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**Title: A qualitative study exploring models of supportive care in men and their partners/caregivers affected by metastatic prostate cancer**

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- Multinational Association of Supportive Care in Cancer (MASCC/ISSOO) Washington DC, USA, 22-24 June 2017 Poster Presentation.
- European Association of Urology (EAU), London, UK, 24-28<sup>th</sup> March 2017, Poster Presentation.
- American Urological Association (AUA), Boston, USA, 12-16<sup>th</sup> May 2017, Podium Presentation.

**Abstract:**

**Purpose/Objectives:** To explore the experience of patients and their partner/caregiver as well as multidisciplinary team (MDT) members of a nurse-led multimodality supportive care intervention in men with metastatic prostate cancer as well as standard care.

**Research approach:** Qualitative.

**Participants:** Nineteen patients, seven partners/caregivers and seven MDT members from across four hospitals at NHS Tayside, Scotland.

**Methodologic Approach:** Thirty-three semi-structured interviews were conducted to explore their experience of supportive care and framework approach was used to analyze the data.

**Findings:** Men and their partner/caregivers experienced a range of unmet supportive care needs related to physical, psychological and informational needs. The participants in the intervention group, reported overall high satisfaction with the use of holistic needs assessments and self-management plans, with decrease of unmet needs compared to standard of care over time. The Prostate Cancer Specialist Nurse was perceived as the hub of survivorship care. Members of the MDT perceived benefit in the nurse-led multimodal supportive care intervention.

**Conclusion:** Men and their partner/caregivers affected by metastatic prostate cancer benefit from the multimodal supportive care interventions in the short term, experiencing decreased unmet needs compared to the standard of care group.

**Interpretation:** This study identifies that greater consideration needs to be focused on personalizing care, with supportive care interventions targeted at the individual level of need.

**Implications for Nursing:** Care can be improved by incorporating holistic needs assessments to target specialized intervention for optimized care plans at an individual level. Intervention seminar encouraged self-management and self-efficiency to greater satisfaction for participants.

**Knowledge Translation:**

- This study has demonstrated that the novel ThriveCare intervention for men and their partners/caregivers affected by metastatic prostate cancer decreased unmet supportive care needs over time.
- Future studies in other tumor groups should carefully consider targeting individuals with significant issues or unmet needs, and strive to deliver a model of care that is individualized 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.

### **Introduction:**

Currently, there are more than 330,000 men living with prostate cancer in the UK, with more than 44,000 being diagnosed every year (Prostate Cancer UK, 2016). Newer palliative therapies for metastatic prostate cancer have improved survival rates (Gilson, Manickavasagar, & Chowdhury, 2015) and therefore, larger numbers of men are requiring on-going supportive care. The treatment for metastatic prostate cancer disease aims to reduce systematic testosterone levels, which can be achieved surgically or by chemical castration (also known as androgen deprivation therapy (ADT) or androgen suppression therapy) (NICE, 2014). Men undergoing ADT can experience a range of symptoms that can negatively affect the quality of life and can increase the need for supportive care intervention. Side effects identified as particularly challenging include: (i) body feminization; (ii) changes in sexual performance; (iii) relationship changes; (iv) cognitive and affective symptoms; and (v) fatigue, sleep disturbance, and depression (Carter, Miller, Murphy, Payne, & Bryant-Lukosius, 2014; Fitzpatrick et al., 2014; Grossmann & Zajac, 2011; A. B. Kornblith, H. W. Herr, U. S. Ofman, H. I. Scher, & J. C. Holland, 1994; Lewis, Khan, & Payne, 2013; Wittmann et al., 2009). Acknowledgeable evidence has identified that unmet supportive care needs are prevalent in contemporary healthcare, (Paterson, Robertson, Smith, & Nabi, 2015) with a particular focus in the context of individuals affected by metastatic prostate disease (Donovan, Walker, Wassersug, Thompson, & Robinson, 2015; McLeod, Walker, Wassersug, & Robinson, 2014; Paterson, Kata, Nandwani, Chaudury, & Nabi, 2016; Ream et al., 2008; L. M. Walker, Hampton, Wassersug, Thomas, & Robinson, 2013; L.M. Walker, Tran, Wassersug, Thomas, & Robinson, 2013). Supportive care is a person-centered 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, or follow-up phases including issues of health promotion and prevention, survivorship, palliation and bereavement (Polley et al., 2016). The consequences of metastatic prostate cancer and treatment side-effects, affect the couple living with this disease, not just the man. Evidence acknowledges that partner/caregivers can experience unmet needs in relation to their care burden, relationship/sexual needs, and physiological distress (Bobridge, Bond, Marshall, & Paterson, 2015; Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2010; Donovan et al., 2015; A.B. Kornblith, H.W. Herr, U.S. Ofman, H.I. Scher, & J.C. Holland, 1994; McLeod et al., 2014).

