ENACTING PSYCHOLOGICAL CARE FOR MEN WITH PROSTATE CANCER AND THEIR FAMILIES
Enacting Psychosocial Care for Men with Prostate Cancer and their families

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The Psychological Distress Associated with Prostate Cancer

- Over 200,000 men with prostate cancer in Australia
- 11 – 27% of prostate cancer survivors experience high psychological distress
- Up to one in four men experience anxiety and up to one in five report depression
- Increased risk of suicide compared with controls, first 6 – 12 months post-diagnosis a period of heightened risk
- Suicidal ideation reported by approximately 12% of men and may persist for many years
- Long term negative outcomes for mental well being and life satisfaction
Ten-year quality of life outcomes in men with prostate cancer

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1 | BACKGROUND

Although men with prostate cancer are living longer, they are not necessarily living well, with symptom burden increasing and HRQoL declining over time.\textsuperscript{1} For many men, the first five years after diagnosis is marked by unmet needs, debilitating disease and treatment-related bowel, urinary and sexual symptoms.\textsuperscript{2} To date, few studies have examined the trajectories of men over the 10 years after diagnosis.\textsuperscript{3} To advance survivorship care, it is crucial to understand what factors drive long-term (10 year) health outcomes after a prostate cancer diagnosis. Accordingly, this study extends our previous research\textsuperscript{4} to report physical and mental HRQoL, life satisfaction and symptom burden of men over the 10 years after prostate cancer diagnosis.

2 | METHOD

2.1 | Study setting and participants

This study of newly diagnosed adult men with prostate cancer was conducted in Queensland, Australia. Sampling strategy and methods are previously described.\textsuperscript{4} Ethical approval was obtained from the Queensland University of Technology Human Research Ethics Committee (Approval No.629H). In total, 1291 men were approached, 1064 consented, and 598 (56%) completed the final 10-year questionnaire. Self-administered questionnaires and computer-assisted telephone interviews were completed at baseline, and 2,6,12,24,36,48,60,72,84,96,108 and 120 months after the commencement of treatment.

2.2 | Measures and statistical analyses

Participants’ demographics and clinical characteristics have been previously described.\textsuperscript{4} Outcome measures included Disease-specific (Expanded Prostate Cancer Index Composite; EPIC) and HRQoL (Short Form 36; SF-36); Satisfaction with Life (Satisfaction with Life Scale; SWLS) [see Figures 1a-1c].\textsuperscript{5-7} Growth mixture models (GMMs) in Mplus (Muthen and Muthen, 2015, Mplus User’s Guide http://www.statmodel.com/usersguide/chapter8.shtml) were adopted to identify trajectory classes and predictors using 10-year follow-up data, with EPIC longitudinal subscales as time-varying covariates.\textsuperscript{4} Missing EPIC
Quality of Life SF36 Mental Health Domain

Class 1  
Mental Health QoL decreased from a lower level and then increased 7 years 
*Lower income and high levels of comorbidity*

Class 2  
Mental Health QoL increased gradually from a lower-level start and then decreased at 5 years 
*Lower income and ≥ 3 comorbid conditions*

Class 3  
Constantly high Mental Health QoL
Satisfaction with Life (SWL)

Class 1  SWL decreased from a medium level then increased at 6 years

Class 2  Constantly low SWL
          *Younger age, never/married/widowed/divorced/separated, lower income, ≥ 3 comorbid conditions*

Class 3  Constantly high SWL
Screening for Distress in Men with Prostate Cancer

• Risk factors for higher distress include: younger age at diagnosis; lower education and income; advanced stage disease; comorbidities; un-partnered status

• Higher early distress predicts later ongoing distress

• Brief screening is effective in detecting increased distress in men with prostate cancer: sensitivity 78.95% and specificity 79.74%

• Referral to appropriate evidence-based psychological care services the next crucial step
The validity of the distress thermometer in prostate cancer populations

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Abstract

Background: The Distress Thermometer (DT) is widely recommended for screening for distress after cancer. However, the validity of the DT in men with prostate cancer and over differing time points from diagnosis has not been well examined.

Method: Receiver operating characteristics analyses were used to evaluate the diagnostic accuracy of the DT compared with three commonly used standardised scales in two prospective and one cross-sectional survey of men with prostate cancer (n = 740, 189 and 463, respectively). Comparison scales included the Impact of Event Scale – Revised (IES-R, Study 1), the Hospital Anxiety and Depression Scale (HADS, Study 2) and the Brief Symptom Inventory-18 (BSI-18, Study 3).

