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**Applying health psychology theory to practice:
cognitive behaviour therapy, motivational
interviewing and mindfulness-based
interventions for improving mental and
physical health**

Belinda Hemingway

Submitted in fulfilment of the requirements of the
Professional Doctorate in Health Psychology

School of Health Sciences, City University of London

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FOR DATA PROTECTION REASONS:**

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p. 301, Appendix C18: emails

p. 311-2, Appendix C19: emails

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DECLARATION

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SECTION A

PREFACE

PREFACE

This portfolio of competence was completed alongside working as a Health Promotion Strategist in Behaviour Change and a Team Leader for a mental health promotion and psychological therapy service. Prior to embarking on the Professional Doctorate in Health Psychology, the author had held a range of positions in the NHS that facilitated research, health promotion, behaviour change and self-management; and had therefore built up a range of knowledge, skills and experience. However, completing the Professional Doctorate has enabled an enhanced application of health psychology theory and principles to meet the requirements of the qualification. The portfolio therefore evidences this development and how professional practice has contributed to interventions for both physical and mental health.

Section B – Research

Thesis

The author's practice has helped to shape competencies, as well as a desire to develop research that contributes to clinical practice. Following completion and application of an MSc module in psychological treatments in behavioural sleep medicine in 2012, and proactively contacting key figures in the field to assess the need for research where health psychology could contribute, the research study described here evolved.

Sleep is a key issue in maintaining good mental and physical health, but increasingly people are suffering with insomnia and experiencing poor health-related quality of life and daytime functioning as a result. Cognitive Behaviour Therapy for Insomnia (CBT-I) has been shown to be effective (Espie & Kyle, 2009). However, there has been little research conducted which compares the efficacy of different treatment modalities on health-related quality of life alongside other measures related to patients' experience of insomnia, such as daytime functioning, depression and anxiety; and treatments are not widely available or well understood. This original study therefore explored the effectiveness of three UK CBT-I treatment interventions, namely a manual-guided five-week group (Espie et al., 2001; 2007), a one-day workshop (Swift et al., 2012) and an online programme (Espie et al., 2012), on outcomes and participatory experience. The study used a mixed methods approach. This included a randomised controlled pilot study assessing key outcomes, alongside exploring participatory experience of patients

in each intervention through the completion of a patient experience questionnaire, and semi-structured interviews from each intervention to form a case study.

Findings revealed that CBT-I treatment resulted in significant improvements in insomnia severity, dysfunctional beliefs and attitudes about sleep, depression, anxiety, daytime functioning and health-related quality of life, mental health or insomnia related medication use, time in bed, sleep onset latency, wakefulness after sleep onset, and sleep efficiency across interventions. No significant differences between the effectiveness of the three CBT-I interventions were found, apart from more time in bed, for the online programme. Therefore, the current five-week group was assessed to be no more effective overall than a one-day workshop or an online programme on key outcomes. Secondary findings provided useful information on participant experience, which could provide future options and choice for individuals in determining what would be the most beneficial intervention for them based on their specific needs.

The success of interventions in this pilot study therefore contributes to the ongoing development of accessible and effective stepped-care treatment. Findings from this research could also contribute to matching individual patient needs to treatment interventions. Through improving service delivery and funding training, savings could also be made by enabling sleep specialists to see only the most severe cases of insomnia, in addition to potential reductions of long-term use of medication in the general population. A challenge for the future is therefore to disseminate evidence-based therapies to both patients and health care professionals in order to make treatments more widely available and deployable, as well as enable better understanding of current approaches and options. Results will contribute to evidence for choice and accessibility to a greater range of interventions in future, led by feedback from participant experience. The results have positive implications for improving the management of insomnia for a large number of patients, and thereby improving the well-being, mental and physical health of many people with sleep problems. As the interdependence between mental and physical health is more widely recognised, health psychology can make a valued contribution to research, training and delivery of CBT-I interventions.

Supplementary research

Four supplementary research papers were also devised and published: a careers article in *The Psychologist* (May 2014); how health psychology can contribute to improving insomnia in *PsyPAG Quarterly* (December 2014); improving emotional well-being for respiratory patients in *Breathing Matters* magazine (March 2015); and a

respiratory service improvement project in Health Psychology Update (Autumn 2016 edition). These publications further emphasised the importance of considering mental and emotional health in physical health care. The service improvement project, for example, explored the relationship between patient activation and outcome in pulmonary rehabilitation. Activation was assessed using the Patient Activation Measure (PAM) (Hibbard et al., 2004), as part of pre and post-assessment questionnaires. Measures of depression and anxiety routinely given were also included. Baseline scores for those that completed pulmonary rehabilitation were compared with those that did not. Results showed a significant difference in pre and post-assessment PAM scores for patients completing. However, there were no significant differences between those completing and those who did not. Significant differences were found for pre and post-assessment scores for depression and anxiety, and those not completing were significantly more depressed and anxious than those completing the programme. Completion of pulmonary rehabilitation can therefore improve outcomes for patient activation, depression and anxiety. The PAM was not able to predict whether a patient will complete pulmonary rehabilitation, but currently used measures for depression and anxiety were. Further research is needed to understand the mechanisms of action, but this project could help inform the development of targeted psychological interventions to support respiratory patients.

Section C – Professional Practice

Teaching and training of health professionals

This competence was met through the planning, design, delivery and evaluation of a programme of health promotion and behaviour change skills training for health and social care frontline staff, using concepts and evidence from health psychology. The challenge was to deal with issues of cost, capacity and low attendance at previous training, whilst providing a programme that participants valued and that equipped them with the skills to successfully enable lifestyle behaviour change. Overall the training programme achieved this through successfully drawing together health promotion knowledge, with the skills and good practice of Motivational Interviewing (MI) (Miller & Rollnick, 2002).

Teaching and training of the general population

The author was approached to deliver a sleeping well workshop for a local mental health promotion week. A standalone session was developed, delivered and evaluated,

which enabled members of the public to learn knowledge, skills and practices in health psychology, specifically around sleep.

Consultancy

For this competency, the author carried out a consultancy project for a local public health department, producing a series of mental health podcasts for a local radio station. These podcasts consisted of advice and support for people who may be struggling with issues relating to their mental health and/ or emotional well-being. The author was able to apply theoretical health psychology knowledge, informed by evidence-based practice and knowledge of delivering effective health promotion to a wide audience. Additionally this was embedded in existing organisational structures, which suggested a positive outlook for future consultancy requests.

Behaviour change interventions

The author was contacted by a respiratory physiotherapist requesting psychological input into a rolling pulmonary rehabilitation programme, for patients with chronic obstructive pulmonary disease and other lung conditions. Needs were assessed, and a psychoeducational intervention was formulated, implemented and evaluated over eighteen months. Overall, utilising health psychology theory and models to inform structure and content contributed to the implementation of an appropriate, effective behaviour change intervention. The intervention met the aims of the request, and as a result patients gained awareness and support around managing their emotional well-being. The intervention gave patients permission to talk about emotions, and to discover that they are not alone in their struggles to manage their condition and its impact.

Section D – Systematic Review

With supporting evidence that mindfulness enhances psychological well-being, and that positive psychological well-being is associated with a reduced risk of cardiovascular disease, evidence was needed to identify the specific physical health outcomes that are impacted by mindfulness. A comprehensive review was conducted to identify the effects of mindfulness-based interventions on physical health outcomes. The search strategy established a total of 770 studies, of which 9 met the inclusion criteria and were included in the review.

Mindfulness-based interventions appear to be effective in enhancing the physical rehabilitation of adults with and at risk of coronary heart disease, but this was not an entirely consistent finding. The intervention may have beneficial effects by improving psychological distress, increasing awareness and helping people to feel more in control of and cope with the impact of coronary heart disease, rather than its effect on specific physical health outcomes. Mindfulness-based interventions could therefore be included as part of health education or treatment programmes in order to contribute to secondary prevention through encouraging lifestyle and health behaviour change. Future studies need to consider employing randomised controlled designs, large sample sizes with male and female participants from a range of socio-economic backgrounds, and long-term follow-up of at least one year.

Conclusion

This portfolio demonstrates the competencies of working as a reflective scientist-practitioner in physical and mental health care. The author now regularly uses MI and behaviour change skills, mindfulness approaches, and CBT-based interventions across their practice; therefore developing a somewhat unique role as a health psychologist working in mental health promotion and psychological therapy.

SECTION B

RESEARCH

**Cognitive Behaviour Therapy for Insomnia
(CBT-I): a mixed methods pilot study to explore
the effectiveness and participatory perspectives
of treatment delivery interventions on key
outcomes and experiences**

ABSTRACT

Introduction

Sleep is a key issue in maintaining good mental and physical health, but increasingly people are suffering with insomnia and experiencing poor health-related quality of life and daytime functioning as a result. Cognitive Behaviour Therapy for Insomnia (CBT-I) has been shown to be effective. However, there has been little research conducted which compares the efficacy of different treatment modalities on health-related quality of life alongside other measures related to patients' experience of insomnia, such as daytime functioning, depression and anxiety; and treatments are not widely available or well understood. This original study therefore explored the effectiveness of three UK CBT-I treatment interventions, namely a manual-guided five-week group, a one-day workshop and an online programme on outcomes and participatory experience.

Method

The study used a mixed methods approach. This included a randomised controlled pilot study assessing insomnia severity, beliefs and attitudes about sleep, depression, anxiety, daytime functioning and health-related quality of life, sleep diary measures, use of psychotropic medication, non-prescription drugs, and alcohol use across and between interventions. The secondary aim of the study was to explore participatory experiences of patients in each intervention through the completion of a patient experience questionnaire (analysed with content analysis), and semi-structured interviews from each intervention to form a case study (analysed with interpretative phenomenological analysis).

Results

The findings revealed that CBT-I treatment resulted in significant improvements in insomnia severity, dysfunctional beliefs and attitudes about sleep, depression, anxiety, daytime functioning and health-related quality of life, mental health or insomnia related medication use, time in bed, sleep onset latency, wakefulness after sleep onset, and sleep efficiency across interventions. No significant differences between the effectiveness of the three CBT-I interventions were found, apart from more time in bed, for the online programme. Therefore, the one-day workshop and the online programme were assessed to be as effective overall on key outcomes as the five-week group. Secondary findings provided useful information on participant experience, which could provide future options and choice for individuals in determining what would be the most beneficial intervention for them based on their specific needs.

Discussion

The success of interventions in this pilot study therefore contributes to the ongoing development of accessible and effective stepped-care treatment. Findings from this research could also contribute to matching individual patient needs to treatment interventions. Through improving service delivery and funding training, savings could also be made by enabling sleep specialists to see only the most severe cases of insomnia, in addition to potential reductions of long-term use of medication in the general population. A challenge for the future is therefore to disseminate evidence-based therapies to both patients and health care professionals in order to make treatments more widely available and deployable, as well as enable better understanding of current approaches and options. Results will contribute to evidence for choice and accessibility to a greater range of interventions in future, led by feedback from participant experience.

Conclusion

The results have positive implications for improving the management of insomnia for a large number of patients, and thereby improving the well-being, mental and physical health of many people with sleep problems. As the interdependence between mental and physical health is more widely recognised, health psychology can make a valued contribution to research, training and delivery of CBT-I interventions.

INTRODUCTION

Sleep is a key issue in maintaining good mental and physical health. However, research has shown that a third of adults have sleep problems including insomnia (Morphy, Dunn, Lewis, Boardman & Croft, 2007; Roth, 2007; Ohayon & Reynolds, 2009; Léger, 2010). Insomnia describes poor quality sleep over a period of time, either as an acute condition lasting less than a month, or it may develop into a chronic, long-term condition.

Primary insomnia

Insomnia can present independently or share its risk factors, cause or consequence with another medical condition (e.g. chronic pain, and some cardiovascular, pulmonary and gastrointestinal disorders) or psychiatric illness (e.g. depression, generalised anxiety) (National Institutes of Health, 2005). Other associated sleep disorders can also contribute to insomnia, particularly obstructive sleep apnoea, restless legs syndrome, or periodic limb movement disorder. In the absence of co-morbid conditions however, insomnia is thought to be a primary disorder in itself (National Institutes of Health, 2005).

A person with primary insomnia is likely to view their sleep as unacceptable, in terms of quality and pattern, often noticing impairments in their daytime functioning (Espie & Kyle, 2009). Individuals are often extremely concerned about falling asleep, returning to sleep, and the unpredictable nature of their sleep, further exacerbated by concern over the daytime consequences of lack of restorative sleep (Espie & Kyle, 2009). Insomnia is the most prevalent sleep disorder and it carries a heavy burden for both patients and the health care system (Morin & Benca, 2012).

Chronic primary insomnia should be distinguished from acute (short-term) insomnia, which may occur in anyone at one time or another, e.g. the night before an important event the next day or the impact of jet lag. For the purposes of this research, the use of the word insomnia will relate to chronic primary insomnia.

