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



Addie C. Wootten^{a,b,c,*}, Jo-Anne M. Abbott^d, Katherine Chisholm^{a,e}, David W. Austin^e, Britt Klein^{f,g,h}, Marita McCabe^e, Declan G. Murphy^{b,i}, Anthony J. Costello^{a,b,c}

^a Department of Urology, Royal Melbourne Hospital, Parkville, VIC, Australia

^b Epworth Prostate Centre, Epworth Healthcare, Richmond, VIC, Australia

^c Australian Prostate Cancer Research, East Melbourne, VIC, Australia

^d National eTherapy Centre, Swinburne University of Technology, Hawthorn VIC, Australia

^e Department of Psychology, Deakin University, Burwood, VIC, Australia

^f DVC-Research & Innovation Portfolio, School of Health Sciences, Collaborative Research Network, Federation University, Ballarat, Australia

^g National Institute for Mental Health Research, The Australian National University, Canberra, Australia

^h Faculty of Health, Arts and Design, Swinburne University of Technology, Hawthorn, VIC, Australia

ⁱ Peter MacCallum Cancer Centre, East Melbourne, VIC, Australia

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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) (AIHW, 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 (AIHW, 2010). Considering survival rates of prostate cancer are high, issues surrounding quality of life (QoL) become

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

* Corresponding author at: Department of Urology, Royal Melbourne Hospital, Parkville, VIC, Australia.

E-mail addresses: addie.wootten@mh.org.au (A.C. Wootten), jmabbott@swin.edu.au (J.-A.M. Abbott), kechi@deakin.edu.au (K. Chisholm), david.austin@deakin.edu.au (D.W. Austin), b.klein@federation.edu.au (B. Klein), marita.mccabe@deakin.edu.au (M. McCabe), Declan.murphy@petermac.org (D.G. Murphy), Anthony.costello@mh.org.au (A.J. Costello).

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;



Fig. 1. My Road Ahead dashboard to navigate through modules.

2) being aged 18 years or over; 3) willingness and ability to commit at least 1 h per week, for a minimum of 6 weeks; and 4) regular access to the internet. Men were recruited from October 2011 to January 2012. Participants were recruited to participate through distribution of project flyers through support groups, hospital settings and links on relevant websites (e.g. *beyondblue*, Prostate cancer foundation of Australia and Men's Shed Online) as well as promotion at conferences, seminars and community events.

2.4. Measures

Measures used were administered online and all were validated, except for the programme and forum satisfaction questionnaires, which were based on previously used programme satisfaction measures (Klein et al., 2006, 2011).

Demographic details obtained included age, date of birth, marital status, employment status, gross annual income, ethnicity, languages spoken, postcode, prostate cancer date of diagnosis, date of treatment, and type of treatment. Psychological distress was measured using the Depression Anxiety and Stress Scales (DASS-21) short version (Lovibond and Lovibond, 1995). Erectile and sexual function was assessed using the 15-item International Index of Erectile Function (IIEF) (Rosen et al., 1997). Higher scores on this scale indicate better functioning. A questionnaire was developed to assess participants' level of satisfaction and use of both My Road Ahead and the forum based on previously used satisfaction scales (Klein et al., 2011). An overall rating of satisfaction was obtained using a scale from 1 to 10 (10 being the most satisfied). Examples of the satisfaction questions include "Please rate how satisfied you are with the My Road Ahead program?" and "How much did you enjoy using the program?". Respondents were also given open-ended questions to express their opinion of the best and worst part of the intervention and how the intervention could be improved, including any additional features they might find useful. If men did not work through all the modules they were asked what prevented them from doing so. Questions were also included about the level of inclusion of partners as well as any technical difficulties and areas of the interventions in need of improvement.

3. Results

3.1. Participant characteristics – who is logging in?

A total of 75 men registered and consented to participate in the study. Eleven participants were excluded because they did not fit the inclusion criteria of localised disease. Therefore, 64 participants were eligible and were provided with access to the My Road Ahead intervention and the forum. In total, 64 participants provided complete sets of baseline data and 44 participants provided intervention feedback and satisfaction data. Of the 64 participants that gave baseline data and met inclusion criteria the mean age was 62.46 years (see Table 2). The majority of participants had undergone radical prostatectomy. Only 42% of participants had previously seen a urology or prostate cancer nurse and very few had accessed a psychologist in the past.