Our study aimed to gain an understanding of men and their partners/caregiver affected by metastatic prostate cancer and their experience of a multimodal supportive care intervention (called ThriverCare) and the experience of men and their partners/caregiver receiving standard

of care. The experience of the supportive care was explored from the perspectives of patients and partner/caregivers and the multidisciplinary team. The primary end point was the experience of unmet supportive care needs at 3 months of intervention compared to no intervention.

### **Material and methods:**

This study will report the qualitative component of a sub-set of participants from a feasibility randomized controlled trial (RCT). The design of study of the RCT is shown in **Figure 1** and described by our group in a separate publication. Ethical approval was obtained (16/ES/0024) following review of protocol by an independent ethics committee.

### **Intervention: ThriverCare**

The intervention comprised four main components 1) holistic needs assessment, 2) individualized self-management care plans, and 3) group-based seminar and educational materials. The intervention and associated materials were developed in consultations with multidisciplinary healthcare experts including patient representatives.

### **Holistic needs assessment and individualised care plans**

The intervention group (patients and their partners/caregivers) completed Macmillan's Holistic Needs Assessment questionnaire (MacMillan, 2017), called a PRO (Patient Reported Outcome) in a quiet room in the hospital immediately prior to their routine 3 monthly clinical review appointment with a Prostate Cancer Specialist Nurse. Following the completion of the PRO questionnaire, the Prostate Cancer Specialist Nurse then met with the patient and their partner/caregiver and used the information collected from the questionnaires to direct discussions within the clinical consultations, to identify supportive care needs and tailor self-management support intervention accordingly.

The Prostate Cancer Specialist Nurse was asked to document supportive care needs identified during the consultation and any subsequent evidence-based interventions initiated based on the questionnaire assessment. The theoretical model used to inform the intervention was the Model of Consultation for Prostate Cancer Care (Paterson & Nabi, 2016) and evidence-based guidelines for the treatment and management of metastatic prostate cancer for nurse-led care delivery (Paterson, Alashkham, Windsor, & Nabi, 2015).

### **ThriverCare Seminar**

The half day 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 with a prostate cancer specialist nurse. The seminar also provided a custom made evidence-based self-management booklet entitled “*A Prostate Cancer Guide to Thrivership: Men it is time to Thrive*” (see supplementary information).

**Standard of care:** Patients in the control group received standard of care as was offered at clinical sites. This involved 3 monthly outpatient clinic reviews with a Consultant Urologist/medical staff with PSA testing. Participants (patients and partners/caregivers) randomized to standard care did not use PRO questionnaires, evidence-based self-management plans or self-management seminars.

**Data collection:** Exploratory purposive semi-structured interviews were conducted using a topic guide informed by existing literature, the primary outcome and the classification of supportive care needs (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2011; Hui, 2014; Paterson, Robertson, et al., 2015; Rittenberg, Johnson, & Kuncio, 2010) (see **Table 1**) at 3 months. This interview guide focused on the experience of the provided care, the advantage and disadvantage of the two models and on the feasibility and implementation of the intervention into current care.

Purposive sampling of the interviews ensured maximum variation by: patients’ age (67 to 84 range), socio-economic background (Scottish Index of Multiple Deprivation 1-5), time since diagnosis (7 to 56 months) and prevalence of the number of existing co-morbidities (0-5 range). The study sample was designed to enable the researchers to explore some diversity in men’s and partners/caregivers experiences of follow-up care. The common themes were continually reviewed. Field notes were written immediately following the interviews to record any unrecorded conversations before and after the “formal” interview. Data saturation was considered having been reached when no new information relating to the experience of care or themes were identified during the interview process.