The International Classification of Sleep Disorders (ICSD-2) (American Academy of Sleep Medicine, 2005) defines primary insomnia as **A + B + C**:

A

One or more of the following symptoms:

- Difficulty initiating sleep
- Difficulty maintaining sleep
- Waking up too early
- Non-restorative sleep

B

Sleep difficulty occurs despite adequate opportunity for sleep

C

At least one of the following daytime symptoms related to the night-time sleep difficulty reported:

- Fatigue or malaise
- Attention, concentration, or memory impairment
- Social or vocational dysfunction or poor school performance
- Mood disturbance or irritability
- Daytime sleepiness
- Motivation or energy or initiative reduction
- Proneness for errors or accidents
- Tension headaches or gastrointestinal symptoms, or both
- Concerns or worries about sleep

The most common type of primary insomnia is **psychophysiological insomnia** (Espie & Kyle, 2009). The ICSD defines psychophysiological insomnia as “*a disorder of somatized tension and learned sleep-preventing associations that results in a complaint of insomnia and associated decreased functioning during wakefulness*” (American Academy of Sleep Medicine, 2005: 29). Individuals therefore typically react to stress and stressful events physically, whilst also learning sleep-preventing associations that not only increase the physical symptoms but also directly interfere with sleep, for e.g. trying too hard to sleep (internal factor), or associating sleeplessness with situations and behaviours (external factor) (American Academy of Sleep Medicine, 2005). For some patients, both internal and external associations can be learnt during an acute period of insomnia caused by other precipitating factors, e.g. pain or a disturbed sleep environment. Psychophysiological insomnia then persists even after these factors have gone. For other patients, poor sleep develops gradually over time, and concerns about sleep quality grow as sleep deteriorates, until it becomes a real cause for concern. This focus on sleep however, is also accordingly contributing to sleeplessness and becoming a fixed condition for the majority of the time (American Academy of Sleep Medicine, 2005). This arousal of the mind and body is therefore a combination of thoughts, behaviour and physiology (Robatham, 2011).

Paradoxical insomnia, or sleep-state misperception, is *“a disorder in which a complaint of insomnia or excessive sleepiness occurs without objective evidence of sleep disturbance”* (American Academy of Sleep Medicine, 2005: 33). Typically, a patient will complain of an inability to fall asleep, having inadequate sleep, or the inability to sleep at all. However, a significant discrepancy will exist between the complaint and objective polysomnographic findings, even if the patient states that the primary symptom was present during the night of objective testing.

Idiopathic insomnia is defined as *“a lifelong inability to obtain adequate sleep and is presumably due to an abnormality of the neurologic control of the sleep-wake system”* (American Academy of Sleep Medicine, 2005: 35). In most patients with idiopathic insomnia, psychological functioning remains remarkably normal as long as the sleep disturbance is either mild or moderate. If idiopathic insomnia is severe, daytime functioning can be seriously impacted (American Academy of Sleep Medicine, 2005; Espie & Kyle, 2009).

Inadequate sleep hygiene is defined as *“a sleep disorder due to the performance of daily living activities that are inconsistent with the maintenance of good-quality sleep and full daytime alertness”* (American Academy of Sleep Medicine, 2005: 73).

Inadequate sleep hygiene therefore applies to a sleep disorder that develops out of normal behaviours that for another person usually would not cause a sleep disturbance (American Academy of Sleep Medicine, 2005; Espie & Kyle, 2009).

The impact of insomnia

As can be seen from the ICSD-2 (American Academy of Sleep Medicine, 2005), insomnia is not only a condition that impacts people's experience of sleep; it can also have a significant effect on psychological, social and physical functioning. The National Institutes of Health (2005) reported that insomnia is often associated with a wide range of undesirable conditions, including mood disturbances, difficulties with concentration, and memory. Either difficulty initiating or maintaining sleep, or both initiating and maintaining sleep, can be associated with reduced daytime alertness and productivity, poorer quality of life, higher rates of relationship difficulties, and increased ill-health (Espie et al., 2007). Research has found that individuals with insomnia report decreased mood and cognitive abilities, coupled with elevated levels of anxiety, fatigue and physical pain or discomfort, compared to people who do not report problems with their sleep (Kyle, Morgan & Espie, 2010). In their review, the authors also state that

insomnia has been connected to: increased rates of health care utilisation, such as GP visits and medication prescriptions; long term health conditions; increased work absenteeism; reduced work productivity; and greater frequency of accidents. In addition, insomnia can be a significant risk factor for psychiatric illness (Edinger & Means, 2005; Roth, 2007), and many people also drink alcohol to aid sleep (Mental Health Foundation, 2011), which can impact on their physical health.

Daley, Morin, LeBlanc, Grégoire and Savard (2009) estimated the direct and indirect costs of insomnia from a societal perspective, and found that the largest proportion of economic burden could be attributable to insomnia-related work absences and reduced productivity. The authors suggested that the economic burden of untreated insomnia is much higher than that of treating insomnia itself. In a recent review of the societal costs of insomnia, Léger and Bayon (2010) point out the need to include direct, indirect, and related economic costs of insomnia, but also to consider the impact of insomnia on quality of life.

Insomnia in today's society

Evidence suggests that self-reported sleep duration has declined in the last fifty years (National Sleep Foundation, 2003; Cauter et al., 2008; Kronholm et al., 2008; Calem et al., 2012). Bixler (2009) reported that whilst it remains to be determined whether reductions in sleep duration are reflective of changes in modern lifestyle such as the internet, television and longer working hours, it is most likely a complex combination of individual and health-related factors. Bixler (2009) concludes that socioeconomic status, lifestyle choices, sleep complaints, stress and age all appear to influence sleep duration.

Calem et al's (2012) large-scale and long-term study from 1993 to 2007 showed that insomnia is on the rise in the United Kingdom. The researchers utilised data from three separate national surveys, and over twenty-thousand UK residents were included. Over the fifteen-year period, greater numbers of people reported having sleep problems that fitted the definitions of insomnia. The biggest increase over the study period was for having an insomnia diagnosis, which was reported to have nearly doubled. Insomnia of all types was more likely to affect women, the unemployed, people who were divorced, separated or widowed, as well as those less educated and those at the low end of the economic spectrum. Age was also a factor, and being older presented a greater risk. Worry and thinking were the most commonly reported

reasons for sleep problems, reported across all three surveys, followed by illness and discomfort, noise, shift work and too busy to sleep, needing to go to the toilet, being tired, and medication. Sleep medication use doubled between the first two surveys, but there was no further increase between the last two. The authors concluded that further research is needed to examine the effects of this gradually increasing prevalence of insomnia on the health, well-being, and functioning of people living in modern society. They also highlighted the need to develop effective, targeted and accessible interventions across primary and secondary care.

The 2012 Great British Sleep Survey (Sleepio, 2012) also examined the responses for over twenty-thousand people in the UK. Respondents were generally those who were worried about their sleep, so results cannot be inferred to the general population, but they can provide useful information on particular subgroups such as age and gender. Thoughts and worries were reported as the main cause of sleeplessness. Like Calem et al. (2012), bodily discomfort impacted the greatest number of people in terms of physical factors, followed by noise, their partner, room temperature, and light levels. The authors compared good sleepers, who stated that they do not have a sleep problem, with long-term poor sleepers, who reported having had a sleep problem for more than three months and find all areas of their life affected by poor sleep. They found that poor sleepers are: seven times more likely to feel helpless; five times more likely to feel alone; three times more likely to struggle to concentrate; twice as likely to suffer from fatigue; twice as likely to have relationship problems; twice as likely to suffer from low mood; and twice as likely to struggle to be productive, compared with good sleepers. Women had a ten percent lower average sleep score than men. However, the daytime areas most impacted by poor sleep were very similar for both men and women, and these were energy, relationships and mood. Sleep quality decreased with age, and sleep became more broken. Finally the report found that forty-two percent of respondents taking sleeping medication had sleep problems for over ten years. Sleep medication was also associated with poorer general well-being, increased helplessness, loneliness and being out of control. These results provide a useful reflection on sleep problems in the UK, and also further support the findings of Calem et al. (2012) for gender, age, and attributed causes.

In 2014, the Great British Bedtime Report (The Sleep Council, 2014) described results of a survey of just over five-thousand adults in the UK. Twenty-two percent reported poor quality sleep, and forty-seven percent stated that they lose sleep as a result of stress and worry. However forty-eight percent said that they sleep fairly well most nights, with a quarter sleeping very well. Following the trends of previous research, this

report found that men appeared to have better quality sleep than women, and men were more than twice as likely to say that nothing keeps them awake at night. Again sleep quality was found to deteriorate with age, with middle-age being the worst affected. Like previous studies, this report also found other disturbances related to the environment and noise, light, children, and health problems such as stress, obesity, arthritis, back pain, diabetes and asthma.

Age

Previous research has explored age in relation to sleep and insomnia. Foley et al. (1995) reported that older adults experienced difficulty both initiating and maintaining sleep, whereas young adults with insomnia tended to complain of fatigue but not daytime sleepiness. Older adults complained of waking up too early, which the authors suggest may be related to a decreased drive to sleep and to changes in the circadian system that occurs with ageing. In younger patients, difficulty falling asleep was a more prominent symptom (Foley et al., 1995). Ohayon, Zulley, Guilleminault, Smirne and Priest (2001) however, found that age itself is not responsible for the increase of insomnia often reported in older people; but instead it is lack of activity, dissatisfaction with social life, and the presence of health disorders that better predicted insomnia. In their sample, the authors found that older people without health disorders had a prevalence of insomnia similar to younger populations, and that being active and satisfied with social life is a protective factor against insomnia at any age. On the other hand, Klerman and Dijk (2008) found that in the absence of social constraints, both daytime sleep tendency and the maximum capacity for sleep were reduced in older people in an inpatient setting, having factored in habitual sleep at home. Roth (2007) stated that age and gender are the most clearly identified demographic risk factors for insomnia, with an increased prevalence in women and older adults. Zee (2008) suggests that clinicians should be proactive in screening for sleep disorders such as insomnia in older patients, particularly as older populations are at an increased risk for comorbid medical and psychiatric conditions, important contributing factors for insomnia.

Gender

An epidemiological review by Ohayon (2002) demonstrated that women are more likely than men to report insomnia symptoms, daytime consequences, dissatisfaction with sleep, and have an insomnia diagnosis. This disparity grows as men and women reach middle age and older age, particularly at menopause and perimenopause. Jaussent et al. (2011) explored frequency of insomnia symptoms and found that more than seventy percent of men and women reported at least one insomnia symptom, difficulty

maintaining sleep being the most prevalent symptom in both men and women. Women reported two or three insomnia symptoms more frequently, whereas men reported only one. The authors suggest that women may have specific predisposing factors for multiple insomnia symptoms, which may involve both behavioural and hormonal factors, and that identification and treatment of these risk factors may form the basis of interventions to reduce insomnia symptoms.

Ethnicity

There is limited research on culture or ethnicity and insomnia. Evidence so far suggests that there are differences in health-related quality of life and sleep among ethnic minority and non-minority groups with insomnia symptoms, with ethnic minority groups tending to have poorer physical health generally (Baldwin et al., 2010). Goodin, McGuire and Smith (2010) found that lower perceived social status is related to greater impairment in sleep quality for Asians and African Americans, but not for Caucasians. Furthermore, a meta-analysis (Ruiter, DeCoster, Jacobs & Lichstein, 2010) found that African Americans have a higher prevalence and greater severity of sleep-disordered breathing, but Caucasian Americans report more insomnia symptoms. Most recently, insomnia was reported to be more prevalent in minority racial and ethnic groups (Kaufmann et al., 2016). Ethnicity should therefore be considered in exploring and treating insomnia.

Employment

Linton and Bryngelsson (2000) found, as other research has shown, that poor sleep was linked to absenteeism, employment status, work hours, and the psychosocial work environment. Moreover, poor sleep was associated with reduced work capacity such as reduced concentration, listlessness, and difficulties in making decisions. However, not being employed also increased the risk for sleep problems. The authors therefore concluded that there is a reciprocal link between sleep and work. Perceived work stressors have since been linked to the development and maintenance of insomnia (Jansson & Linton, 2006). Henry, McClellan, Rosenthal, Dedrick and Gosdin (2008) explored the role of work in patient narratives about their insomnia experiences, and found links between sleeplessness and modern working lifestyles, in which work seemed to go beyond the physical workplace. Participants often cited work as the main cause of their insomnia, the primary reason for needing to sleep well, the reason for seeking medical assistance, and as an impact on how they complied with a medicine regimen. Vedaa et al. (2016) investigated the reciprocal relationships between personality traits, lifestyle factors, mental health, and work-related stressors against insomnia, and their results suggested that insomnia more often emerges as a

consequence of individual and work-related factors rather than as a precursor. The authors suggest that insomnia should be considered in prediction models for mental illnesses and as an outcome of adverse work-related experiences, which echoes the bilateral link that Linton and Bryngelsson (2000) suggested.

The 'information generation'

Health and science news stories can have a widespread influence on public health (Sumner et al., 2014), and insomnia now regularly hits the headlines. There appears to be an increasing awareness of sleep problems, including insomnia, alongside the rising prevalence. However, understanding how audiences engage with media, whether it is informational, educational or a mixture of these, needs to be better understood (Attwood, Barker, Boynton & Hancock, 2015), especially if mis-information could fuel unhelpful myths, beliefs and perceptions. On the other hand, the media has the potential to help educate and shape public knowledge and perception, whilst also correcting mis-information (Carducci, Alfani, Sassi, Cinini & Calamusa, 2011; Goodfellow, Almomani, Hawwa & McElnay, 2013). Phillips (2011) suggests that increasingly patients are using social media to seek help, find information and link up with people with similar concerns. He suggests that this can increase levels of activation or self-management. In the case of quantity of media-based health information, large amounts have been positively associated with health decision-making and medical advice-seeking behavior, which can serve as an influential cue to action in certain populations (De Jesus, 2013).