Results: Study 1: the DT showed good accuracy against the IES-R at all time points (area under curves (AUCs) ranging from 0.84 to 0.88) and sensitivity was high (>85%). Study 2: the DT performed well both against the anxiety and depression subscales for HADS at baseline (AUC = 0.84 and 0.82, respectively), but sensitivity decreased substantially after 12 months. Study 3: validity was high for the anxiety (AUC = 0.90, sensitivity = 90%) and depression (AUC = 0.85, sensitivity = 74%) subscales of the BSI-18 but was poorer for somatization (AUC = 0.67, sensitivity = 52%). A DT cut-off between ≥3 and ≥0 maximised sensitivity and specificity across analyses.

Conclusions: The DT is a valid tool to detect cancer-specific distress, anxiety and depression among prostate cancer patients, particularly close to diagnosis. A cut-off of ≥4 may be optimal soon after diagnosis, and for longer-term assessments, ≥3 was supported.

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PROSTATE CANCER DISTRESS SCREEN

The experience of prostate cancer is for many men a difficult time. I would like to ask you a few brief questions to check how you have been feeling and ask about your main concerns. Thinking about how you have been feeling over the past week including today, how distressed do you feel on a scale of ‘0’, no distress to ‘10’, extreme distress? (circle)

[0-10 scale]

No distress  Extreme distress

This is a list of problems that some men with prostate cancer experience. Do any of these problems apply to you? (Read the list below, tick if yes)

**Practical Problems**
- Work
- Financial/Insurance

**Family Problems**
- Partner

**Emotional Problems**
- Depression
- Uncertainty about the future
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

**Physical Problems**
- Pain
- Fatigue
- Sexual
- Urinary
- Bowel
- Hot Flashes
- Weight Gain
- Weight Loss
- Loss of Muscle Mass
- Memory/Concentration
- Sleep

**Other Problems** (please list)

__________________________

__________________________

__________________________
New Challenges in Psycho-Oncology Research III: A systematic review of psychological interventions for prostate cancer survivors and their partners: clinical and research implications

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1 | BACKGROUND

The medical and social context of prostate cancer (PCa) has changed dramatically since the introduction of PSA testing for early detection in the late 1980s,1 leading to a peak in incidence in the developed world in the 1990s and again a decade later.2 Since that time, novel PCa treatments have rapidly emerged in the radiation and medical oncology field, as well as surgical advances.3 The recent emergence of active surveillance for low-risk disease has further expanded possible treatment approaches.4 Market forces from consumers, clinicians, and the therapeutic industry have driven changes in clinical and surgical management and treatment; however, psycho-oncological research and survivorship care arguably has lagged behind. Specifically, although men are surviving longer, they may not be surviving well. In 2012, there were over 1.1 million incident cases of PCa diagnosed and more than 300,000 deaths worldwide.5 Five-year prevalence estimates suggest that there are over 3.8 million PCa survivors globally6 with this expected to increase rapidly in future.7 The challenges we face in meeting the needs of these men and their families into the future are vast.

Up to 75% of men treated for localised PCa report severe and persistent treatment side-effects including sexual dysfunction, poor urinary or bowel function.8 Psychosocial concerns are prevalent with 30%-50% of PCa survivors reporting unmet sexuality, psychological, and health system and information needs9,10 and 10%-23% of men clinically distressed.11 Risk of suicide is increased after PCa diagnosis12,13 and can persist for a decade or more.14 In the longer term, 30%-40% of PCa survivors report persistent health-related distress,
Health literacy and the health status of men with prostate cancer

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Abstract

Objective: To test the Health Literacy Questionnaire (HLQ) in a sample of men with prostate cancer and examine the components of health literacy that are most strongly associated with mental and physical health-related quality of life in men with prostate cancer.

Method: Members (N = 565) of a state-wide prostate cancer support network in Queensland, Australia (M\textsubscript{age} = 71.14, SD = 8.68) completed the HLQ along with the Medical Outcomes Study, 36-item short-form health survey (SF-36). Confirmatory factor analysis was employed to assess the internal structure of the HLQ. The effects (bs) of each of the nine health literacy factors on mental and physical health status were graphed and compared using Fishers exact test for comparing parameter estimates.

