**(1): p. 579-616.
21. Shiffman, S., A.A. Stone, and M.R. Hufford, *Ecological momentary assessment*. Annual Review Of Clinical Psychology, 2008. **4**: p. 1-32.
22. Janssen, A., et al., *Interdisciplinary eHealth Practice in Cancer Care: A Review of the Literature*. International Journal of Environmental Research and Public Health, 2017. **14**(11): p. 1289.
23. Scottish Government. *eHealth Strategy 2014-2017*. 2015 [cited July 2018; Available from: <http://www.gov.scot/Publications/2015/03/5705>].
24. Paterson, C.I.E., A.F. Robertson, and G. Nabi, *Exploring prostate cancer survivors self-management behaviours and examining the mechanism effect that links coping and social support to health-related quality of life, anxiety and depression: A prospective longitudinal study*. European Journal of Oncology Nursing, 2014. **19**(2): p. 120-128.
25. Paterson, C., *Exploring prostate cancer survivors' self-management behaviours and social supportive experiences using questionnaires and electronic behavioural diaries: Does social support buffer the relationship between coping and health-related quality of life?*, in *School of Nursing and Midwifery*. 2013, University of Dundee: Dundee.
26. Paterson, C., et al., *What is the mechanism effect that links social support to coping and psychological outcome within individuals affected by prostate cancer? Real time data collection using mobile technology*. European Journal of Oncology Nursing, 2015. **17**(6): p. 150-8.
27. Liao, Y., et al., *A Systematic Review of Methods and Procedures Used in Ecological Momentary Assessments of Diet and Physical Activity Research in Youth: An Adapted STROBE Checklist for Reporting EMA Studies (CREMAS)*. J Med Internet Res, 2016. **18**(6): p. e151.
28. Cohen, S. and G. McKay, *Social support, stress and the buffering hypothesis: A theoretical analysis*, in *Handbook of psychology and health*, S. Baum, S. Taylor, and J. Singer, Editors. 1984, Hilldale: New York.
29. Cohen, S., L. Underwood, and B. Gottlieb, *Social support measurement and intervention 2000*, New York: Oxford University Press.
30. Schulz, U. and R. Schwarzer, *Soziale Unterstützung bei der Krankheitsbewältigung. Die Berliner Social Support Skalen (BSSS) [Social support in coping with illness: The Berlin Social Support Scales (BSSS)]*. Diagnostica, 2003. **49**: p. 73-82.
31. SCHOLZ, U., et al., *Effects of provision and receipt of social support on adjustment to laparoscopic radical prostatectomy*. Anxiety, Stress & Coping, 2008. **21**: p. 227-241.
32. LUSZCZYNSKA, A., et al., *Patients' coping profiles and partners' support provision*. Psychology and Health, 2007. **22**: p. 749-764.
33. LUSZCZYNSKA, A., N. MOHAMED, and R. SCHWARZER, *Self-efficacy and social support predict benefit finding 12 months after cancer surgery*. Psychology, Health & Medicine, 2005. **10**: p. 365-375.
34. BOEHMER, S., L. ALEKSANDRA, and R. SCHWARZER, *Coping and quality of life after tumor surgery: Personal and social resources promote difference domains of quality of life*. Anxiety, Stress & Coping,, 2007. **20**: p. 61-75.
35. SCHWARZER, R., et al., *Changes in finding benefit after cancer surgery and the prediction of well-being one year later*. Social Science & Medicine, 2006. **63**: p. 1614-1624.
36. Hobb, N., et al., *Can the theory of planned behaviour predict the physical activity behaviour of individuals?* Psychol 2013. **1e**(16).
37. MORRISON, K., et al., *Pocket interview - a secure electronic data collection and diary tool*. eHealth International Journal, 2009. <http://www.ehealthinternational.org/>.

38. Bate, P. and G. Robert, *Experience-based design: from redesigning the system around the patient to co-designing services with the patient*. *Quality and Safety in Health Care*, 2006. **15**(5): p. 307.
39. KIM, H., *Development and evaluation of self-care agency promoting programme for prostatectomy patients*. *International Journal of Urological Nursing*, 2011. **5**(34-44).
40. WILSON, F., et al., *The effect of low literacy on the self-care behaviors of men receiving radiation therapy*. *Nursing Science Quarterly*, 2010. **23**: p. 326-333.
41. DODD, M., *Measuring self-care activities*. In: FRANK-STROMBORG, M. & OLSEN, S. (eds.) *Instruments for clinical healthcare research*, 1997. **Boston**: (Jones and Bartlett Publishers.).
