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### Development, feasibility and usability of an online psychological intervention for men with prostate cancer: My Road Ahead



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#### ABSTRACT

Men with prostate cancer are not routinely offered psychosocial support despite strong evidence that being diagnosed with prostate cancer poses significant quality of life concerns and places the patient at elevated risk of developing a range of mental health disorders. The objective of this study was to develop an online psychological intervention for men with prostate cancer and to pilot test the feasibility and acceptability of the intervention. Development of the intervention involved a multidisciplinary collaboration, adapting face-to-face and group intervention strategies for an online format. The full online intervention and moderated forum were pilot tested with 64 participants who were recruited from urology practices in Melbourne, Victoria, Australia. After consenting to participate and creating a personal account in the online programme, participants completed baseline demographic questionnaires. Participants were provided access to the programme for 6-12 weeks. After completing the programme participants completed an online survey to assess intervention and forum utilisation and satisfaction, as well as suggest intervention refinements following their use of the intervention. Patient satisfaction was calculated using mean responses to the satisfaction questionnaire. The intervention was received positively with 47.82% of participants highly satisfied with the programme, and 78.26% said they would recommend it to a friend. Participants' qualitative feedback indicated good acceptability of the online intervention. A number of technical and participant engagement issues were identified and changes recommended as a result of the feasibility testing

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#### 1. Introduction

Cancer of the prostate is the most common cancer in Australia (excluding non-melanoma cancer) (AlHW, 2010). Although the incidence of prostate cancer is growing, treatment of localised disease has become increasingly effective, with many patients living longer than in previous decades (AlHW, 2010). Considering survival rates of prostate cancer are high, issues surrounding quality of life (QoL) become

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significant, as many men live with the impact of both cancer and its treatment on their lives.

Prostate cancer and its treatment are known to have an impact on both a patient's physical and emotional QoL (Manne et al., 2010). In addition to a cancer diagnosis, men treated for prostate cancer are faced with several morbidities, including urinary and sexual dysfunction. These side effects commonly impact upon a man's social, mental, emotional and physical wellbeing (Albaugh and Hacker, 2008; Stanford et al., 2000; Weber and Sherwill-Navarro, 2005). The significant QoL impact not only appears to be associated with high levels of psychological distress but it also puts men at increased risk of developing a range of mental health disorders, including depression and anxiety (Couper et al., 2006; Wootten et al., 2007). The mechanisms by which this detriment to physical functioning leads to psychological distress and mental health concerns have long been researched and, recently, constructs of

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masculinity and masculine identity have started to emerge in the literature as an important factor (Zaider et al., 2012), particularly in relation to the sexual domain. Depression has also been implicated in treatment decision making and higher mortality rates (Prasad et al., 2014). This population-based database study found that men diagnosed with intermediate or high risk prostate cancer who also had a diagnosis of depression were less likely to undergo definitive treatment and had worse overall survival (Prasad et al., 2014) indicating that depression is a significant concern in the context of prostate cancer.

Recent reviews have reported poor quality of current interventions to address the needs of men with prostate cancer and their partners (Chambers et al., 2011; Chisholm et al., 2012) Nevertheless, the authors in these reviews concluded that cognitive–behavioural therapy (CBT) and psycho-educational interventions demonstrated some evidence for efficacy (Chambers et al., 2011) and that interventions with more complex strategies to address sexual function had a more positive impact than those utilising basic symptom management (Chisholm et al., 2012).

Online interventions have the potential to make psychosocial support more widely available and cost-effective (Schover et al., 2012) and can overcome barriers to uptake of psychosocial services such as geographical isolation, stigma concerns or a dislike of face-to-face treatment (Chambers et al., 2010; Gega et al., 2004; Klein, 2010). Although there is considerable evidence for the effectiveness of online interventions in mental health generally (e.g., (Barak et al., 2008; Griffiths et al., 2010; Spek et al., 2007)) and for the psychosocial impact of chronic illnesses and for health behaviour change (Beatty and Lambert, 2013; Spek et al., 2008; Webb et al., 2010), research investigating online interventions for patients with cancer has only recently begun emerging (Beatty et al., 2011; Carpenter et al., 2012; Duffecy et al., 2013; Leykin et al., 2012; Owen et al., 2005; Ritterband et al., 2012; van den Berg et al., 2013). In a randomised controlled trial, Schover et al. found that therapist-assisted internet-based sexual counselling for couples after prostate cancer treatment was as effective as face-to-face counselling for improving sexual outcomes (Schover et al., 2012). Although this study demonstrated the effectiveness of a therapist-assisted online intervention, little is known about the efficacy of self-directed online interventions addressing a range of needs identified as important for men treated for localised prostate cancer.

