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Grinfeld, Elizabeth and Hunter, M.S. and Yousaf, O. (2017) Men's experience of a guided self-help intervention for hot flushes associated with prostate cancer treatment. *Psychology, Health & Medicine* 22 (4), pp. 425-433. ISSN 1354-8506.

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# Men's experience of a guided self-help intervention for hot flushes associated with prostate cancer treatment

**Grunfeld EA<sup>1</sup>, Hunter MS<sup>2</sup>, Yousaf O<sup>1</sup>**

1 Centre for Technology Enabled Health Research, Faculty of Health and Life Sciences, Coventry University, Coventry, UK

2 Institute of Psychiatry, Psychology and Neuroscience, Kings College London, London, UK

3 Department of Psychology, University of Bath, UK

## **Corresponding author**

Elizabeth Grunfeld

Faculty of Health and Life Sciences

Coventry University,

Coventry CV1 2NL

[beth.grunfeld@coventry.ac.uk](mailto:beth.grunfeld@coventry.ac.uk)

## Abstract

Up to 80% of men who receive androgen deprivation therapy report hot flushes and for many these are associated with reduced quality of life. However it is recognised that there are a number of barriers to men's engagement with support to manage symptoms and improve quality of life. This qualitative study was embedded within a larger randomised controlled trial (MANCAN) of a guided self-help cognitive behavioural intervention to manage hot flushes resulting among men androgen deprivation therapy. The study aimed to explore the engagement and experiences with the guided self-help intervention. Twenty men recruited from the treatment arm of the MANCAN trial participated in a semi-structured interview exploring acceptability of the intervention, factors affecting engagement and perceived usefulness of the intervention. Interviews were audio-recorded, transcribed verbatim and analysed using a Framework approach. Over two thirds of respondents (69%) reported reading the intervention booklet in full and over 90% reporting practising the relaxation CD at least once a week. Analysis of the interviews identified three super-ordinate themes and these related to changes in hot flush symptomatology (*learned to cope with hot flushes in new ways*), the skills that participants had derived from the intervention (*promoting relaxation and reducing stressors*), and to a broader usefulness of the intervention (*broader impact of the intervention and skills*). The present study identified positive engagement with a guided self-help intervention and that men applied the skills developed through the intervention to help them undertake general lifestyle changes. Psycho-educational interventions (e.g. cognitive behaviour therapy, relaxation, and positive lifestyle elements) offer the potential to be both effective and well received by male cancer survivors.

## Introduction

Prostate cancer is the second most common cancer in men (Jemal, Bray, Center, Ferlay and Forman, 2011). Androgen deprivation therapy (ADT) may be prescribed to men with advanced disease (where the cancer has not spread) or in cases of locally advanced disease where other treatments have failed (NICE 2014). ADT aims to inhibit prostate cancer progression by reducing the effects of androgens (including testosterone) (Graham, Baker, Macbet and, Titshall, 2008). However, ADT is associated with debilitating side effects and between 34- 80% of men who receive ADT report hot flushes (Frisk, 2010; Schow, Renfer, Rozanski and Thompson, 1998), which are associated with distress (Ulloa, Salup, Patterson and Jacobsen, 2009). The mechanism of hot flushes in men receiving hormone treatments is unclear although the flushes are thought to be an attempt by the thermoregulatory centre on the hypothalamus to regulate body temperature. It is thought that this thermoregulatory system becomes unstable as a consequence of sex steroids producing changes in brain neurotransmitters (e.g. noradrenalin and beta-endorphins) that are associated with normal functioning of the thermoregulatory centre.

Not all men are aware that hot flushes are a side effect of ADT leading to confusion and anxiety (Grunfeld, Halliday, Martin and Drudge-Coates, 2012). In addition, embarrassment and perceptions of altered masculinity may result from hot flushes and men may report feelings of powerlessness and difficulties adjusting to bodily changes associated with treatment (Eziefula, Grunfeld and Hunter, 2013). Clinical management guidelines suggest offering men medroxyprogesterone to treat troublesome hot flushes (NICE 2014), however, such medications have side-effects, which may have a detrimental impact on quality of life (Frisk, 2010). Hence, there is a need to develop non-medical interventions for hot flushes that do not come with unwanted side-effects. Research exploring the alleviation of hot flushes among men is sparse, however cognitive behavioural interventions for women with hot flushes following breast cancer treatments have been found to be effective (Mann et al., 2012; Duijts et al., 2012). Evidence suggests that changes in beliefs about hot flushes mediate improvement following cognitive behavioural treatment (CBT) (Norton, Chilcot and Hunter 2014). The CBT intervention was equally as effective when delivered in self-help format or group format (Ayers, Smith, Hellier, Mann and Hunter 2012).