Recent work building upon smart phone applications or web-enabled pedometer and actigraphs such as the FitBit (<http://www.fitbit.com/>) that provide 24-hour sleep-wake activity monitoring and personalised feedback on basic sleep parameters are increasingly popular (Vitiello, McCurry & Rybarczyk, 2013), and may assist in individuals perception of how they sleep versus how they actually sleep. However, as one of the key features of insomnia is increased arousal or focus on not being able to sleep, this further focus on sleep could be detrimental. Future research is needed to explore whether the knowledge of current generations, and increased awareness through social media and other channels, is unearthing a problem that has always been there, or whether we are simply more switched on to our health and the need for quick fixes in current times.

Cognitive Behaviour Therapy for insomnia (CBT-I)

Mechanisms underlying insomnia are unclear. However there is general agreement that the condition is perpetuated by a variety of cognitive and behavioural factors (Edinger & Means, 2005). Typically people complain of a racing mind and get into a cycle of poor sleep, which can lead to them having concerns about poor sleep, which then leads to patterns of thoughts and behaviour that maintain the cycle (Robatham, 2011). People can make misattributions about the causes of insomnia, develop misconceptions about sleep needs and the effects of sleep loss, have concerns about the consequences of poor sleep, and dysfunctional beliefs about sleep promoting practices. These cognitions encourage disruptive sleep habits and responses that can interfere with sleep or serve as behavioural blocks to sleep (Edinger & Means, 2005).

As a result, a number of interventions have been developed to directly target aspects known to impact upon sleep pattern, sleep quality and daytime functioning. Many of these interventions have been based on Cognitive Behaviour Therapy (CBT). CBT is a talking therapy that explores how someone thinks about themselves, the world and other people, as well as how what they do affects their thoughts and feelings. CBT can help to change how someone thinks (cognitive) and what he or she does (behaviour), in order to feel better. Unlike other therapies which focus on the causes of distress or symptoms in the past, CBT focuses on present problems and difficulties, and looks for ways to improve state of mind now (Royal College of Psychiatrists, 2013).

CBT arose from behaviour therapy (BT) (Wolpe, 1958) and cognitive therapy (CT) (Beck, 1963; 1964). Behaviourists looked for associations between observable events and responses, applying learning theory to explain how new behavioural and emotional associations were made, and how these could be modified (Westbrook, Kennerley & Kirk, 2013). In order to factor in mental processes such as thoughts and beliefs, cognitive therapy became increasingly significant during the 1970s, particularly following Beck et al's book on cognitive therapy for depression (Beck, Rush, Shaw & Emery, 1979). Over the following years, the two therapies developed together and influenced each other to such an extent that CBT as an approach emerged (Westbrook, Kennerley & Kirk, 2013).

CBT proposes that cognitions determine someone's interpretation of an event and emotional reaction, not the event itself. Different cognitions give rise to different emotions; therefore by helping people change their cognitions, they can be supported to change the way they feel (Westbrook, Kennerley & Kirk, 2013). The behavioural

principle applies in terms of maintaining or changing psychological states. Therefore CBT believes that behaviour can have a strong impact on thought and emotion, and by changing what you do, thoughts and emotions can be changed in a powerful way. Mental health problems are therefore conceptualised as exaggerations of normal processes rather than pathological states (Westbrook, Kennerley & Kirk, 2013).

Padesky and Mooney (1990) developed a model to explain how the elements of cognition, emotion, behaviours and physiology interact with each other and the environment, see Figure B1. By breaking these elements down in more detail, it is possible to determine where the unhelpful interactions arise, question the assumptions behind thoughts, and therefore target specific aspects of a problem.

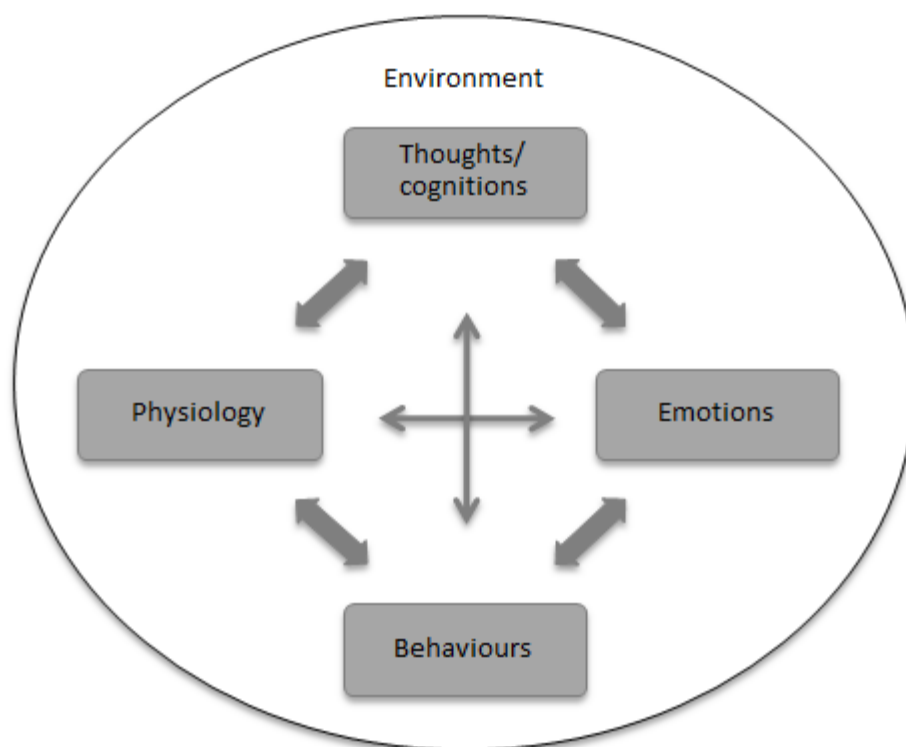


Figure B1: Adapted from Padesky and Mooney (1990)

CBT has been evidenced to be efficacious in treating depression, panic, agoraphobia, generalised anxiety disorder, specific phobias, social phobia, obsessive-compulsive disorder, post-traumatic stress disorder, bulimia, and some personality disorders (Roth & Fonagy, 2005). There is also evidence demonstrating the effectiveness of CBT from the National Institute for Health and Clinical Excellence (NICE), which has produced guidelines on the use of CBT for schizophrenia (NICE, 2009a), depression (NICE, 2009b), bulimia (NICE, 2004a), generalised anxiety disorder and panic (NICE, 2004b), obsessive-compulsive disorder and body dysmorphic disorder (NICE, 2005).

Approximately forty percent of adults with insomnia also have a diagnosable psychiatric disorder, most notably depression; and a comorbid psychiatric disorder such as depression or anxiety may be a consequence of as well as a risk factor for disrupted sleep (Roth, 2007). Typical cognitions in depression are negative views about oneself, the world in general, and the future, alongside loss of pleasure in activities that can lead to changes in behaviours. A wide range of biological, psychological and social factors can also have a significant impact on the course of depression and response to treatment (NICE, 2009b). The focus of CBT on what is happening in the present, and the processes that are maintaining the problem, rather than the processes that might have led to its development (Westbrook, Kennerley & Kirk, 2013), is effective for depression (2009b), as well as the overestimation of threat or unwanted outcomes and excessive worry in anxiety presentations and associated behaviours (NICE, 2004b).

CBT for insomnia (CBT-I) has also developed as a brief, focused and multimodal intervention (Morin & Espie, 2003; Edinger & Means, 2005; Edinger & Carney, 2008), which has the objective to change factors that perpetuate insomnia, including behavioural factors (e.g. poor sleep habits, irregular sleep schedules), psychological factors (e.g. unrealistic expectations, worry, unhelpful beliefs), and physiological factors such as tension (Morin & Benca, 2012). Thoughts and feelings about sleep play a large role in perpetuating insomnia (Harvey, 2002), and people with chronic insomnia often associate sleep and bedtime with a range of negative thoughts and feelings.

The most common cognitive-behavioural therapies for insomnia are: sleep education and sleep hygiene, stimulus control, sleep restriction, relaxation training, and cognitive therapy; and most clinical practice adopts a multicomponent approach to treatment (Espie et al., 2007; Perlis, Jungquist, Smith & Posner, 2008; Espie & Kyle, 2009; Perlis, Aloia & Kuhn, 2011). These components have been shown to not only improve sleep, but also daytime functioning and health-related quality of life (Espie & Kyle, 2009).

Sleep education and sleep hygiene

Sleep education and sleep hygiene is recommended for both sleep initiation and maintenance problems. It is a psychoeducational intervention, aimed to address a variety of behaviours that may influence sleep quality and quantity (Perlis et al., 2008). Interventions may include learning about normal sleep processes (e.g. the need for sleep and its functions and sleep patterns across the lifetime), and sleep disorders (e.g. factors that adversely affect sleep pattern and sleep quality, the effects of sleep loss and the concept of insomnia). Practical steps towards developing a healthy sleep

pattern without medication may also be introduced, e.g. creating a bedroom environment that is comfortable for sleep, sticking to a healthy diet and regular physical activity, reducing caffeine, nicotine and alcohol consumption (Espie et al., 2007).

Stimulus Control Therapy (SCT)

Stimulus Control Therapy is also recommended for both sleep initiation and maintenance problems. The principle underlying stimulus control is that sleep will come more quickly and it will be easier to stay asleep if the mind and body can respond to the cue of the bed and bedroom. For good sleepers, pre-bedtime and the environment trigger positive associations of sleepiness and sleep. For the poor sleeper, however, the bedroom triggers associations with restlessness and nighttime waking via a stimulus-response relationship, thereby continuing to promote wakefulness and arousal (Espie & Kyle, 2009). Treatment involves removing all stimuli that are potentially incompatible with sleep from the bedroom, such as reading and watching television, whilst sleeping is excluded from living rooms and the daytime, for e.g. napping. In addition, wakefulness is excluded from the bedroom, and the individual is instructed to only go to bed when sleepy, and get up if not asleep within fifteen to twenty minutes or if wakeful during the night (Espie & Kyle, 2009). It is recommended that patients keep a fixed wake time seven days a week, irrespective of the amount of sleep obtained. The intention of SCT is to strengthen the association between the bed or bedroom or bedtime with rapid, well-established sleep (Perlis et al., 2008).

Sleep Restriction Therapy (SRT)

Sleep Restriction Therapy, or sleep scheduling, is also recommended for both sleep initiation and maintenance problems. It involves recording a baseline sleep diary and calculating average nightly sleep duration. The aim is then to obtain this average each night, which restricts sleep to the length of time that an individual is likely to sleep, and improves sleep efficiency (Espie & Kyle, 2009). Sleep efficiency is the ratio of time asleep to time in bed, and it can be improved either by increasing total sleep time or by reducing time in bed. People with insomnia generally seek the former, but this may not be necessary, either biologically or psychologically. SRT is mostly indicated when sleep efficiency is less than eight-five percent in adults, or less than eighty percent in older adults (Spielman, Yang & Glovinsky, in Perlis et al., 2011). The goal of increasing total sleep time is achieved by setting a fixed rising time each day, and delaying going to bed until a fixed time, which allows this designated amount of sleep. Thus, the sleep period is reduced and sleep efficiency is likely to increase (Espie & Kyle, 2009). Progress can then be measured week by week and time in bed or asleep increased in fifteen-minute increments in response to sleep efficiency improvements (Espie & Kyle,

2009). Therefore, as treatment continues through adjustments to time in bed, a balance is sought whereby improved daytime functioning is restored while sufficient sleep quality is maintained (Spielman et al. in Perlis et al., 2011).

SRT is thought to be effective as: it prevents patients from coping with their insomnia by spending longer in bed which, whilst increasing the opportunity for sleep, produces sleep that is shallow and fragmented; and the initial sleep loss that occurs is also thought to increase the homeostatic pressure for sleep, which in turn helps patients to fall asleep quicker (sleep onset latency), wake less in the night (wake after sleep onset), and increase sleep efficiency (Perlis et al., 2008). However, the increased drive for sleep produced by SRT, especially at the start of treatment, will make patients sleepy and certain individuals should not engage in SRT. Side effects such as fatigue, irritability, memory or concentration impairments may become intolerable, and therefore willingness and adherence to the regime, alongside the associated benefits, may be negatively impacted (Spielman et al. in Perlis et al., 2011).

Relaxation therapy

This type of intervention may be most suitable for patients that describe their insomnia as an inability to relax and/or for patients with multiple comorbidities (Perlis et al., 2008). Relaxation is more effective for sleep initiation than sleep maintenance, and requires regular practice for therapeutic benefit (Lichstein, Taylor, McCrae & Thomas, in Perlis et al., 2011). There are a wide range of relaxation methods including progressive muscle relaxation to reduce tension, diaphragmatic breathing to induce slower deeper breaths, developing a pre-bed relaxation routine, imagery training, and meditation (including yoga and mindfulness) (Perlis et al., 2008; Espie & Kyle, 2009).