Another means through which men can receive support and address needs is through peer support interventions. Although it is widely accepted that peer support can play a major role for men with prostate cancer, there has been limited research on the role of online peer support, such as online support groups and moderated forums (Duffecy et al. 2013)

In this paper we describe the development, feasibility and usability testing of an online self-directed psychological intervention for men treated for prostate cancer (My Road Ahead) to assist them to cope with a range of physical, emotional and social difficulties following treatment. In addition, a moderated online forum was created and evaluated. The aims of this study included: (1) development of a self-directed online intervention and forum for men treated for localised prostate cancer; (2) assessment of the feasibility and usability of the intervention and forum; (3) exploration of the characteristics of users participating in this feasibility study; and (4) to understand the needs of men engaging with the intervention and forum. A brief overview will be provided on the development of the online intervention and forum, with a focus in this paper on the feedback from participants, lessons learnt and subsequent refinements to the online intervention.

#### 2. Methods

#### 2.1. Development of the My Road Ahead programme

This online intervention was created based on the previously identified psychosocial needs of men and their partners and research

evaluating the effectiveness of psychosocial treatments for men treated for prostate cancer. Furthermore, intervention content was informed by a CBT group-based psychotherapy programme called *Below the Belt* (Siddons et al., 2013). The validated programme manual developed and used in the *Below the Belt* programme was adapted for use in the online environment. A senior clinical team involved in both the face-to-face group therapy and the online intervention and an expert panel of psychologists and urologists reviewed all the developed content. The structural components of the online programme were based on the past online interventions in settings other than cancer (Klein et al., 2011) and recently published recommendations (Leykin et al., 2012) for cancer.

The completed online intervention comprised 6 self-directed modules, based on CBT principles, and worked through sequentially from modules 1 to 6. The intervention was designed to support both single men and men in an intimate relationship. The design of the intervention was developed to represent a road map of a person's journey through the intervention (see Fig. 1). The different modules of the intervention were shown on the road map. The content of each of the modules is summarised in Table 1.

There was an interactive mood monitor at the beginning and end of each module (see Figs. 2 and 3), where participants could rate their emotions and note any influences on their feelings. Emotional states monitored included levels of happiness, anger, feeling informed and feeling in control. The results of the mood monitor were depicted graphically over the course of the intervention and stored in the participant's online log book and provided direct visual feedback for the participant to monitor.

The modules contained information, interactive exercises, videos of men's real life experiences, advice from health professionals, graphics, and audios. The modules ended with offline exercises for the men to complete and optional information and exercises for a partner or friend. Throughout the modules there were logbook exercises designed to encourage participants to reflect on their experiences and practise using new strategies to enhance coping with the challenges related to prostate cancer and its treatment. Men could also bookmark subjects of interests to refer to later.

A moderated online forum was also developed containing topics on which participants could post comments, questions and accounts of their experiences. The purpose of the forum was to facilitate exchange of information and peer support. Posts on the forum were moderated by one of the researchers. Participants could remain anonymous while participating in the programme and were told that the programme was confidential and that all data were stored securely.

#### 2.2. Study design

Ethics approval was obtained from the Human Research Ethics Committees at Royal Melbourne Hospital, Swinburne University of Technology and Deakin University. Participants created and validated a personalised online account after reading the information and providing informed consent online. Participants completed baseline demographic questionnaires as well as an online survey to assess intervention and forum utilisation and satisfaction, as well as suggest intervention refinements following their use of the intervention. Participants were provided with access to use the intervention for 6–12 weeks. This study did not seek to obtain efficacy data for the intervention as the aim was to assess the usability and functionality of the programme in order to make any required refinements and improvements and to ensure user engagement, prior to the conduct of a formal efficacy trial.

#### 2.3. Participants

Eligibility criteria for participation consisted of the following: 1) diagnosis and treatment for localised prostate cancer in the last 5 years;

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