Although there is growing interest in developing interventions that are tailored and targeted to men, there is little evidence available regarding the best approach to deliver services to address men's needs. Prostate cancer patients may prefer individualised informational support (Shapiro et al., 2004) and both telephone support services or guided self-help can be accessed by men living at a distance and may be well received. The MANCAN (from "*man can*") trial evaluated a guided self-help CBT

intervention (Yousaf, Stefanopoulou, Grunfeld and Hunter, 2012), which consisted of a booklet and a compact disk (CD) outlining paced breathing and relaxation techniques. CBT was successful in reducing the problem ratings and frequency of hot flushes in the treatment group, compared to the treatment as usual group, 6-weeks following randomisation (Stefanopoulou, Yousaf, Grunfeld and Hunter, 2015). In addition to being the first CBT-based self-help intervention for men with hot flushes, MANCAN also sought to understand how men engaged with the intervention, and to identify barriers to engagement with a self-help CBT intervention. Barriers to men's engagement with healthcare services include embarrassment, anxiety, poor communication with healthcare professionals and a disinclination to disclose health concerns (Yousaf, Grunfeld and Hunter, 2014; Fish et al, 2015). The MANCAN intervention materials were designed to optimise men's engagement by utilising telephone support and incorporating a strong informational component (Yousaf et al., 2012). This qualitative study was embedded within the main MANCAN trial and aimed to explore the experiences of men participating in a guided self-help intervention examining how men engaged with the intervention, factors affecting engagement and perceived usefulness of the intervention.

## Methods

### Participants

Participants were recruited through the treatment arm of the MANCAN trial (Stefanopoulou et al. 2015) although the interviews were conducted independently of the trial by a researcher (OY) blinded to the patient outcomes. Twenty men (61% of the men in the treatment arm) agreed to participate in a semi-structured interview. Consecutive recruitment was undertaken and recruitment ceased once 20 men had been recruited. The men ranged in age from 57 to 83 years ( $M = 69$ ) and categorised themselves as either White British ( $n = 18$ ) or Black British ( $n = 2$ ) (see Table 1). Fourteen participants had localised prostate cancer, while 6 had locally advanced prostate cancer.

### Procedure

Ethical approval was obtained from the local Research Ethics Committee (11/LO/1114) and written consent obtained prior to the start of the interviews. Individual semi-structured interviews were conducted at the 6 month follow-up period within the MANCAN trial (mean 35 weeks following recruitment into the trial (range 28-65 weeks)) between November 2012 and May 2014. The timing of the interviews allowed exploration of how participants experienced the intervention over time. The participants in the intervention arm had a copy of materials at home during and after the trial. A copy of the intervention booklet was available during the interview process to serve as a reminder if required. Interviews explored how men engaged with the intervention, factors that affected engagement and perceived usefulness the intervention on hot flushes and more generally. Interviews ranged in duration between 10 and 52 minutes (mean = 29 minutes), were audio-recorded and

transcribed verbatim. To maintain confidentiality, each participant was assigned a pseudonym. Accuracy of the transcripts was checked against the original recordings.

### **Analysis**

Data from the first ten interviews were analysed independently by two authors (OY and EAG) who developed a preliminary coding framework to guide analysis of subsequent interviews. Throughout the analysis process authors discussed and revisited the original framework. A “Framework” analysis approach (Ritchie, Spencer and Nicholls, 2013) was used which involves an iterative approach that primarily follows the constant comparison method (Glaser, 1965). Within the framework approach one piece of data is compared with all others to develop conceptualizations of possible relationships between pieces of data. Each transcript was analysed by noting units of meaning and creating free codes, which were then grouped into coherent themes. Once themes were identified for each participant they were then integrated across all participants into a list of superordinate themes focused on participants’ shared experiences.