Cognitive therapy

This type of intervention targets preoccupation with the potential consequences of insomnia or the complaint of unwanted intrusive thoughts or worries. Helping individuals to challenge negative thoughts and beliefs about their condition and its consequences is thought to decrease the anxiety and arousal associated with insomnia (Perlis et al., 2008). In addition, cognitive therapy targets thoughts that may prevent sleep onset, through activities such as spending fifteen to twenty minutes in the early evening to reflect on the day and plan ahead for the next (Espie & Kyle, 2009). Cognitive therapy also includes specific strategies based on paradoxical intention and cognitive restructuring. Compared with someone with insomnia, good sleepers do not really think about sleeping, or do anything in particular to help themselves sleep (Espie, in Perlis, 2011). Paradoxical intention techniques allow sleep to occur naturally through

attempting to remain awake rather than attempting to fall asleep. Other techniques include thought suppression and attempting to interrupt the flow of thoughts (Espie & Kyle, 2009). Cognitive restructuring is the process of identifying negative or unhelpful thinking styles or beliefs, and testing these against evidence and real-life experience, allowing learning of alternative responses (Espie & Kyle, 2009). The technique is appropriate for an excessive focus on thoughts and beliefs related to misattributions about insomnia and the consequences of sleep disturbance or sleep loss (Espie & Kyle, 2009; Perlis & Gehrman, in Perlis et al., 2011).

Current treatment practices for insomnia

Research has shown that CBT-I is a highly effective treatment for insomnia, and that the beneficial effects are known to persist for months or years after the treatment course is completed (Espie & Kyle, 2009). A recent systematic review and meta-analysis confirmed this still to be the case, finding significant alleviation of symptoms and showing efficacy over time (Trauer, Qian, Doyle, Rajaratnam & Cunnington, 2015). However, despite evidence to support CBT as an intervention for insomnia, the overwhelming majority of insomnia patients in routine practice are treated with medication, even though this is not evidence-based for chronic insomnia (Espie & Kyle, 2009).

NICE guidance only currently exists on the use of hypnotic medication for the short-term management of insomnia (2004c). Hypnotic drugs are used to induce sleep and can therefore provide relief from the symptoms of insomnia. However, they do not treat any underlying cause and can have sedative effects into the next day, tolerance, dependence and withdrawal symptoms (NICE, 2004c). NICE therefore state that if a medicine is considered to be the most appropriate way to treat severe insomnia that is interfering with normal daily life, this should be prescribed only for short periods of time and strictly according to the licence for the drug. The guidance also states that non-medical interventions (e.g. cognitive behavioural therapies) have been shown to be effective in the management of insomnia. However access to many therapeutic interventions is restricted through a combination of a lack of trained providers, cost and a poor understanding of available options. The guidance therefore acknowledges that insomnia is generally not well managed and medication is commonly prescribed for minor degrees of insomnia and for long periods, which can increase the likelihood of dependence. The guidance was last updated in 2004.

Morgan, Dixon, Mathers, Thompson and Tomeny (2004) evaluated the clinical outcomes and cost impact of providing a CBT-I package to long-term hypnotic medication users with chronic sleep difficulties in routine general practice settings. The authors found that psychological treatment for insomnia can improve sleep quality, reduce hypnotic medication use, and improve health-related quality of life at a favourable cost among this group. These positive outcomes appeared robust over time, persisting for at least one year among the more treatment-adherent patients.

Morin et al. (2009) found that in patients with chronic insomnia, the addition of medication to CBT produced added benefits during acute therapy, but long-term outcome was optimised when medication was discontinued during maintenance CBT. The authors discuss the advantages of combining the rapid action of medication and the durability of CBT, versus the disadvantages of undermining compliance with CBT and the development of beneficial self-management skills, the risk for attribution of sleep improvements to medication alone, and the risk of dependency on medication. It was therefore suggested that CBT should be considered first, then if no response to add medication with ongoing review. In a follow-up study, Morin et al. (2014) considered the speed and trajectory of changes during short-term treatment of insomnia with CBT versus CBT combined with medication, and found that adding medication to CBT produced faster sleep improvement than CBT alone. However, the extent of early treatment response was not predictive of final response after the six-week therapy. The authors suggested that additional research is needed to examine the mechanisms involved.

A recent systematic review also concluded that CBT-I is effective for treatment for insomnia when compared to medication, and its effects may be more durable than medication. The review therefore recommended that primary care providers should consider CBT-I as a first-line treatment option for insomnia (Mitchell, Gehrman, Perlis & Umscheid, 2012). However, there are gaps between this evidence and current treatment practices.

Help-seeking behaviours and GP management practices

Perceived impact on daytime functioning appears to serve as an important factor in driving help-seeking behaviour among individuals with insomnia, rather than simply perceived sleep loss. Carey, Moul, Pilkonis, Germain and Buysse (2005) found that daytime symptoms, such as fatigue, irritability, and decreased performance, are often

described as more impactful than sleep difficulties when reporting problems associated with insomnia. Morin, LeBlanc, Daley, Grégoire and Mérette (2006) agreed, and reported that that four out of five of the most commonly cited reasons for seeking a sleep-related consultation with a health professional were daytime consequences of fatigue, psychological distress, physical discomfort, and reduced work productivity. This indicates that once a threshold of noticeable impact on daytime functioning is reached, individuals feel motivated to seek medical advice.

However, few individuals with insomnia actually seek professional help (Morin & Benca, 2012). A UK study found that sixty-three percent of participants with baseline insomnia and psychological distress had not made use of relevant health care (defined as a GP consultation for anxiety, depression, or insomnia or prescription for anti-depressant, anti-anxiety or hypnotic medication) after one year (Hayward, Jordan & Croft, 2010). The Great British Bedtime Report (The Sleep Council, 2014) found that forty-nine percent of respondents had never taken steps to improve their sleep, even though thirty-two percent admitted that they slept poorly. The Report revealed that one in ten people had consulted their GP about their sleep, but three times this number had taken medication or over-the-counter remedies in an attempt to relieve the problem. However, people with severe sleep problems, such as insomnia, were prepared to ask for help, with forty-two percent asking their GP for help, fifty-one percent having taken medication and forty-one percent having tried over-the-counter remedies.

The determinants of help-seeking behaviour are complex, and health provider support variable, so often people choose interventions to treat themselves, including supplements, over the counter medications, and complementary and alternative medicine (Morin et al., 2006). Stinson, Tang and Harvey (2006) found that the most commonly endorsed reasons for not seeking treatment in the UK were the perception of insomnia as benign, trivial, or a problem that someone should be able to cope with alone, or that will resolve spontaneously. Other factors affecting help-seeking behaviour include lack of awareness of treatment options and the perception of the available treatment options being ineffective and unattractive. Henry, Rosenthal, Dedrick and Taylor (2013) explored beliefs and behaviours surrounding insomnia, particularly those related to self-diagnosis, management, and self-treatment. They identified barriers to seeking help involving general social stigma and personal isolation, where sleep problems were not taken seriously. However, the study also found that lack of awareness of treatment options was a reason for consultation, and that individuals would still find some effectiveness in options at certain times and situations, which is in contrast to Stinson et al. (2006). They would still seek treatment,

but then supplement with information from different sources such as the Internet, friends, family and work colleagues.

Morin (2014) also stated that individuals with insomnia do not seek professional treatment for fear of stigma and rely on passive strategies such as reading and relaxation due to lack of knowledge and information about treatment options. Morin (2014) described the frequent first line of active treatment as involving natural, herbal or dietary products, alongside over the counter drugs, and alcohol. When professional help is sought, treatment often involves medication such as sedating anti-depressants, rather than a hypnotic medication, as recommended by NICE guidelines (2004c).

Issues of appropriateness and effectiveness of hypnotics remain. Siriwardena, Qureshi, Dyas, Middleton and Ørner (2008) found that ninety-five of participants in their study had taken hypnotic medication for four weeks or more, forty-five percent had been advised to continue treatment for a month or more, and a further forty-two percent had not been advised on duration. Ninety-two percent were on repeat prescriptions, and over eighteen percent wanted to stop their medication.

Research regarding GP management preferences for sleep problems (Siriwardena et al., 2010) has found that GPs were negative in attitude towards hypnotic medication and positive towards reducing prescribing for sleep problems. However, they acknowledged that they needed to develop resources and better strategies for assessment and non-medical management of patients presenting with insomnia for the first time as well as those on long-term medication. The same researchers also looked at patient and clinician's experiences of consultations regarding insomnia (Dyas et al., 2010). As other research has shown, patients often tried to resolve their insomnia themselves, only seeking help when their symptoms became unmanageable. On seeking help they reported feeling that they needed to convince practitioners of the seriousness of their difficulties, and the impact it was having on their life, rather than exploring the possible underlying causes of their insomnia. Many patients expected a prescription, and practitioners assumed this was what patients' wanted, thinking non-medicine treatments would not be accepted. There was also an expectation that patients would be resistant to stopping sleep medication if they were already taking it, although patients were often open to alternatives. Therefore, eliciting and understanding patient preferences and expectations appears key to successful management of insomnia, with educational support for practitioners around strategies to enable this.

Similar findings emerged from a study by Davy, Middlemass and Siriwardena (2015), where practitioners described providing stepped care for insomnia focusing on sleep hygiene, which patients often disregarded, rather than CBT-I. There was a focus on treating the cause of insomnia rather than the insomnia itself, and practitioners were ambivalent towards hypnotic medication but often colluded with patients to prescribe to *“avoid confrontation or express empathy”* (2015: 1371). Despite this, in addition to taking hypnotic medication, patients sometimes took over the counter medication. The authors concluded that both patients and practitioners needed help to better understand current approaches and options in primary care. A further study by Everitt et al. (2014) found that GPs often find sleep hygiene advice insufficient and frequently prescribed medication based on perceived patient pressure for a prescription. GPs reported a lack of knowledge and confidence in the provision and use of psychological therapies such as CBT, and therefore rarely offered this to patients, despite the evidence for its potential effectiveness.

Cheung, Bartlett, Armour, Glozier and Saini, B (2014) carried out a study to explore help-seeking experiences and behavioural patterns of patients with insomnia who were seeking or receiving specialist care. They identified three key themes, namely patients' sleep beliefs around the causative factors of their insomnia, treatment beliefs that they would be offered limited options such as sleep hygiene advice or medication, and relief at accessing specialised care after unsuccessful treatment attempts. There were some concerns among patients with no psychological comorbidities that this specialised care fell under the medical specialty of mental health, as participants did not see the relevance of mental health for a problem that they believed was purely related to their sleep. As previous research has shown, increasing daytime symptoms from insomnia functioned as important reasons for patients to seek medical help.

Morin and Benca (2012) stated that insomnia is often unrecognised and untreated because of barriers to assessment and management, including time and scarce availability of clinicians with CBT skills. Morin (2014) confirmed that health care providers may have a lack of training and understanding of treatments, alongside assigning a low priority to insomnia. Patient preference and compliance also play a part, as not everyone is willing to take medication or comply with behavioural recommendations (Morin, 2014). As a result, the majority of patients with insomnia remain untreated and CBT is under utilised by health care practitioners. There are also practical problems in making CBT widely available despite recommendations for CBT relative to medication for chronic insomnias (Lamberg, 2008; Espie and Kyle, 2009). As

with many chronic health conditions, it appears that the translation of research to clinical practice can be challenging.

Stinson et al. (2006) suggested that programmes of public health awareness designed to reduce the perception of insomnia as trivial and to increase awareness of the effective treatments available might be important for reducing the prevalence of insomnia in the UK. Espie (2014) agreed that the primacy of sleep and circadian function in health and well-being across the lifespan needs to be recognised, alongside a focus on sleep as a topic of fundamental importance to public health and to society.

Improving access to CBT-I

CBT itself is considered adaptable across a range of disorders, and in the UK, stepped care forms the basis of the need to increase access to psychological therapies, and therefore the ongoing development of Improving Access to Psychological Therapies (IAPT) services in mental health commissioning (Department of Health, 2007).

Alongside improving access, services need to be able to provide the most effective psychological interventions available that are appropriate to meet the needs of the local population. The stepped care approach therefore provides the responses and treatments required from services for those with mental ill-health at different levels of need; and the aim is *“to provide patients with the most cost effective and appropriate treatment, in the least invasive manner, as close to home as possible”* (Department of Health, 2007: 11). The talking therapy treatments are recommended in the guidelines issued by NICE, and offer people a realistic and routine first-line treatment, combined where appropriate with medication. Although treatments vary according to the individual, an individual would usually start with the least intensive treatment that offers a reasonable chance of success, and, if necessary, should then ‘step up’ to a more intensive treatment (Department of Health, 2007: 11).

Van Stratan and Cuijpers (2009) point out that the amount of evidence for CBT in the treatment of insomnia makes it difficult to ignore, and agree that it would appear that fitting such therapies into clinical practice for insomnia also relies upon employing a *“stepped care approach”* (2009: 69). The authors suggest that only the most severe cases of chronic insomnia need to be treated by a specialist sleep practitioner. The majority of people who are suffering from poor sleep therefore might benefit from simple, non-intrusive methods based upon the principles of CBT, and that this would be far more efficient in terms of health spending (van Stratan and Cuijpers, 2009).