**Rigor:** To ensure rigor of the study, four concepts was utilized: credibility, transferability, dependability, and confirmability as identified by Lincoln and Guba (Lincoln & Guba, 1985). The researcher conducting the interviews ensured credibility through reflection after each interview by tape recording impressions, thoughts and notes immediately after each interview. In addition, peer checking of interview data from C. Paterson and G. Nabi was conducted to verify the identified themes. Transferability was conducted by providing detailed description of the study setting and study sample. Dependability was addressed from the audit trail from the research group through research notes for the decision making process as the study progressed as well as during the analytic process. Confirmability was ensured through clarification during interviews

with open-ended and repetitive questioning, the reflective process after interviews and peer discussion for data interpretation and verification.

**Description of Interview:** C. Primeau conducted the majority of the interviews in the participants' homes or in a cancer care center. Interviews were digitally recorded with the patient's written consent. The interviews began with an open-ended, non-directive question to encourage participants to speak about their experiences of their follow-up care. Open-ended probe questions were also used to elicit greater detail of experiences shared by participants.

**Analysis of qualitative and quantitative data:** The semi-structured interviews lasted 40-90 minutes. Recordings were transcribed verbatim, cross-checked for accuracy and identifying information removed. C. Primeau coded all of the interviews and coding was subsequently verified by C. Paterson, and where needed a third arbiter G. Nabi, ensuring a close match. Framework Analysis (Ritchie, Lewis, Nicholls, & Ormston, 2013) was used to examine commonalities and differences within and between the transcripts. Broad themes were identified and an electronic matrix display (in Microsoft Excel) was used to keep a transparent account of how themes were derived and this display included original links to the data. Triangulation strategies included comparison of the study results with those in previous studies conducted in the patient population (Carter et al., 2011; O'Brien et al., 2011; Ritchie et al., 2013) and with the data collected from the prospective questionnaire survey.

### **Results:**

In total, nineteen patients, seven partners/caregivers and seven MDT members consented to take part in semi-structured interviews from across four hospitals at NHS Tayside, Scotland (see **Table 2**) for clinical and demographic characteristics. Participants with a "/1" suffix are intervention group.

Qualitative themes clearly emerged across the standard of care group and the intervention group (see **Box 1**). Certain themes clearly emerged in the standard care group that related to a range of unmet supportive care needs, which included physical, psychological/emotional, intimacy/sexual, and patient/clinician communication needs that was experienced. Participants in the intervention group reported overall high satisfaction with the intervention and acceptance of PROs in routine clinical practice. Description of themes and illustrative quotes are included below.

### **The standard group**

**Physical needs:** The main physical needs were related to managing the long-term side-effects of ADT and men spoke mainly about grappling with tiredness, loss of enthusiasm, weight gain and

hot flushes and how these affected their daily lives. Other gentlemen associated the lack of energy and weakness due to the aging process rather than their therapy, and had resigned to acceptance of these issues as unavoidable. Men articulated a lack of self-management support in managing these side effects:

*"I would have liked some advice on how to cope with this tiredness" (partner 6/1)*

*"And I am tired most of the time ... I used to do a lot of DIY stuff, help neighbors, that sort of stuff. Can't do that anymore. I don't have the energy. My whole attitude towards work has changed. I can't be bothered" (patient 160/0)*

**Psychological/emotional needs:** Around the time of diagnosis concerns of fear of death and dying was common across all participants and partners/caregivers. The participants were worried about their cancer no longer being a curable disease and having to come to terms with their treatment continuing for the rest of their lives. In addition, both men and their partners/caregivers expressed uncertainty about the treatment and progression of cancer; assessing if their metastases had diminished, remain the same or spread further, and a lack of understanding of how their care team would monitor their condition. Also, men experienced perceptions of a lack of compassion to their emotional needs from their care team:

*"...is it going to spread more, and how would they know, other than asking her (the Specialist Nurse) if he could have a scan to see if it was spreading?" (partner 7/1)*

*"I was handed a leaflet, I was told that I would have hormone treatment and if that didn't work then they would try something else. Fine. And that was the end of the story" (patient 3)*