Baseline erectile function and mood data for all participants are presented in Table 3. These data indicate that participant baseline erectile function, orgasm function, intercourse satisfaction and overall sexual satisfaction were much lower than the published healthy control data presented in the IIEF validation study (Rosen et al., 1997). At baseline, 67% of participants met the criteria (Cappelleri et al., 1999) for severe erectile dysfunction, 8% moderate, 6% mild-moderate, 3% mild and 16% no erectile dysfunction.

The percentage of participants scoring in the clinical range categories of the DASS-21 is listed in Table 4. These data indicate that 15% of participants scored in the moderate–severe depressive symptom range and 11% of participants scored in the moderate–severe anxiety symptom range.

3.2. Participant satisfaction and feedback

Of the 64 participants included in baseline analysis, 20 (31%) did not complete post-intervention satisfaction questionnaires. Reminder emails were sent to participants 2, 5 and 10 days following the questionnaire due date. This left a total of 44 participants who gave satisfaction responses; some providing feedback on My Road Ahead and some for the forum and some for both.

Table 1
Content of the My Road Ahead programme.

Module	Content
1. Introduction to the programme and the emotional impact of prostate cancer	<ul style="list-style-type: none"> • Common emotional reactions to prostate cancer and its treatment • Psycho-education about anxiety and depression • Treatment of anxiety, depression and other emotional problems • Anger management • Looking after oneself • Talking to one's partner, friend or family member, including about feelings
2. Tools for helpful thinking and effective communication	<ul style="list-style-type: none"> • The role of communication in coping with prostate cancer • Communication mistakes • Communication styles • Developing assertiveness skills • Understanding the relationship between thoughts, feelings and behaviours • Monitoring thoughts and identifying unhelpful ways of thinking
3. Coping with physical changes	<ul style="list-style-type: none"> • Physical changes that can occur with prostate cancer • Coping with incontinence • Challenging unhelpful thoughts • Stress management • Relaxation • Worry exposure
4. Sexuality and masculinity	<ul style="list-style-type: none"> • How prostate cancer treatment affects sexual function • Erectile dysfunction • Definitions of masculinity • Identify and challenging negative thoughts about sexuality and manhood • Unhelpful beliefs about sexuality
5. Sexuality and intimacy	<ul style="list-style-type: none"> • The impact of erection problems on intimacy • How to enjoy intimacy and sexual interactions even when an erection is not possible • Redefining 'good sex' • Practical strategies specific to communication about sex and intimacy • Information about erectile function aids and devices
6. Planning for the future	<ul style="list-style-type: none"> • The impact of cancer on beliefs about death and mortality • Thoughts and beliefs about the future and fears about prostate cancer • Tools for coping with fears about cancer recurrence and uncertainty in the future • Programme review: review of learning and achievements

3.3. My Road Ahead feedback

Twenty-six men provided feedback on their satisfaction with the intervention. Reasons for using the intervention included anonymity ($n = 7$), curiosity ($n = 9$), convenience ($n = 7$), a preference for self-help methods of support ($n = 6$), wanting to contribute to research ($n = 6$) and feeling there was no other support available ($n = 2$). In terms of overall satisfaction, 47.82% of men were satisfied with the intervention (score of 6 or more on a scale from 1 to 10) and 78.26% said they would recommend it to a friend, colleague or family member with prostate cancer.

Qualitative feedback indicated that the content of the intervention was useful and engaging: *"It encouraged me to think about issues that have an impact on life and relationships"*; *"Learning how others felt and what they experienced. Made me realise that I was not the only one"*; *"Learning the relationship between thoughts, feelings and behaviour was useful"*; *"It gave me better insight into my issues and thought processes, and how to manage them constructively"*.

Although the intervention was designed so men could involve their partners through various exercises and activities, only four participants

reported doing so. Reasons for not involving partners were given by 16 men and included: partner not being able to or not interested ($n = 6$), wanting to work through the programme independently ($n = 4$), the idea of involving their partner did not occur to them ($n = 2$), feeling uncomfortable discussing the intervention with partner ($n = 2$); not possible due to time or illness ($n = 2$). Qualitative feedback indicated mixed reasons associated with the decision to engage the partner or not: *"Embarrassed, her lack of understanding of me and the difficult challenges I face daily"*, *"was too hard to talk"*, *"not interested"*. One participant who did engage his partner indicated that he felt this to be a beneficial aspect of the programme: *"The offline exercises were helpful as they resulted in my wife and I communicating – this was the real benefit for me (and her too I think) – we talked about the issues"*.