Results: Fit indices including RMSEA (0.069, CI = 0.066-0.072), CFI (.853), and TLI (.839), alongside item loadings and internal consistency (Cronbach alphas >0.80) for the nine-factor model, supported the robustness of the HLQ for use in this prostate cancer sample. Health literacy factors reflecting social and health provider support, navigating health systems, finding and understanding health information, and active engagement with providers shared small to moderate associations with mental health status and little to no association with physical health status.

Conclusion: Findings provide support for the use of the HLQ as a valid and reliable measure of health literacy in men with prostate cancer. Although further research is required to establish causality, interventions that aim to improve skills in connecting and effectively communicating with health care services and providers might lead to better mental health related quality of life for men with prostate cancer.
Measuring Masculinity in the Context of Chronic Disease

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Masculine beliefs are influential in men’s responses to illness; however, current measures of masculinity may not be salient for highly prevalent chronic diseases such as prostate cancer. To address this gap, a contextualized measure of masculinity for men with prostate cancer was developed. A novel measure of masculinity, the Masculinity in Chronic Disease Inventory (MCD-I), was developed based on existing qualitative data and tested for acceptability and face validity with 19 men previously treated for prostate cancer. A cross-sectional survey of 403 Australian men with prostate cancer ($M_{age} = 70.34$ years; $SD = 7.25$) then assessed convergent, divergent, and discriminant validity for the MCD-I using existing reliable and valid measures of masculinity, masculine self-esteem, quality of life, erectile dysfunction, and sexual help seeking. A 6-factor structure for the MCD-I (22 items) was confirmed with good to excellent internal reliabilities ($alpha = 0.69-.92$) for the subscale domains of Strength, Sexual Importance/Priority; Family Responsibilities; Emotional Self-Reliance; Optimistic Capacity; and Action Approach. Acceptable convergent and divergent validity was supported, and the MCD-I was also able to discriminate between men with severe versus moderate to mild erectile dysfunction ($p = .002$) and the Sexual Importance/Priority domain discriminated between men who had sought sexual advice and those who had not ($p = .005$). A contextual approach to measuring masculinity in men with prostate cancer may help avoid reductionist approaches for focusing on erectile dysfunction in these populations. This also presents a way forward for gender-sensitive psychosocial services and programs for men experiencing prostate cancer.

Keywords: prostate cancer, masculinity, chronic disease, sexual adjustment, help seeking
Psychosocial Interventions for Men with Prostate Cancer

- Multi-modal psychosocial and psychosexual care for men with prostate cancer is acceptable and effective for improving decision-related distress, mental health, domain-specific, and health-related QOL
- Combinations of educational; cognitive behavioural, communication, and peer-support most commonly applied and found effective; followed by decision support and relaxation
- Face-to-face and remote technologies, with therapist, nurse or peer supports provide a range of mechanisms and sources of support
- Life course and masculinity must be considered in planning care and developing services
- Services need to be responsive to differing levels of health literacy which may require tailoring of patient education
THE TIERED MODEL OF PSYCHOSOCIAL INTERVENTION IN CANCER: A COMMUNITY BASED APPROACH

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SUMMARY

Clinical practice guidelines for the management of psychosocial distress in people with cancer have been produced in Australia and North America and these provide direction for the provision of psychosocial care for patients with cancer and their families. This report describes a tiered intervention model to operationalise psychosocial care in oncology in the community and outlines a framework for integrating services across sectors. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS: psychosocial care; community based; tiered intervention; cancer; oncology
Tiered Model of Psychosocial Care after Prostate Cancer

Adapted from Hutchison, Steginga, Dunn (2006)

ACUTE CARE:
Intensive or comprehensive therapy for acute and complex psychological problems.

SPECIALISED CARE:
Specialised therapy for depression, anxiety, relationship or marital distress.

LOW INTENSITY CARE:
Cognitive behavioural intervention, stress management, coping skills training, psychoeducation, decision support.