**Daily practical/financial needs:** Across the majority of the participants, the ADT treatment and travel to hospital appointments did not cause a burden on daily practical needs, but men vocalized frustration due to a lack of motivation and the affect it had on their lives. Other couples spoke about the financial implications of the man living with a palliative cancer diagnosis and the financial consequences:

*"I can't be bothered a lot of times, my enthusiasm and motivation for doing things has virtually disappeared. I am not interested anymore. I don't know what the word I am looking for really is ... loss of enthusiasm, really. I can't be bothered" (patient 160/0)*

*"I mean I gave up my work, I was due to retire, but I gave up my work earlier ... I would have probably carried on working as I was not due state pension until now, but I do get an occupational*



*pension as well. I took the decision to be the carer. But I just felt that I was not giving my best to my job, and so I felt it was time to stop” (partner 15/1)*

**Intimacy and sexual needs:** Across the majority of participants they accepted the inevitable consequence of ADT on intimacy and changes in relationships, which did not adversely affect quality of life for most men or their partners. Most couples took comfort in the fact that they still had each other and seems to appreciate their continued companionship and accepted the adjustment in their intimacy. However, some couples did find that change in sexual function had a major negative impact on their quality of life, which they struggled to adjust to. Men also spoke about changes in their masculinity in regards to changes in their appearance from the hormone treatment:

*“You weight it all up, I would rather have Mr N (patient 150/1), I would rather have companionship and Mr N than a sex life, you know, life changes and priorities, you know. Rather companionship, I just put up with it” (partner 15/1)*

*“(…) it’s just a male thing isn’t it... you don’t want these things... got boobs, do you? Sometimes I am a bit embarrassed about that, dare I say nipples are starting to protrude a bit” (patient 70/1)*

**Patient/clinician communication:** Patients perceived that the time during consultations were limited and primarily focused on bloods results, rather than overall holistic care and self-management advice. Generally, patients felt they lacked clinical information on their diagnosis and treatment and expressed frustrations of not fully understanding the information or the implications thereof:

*“They honestly don’t really discuss anything more, he (Clinician) checked the blood and then see you in 3 months or so” (patient 4)*

*“He (Clinician) said it was prostate cancer and he (husband) had hot spots. But they never explained to us what the hot spots were, and where they were” (partner 6/1)*

### **Intervention group**

Men and partners/caregivers perceived that they had derived benefit from this model of care. Certain themes clearly emerged as important for participants, including being listened to by someone who could facilitate emotional expression, being provided with individually tailored information and receiving practical help and evidence-based advice for managing the consequences of cancer and its associated treatment.

**Emotional Support:** Patients and partners/caregivers felt that they were given time to share their emotional concerns with the Prostate Cancer Specialist Nurse during consultations and felt that their symptoms were given appropriate consideration through the usage of the PRO's. Patients felt that their diagnosis and treatment were explained to them by the Prostate Cancer Specialist Nurse in a language that they were able to understand and felt that the Prostate Cancer Specialist Nurse was supported not only in a clinical setting that that they could reach out to the nurse for additional emotional support:

*"(...) she (Specialist Nurse) answered my questions when I asked about what hot spots was, and she explains it to you in detail and you understand what she is saying, since we have come into contact with the Specialist Nurse we have been able to ask her things, because she sits and listens to you and asks you questions"* (partner 6/1)

**Informational Support:** Across all participants in the intervention group, no unmet informational needs were perceived. Although, one patient expressed difficulty in contacting the specialist nurse by telephone for informational support but found resolution in being able to contact the nurse through digital contact using e-mails. A common theme was that patients and partners/caregivers viewed the role of the specialist nurse as the hub of survivorship care and embedded in multidisciplinary team as a wider support for the working of the nurse. One patient expressed unmet informational needs that were addressed following a later consultation with the Specialist Nurse:

*"She (Specialist Nurse) has definitely been able to answer my questions. She's been very good. She knows her job, and she's got so many experts (members of the MDT) around her, you know, to help her"* (patient 100/1)

*"I did not know it was a hormone treatment, because em, only when I met the specialist nurse, I then knew it was hormone treatment and how it worked. I assumed it was maybe a form of chemotherapy before. It was not explained to me"* (patient 30/1)