Espie (2009) also proposes that a stepped care model would enable CBT-I to be applied in an efficient way to achieve development of insomnia services for patients presenting with varying levels of insomnia severity and complexity, as well as providing best clinical care. Espie (2009) proposed a five level hierarchy, with ongoing assessment of need determining the level required, and increasing resource requirement in terms of time, cost and expertise – see Figure B2.

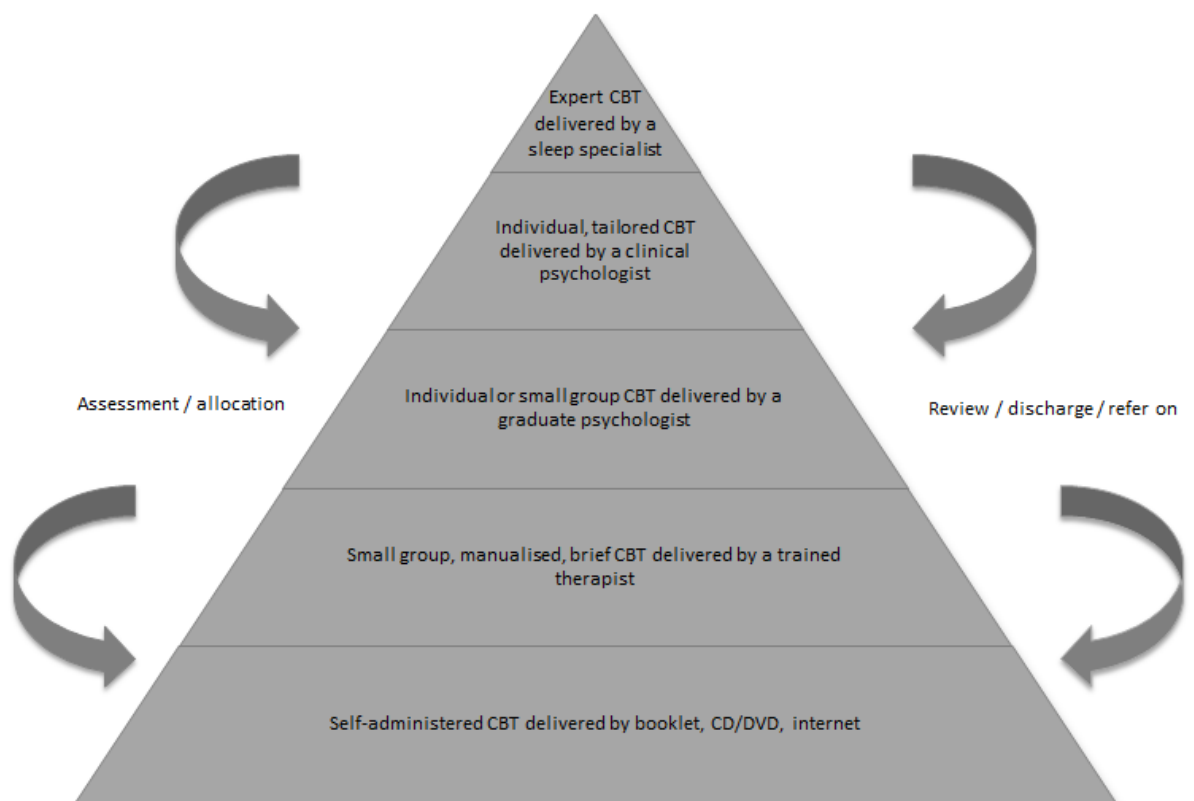


Figure B2: Adapted from Espie (2009)

The first step needs to be evidence-based and cost-effective to benefit a substantial proportion of patients without risking adverse effects. Self-administered CBT delivered by booklet, DVD or Internet is suggested as the least restrictive entry-level treatment with acceptable outcomes, with manualised small group CBT delivered by a trained therapist such as a nurse or other professional at the next step. This is followed by individual or small group CBT at the third step, delivered and tailored to needs by a graduate psychologist. The fourth step is individual, tailored CBT delivered by a clinical psychologist or psychologist who has extensive generic training in CBT that could be applied to insomnia. Finally the fifth step is expert CBT delivered by a behavioural sleep medicine specialist, working with individual complex cases at a sleep centre. Espie (2009) suggests that the three lowest levels might be best provided in primary

care, and, depending on local service provision, it might be possible to also deliver the fourth level in primary care. The fifth level is likely to be delivered in a specialist sleep centre. Espie (2009) also suggests that whilst evidence-based treatment for insomnia includes both CBT and medication, medication for insomnia can be accommodated within the stepped care approach if required. This is as a result of the approach not influencing clinical practice in one direction or another.

However, it is emphasised that for such a stepped care system to work on a large scale, a range of common, validated and simple tools for initial assessment would need to be used to assess needs and direct treatment, and then review post intervention. Espie's (2009) article highlights the clinical governance issues relating to a stepped care model and suggests that clinical psychology professionals are best placed to safely and effectively oversee such practice. However, he also recommends that work exploring the advantages to patient care of developing an inter-disciplinary approach to behavioural sleep medicine practice should take place, in order to make the most of time and resources across professional groups.

Others have focussed on how to broaden the provider base so that clinicians other than clinical psychologists provide CBT-I, and increase CBT-I treatment accessibility, still within a stepped care model (Manber et al., 2012; Fields, Schutte-Rodin, Perlis and Myers, 2013). These authors suggest that multiple pathways for disseminating CBT-I training are needed, including expansion of standardised training within nursing, medical, psychology, social work, and postgraduate programmes. This training would need to be tailored to the training participants' backgrounds, experiences, knowledge and disciplines, clinical settings, and patient populations whilst fitting with professional obligations. The fact that CBT has emerged as a key treatment for insomnia may also impact how people perceive their insomnia. If treatment is more readily available in a stepped care model and through a range of providers, this may help to alleviate the patient concerns identified by Cheung et al. (2014), that the best treatment for insomnia is based in psychological rather than physical therapy.

Siriwardena et al. (2009) designed a pilot randomised controlled trial to evaluate the effectiveness of an educational intervention for general practitioners, primary care nurses and other staff in the primary care team. The aim was to provide problem-focused therapy comprising assessment and use of modified CBT-I compared with usual care to patients with sleep problems. This work is still continuing as the Resources for Effective Sleep Treatment (REST) project. This project aims to improve treatment for people suffering with sleep problems by promoting a range of treatment

options. A multimedia e-learning package is available, which takes up to two hours to complete, and is designed for health professionals working in primary care.

O'Sullivan, Rahim and Hall (2015) ascertained the extent to which clinical staff understood a diagnosis of insomnia in a UK mental health secondary care service. The study highlighted inadequacies in provision of evidence-based interventions for sleep difficulties. The authors recommended that clinicians should be trained in: the effective identification of insomnia and in the provision of evidence-based interventions; provision of high volume cost-effective transdiagnostic group psychological interventions, such as day-long workshops and rolling four-week groups; and formalising assessment and treatment pathways for service users with sleep difficulties alongside evaluation of effectiveness.

CBT-I formats

Since individual, face-to-face therapy with a sleep specialist is not always possible, or indeed essential from the above findings, research has looked at other formats and professionals for delivering CBT-I.

Self-help

Van Stratan and Cuijpers (2009), Bjorvatn, Fiske and Pallesen (2011), and Morgan, Gregory, Tomeny, David and Gascoigne (2012) suggest that self-help CBT-I, using printed materials, videos or internet-based programmes, offers a practical first-line treatment for people reporting insomnia symptoms in primary care as part of a stepped care model. Although these different self-help treatment delivery models can ease treatment access, it has been suggested that follow-up visits are often necessary in order to monitor progress, address compliance issues, optimise outcome and provide guidance and support (Morin & Benca, 2012). A meta-analysis of self-help CBT-I (Ho et al., 2015) supported this previous research, and found that self-help CBT improved sleep, sleep-related cognitions, and anxiety and depression symptoms, particularly with an added telephone consultation.

Psycho-educational workshops

Swift et al. (2012) suggest that another possible approach is to deliver CBT-I in a day-long psycho-educational workshop format. The authors developed workshops for up to thirty people, to which members of the public could self-refer, thereby creating an accessible intervention with a large capacity. They evaluated the effectiveness of these

workshops through a randomised controlled trial. Results indicated that CBT-I workshops appeared to be an accessible, clinically effective intervention for people with insomnia symptoms, as well as being an acceptable service to members of the public. The same group of researchers went on to assess the cost effectiveness of these workshops (Bonin, Beecham, Swift, Raikundalia & Brown, 2014) and found that community-based CBT-I workshops are likely to be a cost-effective intervention for improving symptoms of insomnia, that could be included in the range of low-intensity treatment options available within the UK as part of increasing access to psychological therapies.

Internet-based interventions

Following a number of studies demonstrating the potential of using the Internet to deliver CBT-I (Ström, Pettersson & Andersson, 2004; Ritterband et al., 2009; Vincent & Lewycky, 2009; Cheng & Dizon, 2012), Espie et al. (2012) set out to determine the effectiveness of a novel web-based CBT course delivered by an automated virtual therapist, when compared to a placebo. This research found that CBT delivered using a media-rich web application with automated support and a community forum is effective in improving the sleep and associated daytime functioning of adults with insomnia disorder. It is not known whether the community forum in itself had an effect, or whether results were maintained long-term, but the research provided evidence for a new and innovative approach to overcoming treatment access barriers, as well as achieving large treatment effects without clinician support. It has been well-accepted by the scientific community, with Ritterband and Thorndike (2012) describing it as one of the most rigorous trials to date, with the result being a programme which is visually appealing, tailored to the user and engaging, taking full advantage of the multimedia elements of the Internet. They do however point out the cost of developing, implementing and maintaining such a programme, although this is scaleable as participants increase.

Other recent studies have found support for sleep improvements through guided Internet-delivered CBT-I (Anderson, Goldsmith & Gardiner, 2014; van Straten et al., 2014; Kaldo et al., 2015) as well as reducing co-morbid psychological and fatigue symptoms (Thorndike et al., (2013). Zachariae, Lyby, Ritterbrand and O'Toole's (2015) systematic review and meta-analysis further confirmed the efficacy of Internet-delivered CBT-I, considering it a viable option in the treatment of insomnia as the effects were comparable to those found for face-to-face CBT-I. Research has also recently begun to compare Internet-based treatments with different modalities. De Bruin et al. (2014) assessed feasibility and efficacy of CBT-I in a pilot study for

adolescents in both group and Internet settings. The authors found significant improvements across both treatments, with no differences between the groups. They concluded therefore that CBT-I is an effective treatment for insomnia in adolescents in either group or Internet formats.

Blom et al. (2015) compared guided Internet-delivered CBT-I with group CBT treatment in a randomised controlled trial investigating treatment effects post-treatment and at six month follow up. This study also utilised clinical psychology masters students with theoretical and practical training in CBT, including at least twelve months of supervised practice in delivering one-to-one psychotherapy. Supervision for the study was provided by a clinical psychologist and CBT therapist, and a psychiatrist was available if necessary. The materials used in both the Internet-delivered and group sessions were the same. The authors found that the modalities were efficacious, with both treatment groups showing significant improvements in Insomnia Severity Index and sleep diary outcomes, additionally strengthening the evidence for Internet-delivered CBT-I as a viable treatment alternative.

Lancee, van Straten, Morina, Kaldò and Kamphuis (2015) also carried out a randomised controlled trial comparing three CBT-I interventions; guided online, individual and a wait list control. This research showed better outcomes for those in the individual treatment relative to the online treatment. However, results also suggested that online interventions might offer a cost-effective alternative due to surpassing the wait list control in insomnia severity scores, sleep diary estimates, and anxiety measures.

Small group CBT delivered by trained professionals

Espie et al. (2001) and Espie, Inglis, Tessier and Harvey (2007) investigated the clinical effectiveness of CBT-I delivered by primary care nurses, in a randomised controlled trial comparing group CBT-I in five (2007) or six (2001) weekly sessions to self-monitoring control. These nurses had to demonstrate competence in using a manualised therapy approach, having participated in a brief CBT course, ongoing mentoring by a clinical psychologist, and evaluation of audiotapes from therapy sessions. The sessions were delivered in routine medical practice. The studies found that CBT-I administered by nurses, with training and supervision, offered a clinically significant treatment for insomnia in primary care settings. Health-related quality of life improvements were also found in the domains of mental health and vitality. Improvements, however, were not maintained at six-month follow-up. Following on from this, the University of Glasgow Sleep Centre has since trained other health

professionals in psychological treatments in behavioural sleep medicine practice in order to be effective facilitators of this manual-guided therapy approach.

Bothelius, Kyhle, Espie and Broman (2013) carried out a randomised controlled study to investigate the clinical effectiveness of manual-guided CBT for insomnia delivered by four primary care nurses and one social worker in general medical practice in Sweden. The CBT group received manual-guided CBT in five small group sessions (60–90 minutes), with between four and six participants, using an adapted version of Espie et al's (2001) manual. The staff involved already had CBT training, but had an additional two days of training in how to use the manual. The CBT group improved significantly more than the waiting list control group using the Insomnia Severity Index and sleep diaries as outcomes. However, for all measures there was a significant deterioration at eighteen-month follow-up assessments. As this study included primary care patients who complained about sleep problems to their family doctor, and health care staff delivered treatment, the results can be generalisable to the population. However, the fact that the primary care staff had formal training in CBT before entering the study limits the wider value of the study, as it cannot be concluded that staff without previous knowledge in CBT would show the same results. Nonetheless, it does provide additional information for who could provide CBT-I treatment as part of a stepped care model.