UNIVERSAL CARE:
Patient education, emotional support, practical assistance, peer support, physical activity, and exercise medicine, screening for distress and referral.
A PSYCHOSOCIAL CARE MODEL FOR MEN WITH PROSTATE CANCER
SEPTEMBER 2019
National Position Statement on Screening for Distress and Psychosocial Care

1. After the diagnosis of prostate cancer and regularly through treatment and surveillance men who have been diagnosed with prostate cancer should be screened for distress and their psychological and quality of life concerns should be explored

2. Men who have high levels of distress should be further evaluated for anxiety and/or depression and evidence of suicidality

3. Men who have high distress or need for support should be referred to evidence-based intervention matched to their individual needs and preferences for support

4. Research is needed to develop effective methods to identify partners of men with prostate cancer with high distress or who are at risk of high distress as well as effective interventions for partners and for couples where the man has a diagnosis of prostate cancer

5. Investment in prostate cancer survivorship research is a national health priority
The psychological toll of prostate cancer

Suzanne K. Chambers and Peter Heathcote

Matta et al. report that men with prostate cancer who underwent surgery or radiotherapy, but not active surveillance, had greater odds of receiving antidepressants than controls. However, methodological limitations preclude the interpretation of a psychological benefit for men on active surveillance. Screening for distress and referral to evidence-based intervention should be a priority.

A recently published report by Matta et al. exploring the use of antidepressants among men with nonmetastatic prostate cancer compared with propensity-score-matched members of the general population is timely given the increasing recognition over the past decade of the psychological toll associated with the diagnosis and treatment of this disease. Intriguingly, men with prostate cancer treated actively through surgery or radiotherapy surveillance. In addition, the large number of sampling exclusions (for example, only 23% of Ontario-based men on active surveillance were included in the study) raises questions about unexplained study bias. These issues, in addition to the lack of important clinical data about disease stage, grade and PSA levels, call for caution in the interpretation of the findings.


Men will have different risk profiles for poor or favourable outcomes on the basis of their general health, prostate cancer stage and grade, degree of sociodemographic disadvantage, and social and support networks, as well as pre-existing physical and psychological health concerns. A consideration of these factors by the oncology treatment team is required at all stages of the prostate cancer experience.

In contrast to the study by Matta and co-workers, Taylor et al. — who used a different methodology to track newly diagnosed men with low-risk prostate cancer — found that, over time, men on active surveillance had a better physical quality of life with no difference in rates of depression, but higher levels of both general and prostate-cancer-specific anxiety, than men on active treatment. These findings and those of previous research point to the risk that anxiety about surveillance not only decreases overall quality of life but also can lead to conversion to active treatment sooner than is clinically indicated.

"Men with prostate cancer should be screened regularly for psychological distress."

References
‘Feelings, and feelings, and feelings. Let me try thinking instead’: Screening for distress and referral to psychosocial care for men with prostate cancer

In 1961, CS Lewis observed that grief felt like fear, or being concussed, with ‘an invisible blanket between the world and me’ (Lewis, 1961). During his exploration of grief, Lewis observes that from feelings one can move to thinking, that is, to apply the rational self as a point from which to move forward. And so to prostate cancer.

The global burden of prostate cancer is escalating with over 1.2 million men diagnosed each year (Bray et al., 2018). The face of prostate cancer has changed over the past three decades since the advent of the prostate-specific antigen test and the promise of early detection and cure (Schröder, Hugoson, Carlsson, et al., 2012; Schröder, Hugosson, Roobol, et al., 2012), and new approaches to the treatment of advanced disease (Emmett et al., 2017). Clinical research and technological advances have expanded treatment possibilities for these men—theranostics and personalised medicine offer new hope (Huey, Hawk, & Offodile, 2019). However, the personal experience of prostate cancer and the feelings that surround prostate cancer are connected to physical, social, psychological and relationship challenges that for many men will be long term, if not lifelong (Chambers, Ng, et al., 2017; Chambers, Occhipinti, et al., 2019). The data are clear. After diagnosis, up to one in four men experience anxiety and up to one in five report depression (Watts et al., 2015). Heightened distress occurs across all treatment approaches, exacerbated when disease or symptom effects are advanced (Chambers, Ng, et al., 2017; Coughlin et al., 2018; Meissner, Herkommer, Marten-Mittag, Gschwend, & Dinkel, 2019).
Next Steps

• On line training program for distress screening for men with prostate cancer currently under trial with Specialist Prostate Cancer Nurses

• Lead clinician working group formed by PCFA with key stakeholders to develop tools and processes for dissemination

• Leveraging with clinical and community champions led by PCFA

• Psychological therapy manual for men with advanced prostate cancer in development
Our Partners
Thank you!

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