**Evidence-based self-management plans:** All participants in the intervention group were agreeable to completing PRO questionnaires prior to meeting with the Specialist Nurse in the outpatient setting, which permitted systematic assessment of supportive care needs. Across the majority of participants the main concerns were related to lack of energy and fatigue which facilitated discussion for the option of referral to tailored exercise programs with other men reporting benefits from self-management plans. Others reported PRO concerns in relation to hot flushes, which allowed tailored self-management plans:

*“She (Specialist Nurse) put me through for the Keep Fit, Movement for Life” (patient 100/1).*

*“Oh yes. They went through it (PRO questionnaire) very carefully, and seemed quite happy that the worst thing to me was the sweats. The Specialist Nurse did offer me alternative options help and a tablet to help me with the sweats, but I didnae (did not) wanna (want to) go down that road. I thought I could cope with the sweats” (patient 100/1)*

**Evidence-based self-management seminar:** All participants randomized to the intervention arm attended the seminar except for one patient, who was an inpatient in hospital and unable to attend. Both patients and partners/caregivers perceived benefit in the intervention in the form of information and support. Participants felt they were given information in a clear and understandable manner, which was educational to discuss the topics during the breaks with other participants. Participants also perceived benefit from the evidence-based self-management Information Booklet and generally, felt well advised on how to look after themselves in their own home after participation of the seminar.

*“Well I read it and read it again, the booklet that we got at the seminar and its quite handy (..) I could have done with that booklet when I first got prostate cancer. They told us what treatment I was getting and that’s that. But I didn’t really know much about the prostate cancer or how to look after myself. Whereas that booklet told you a lot of stuff. I got a lot of information out of that” (patient 70/1)*

### **MDT members**

Members of the MDT team did acknowledge that there are gaps in the current care model concerning informational needs and they perceived benefit in the holistic approach to patient care in the intervention model of supportive care being nurse lead and with the addition of the seminar. Members of the multidisciplinary team perceived the advantages to the intervention model of supportive care to include greater access to specialist nurses, target unmet supportive care needs through the routine use of PROs in clinical practice and scope to release consultant time for theatre capacity. In addition, it was also identified that follow-up care for this patient group with prostate cancer is about the quality of life and that the seminar provided encouragement for self-management and greater self-efficiency.

*“Information about keeping active, diet, options for managing hot flushes, that keeping active is a way of managing fatigue, issues about how to manage impotence, erectile dysfunctions. There is a huge amount of information that in an ideal world, if we had time, and the patient had time to absorb it all, you would give at the time of starting hormone treatment, but the problem is that is tends to be done in the middle of a fairly hectic clinic and I don’t’ think that the information*

*given about how to manage the side-effects, and the various physio-social effects of treatment we give is essential” Consultant Clinical Oncologist (MDT06).*

*“Addressing the problems on toxicity they are having with the standard hormone treatment, are perhaps not addressed in a systematic way. That would be my concern, I think that generally the nurse-led model intervention I suspect, patients are having their toxicity and holistic needs addressed better than the cohort who are missing out” Consultant Clinical Oncologist (MDT06).*

### **Discussion:**

This qualitative study aimed to understand patients and their partner/caregivers experience of two models of supportive care delivery for metastatic prostate cancer. To our knowledge, this is the first qualitative study that explore the experience of men as well as their partners/caregivers affected by metastatic prostate cancer in a multimodal supportive care intervention as well as the experience of standard care, with the inclusion of the perspectives of members of the MDT. Few publications have included partner/caregivers as part of intervention studies despite the acknowledgement of their needs in relation to their care burden, relationship/sexual needs, and physiological distress (Bobridge et al., 2015; Carter et al., 2010; Donovan et al., 2015; Hampton, Walker, & Beck, 2013; A.B. Kornblith et al., 1994) and the influence on quality of life for the patient by the partner/carer (Gustavsson-Lilius, Julkunen, & Hietanen, 2007; L. M. Walker et al., 2013; L.M. Walker et al., 2013). Patients and their partner/caregivers can experience a range of unmet supportive needs (Paterson et al., 2016) irrespective of the clinical characteristics and length of treatment relating to physical and psychological needs. This can include fears of cancer spreading further, uncertainty of the future as the cancer is not curable, needs relating to intimacy and sexual desire, and a lack of a personal holistic care as a support mechanism.