Suggestions for helping men engage more with the intervention included the use of email support or reminders ($n = 6$), SMS reminders ($n = 2$), a chat room ($n = 5$), telephone support ($n = 3$) and the use of more online activities ($n = 3$). Opinions about the best parts about the intervention included learning about oneself ($n = 4$), being able to help research ($n = 3$), the intervention being easy and convenient to use ($n = 3$), and getting support from other men ($n = 2$). Some of the worst features of the intervention were reported as the time commitment involved ($n = 3$), the questionnaires being too long ($n = 3$), and the lack of feedback or support ($n = 3$). Qualitative feedback suggested that the intervention may be beneficial closer to diagnosis: *"Should be used when first diagnosed"*.

One significant aspect of the intervention that participants reported reduced engagement was the gated sequence progress through the modules. *"Being unable to bypass certain parts & return to them later was annoying. I just became frustrated with this aspect of the program, this was the reason I stopped using the program"*.

3.4. Forum feedback

Thirty men provided feedback on the forum. Satisfaction with the moderated forum was lower than that for the intervention, with only 41.38% rating their satisfaction as 6 or more on a scale from 1 to 10. Most (65.52%) said that the forum was easy to use, however, only 37.93% reported that other men's posts were useful and 31.03% reported that moderator posts were useful. Several ($n = 5$) men reported that the worst part about the forum was the low level of information posted by others, however others reported that the forum provided a sense of normalisation *"Knowing other men had the same problems as me"*, or a way in which to support others *"My situation may help others"*.

Reasons for not using the forum included a lack of motivation ($n = 7$), being too busy ($n = 6$), not finding the forum useful ($n = 6$) and technical difficulties ($n = 5$). Many participants indicated that engaging more men to use the forum would increase the benefit *"get people on it"*; and that the moderator could generate discussion *"stronger moderator presence"*, *"Need to seed it with comments"*.

3.5. Improvements to the intervention and forum

As a result of the findings of the feasibility study, and qualitative feedback from users and technical consultants, a number of changes to the intervention and forum were implemented.

3.5.1. Sequential progress through modules

The original design of the intervention required participants to work through all 6 modules sequentially, using a gate keeping function. Each subsequent module was only released once they had worked through the preceding one. Feedback from users indicated that an open approach to navigation would be preferable, so that men were free to focus on topics of particular interest, strengthening their motivation to use the programme.



Fig. 2. Mood monitor.