Bothelius, Kyhle, Gordh and Fredrikson (2015) carried out further exploratory analysis on the 2013 baseline data to identify predictors for treatment success. The authors refer to Mack and Rybarczyk's (2011) paper, which suggests that in a stepped care approach, the individuals who do not benefit from one step should be offered a higher step on the treatment ladder, using a more tailored and more expensive treatment. However, Bothelius et al. (2015) point out that the credibility of the next treatment step might be compromised by the experience of having taken part in a similar, but non-effective, intervention. They further stated that if individuals were referred to the correct level of intervention from the start that this problem could be avoided. The authors therefore evaluated individually linked predictors for treatment success following their 2013 study and found that longer total sleep time at baseline assessment was the only statistically significant predictor for participants responding to treatment. They therefore concluded that sleep time may be important to consider before enrolling patients in low-end treatments, as strictly manual-guided treatments may be too inflexible for some individual differences. It may also be that individuals with short reported total sleep time need a completely different treatment approach. Number of sessions attended was also critical for treatment outcome, so it can be argued that it is important

to motivate patients to comply with the treatment, although this does not account for how well the individual patient actually complied with the treatment regime.

Individual or small group CBT delivered by psychologists

CBT has been typically delivered in the context of four to six therapy sessions at weekly intervals, although the number of follow-up visits can vary as a function of insomnia severity, comorbidity, and patient motivation (Morin & Benca, 2012). Bastien, Morin, Ouellet, Blais and Bouchard (2004) directly compared different treatment formats using a treatment manual (individual, group, or brief consultations over the telephone), delivered by clinical psychologists or supervised doctoral students in psychology with prior clinical experience. In this study, CBT-I did not lose its potency when delivered in a group format or delivered over the telephone. However, the authors concluded that there is not enough empirical evidence to say that individually administered CBT-I is significantly more effective than group-administered CBT-I, and that group CBT-I is more effective than self-help CBT-I. Verbeek, Konings, Aldenkamp and Declerck (2006), however, investigated group versus individual CBT treatment for individuals with insomnia and found that CBT for insomnia is effective for both individual and group treatment, with improvements seen in subjective sleep parameters, quality of life, attitudes about sleep and sleep evaluation in general.

A decade on and treatment variations are still being explored in order to meet the needs of patients with insomnia. Lovato, Lack, Wright and Kennaway (2014) explored the efficacy of a brief, group-based CBT-I treatment programme for older adults with chronic primary insomnia, compared to a waitlist control. The study found improvements across timing and quality of sleep, as well as reductions in insomnia severity, fatigue, anxiety, dysfunctional beliefs and attitudes, and increased sleep self-efficacy. The authors suggest that the four weekly sixty-minute programme, delivered in small groups, demonstrates potential for a brief, inexpensive and effective treatment for insomnia in the older adult population.

Recently Ellis, Cushing and Germain (2015) explored the efficacy of a single sixty to seventy minute session of CBT-I with an accompanying self-help booklet for people with acute insomnia. This randomised controlled trial found that participants in the intervention group reported significantly lower insomnia severity scores compared to the control group at follow up. The authors concluded that this single session of CBT-I is sufficiently efficacious to be considered as a brief form of CBT-I in the stepped care model of insomnia.

The research into CBT-I formats has significant implications for the proposed stepped-care model of insomnia treatment, because it supports the view that some patients might need little guidance and be manageable in primary care clinics (Morin & Benca, 2012), that using alternative treatment delivery models to improve access to CBT can be effective (Morin et al., 2006) and provides evidence that health professionals, other than sleep specialists, can successfully deliver CBT-I. A challenge for the future is therefore to disseminate evidence-based therapies to both patients and health care professionals.

Health-related quality of life

As research moves towards a more holistic view of patient care, the importance of including a wider psychosocial context across health conditions has been emphasised (Armstrong, Lilford, Ogden and Wessely (2007). Kyle et al's (2010) review specifically explored insomnia and health-related quality of life, considering both measurement and the impact of treatment. The authors report that measures for both quality of life and health-related quality of life are frequently used to assess outcomes of interventions, but that the terms are often used interchangeably. Kyle et al (2010) state that health-related quality of life better quantifies the impact of disease or illness on aspects of functioning, therefore is helpful in the context of insomnia. Specifically considering health-related quality of life in this review, the authors found that insomnia has a wide-ranging negative impact, and that interventions can improve physical, social and emotional functioning. They suggest that the future research agenda should include the comparison of different treatment modalities on health-related quality of life primary outcomes, alongside other measures that are relevant to the insomnia experience such as social, occupational and relationship functioning, within the same study. Vitiello et al. (2013) agree that although insomnia treatments consistently report statistically significant and reproducible changes on self-report and objectively measured sleep parameters, the bigger question is the extent to which these changes are considered meaningful in patient's lives. Like Kyle et al. (2010), Vitiello et al. (2013) propose that future research on CBT-I should focus on increasing treatment effectiveness and potential for translation into the community, with a particular focus on variants of CBT-I and alternative delivery modalities within primary healthcare systems, as well as increasing practitioner training and dissemination.

Bearing in mind the chief driver of treatment seeking reported to be impact on daytime functioning (Morin et al., 2006), further research support is required for evidencing

improvements in daytime functioning and quality of life (Kyle et al., 2010). Fortier-Brochu, Beulieu-Bonneau, Ivers and Morin (2010) agree and suggest that the assessment of daytime functioning ought to cover many aspects, including fatigue, physical health and mental health. Although it is helpful to consider both subjective sleep and daytime symptoms, Jansson-Fröjmark (2014) reported that very few clinical investigations have used instruments to explore dysfunction, despite functional impairment being considered a diagnostic feature of insomnia.

In addition, links between specific variables that may impact on daytime functioning should be explored, such as age, mental health problems, sleep onset, and sleep maintenance (Ustinov et al., 2010). Ustinov et al. (2010) reported that individuals' perceptions of their sleep were related to differences in their reported daytime functioning. This implies that reports of insomnia may be related to specific cognitive factors, such as depression and anxiety, which cause individuals to be more distressed with their sleep and increase their dissatisfaction with daytime functioning. The direction of this relationship it is not clear, however it highlights the need for treatment to address both sleep perceptions and quantitative assessment of sleep (Ustinov et al., 2010).

Further considerations

Edinger and Means (2005) state that the ultimate success of CBT depends on patients' willingness, ability, and motivation to learn and implement behavioural changes at home. This requires acceptance of CBT as a potential solution to their sleep difficulties, as well as adhering to recommendations by transferring skills learned to their day-to-day lives. Different people are likely to need different treatment approaches, and the more options available, particularly those that can be made widely available, the greater likelihood that those seeking help can obtain it (Ritterband and Thorndike, 2012).

Research objective

CBT-I has been shown to be effective. However there has been little research conducted which compares the efficacy of different treatment modalities on health-related quality of life alongside other measures related to patients' experience of insomnia such as daytime functioning, depression and anxiety. Treatments are not widely available or well understood. This study therefore compared the effectiveness of three UK CBT-I treatment delivery interventions, namely a manual-guided five-week group (Espie et al., 2001; 2007), a one-day workshop (similar to Swift et al., 2012) and an online programme (Espie et al., 2012), on key outcomes; insomnia severity, daytime functioning, health-related quality of life, beliefs and attitudes about sleep, anxiety and depression.

The secondary aim of the study was to explore participatory experience of patients in each intervention through the completion of a patient experience questionnaire (for all treatment completers), and semi-structured interviews from a purposive sample of one participant from each of the three interventions to form a case study for each intervention.

The primary objective was:

To compare the effectiveness of a manual-guided five-week group to a one-day workshop and an online programme, assessed by key outcomes, both across and between interventions.

- Key outcomes were - insomnia severity, beliefs and attitudes about sleep, depression, anxiety, daytime functioning and health-related quality of life, sleep diaries, and use of psychotropic medication, non-prescription drugs and alcohol.

The secondary objective was:

To understand the experiences of patients who participated in each intervention.

Hypothesis:

Given the effectiveness of the three CBT-I interventions already evidenced from previous research, it was predicted that there would be improvements in outcomes across interventions, with no significant differences between interventions. It was anticipated that this would contribute to evidence for choice and accessibility to a greater range of interventions in future, led by feedback from participant experience.

METHOD

The research was conducted at the Insomnia Clinic at The Royal London Hospital for Integrated Medicine (RLHIM), located within University College London Hospitals (UCLH) NHS Trust. RLHIM is the largest public sector provider of integrated medicine in Europe, combining complementary and alternative medicine treatments with conventional medicine. The Insomnia Clinic receives referrals from general practitioners, health professionals within UCLH/ RLHIM, other sleep disorder centres and specialists such as cardiologists or neurologists. There is an approximate forty-week wait for treatment from receipt of referral. Following assessment, all patients deemed appropriate are offered the standard treatment for insomnia at the clinic, which is the five-week manualised group programme devised by the University of Glasgow Sleep Centre (Espie et al., 2007). The psychiatry team and colleagues at RLHIM facilitate these groups, running approximately six groups a week, of eight participants per group.

The team have occasionally delivered a one-day workshop for patients who live a long distance from the hospital or who cannot attend the five-week group for other reasons. This has been based on the content of the five-week programme in order to form a full day of CBT-based psycho-education delivered as a group.

Design

The study used a mixed methods approach (Dures, Rumsey, Morris & Gleeson, 2011). This included a randomised controlled pilot study with three interventions, including the standard five-week group as the active control and a qualitative participant experience questionnaire. The study experienced some of the challenges often associated with 'real-life' research, namely participant drop-out and low follow-up response rates (see Figure B3). Due to these factors it was felt that an integration of a further qualitative aspect to the research would help gain perspectives and insights that could not be obtained through the use of a single approach. Therefore, an ethics amendment was applied for, in order to further investigate participatory experiences. Semi-structured interviews were conducted of a purposive sample of participants who had already completed their treatment, one from each of the three interventions, in order to form case studies.

The study was coordinated and interviews completed, by the author. The five-week group and one-day workshop interventions were delivered by the psychiatry team at the Insomnia Clinic at RLHIM, and access to the online programme was administered by the author. The author held an Honorary Research Contract with RLHIM and UCLH for the purposes of the research. Approval from the local Research Ethics Committee (REC) and Research and Development committees was obtained in May 2014. An application for ethics amendment was submitted in May 2016 and approval was given in June 2016.

Sample

Forty-nine participants who met the inclusion criteria were identified by the psychiatry team at Insomnia Clinic appointments. They were introduced to the research, and given the invitation letter and participant information sheet (see Appendix B1 and B2). Anyone interested in finding out more about the study were asked to complete an Initial Contact Consent Form that was transferred to the author (see Appendix B3). An additional seventeen participants were identified from the Insomnia Clinic waiting list and, of those successfully contacted, two were interested in participating following a conversation with the Lead Clinician. Three further participants were identified from internal referrals to the Insomnia Clinic.

Prior to the study it was anticipated that potential participants would be identified on receipt of referral at the Clinic and would be sent an invitation letter and information sheet with their initial appointment letter. If they were interested in participating, they would have the option of contacting the author directly or finding out more at their appointment. The identification of participants at their first appointment was planned as a secondary method of recruitment, but due to administration challenges the latter became the main method of identification. Giving the invitation letter and information sheet to patients waiting for appointments in the Clinic was discussed in the Clinic team, in order to introduce the study and promote the opportunity to ask questions in appointments, but this was not progressed due to lack of administrative support.

Sample size

Sample sizes between twenty-four and fifty have been recommended for pilot studies (Brown, 1995; Julious, 2005; Sim & Lewis, 2012; Billingham, Whitehead & Julious, 2013). Alongside these recommendations, calculations for this study were based on the clinic receiving approximately two-hundred annual referrals that would be

considered eligible. The aim for this study therefore was to recruit at least fifty participants within an anticipated six-month data collection period. However, this proved to be a considerable challenge as the number of eligible and interested participants was much lower than expected. The Lead Clinician reported that the majority of patients did not wish to participate, as they did not want to risk being randomised to the online programme. Many reported that they felt their insomnia was too serious a problem not to be dealt with in person at the clinic, and that they wanted the support of attending the clinic for motivation, having tried numerous self-help techniques before and wanting something different. A total of forty-nine participants were recruited over a period of twenty-three months from May 2014 to April 2016 (see Figure B3).

Of the forty-nine participants, one was excluded due to not being able to be contacted; twelve dropped out of treatment (three from the five-week group, three from the one-day workshop, six from the online programme), and five did not complete the follow up measures. Thirty-one participants therefore completed the whole process (see Figure B3).

Attrition

Of the three who dropped out of the five-week group, one chose not to continue after session one with no feedback given, one chose not to continue after session two with feedback (see Results) and one participant was uncontactable after allocation.