PROs are described as a standardized and validated questionnaires completed by the patient to evaluated their own perceptions of needs in relation to quality of life and symptom burden (Dawson, Doll, & Fitzpatrick, 2010). The PROs have the advantage of giving a focus to the healthcare professional of area of highest concern to the patient and the partner/caregiver enabling personalized self-management plans to be developed in partnership. Without the use of PROs, symptoms and consequences of hormone treatment may be under-recognized and under-treated within oncology practice, which was apparent from the experience of the standard care (control) group within this study. Effective assessment through PROs and care planning provided by the specialist cancer nurse facilitated the identification of individual concerns and needs that prompted early interventions, improve communication and personalize supportive care as articulated experience from the patients in the current study, and reported elsewhere (Greenhalgh, 2009; Robertson, Windsor, & Smith, 2013). The majority of the patients in this study still experienced concerns about the uncertainty of the future with worries of death and dying

and fear of the cancer spreading which is a consistent experience of living with cancer as a chronic illness (Mishel et al., 2009). Integrating the evidence-based seminar with the use of PROs in routine clinical practice permitted a tailored, personalized model of care and targeted self-management plans. The results from this study seems to suggest that by implementing PRO measures in routine clinical practice across the multidisciplinary cancer team can improve supportive care experience.

Further, what emerged from this study was the added benefit of the intervention seminar that educated and encouraged patients and their partners/caregivers on self-management of their individual needs. The self-management seminar promoted discussion of the diverse needs of patients and partner/caregivers. Self-management can be defined as the ability of an individual to manage symptoms, effect of treatment, physical and psychosocial consequences and lifestyle changes for patients living with a chronic condition, such as cancer. Efficient self-management includes the ability to oversee one's condition and to affect cognitive, behavioral, and emotional actions necessary to maintain a satisfactory quality of life. Within cancer literature, the term self-management refers to an iterative process whereby individual responses and behaviors are used to cope with the physical and psychological consequences of cancer rather than prevention or elimination of symptoms (McCorkle et al., 2011). Effective self-management of the consequences of cancer and its treatment can improve the quality of life (Hammer et al., 2015). Addressing the individual's needs across the broad spectrum of metastatic prostate cancer consequences can be difficult to target in a routine clinical setting. In this study, we observed that participants in the intervention group perceived empowerment in their self-management through participation in the seminar, the evidence-based self-management information booklet and sharing experiences with other individuals.

There are a number of limitations to this study worthy of comment. The sample size was small and in favor of white British participants and with limited follow-up. Some caution should be taken in the interpretation of these findings and requires the study to be repeated with a larger multi-centered sample, to include men from minority groups to be equally represented. Also, there is lack information on the actual self-management behaviors performed by participants and how this impacted upon their experience of supportive care, as well as if there are any differences in experience of the care needs for men and their partners/caregivers based on the length of receiving ADT.

The strength of this study is the qualitative methodology that allowed exploration of experience in greater detail of the lived experience of men as well as their partners/caregivers. This is the first multimodal supportive care intervention to be delivered in the context of metastatic prostate cancer, with the added advantage of targeting supportive care to both the men and their partners/caregivers.

**Implication for Nursing:**

The results of this study can be used to inform nursing practice for men and their partner/caregivers affected by metastatic prostate cancer receiving ADT. In particular, the results have shown how the care of men and their partners/caregivers dealing with metastatic prostate cancer delivered by Specialist Cancer Nurses can be improved by a multi-modal supportive care intervention. Through incorporating holistic needs assessment in clinical practice, it permitted a person-centered evaluation and targeted individualized self-management interventions for optimized supportive care. One of the most important nursing implications is that the novel ThriverCare intervention for men and their partners/caregivers affected by metastatic prostate cancer decreased unmet supportive care needs over time. This study has also highlighted knowledge of the holistic care that a Specialist Cancer Nurse can provide as supported by the wider MDT members at the appreciation from this patient group. These results should inform management and care planning of men with metastatic disease on hormonal treatment. Future studies in other tumor groups should carefully consider targeting individuals with significant issues or unmet needs, and strive to deliver a model of care that is individualized and flexible. Our results accentuate that no longer one size of care delivery fit all; care must be responsive and adaptable to meet the individual needs of people affected by cancer to thrive.