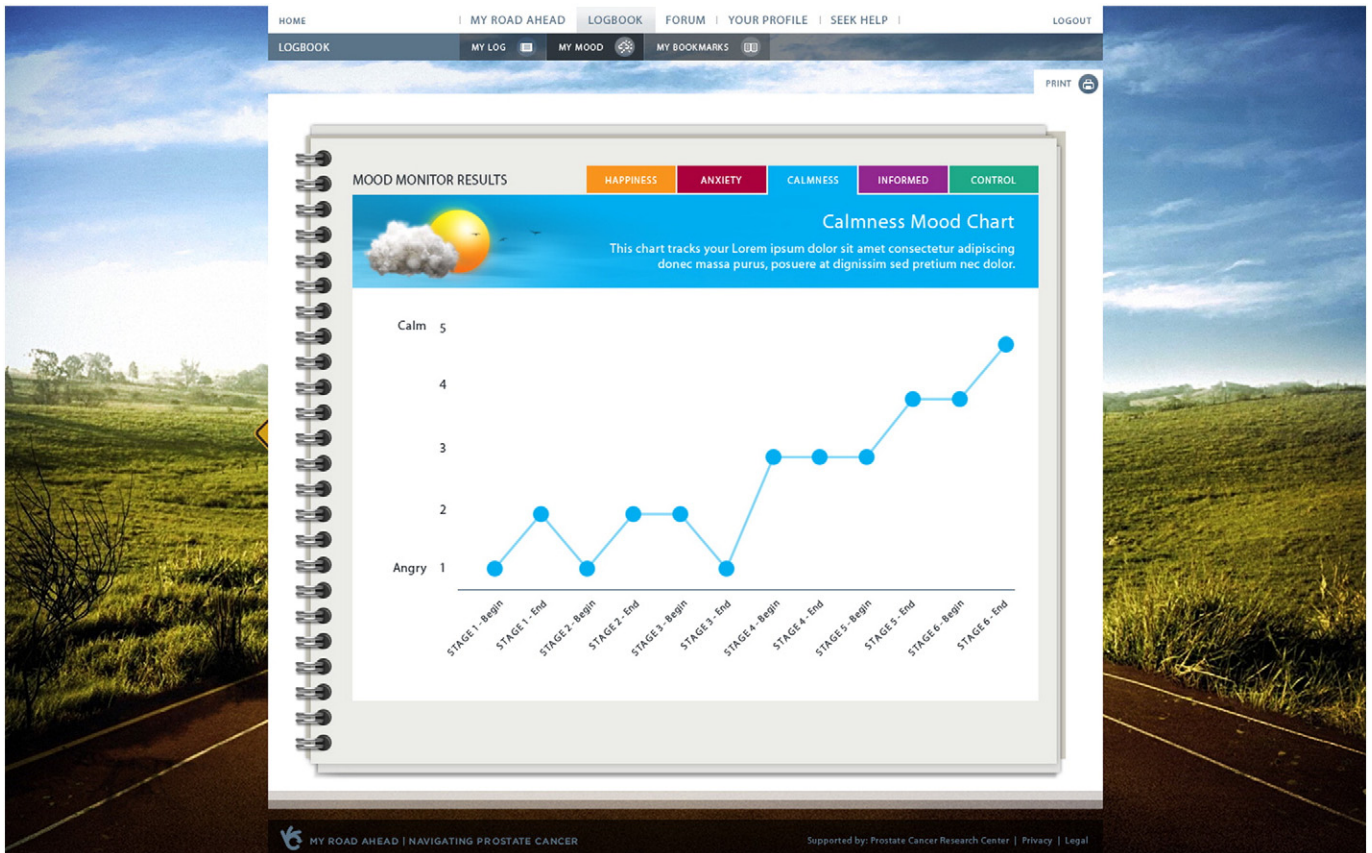


Fig. 3. Graphs illustrating the results of the mood monitor throughout the programme.

Table 2
Participant characteristics.

Age M (range)	62 years (46–78)
Time since diagnosis	27 months (<i>SD</i> = 16.95)
Time since first treatment	23 months (<i>SD</i> = 17.15)
Treatment type	
Radical prostatectomy	98%
Brachytherapy	2%
Sexual orientation	
Heterosexual	84%
Homosexual/bisexual	16%
Relationship status	
Married/partnered	89%
Single	8%
Dating/casual relationship	3%
Education	
University degree	41%
Trade	17%
Other post-school education	12%
Health	
Previous cancer diagnosis	11%
Diabetes	6%
Mental health diagnosis	7%
Support services previously accessed:	
Psychologist	9%
Psychiatrist	2%
Prostate cancer support group	14%
Cancer council information and support service	17%
Urology/prostate cancer nurse	42%
Physiotherapist	31%

3.5.2. Commitment to intervention

At the beginning of the intervention a section called “Your pledge” was added to encourage men to commit to working on the intervention. This provided a clear outline of the requirements and expectations of participants taking part in the research. To encourage users to complete all modules, the intervention was altered so that participants were given feedback about the proportion of the intervention they had completed.

3.5.3. Intervention access time

Feedback indicated that users required longer than 6 weeks to complete the intervention. The intervention was altered so that men could access it for 10 weeks. A fixed time period was considered useful to encourage participants to work through the intervention at a consistent rate. A timer was added to the intervention to show users their remaining access time. Participants were asked to commit to the intervention for 10 weeks.

3.5.4. Weekly emails

User feedback indicated that reminders and encouragement to continue to use the intervention would be beneficial. The intervention was altered so that each participant would receive a weekly email

Table 3
Baseline scores on erectile function and mood.

Continuous variables	Mean (SD)	Min	Max	Reported control means (SD)
IIEF Sexual function^a				
Erectile function	9.66 (9.72)	1	30	25.8 (7.6) (Rosen et al., 1997)
Orgasm function	3.78 (3.33)	0	10	8.8 (2.9) (Rosen et al., 1997)
Sexual desire	5.53 (2.13)	2	10	7.0 (1.8) (Rosen et al., 1997)
Intercourse satisfaction	4.05 (4.78)	0	14	10.6 (3.9) (Rosen et al., 1997)
Overall satisfaction	4.24 (3.48)	0	10	8.6 (1.7) (Rosen et al., 1997)
Total score	27.31 (20.70)	3	71	
Psychological function^b				
Stress	7.97 (9.26)	0	38	
Anxiety	3.85 (7.15)	0	32	
Depression	5.82 (7.10)	0	30	

^a Higher scores indicate better functioning.

^b Higher scores indicate higher levels of distress.

Table 4
Percentage of participants scoring in clinical ranges of the DASS-21.

	Depression	Anxiety	Stress
Normal range	77%	79%	78%
Mild range	8%	10%	8%
Moderate range	9%	5%	8%
Severe range	6%	6%	6%

from the researcher encouraging them to continue working through the programme.