### **Results**

Engagement with the intervention materials was good: all participants reported that they had read the booklet and had listened to the CD. 69% read the booklet in full, 19% read more than half of it. Adherence to practising the relaxation CD was lower: 58% practised twice a week or less, 23% practised it 5-6 times a week, and 12% practised every day. Men spoke of several factors that affected their engagement (positively or negatively) with the intervention. For some men CBT was associated with connotations of mental health issues and there was an attempt to make a distinction between themselves and *others* who might experience mental health issues

*“I think a lot of it applies to other people who have slightly more psychological problems than I have. ....some people get all het up when there is a problem”* (Mark, aged 74)

There was also a tendency among some men to perceive the intervention to be of greater benefit to men who had difficulty coping, which related to a general rhetoric around the idea being someone who was able to cope as opposed to someone who was unable to cope:

*“I don’t really suffer any stress because I’ve learnt to live with the hot flushes. I felt it was more relevant to people in the other extreme than to me.”*(Adam, aged 68)

Men did, however, report that the informational components of the intervention were useful and acknowledged that they had acquired information that not only helped them manage their symptoms but that increased their general understanding of their condition:

*“It gave me more of an insight into the issues.....more information is always good information.”* (Ted, aged 73)

Three super-ordinate themes were identified and these related to the skills that participants had derived from the intervention (Promoting relaxation and reducing stressors), changes in hot flush symptomology (Learned to cope with hot flushes in new ways), and to a broader usefulness of the intervention (Broader impact of the intervention and skills).

#### *Promoting relaxation and reducing stressors*

Participants spoke positively about the paced breathing and relaxation and stress reducing techniques and found them to be beneficial in managing hot flushes, as well as stress more generally. Those who had experience of meditation or yoga, noted similarities in the approaches, and sometimes combined the instructions on the CD with their own techniques. Some participants reported that paced breathing exercises (focused on teaching slow, deep, diaphragmatic breathing to facilitate relaxation) distracted from negative thoughts about hot flushes, for others the exercises allowed them to switch focus onto the breathing, which aided relaxation.

*“I used the relaxation thinking about my beautiful place particularly at night while having a hot flush, or after the hot flush, when I can’t get back to sleep, to try and help me to empty my brain of other thoughts”* (Daniel, aged 67)

Rather than distracting from the hot flushes, others reported a belief that the breathing would have a physiological impact resulting in reduction in hot flushes (e.g. the duration of the flush).

*“I thought perhaps in terms of reducing in duration by using the breathing, by reducing the duration of the flush by using the breathing, and in general of the relaxation being part of life”* (George, aged 60)

Perhaps because hot flushes often bring with them a strong sense of discomfort, many participants reported feeling short-tempered or irritable. The breathing exercises provided the participants with a strategy to manage this sense of irritability resulting in reappraisal of hot flushes as less of a nuisance and more as a natural response to their changing hormone levels.

*“That makes you just become, pragmatic isn’t the right word but you become more accepting of what the present situation is so there is no point in wasting time fighting and becoming tense and emotional and anxious”* (Peter, aged 68)

#### *Learned to cope with hot flushes in new ways*

The majority of men reported improvement in their symptoms and recalled that the diary aspect of the intervention provided a “structure” for documenting their experience and helped the men to identify

triggers or precipitants of flushes (e.g. drinking coffee, rushing) as well as the circumstances under which they were most likely to occur (e.g. when stressed, after eating). This, in turn, was used by the men to gain control over the symptoms, which they operationalized by modifying daily habits and changing behaviours.

*“What I did find useful was making notes of the occurrences, you know, that sometimes helped....I did think that was useful to sort of codify”* (Peter, aged 68)

Some participants expressed a more positive outlook on their hot flushes in the context of their prostate cancer, which was often associated with beliefs about why they experienced hot flushes; *“They [hot flushes] are part of the cure..... they could go on for a long time, they’re not stopping, you know. You’ve had all these injections, they are in your body now but think of them in a positive way which I am, that is why I try to ignore them”* (Jake, aged 57)

Men also reported improved self-efficacy with regard to their ability to cope with the symptoms, and that the intervention provided them with “confidence”. In particular, participants reported that the intervention equipped them with the skills to cope with their symptoms.

*“Very helpful.....because they channelled my thoughts. Gave me something positive to work with - once I was doing it whether I got very hot flushes or not I just ignored them and got on with it and it was fine”* (Jake, aged 57)

#### *Broader impact of the intervention and skills*

Participants described how they integrated new skills into everyday routine. For example whilst most participants used the breathing techniques to reduce the impact of hot flushes, some also used them to alleviate general anxiety and to promote relaxation. One participant explained that the techniques he had learnt through the intervention could be applied whenever he felt stressed, even when unrelated to his hot flushes or to anxiety around his cancer diagnosis.

*“.... it has helped me get to sleep better because the relaxation techniques are very good .... and it happened to me last night actually, I was a bit upset about something, and I went to bed and just laid down and relaxed and took myself to another place, controlled my breathing, and I was asleep within second”* (Eric, aged 60)

The intervention also had wider impact and some participants spoke of how the intervention had motivated them to implement general lifestyle changes, including a renewed interest in activities or hobbies and described the benefit they obtained from increased rest and from engaging with family and friends. The intervention booklet provided advice on several aspects of how behavioural changes

(e.g. diet, exercise) could help manage hot flushes and reduce stress, which encouraged some men to reflect on general eating habits or to increase their exercise.