Of the three who dropped out of the one-day workshop, one was not contactable after allocation, one was not able to make either of the two workshops offered due to work commitments, so chose to opt out and go on the standard clinic wait list instead, and one left halfway through the workshop with feedback given to the facilitator (see Results).

Of the six who dropped out of the online programme, one was not contactable after allocation and did not complete outcome measures, one was uncontactable after allocation but completed initial outcome measures, one completed outcome measures and registered on the programme, but did not start it and was then uncontactable. A further two participants opted out after starting the programme with feedback (see Results) and one moved out of the UK and expressed a wish to start once settled but never did so.

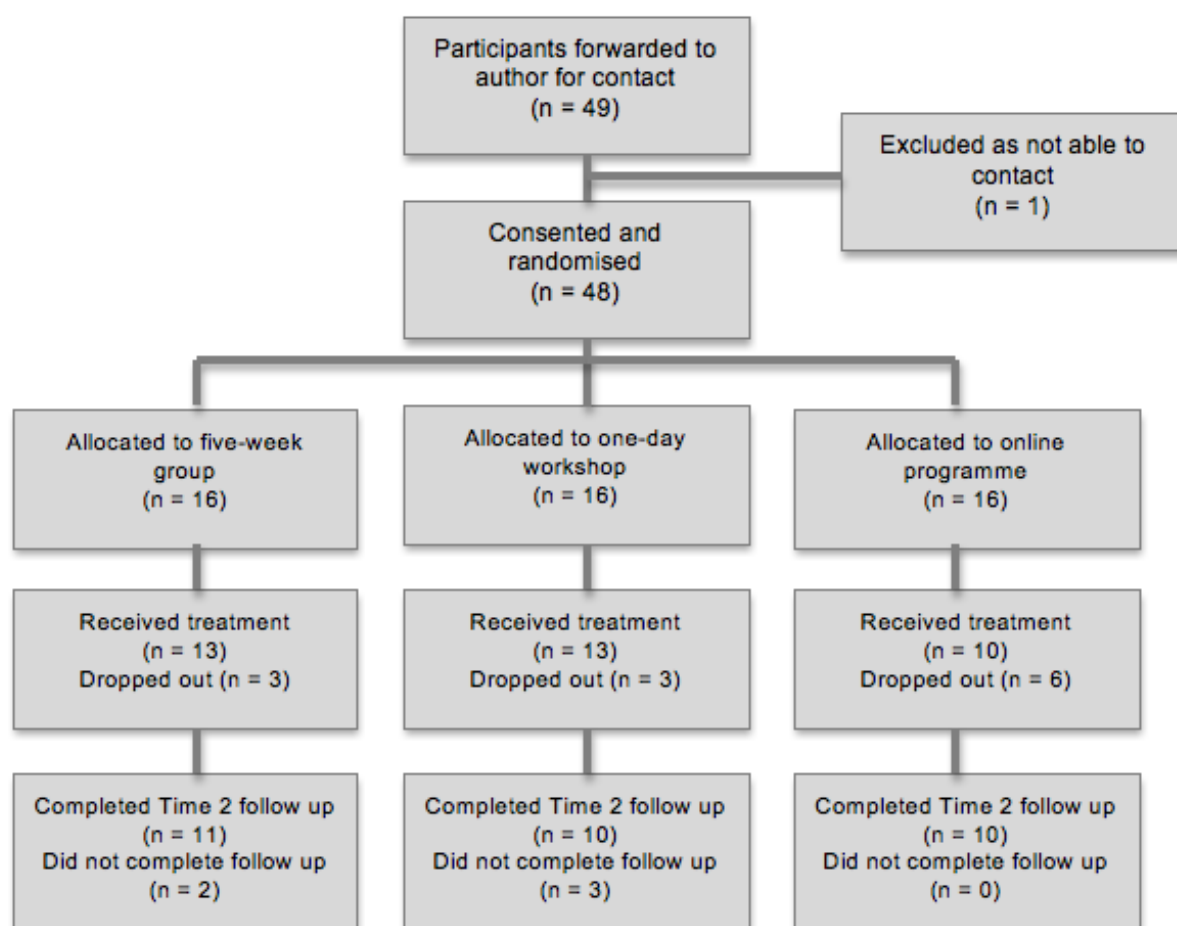


Figure B3: Participant flowchart

The study required participants to meet the following inclusion criteria:

- Aged over eighteen years old
- Had insomnia as defined by the International Classification of Sleep Disorders (ICSD-2) (see Introduction)
- Scored within or above the moderate severity category of the Insomnia Severity Index – a score of 15 or more out of 28 (see below)
- Willing to participate in the study and be randomised into one of the three interventions
- Access to, and proficient in, the use of email and the internet, to enable potential randomisation to the online intervention

Exclusion criteria:

- Patients experiencing severe psychiatric illness, epilepsy, or chronic fatigue
- Patients diagnosed with a circadian rhythm disorder, unmanaged restless legs syndrome, or other sleep disorders/ parasomnias
- Patients with an alcohol or drug dependency

- Deteriorating health or dementia that impacted on ability to participate in CBT-I processes, as judged by the research team
- Incapacitating pain, illness or disability that impacted on ability to participate in CBT-I processes, as judged by the research team
- Patients who did not read or understand the English language, that impacted on understanding of CBT-I processes, as judged by the research team

Interventions

Five-week programme

This was a five-session manualised programme devised by the University of Glasgow Sleep Centre (Espie et al., 2007), providing effective strategies to deal with insomnia, reduce dysfunctional sleep behaviour, attitudes and beliefs, and to help restore normal sleep patterns. Participants assigned to this intervention received weekly one to one-and-a-half-hour group sessions over five weeks. The content of the intervention was based on CBT techniques and focused on sleep education and sleep hygiene, sleep restriction, stimulus control, cognitive restructuring, imagery and relaxation, and paradoxical intention – see Table B1. The psychiatry team and colleagues at RLHIM delivered this programme as part of the standard treatment.

Session 1 Sleep Information	Aim: To learn about normal sleep processes and about sleep disorders	• To understand the need for sleep and its functions • To understand sleep pattern and how it varies during the lifetime • To understand sleep as a process with stages and phases • To understand factors that adversely affect sleep pattern and sleep quality • To understand the effects of sleep loss • To understand the concept of insomnia and how it can be measured • To understand personal sleep histories and patterns in the above context • To begin to correct misunderstandings about sleep and sleeplessness
Session 2 Sleep Hygiene and Relaxation	Aim: To introduce practical steps toward developing a healthy sleep pattern without recourse to drugs	• To create a bedroom environment that is comfortable for sleep • To take regular exercise that promotes fitness and enhances sleep • To develop a stable and appropriate diet • To reduce the undesirable effects of caffeine upon sleep • To moderate alcohol consumption and eliminate “night caps” • To learn relaxation skills to apply at home and in bed

Session 3 Sleep Scheduling	Aim: To reshape sleep patterns to correspond with individual sleep needs and to strengthen sleep rhythms	• To develop a good presleep routine • To distance waking activities (e.g. watching TV) from the bedroom environment • To establish a strong bed-sleep connection • To eliminate wakefulness from bed (rising if not asleep within around 15 minutes) • To define restricted parameters for the individual's sleep period • To increase sleep efficiency through scheduling sleep in relation to current total sleep • To eliminate daytime napping • To establish a stable night-to-night sleep pattern, rising at the same time every day • To encourage and support people in changing their sleep routines
Session 4 Cognitive approaches	Aim: To learn ways of reducing mental alertness, repetitive thoughts, and anxiety that interfere with sleep	• To identify thought patterns that interfere with sleep • To develop accurate beliefs and attitudes about sleep • To prepare mentally for bed by putting the day to rest • To learn thought distraction and imagery techniques • To reduce efforts to control sleep and allow it to happen naturally • To utilise these techniques to combat intrusive thoughts • To encourage and support people in changing their mental approach • To further adjust sleep schedules to maintain sleep efficiency
Session 5 Developing a strong and natural sleep pattern	Aim: To integrate advice from previous sessions and to maintain implementation at home	• To systematically rehearse elements of programme • To address implementation problems experienced • To further adjust sleep schedules to maintain sleep efficiency • To encourage and support people in maintaining their new sleep routines • To encourage and support people in maintaining their new mental approach • To learn relapse-prevention approaches if a sleep problem recurs

Table B1: Adapted from Espie et al. (2007)

One-day workshop

This was devised by the psychiatry team at RLHIM, based on the content of the five-session programme and combined to form a full day of CBT-based psycho-education delivered as a group, as evidenced by Swift et al. (2012). The content of the intervention was based on CBT techniques and focuses on sleep education and sleep hygiene, sleep restriction, stimulus control, cognitive restructuring, imagery and relaxation, and paradoxical intention.

Online programme

This web-based CBT programme (Sleepio) devised by Espie et al. (2012) was a six-session course guided by an animated therapist. Each session took around twenty minutes to complete. It also used email, SMS technology, and motivational tools to prompt and support the user to progressively and systematically implement behavioural and cognitive strategies. The programme provided effective strategies to deal with sleeplessness, to reduce dysfunctional sleep behaviour, attitudes and beliefs, and to help restore normal sleep patterns. The content of the intervention was based on CBT techniques and focuses on sleep education and sleep hygiene, sleep restriction, stimulus control, cognitive restructuring, imagery and relaxation, and paradoxical intention. The programme provides the same content as the five-session programme plus one follow-up session. Agreement for the use of Sleepio was gained from the licence holders.

All participants were informed that should the research show that one intervention is more effective than the others, those previously assigned to the other interventions would be given the opportunity to go on a waiting list for the most favourable intervention upon completion of the study.

Outcome measures

The research employed quantitative questionnaire measures taken at baseline (Time 1) and following completion (Time 2) to determine outcome of the different interventions (see Appendix B4):

Insomnia Severity Index (ISI)

The ISI is a seven-item self-report questionnaire assessing the nature, severity, and impact of insomnia (Bastien et al., 2001; Morin, 1993). The usual recall period is the

“last month” and the dimensions evaluated were: severity of sleep onset, sleep maintenance, and early morning awakening problems, sleep dissatisfaction, interference of sleep difficulties with daytime functioning, noticeability of sleep problems by others, and distress caused by the sleep difficulties. A five-point Likert scale was used to rate each item (for e.g. 0 = no problem; 4 = very severe problem), yielding a total score ranging from 0 to 28. The total score was interpreted as follows: absence of insomnia (0-7); sub-threshold insomnia (8-14); moderate insomnia (15-21); and severe insomnia (22-28).

Numerous studies have used the ISI, and the most recent research to examine psychometric indices also found it to be a reliable and valid instrument to detect cases of insomnia in the population whilst being sensitive to treatment response in clinical patients with excellent internal consistency for both samples (Cronbach alpha of 0.90 and 0.91) (Morin et al., 2011).

Dysfunctional Beliefs and Attitudes About Sleep Scale (DBAS-16)

The DBAS-16 is a sixteen-item self-report measure designed to evaluate a set of sleep related cognitions. Factors reflected (a) perceived consequences of insomnia, (b) worry/ helplessness about insomnia, (c) sleep expectations, and (d) medication.

The DBAS-16 has been found to be reliable, as evidenced by adequate internal consistency (Cronbach alpha = 0.77 for clinical and 0.79 for research samples) and temporal stability (Morin et al., 2007).

Patient Health Questionnaire (PHQ-9)

The nine-item version of the Patient Health Questionnaire was designed to facilitate the recognition and diagnosis of depression in primary care patients. It can be used to monitor change in symptoms over time and provides a depression severity index score as follows: none (0–4); mild (5–9); moderate (10–14); moderately severe (15–19); and severe (20–27) (Department of Health, 2011).

Generalised Anxiety Disorder (GAD7)

Though designed primarily as a screening and severity measure for generalised anxiety disorder, the GAD7 also has moderately good operating characteristics for three other common anxiety disorders, namely panic disorder, social anxiety disorder, and post-traumatic stress disorder. The index scores are as follows: none (0–4); mild (5–10); moderate (11–15); severe (16–21) (Department of Health, 2011)

Work and Social Adjustment Scale (WSAS)

The Work and Social Adjustment Scale is a simple five-item patient self-report measure, which assesses the impact of a person's mental health difficulties on their ability to function in terms of work, home management, social leisure, private leisure and personal or family relationships (Department of Health, 2011). Jansson-Fröjmark (2014) examined the properties of the WSAS as a measure of dysfunction in chronic insomnia, and concluded that it was a reliable and valid measure that could be recommended for both assessment and treatment evaluation (Cronbach alpha = 0.91).

All participants were asked to maintain a standard sleep diary for a week before starting their allocated intervention, and for a week following completion. Diaries measured time in bed, total sleep time, sleep onset latency (time to fall asleep), number of awakenings, wakefulness after sleep onset, and sleep efficiency (see Appendix B5).

Demographic variables (age, gender, ethnicity, employment status) as well as use of psychotropic medication, alcohol and non-prescription drugs were also gathered.

A participant experience questionnaire utilised at Time 2 captured feedback on participating in the different treatment interventions (see Appendix B6).

Procedure

How participants were sampled and recruited

Completed Initial Contact Consent Forms were sent to the author. The author then made either email or telephone contact with the potential participant offering a telephone call. The purpose of the call was to provide an overview of the research; confirm eligibility; discuss the information sheet and what participation entails; confirm their rights as a participant and alternatives to taking part; and to provide an opportunity to ask questions. Potential participants had up to a week to decide whether or not to take part.