3.5.5. Mid-programme check-in questionnaire

A mood assessment was added to week 5 of the 10 week intervention access period. This occurred as a result of participant feedback indicating that they would prefer increased system ‘check-in’ and feedback. As such the mid-point survey was implemented to provide that ‘check-in’ and feedback system.

3.5.6. Moderator posting on the forum

Participant feedback about the forum was that more discussion was needed. Hence, the forum was altered so that the moderator posted a weekly topic to generate discussion.

4. Discussion

In the current study an interactive online psychological intervention and forum were developed to help men cope with the challenges of prostate cancer and its treatment and side effects. A high number of men expressed interest in participating in the online intervention pilot in the short pilot recruitment window indicating strong desire for this style of support and high needs in this population. Feedback from men accessing the intervention and/or forum suggested that these were acceptable to men, the anonymity and convenience were appealing and the intervention helped provide insight into the impact of prostate cancer on quality of life and relationships.

The attrition rate for those who completed the baseline questionnaires and commenced the online intervention and provided feedback was acceptable at 31%. This compares favourably to other internet-based self-help interventions for non-cancer patients (Geraghty et al., 2010; Klein et al., 2011; Lintvedt et al., 2013), with attrition being as high as 99% in some studies (Geraghty et al., 2010). Exploration of underlying reasons for attrition was undertaken as part of this pilot study and a number of areas in need of improvement were identified. These areas of improvement included the need for a more detailed sign up process that explicitly states what is involved in participation of the study, ability for the users to select which modules they would prefer to work through rather than a sequential process through modules and the need to engage participants more regularly using weekly emails.

The study also examined the characteristics of users of the intervention. Participants who used the intervention were aged between 46 and 78 years, had typically started treatment for prostate cancer within the last three years, and were in a relationship, employed, well-educated and with moderate rates of distress. The majority of men in this study reported poor sexual function, as documented in previous literature (Beck et al., 2009; Boehmer and Babayan, 2004; Manne et al., 2010). This supports the need for interventions like My Road Ahead to comprehensively address sexual concerns as well as associated distress and potentially marital conflict. In addition, the majority of men did not involve their partners in their use of the intervention, despite exercises specifically designed for partner involvement. Feedback indicated that for some men engaging their partner was felt to be too difficult or that their partner was uninterested. Further exploration of how to navigate these concerns is required, as these participants are potentially those who might benefit the most from this aspect of the intervention. Future

interventions could consider enrolling partners into the programme as participants in their own right, thereby allowing partners to engage in the programme at their own pace and potentially reducing the fears of the male participants in inviting them to participate in the exercises with them. Alternatively an independent partner programme could be developed and run in parallel with this programme so as to engage both members of the couple in simultaneous, yet independent, interventions. Further research in this area is required to understand the needs of couples in this setting.

Although online interventions have the potential to overcome a range of barriers to accessing psychosocial support, it is important to consider user engagement and technological barriers that could deter use. In the current study, development experiences, feasibility testing and qualitative feedback suggested a number of areas where the programme could be improved to maximise user engagement. This included improving individualisation of the programme by allowing users some choice in the topics they focused on, providing weekly emails, and encouraging men to make a commitment to using the intervention over 10 weeks before consenting to participate. The forum was also refined to include more structured moderation and topic posts. These improvements have been made to My Road Ahead, and a larger randomised controlled trial has now begun.

There are a number of limitations to this study that also need to be considered. Participant click through rates from the main home page as well as individual page view data for participants were not recorded during this pilot study. Comprehensive analytic data capturing these variables would have provided a much deeper understanding of participant engagement and adherence and we have ensured that these variables will be captured in future trials. Another limitation was patient age. Participant age was marginally younger in the current sample than the general Australian prostate cancer patient 62 years compared to an average of 67 years old at diagnosis (AIHW and AACR, 2012) which could indicate some barriers to accessing the programme for older men. This needs to be further explored.

Engagement of users in early feasibility testing and intervention development is highly recommended in order to ensure the development of interventions that meet the specific needs of the target group. With an increasing interest in the development and utilisation of technology-based support programmes, these factors are essential to consider when developing novel interventions. Our experience illustrates the need to develop and refine interventions that can provide tailored support for people experiencing specific difficulties. It is imperative that interventions meet the needs of the users and as such a 'one size fits all' approach is rarely likely to be the optimal approach and therefore tailored interventions are required in order to realise the full potential of technology-based interventions.

Conflict of interest statement

The authors have no financial or otherwise conflict of interest to declare.

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