**Conclusion:**

Men and their partner/caregivers affected by metastatic prostate cancer seemed to benefit from the multimodal supportive care interventions in the short term, experiencing less unmet needs compared to the standard of care group. Future studies are encouraged to tailor interventions at the individual level of need, as opposed to broad targeting interventions as they are likely to be unsuccessful in optimizing tailored personalized self-management.

**References:**

- Bobridge, A., Bond, M. J., Marshall, V., & Paterson, J. (2015). An investigation of the support needs of men and partners throughout the prostate cancer journey. *Psycho-Oncology, 24*, 341-247.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2010). The supportive care needs of family members of men with advanced prostate cancer. *Canadian Oncology Nursing Journal, 20*(4), 166-170.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2011). The Supportive Care Needs of Men With Advanced Prostate Cancer. *Oncology Nursing Forum, 38*(2), 189-198. doi:10.1188/11.onf.189-198
- Carter, N., Miller, P. A., Murphy, B. R., Payne, V. J., & Bryant-Lukosius, D. (2014). Healthcare Providers' Perspectives of the Supportive Care Needs of Men With Advanced

- Prostate Cancer. *Oncology Nursing Forum*, 41(4), 421-430. doi:10.1188/14.onf.421-430
- Dawson, J., Doll, H., & Fitzpatrick, A. (2010). Routine use of patient reported outcome measures in healthcare settings. *BMJ*, 340(464-467).
- Donovan, K. A., Walker, L. M., Wassersug, R. J., Thompson, L. M. A., & Robinson, J. W. (2015). Psychological Effects of Androgen-Deprivation Therapy on Men With Prostate Cancer and Their Partners. *Cancer*, 15, 4286-4298.
- Fitzpatrick, J. M., Bellmunt, J., Fizazi, K., Heidenreich, A., Sternberg, C. N., Tombal, B., . . . de Wit, R. (2014). Optimal management of metastatic castration-resistant prostate cancer: Highlights from a European Expert Consensus Panel. *European Journal of Cancer*, 50(9), 1617-1627. doi:10.1016/j.ejca.2014.03.010
- Gilson, C., Manickavasagar, T., & Chowdhury, S. (2015). Treatment of metastatic prostate cancer. *Trends in Urology & Men's Health*, July/August, 7-12.
- Greenhalgh, J. (2009). The applications of PROs in clinical practice: what are they, do they work, and why? *Quality of Life Research*, 18(1), 115-123.
- Grossmann, M., & Zajac, J. D. (2011). Androgen deprivation therapy in men with prostate cancer: how should the side effects be monitored and treated? *Clinical Endocrinology*, 74, 289-293.
- Gustavsson-Lilius, M., Julkunen, J., & Hietanen, P. (2007). Quality of life in cancer patients: The role of optimism, hopelessness, and partner support. *Quality of Life Research*, 16, 75-87.
- Hammer, M. J., Ercolano, E. A., Wright, F., Dickson, V. V., Chyun, D., & Melkus, G. D. (2015). Self-management for adult patients with cancer: and integrative review. *Cancer Nursing*, 38(2), E10-26.
- Hampton, A. J. D., Walker, L. M., & Beck, A. (2013). A brief couples' workshop for improving sexual experiences after prostate cancer treatment: a feasibility study. *Support Care Cancer*, 21, 3403-3409.
- Hui, D. (2014). Definition of supportive care: does the semantic matter? *Curr Opin Oncol*, 26(4), 372-379.
- Kornblith, A. B., Herr, H. W., Ofman, U. S., Scher, H. I., & Holland, J. C. (1994). Quality of Life if Patients with Prostate Cancer and Their Spouses. *Cancer*, 73(11), 2791-2802.
- Kornblith, A. B., Herr, H. W., Ofman, U. S., Scher, H. I., & Holland, J. C. (1994). Quality of life of patients with prostate cancer and their spouses. The value of a data base in clinical care. *Cancer*, 73(11), 2791-2802.
- Lewis, R., Khan, A., & Payne, H. (2013). Management of breast side-effects in men treated with androgen deprivation therapy. *Trends in Urology & Men's Health*, July/August, 40-42.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. London, UK: Sage Publications.
- MacMillan. (2017). The Recovery Package. Holistic Needs Assesment. Retrieved from: <http://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package - 297633>
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L., Lorig, K., & Wager, E. (2011). Self-management: Enabling and empowering patient living with cancer as a chronic illness. *A Cancer Journal for Clinicians*, 61, 50-62.