42. Aaronson, N., et al., *The European Organisation for research and treatment of cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology*. *Journal of the National Cancer Institute*, 1993. **85**: p. 365-376.
43. van Andel, G., et al., *An international field study of the EORTC QLQ-PR25: a questionnaire for assessing the health-related quality of life of patients with prostate cancer*. *European Journal of Cancer*, 2008. **44**(16): p. 2418-2424.
44. Wildenbos, G.A., L. Peute, and M. Jaspers, *Aging barriers influencing mobile health usability for older adults: A literature based framework (MOLD-US)*. *International Journal of Medical Informatics*, 2018. **114**: p. 66-75.
45. Paterson, C., et al., *Unmet Supportive Care Needs of Men With Locally Advanced and Metastatic Prostate Cancer on Hormonal Treatment: A Mixed Methods Study*. *Cancer Nursing*, 2017. **40**(6): p. 497-507.
46. Fitzpatrick, J.M., et al., *Optimal management of metastatic castration-resistant prostate cancer: Highlights from a European Expert Consensus Panel*. *European Journal of Cancer*, 2014. **50**(9): p. 1617-1627.
47. Carter, N., et al., *Healthcare Providers' Perspectives of the Supportive Care Needs of Men With Advanced Prostate Cancer*. *Oncology Nursing Forum*, 2014. **41**(4): p. 421-430.
48. Kornblith, A.B., et al., *Quality of life of patients with prostate cancer and their spouses. The value of a data base in clinical care*. *Cancer*, 1994. **73**(11): p. 2791-2802.
49. Grossmann, M., et al., *Bone and metabolic health in patients with non-metastatic prostate cancer who are receiving androgen deprivation therapy*. *The Medical Journal Of Australia*, 2011. **194**(6): p. 301-306.
50. Grossmann, M. and G. Wittert, *Androgens, diabetes and prostate cancer*. *Endocrine-Related Cancer*, 2012. **19**(5): p. F47-F62.
51. Grossmann, M. and J.D. Zajac, *Androgen deprivation therapy in men with prostate cancer: how should the side effects be monitored and treated?* *Clinical Endocrinology*, 2011. **74**(3): p. 289-293.
52. McCaughan, E., et al., *A randomized controlled trial of a self-management psychosocial intervention for men with prostate cancer and their partners: a study protocol*. *Journal of Advanced Nursing*, 2013. **69**(11): p. 2572-2583.
53. Cockle-Hearne, J., et al., *The impact of supportive nursing care on the needs of men with prostate cancer: a study across seven European countries*. *British Journal of Cancer*, 2013. **109**(8): p. 2121-2130.
54. Smith, D.P., et al., *Age, health, and education determine supportive care needs of men younger than 70 years with prostate cancer*. *Journal of Clinical Oncology*, 2007. **25**(18): p. 2560-2566.
55. Knight, S.J. and D.M. Latini, *Sexual side effects and prostate cancer treatment decisions: patient information needs and preferences*. *Cancer Journal*, 2009. **15**(1): p. 41-44.
56. Carter, N., et al., *The supportive care needs of family members of men with advanced prostate cancer*. *Canadian Oncology Nursing Journal*, 2010. **20**(4): p. 166-170.
57. Carter, N., et al., *The Supportive Care Needs of Men With Advanced Prostate Cancer*. *Oncology Nursing Forum*, 2011. **38**(2): p. 189-198.

58. Elliott, S., et al., *Androgen Deprivation Therapy for Prostate Cancer: Recommendations to Improve Patient and Partner Quality of Life*. The Journal of Sexual Medicine, 2010. **7**(9): p. 2996-3010.
59. Chambers, S.K., et al., *Experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study*. BMJ open, 2018. **8**(2): p. e019917.
60. Paterson, C. and G. Nabi, *A Model of Consultation in Prostate Cancer Care: Evidence From a Systematic Review*. Cancer Nurs, 2017. **40**(4): p. 276-288.
61. Paterson, C., et al., *Development of a Prehabilitation Multimodal Supportive Care Interventions for Men and Their Partners Before Radical Prostatectomy for Localized Prostate Cancer*. Cancer Nursing, 2018. **Publish Ahead of Print**.
62. Chao-Pin, H., et al., *Symptom self-management strategies in patients with non-metastatic prostate cancer*. Journal of Clinical Nursing, 2014. **23**(3-4): p. 440-449.
63. Foster, C., et al., *Cancer survivors' self-efficacy to self-manage in the year following primary treatment*. Journal of Cancer Survivorship, 2015. **9**(1): p. 11-19.