*“Diet and exercise, I do a lot more exercise than I used to do. I do more, not as much as I probably should but I think I have. Diet, my wife and I, we don’t eat quite the same way we used to. I’m eating smaller, to be honest, than I used to. I don’t want it, I don’t need it, and that’s probably because I’m not doing as much as I used to” (Len, aged 70).*

## Discussion

This study aimed to explore the experiences of men participating in a guided self-help intervention to manage hot flushes and focused on examining how men engaged with the intervention, factors affecting engagement and perceived usefulness of the intervention. Engagement with the intervention was evident from descriptions of how the intervention had motivated participants to implement general lifestyle changes (e.g. related to diet, relaxation, and exercise). Although not a direct aim of the MANCAN intervention this outcome is important given the acknowledgment that more interventions are needed to promote health behaviour change among cancer survivors (Bourke et al 2013; Coa et al 2015). Although the intervention was generally well received some men did reveal a belief that the psychological focus of the intervention might be more applicable to “others” and considered themselves to be different to such men. This tendency may represent a reluctance to acknowledge emotional issues, reflecting masculine social norms around emotional expression (Courtenay 2000). Attempts were made to ensure that the intervention would be applicable to, and well received by, men, for example, by incorporating a strong informational support component, which was well received by the men in this study.

The intervention was designed to allow flexibility in the way in which techniques and exercises were used, and it was encouraging to see that, in addition to the high rate of adherence, participants appeared to adjust their practice to suit their lifestyle. Participants found ways of using the breathing/relaxation strategies in different contexts and reported that it had a generally positive effect on their well-being and quality of life. It is hypothesised that the intervention worked to both reduce hot flushes (through a physiological response initiated by paced breathing) and using behavioural strategies to shift attentional focus away from bodily sensations, which together act to alleviate stress associated with hot flushes and elevate quality of life (Hunter and Mann 2010). Some of the men offered similar explanations (i.e. the role of distraction in reducing the impact of symptoms) for how breathing and relaxation might reduce the impact of symptoms. However, all these findings were based on participants within a controlled trial, which may have influenced the degree of engagement

with materials and to date little evidence exists regarding how men might engage with intervention materials off-trial.

One of the benefits of using a CBT approach was that it helped participants to change their appraisals of hot flushes. There is evidence that negative thoughts (e.g. embarrassment or social anxiety) are associated with more problematic hot flushes among women (Rendall, Simmonds and Hunter, 2008). Results from the full MANCAN trial indicate that there were significant reductions in negative beliefs about hot flushes following the intervention (Stefanoupolou et al, 2015) and a similar reduction in negative beliefs around hot flushes has been observed in other CBT-based interventions aimed at reducing hot flushes in women with (Chilcot Norton and Hunter, 2014) and without breast cancer (Norton et al 2013). The qualitative results of this study are broadly similar to those of women following breast cancer treatment who participated in a trial of group CBT for hot flushes (Balabanovic, Ayers and Hunter, 2012), which revealed that the intervention supported women to develop a clearer understanding of their symptoms, promoting greater acceptance and control.

### **Limitations**

Interviews were conducted 35 weeks following recruitment into the MANCAN trial and while this allowed exploration of the long-term effects of the intervention, it may have led to recall bias (although participants were provided with a copy of the booklet during the interview). Furthermore, participants may have demonstrated demand characteristics (i.e., motivation to give positive or expected responses) in their answers to the questions about the intervention. However, participants were informed that we needed honest feedback in order to improve the intervention, so we would not expect this bias to be significant. In addition, this was a self-selected population in that the men had agreed to participate in an intervention trial to support the management of hot flushes and night sweats and as such may have been highly motivated to engage with the materials. However, the men reported sustained engagement with the materials throughout the trial period and revealed how they had utilised the skills they had learned in situations outside of the trial.

### **Conclusion**

In conclusion, the findings suggest similarities between men and women's experiences of a brief CBT intervention for hot flushes. The intervention promoted a clearer understanding of why they were experiencing hot flushes, which enabled them to tolerate symptoms as well as use the skills developed through the intervention to manage these. Psycho-educational interventions, where CBT, relaxation and positive lifestyle elements are incorporated into a self-help intervention programme, have the potential to be both effective and well received by men.

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**Acknowledgements**

This research was funded through a project grant awarded by a Prostate Cancer UK Project Award (PG10-01).