- McLeod, D. L., Walker, L. M., Wassersug, A. M., & Robinson, J. W. (2014). The sexual and other supportive care needs of Canadian prostate cancer patients and their partners: Defining the problem and developing interventions. *Canadian Oncology Nursing Journal, Fall/Automme*, 271-278.
- Mishel, M. H., Germino, B. B., Lin, L., Pruthi, R. S., Wallen, E. M., Crandell, J., & Blyler, D. (2009). Managing uncertainty about treatment decision making in early stage prostate cancer: A randomized clinical trial. *Patient Education & Counseling, 77*(3), 349-359. doi:10.1016/j.pec.2009.09.009
- NICE. (2014). National Institute for Health and Care Excellence. Prostate cancer diagnosis and management.
- O'Brien, R., Rose, P., Campbell, C., Weller, D., Neal, R. D., Wilkinson, C., . . . Watson, E. (2011). "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, 84*(2), 200-207.
- Paterson, C., Alashkham, A., Windsor, P., & Nabi, G. (2015). Management and treatment of men affected by metastatic prostate cancer: evidence-based recommendations for practice. *International Journal of Urological Nursing, 10*(1), 44-55. doi: 10.1111/ijun.12093
- Paterson, C., Kata, S. G., Nandwani, G., Chaudury, D., & Nabi, G. (2016). 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 (in print)*.
- Paterson, C., & Nabi, G. (2016). A Model of Consultation in Prostate Cancer Carer: Evidence From a Systematic Review. *Cancer Nursing, 40*(4), 276-288.
- Paterson, C., Robertson, A., Smith, A., & Nabi, G. (2015). Identifying the unmet supportive care needs of men living with and beyond prostate cancer: A systematic review. *European Journal of Oncology Nursing, 19*(4), 405-418.
- Polley, M. J., Joliffe, R., Boxell, E., Zollman, C., Jackson, S. M., & Seers, H. (2016). Using a Whole Person Approach to Support People With Cancer: A Longitudinal, Mixed-Methods Service Evaluation. *Integrative Cancer Therapies, 15*(4), 435-445.
- Prostate Cancer UK. (2016). Prostate Cancer Fact and Figures. Retrieved from <http://prostatecanceruk.org/prostate-information>
- Ream, E., Quennell, A., Fincham, L., Faithfull, S., Khoo, V., Wilson-Barnett, J., & Richardson, A. (2008). Supportive care needs of men living with prostate cancer in England: a survey. *British Journal of Cancer, 98*(12), 1903-1909. doi:10.1038/sj.bjc.6604406
- Ritchie, J., Lewis, J., Nicholls, C., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*: Sage.
- Rittenberg, C. N., Johnson, J. L., & Kuncio, G. M. (2010). An oral history of MASCC, its origin and development from MASCC's beginnings to 2009. *Support Care Cancer, 18*(6), 775-784.
- Robertson, A. F., Windsor, P. M., & Smith, A. (2013). Evaluation of a nurse-led service for follow up of patients with prostate cancer. *International Journal of Urological Nursing, 7*(2), 92-97. doi:10.1111/j.1749-771X.2012.01161.x
- Walker, L. M., Hampton, A. J., Wassersug, R. J., Thomas, B. C., & Robinson, J. W. (2013). Androgen Deprivation Therapy and maintenance of intimacy: A randomized

- controlled pilot study of an educational intervention for patients and their partners. *Contemporary Clinical Trials*, 34, 227-231.
- Walker, L. M., Tran, S., Wassersug, R. J., Thomas, B., & Robinson, J. W. (2013). Patients and partners lack of knowledge of androgen deprivation therapy side effects. *Urologic Oncology*, 31, 1098-1105.
- Wittmann, L., Northouse, S. F., Gilbert, F. S., Wood, D. P., Balon, R., & Montie, J. E. (2009). The Psychosocial Aspects of Sexual Recover After Prostate Cancer Treatment. *International Journal Of Impotence Research*, 21(2), 99-106.