As all of the participants had been given a summary of the research alongside the information sheet at their appointment, and as the telephone call was usually about a week after this appointment, all participants felt able to make a decision as to whether to proceed at the point of the telephone call and gave verbal consent. Once verbal

consent had been given, the author arranged for written consent to be provided either by email or post (see Appendix B7), and an ID number was allocated to the participant for the duration of the research. Participants were also advised that they would have an additional opportunity to review their participation once they received the results of their treatment allocation.

Design of the research and procedures followed by the participants during the study

The author requested randomisation to be completed by a fellow doctoral student, who was not involved in the research, using only the participant's ID number.

Randomisation was manual and non-computerised, namely the envelope method. Prior to the start of the study, treatment allocations had been typed on strips of paper, folded and randomly placed in opaque numbered envelopes. Each time a participant was consented, the next envelope was opened to determine allocation. On receiving the allocation, the author informed the participant of their allocation by telephone or email, checked whether they were happy to proceed, and if so arranged to send the baseline questionnaire measures by email or by post.

The author then informed the clinic administration team of the allocation of participants to the five-week group or the one-day workshop, in order to book these participants into interventions. One research-specific five-week evening group was set up during the study; otherwise all other participants were slotted in wherever possible to existing groups. Four one-day workshops took place during the study period. The facilitators of the five-week groups and one-day workshops were blind to which participants were part of this research and who was from the standard clinic list. The author managed the set up and ongoing coordination of those allocated to the online programme.

All participants were required to complete a Time 1 questionnaire and sleep diary before taking part in their allocated intervention. If the questionnaire raised sensitive or risk issues in relation to a participants' emotional or mental health, the author explored and managed this with the support of the Lead Clinician to ensure their safety.

Follow up post-interventions

All participants completing their allocated intervention were contacted by the author and advised that they would receive their Time 2 questionnaire, follow up sleep diary and participant experience questionnaire two months from the start of treatment. When

the time came for completing these, the author arranged with the participant whether these measures would be completed over email or by post using a prepaid envelope. Participants who did not complete measures at Time 2 were followed up by email, telephone, post, and where possible at their follow up appointment. They were also given the opportunity of talking through or completing the measures over the telephone if they preferred. This was the case across all interventions.

As part of standard practice at the Insomnia Clinic, participants were offered a follow-up appointment with the Clinic team approximately three months after completion of their treatment.

Case studies

All participants that had completed treatment were approached by email, with a supplementary information sheet and consent form attached (see Appendix B8), inviting them to take part in a semi-structured interview. Semi-structured interviews allow the researcher and participant to engage in an open dialogue, giving space and flexibility, whilst enabling the researcher to investigate issues in detail with further prompts or questions (Pietkiewicz and Smith, 2012). These interviews explored participation, providing an in-depth insight into interventions, and therefore formed case studies to further investigate participatory experiences. It was stated that selection would be on a first come first served basis, and participants were offered a £10 voucher for taking part. Once written consent was received, the author arranged a time to meet with the participant at a location convenient to them in order to carry out the interview. The questions were developed from the research objectives and the review of the literature as part of this study. Topics included what led to them seeking help, the referral process, thoughts on intervention allocation and experience of participation, which strategies have helped/ not helped, implementing what was learnt, and the impact their treatment has had (see Appendix B9).

Prior to each interview in July 2016, the author outlined the purpose to the participant, and explained how confidentiality and anonymity of the final data would be upheld, including using pseudonyms. Participants were informed that the interview could be concluded at any time. The interviews took an average of thirty-nine minutes, and were audio-recorded with the participants consent. The author used open-ended questions built around themes to allow exploration of the participants' experiences of treatment. Further prompts were used where needed, or to investigate the response in more depth. The author verbally debriefed participants after each interview and explained

how the analysis would take place and be utilised, as well as highlighting the Insomnia Clinic as a source for any further support.

Data analysis

Outcome measures

Data analysis followed an intention-to-treat (ITT) approach using SPSS version 23. All participants who provided baseline data were included in a series of three group (one-day, five-week, online) x two time (before and after treatment) one-way analysis of variance (ANOVA). This analysis included all outcome measures and sleep diary data, as well as additional analysis of individual items before and after between interventions. Paired Sample T-Tests were carried out to explore overall findings across interventions, and for individual items of outcome measures before and after across interventions. For the ITT analysis, missing values were replaced using the last data point carried forward. This methodology has been used to good effect by other similarly designed trials (Espie et al., 2007; Irwin et al., 2014; van Straten et al., 2014).

Participant experience questionnaires

Content analysis was conducted on experience questionnaires received from participants in each intervention. Hsieh and Shannon (2005) defined qualitative content analysis as “...*a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns*” (2005: 2). Content analysis was chosen for this analysis, as the study was interested in the specific experiences of participants in the different interventions, and interpreting rather than generalising findings. Hsieh and Shannon (2005) suggest three approaches to content analysis: conventional, directed, or summative. Participant feedback analysis in this study was completed using conventional content analysis as codes were derived and defined from the data, rather than from theory or relevant research (directed), or interest of researchers or review of the literature (summative). The authors describe conventional content analysis as allowing unique perspectives and categories to flow from the data for new insights to emerge. This is a similar process to the method of inductive content analysis described by Elo and Kyngäs (2008). Method and format of the content analysis drew upon guidance by Graneheim and Lundman (2004), Hsieh and Shannon (2005), and Elo and Kyngäs (2008).

Accordingly codes, sub-categories, categories and themes were identified from participant experience forms to reflect the feedback given in a reliable manner, and then documented into table format (see Appendix B10). In carrying out the analysis in this manner pre-conceived assumptions and categories were avoided. Trustworthiness of the findings was achieved through objective review, by the author's academic supervisor, of codes, sub-categories, categories and themes derived from meaning units.

Case studies

Analysis of the semi-structured interviews was conducted using Interpretative Phenomenological Analysis (IPA). IPA captures the "*quality and texture of individual experiences*" (Willig, 2008: 57). It aims to explore the participant's experience from their perspective, whilst recognising that this involves the researcher's own view of the world, alongside the nature of the interaction between researcher and participant. It is therefore an interpretation of the participant's experience, gained through the identification of themes to integrate into meaningful clusters (Willig, 2008). According to Pietkiewicz and Smith (2012), an IPA researcher can therefore make a comprehensive and in-depth analysis about a participant's experiences and produce a case study of certain phenomena.

The interviews were audio recorded and transcribed verbatim. The author utilised guidance by Willig (2008), Biggerstaff and Thompson (2008), and Pietkiewicz and Smith (2012) to carry out the analysis. The audio recordings were listened to several times, and then the text was read and reread to gain an overall impression. Notes documenting thoughts, observations and reflections were made to the left of the text, then subordinate themes characterising that section of the text were generated and noted in the right margin. These subordinate themes were listed and considered in relation to each other, then clustered into superordinate themes, which were given labels to capture the nature of experiences. Subordinate themes that were insignificant to the phenomenon were excluded, as suggested by Willig (2008). The author then reviewed superordinate themes in relation to the text to ensure they reflected the participant's narrative account. Tables were created to summarise superordinate and subordinate themes, alongside quotes, page and line numbers (see Appendix B11). This led to the development of a narrative account of participant's experiences in the form of a case study, as interpreted and alongside analysis by the author. Reflexivity was important, enabling awareness of the dynamics between author and participant, but also accepting that the analysis will always be an interpretation of the data. By

following this guidance, the author has attempted to give a true picture of phenomena, provided a context for the findings and a method to repeat the study in future research, and demonstrated that findings have emerged from the data. The study therefore aimed to meet the strategies of credibility, transferability, dependability, and confirmability for ensuring trustworthiness, as suggested by Shenton (2004).

RESULTS

Primary findings – statistical analysis

Participant descriptive statistics

Forty-four participants provided data for this study. 52.3% of the participants were female and 47.7% were male. Ages ranged from 21 to 64, with the largest number between the age of 35 and 44. The majority of participants were of White British ethnicity (72.7%) and in full-time employment (56.8%). See Table B2 for details.

Descriptive	Type	n	%
Gender	Male	21	47.7
	Female	23	52.3
Age	18-24	4	9.1
	25-34	9	20.5
	35-44	12	27.3
	45-54	9	20.5
	55-64	10	22.7
Ethnicity	White British	32	72.7
	White Irish	2	4.5
	White Other	4	9.1
	Chinese	1	2.3
	Asian Other	1	2.3
	Black Caribbean	1	2.3
	Black Other	2	4.5
	White and Asian	1	2.3
Employment	Self-employed	7	15.9
	Full-time work	25	56.8
	Part-time work	5	11.4
	Unemployed	2	4.5
	Retired	3	6.8
	Student	1	2.3
	Carer	1	2.3

Table B2: Participant descriptive statistics

Analyses were carried out regardless of compliance with treatment, therefore using the ITT approach. Before imputation, Time 2 data was missing for thirteen participants across interventions – eight dropped out after completing Time 1 measures or during

treatment, and five completed treatment but did not return follow up measures (see Figure B3). Missing values at Time 2 for these thirteen participants was accordingly inputted with their Time 1 data. Outcome measures analysis, apart from sleep diaries, is therefore based on forty-four participants.

Thirteen participants did not have completed Time 1 sleep diaries, as they were booked into the five-week group or the one-day workshop directly by the clinic, which did not provide them. Two participants completed Time 2 sleep diaries but not Time 1 so these were excluded from the analysis. Sleep diary analysis is therefore based on ITT for thirty participants.

Between and within groups analysis

One-way analysis of variance (ANOVA) established that there were no significant differences between or within groups at Time 1 for gender [$F(2,41)=2.49$, $p=0.10$], age [$F(2,41)=0.19$, $p=0.83$], ethnicity [$F(2,41)=1.15$, $p=0.33$], or employment status [$F(2,41)=0.96$, $p=0.39$].

There were no significant differences at Time 1 for insomnia severity [$F(2,41)=1.55$, $p=0.22$], beliefs and attitudes about sleep [$F(2,41)=0.21$, $p=0.81$], depression [$F(2,41)=0.20$, $p=0.82$], anxiety [$F(2,41)=0.13$, $p=0.88$], or daytime functioning and health-related quality of life (assessed by work and social adjustment) [$F(2,41)=0.83$, $p=0.45$].

The outcome measures for insomnia severity, depression and anxiety have clinical interpretations to guide recognition and diagnosis. In this sample, the mean score for insomnia severity at Time 1 was 19.59, which is classified as moderate; the mean score for depression was 11.55 which is classified as moderate; and the mean score for anxiety was 8.14 which is classified as mild.

There were no significant differences at Time 1 for use of medication [$F(2,41)=0.33$, $p=0.72$], non-prescription drugs [$F(2,41)=0.49$, $p=0.62$], or alcohol [$F(2,41)=0.14$, $p=0.87$].

There were also no significant differences at Time 1 for the majority of the sleep diary measures – sleep onset latency [$F(2,27)=0.78$, $p=0.47$], number of awakenings

[F(2,27)=0.78, p=0.47], wakefulness after sleep onset [F(2,26)=1.01, p=0.38], total sleep time [F(2,26)=0.16, p=0.85], or sleep efficiency [F(2,26)=0.96, p=0.40]. However a significant difference was found for time in bed between groups [F(2,27)=5.21, p<0.05]. After Games-Howell post-hoc analysis, it was revealed that time in bed was significantly different between those on the one day workshop and those in the online programme groups at baseline (p<0.05). Therefore for this individual measure, non-parametric analysis between groups was carried out.

Overall findings before and after across interventions

Using Paired Sample T-Tests, and Wilcoxon Matched Paired Test for time in bed, there was a highly significant improvement in insomnia severity, beliefs and attitudes about sleep, depression, and daytime functioning and health-related quality of life (assessed by work and social adjustment). There were also significant improvements for anxiety, mental health or insomnia related medication use, time in bed, sleep onset latency, wakefulness after sleep onset, and sleep efficiency across interventions, as shown in Table B3 and Figures B4-B6.

There were no significant differences in non-prescription drug use [t(43)=1.00, p=0.32], alcohol use [t(43)=-0.57, p=0.57], number of awakenings [t(29)=1.78, p=0.09], or total sleep time [t(28)=-1.52, p=0.14], before and after across interventions.

Outcome	Mean Time 1	Mean Time 2	Significance
Insomnia severity	19.59	15.11	t(43)=4.75, p<0.001***
Beliefs and attitudes about sleep	6.54	5.42	t(43)=5.15, p<0.001***
Depression	11.55	8.41	t(43)=3.89, p<0.001***
Anxiety	8.14	6.68	t(43)=2.62, p<0.05*
Work and social adjustment	19.20	15.41	t(43)=3.76, p<0.001***
Medication use	2.00	2.23	t(43)=-2.49, p<0.05*
Time in bed	469.56	433.80	Z=-3.14, p<0.05*
Sleep onset latency	57.11	31.59	t(29)=2.54, p<0.05*
Wakefulness after sleep onset	93.01	65.85	t(27)=2.74, p<0.05*
Sleep efficiency	67.47	77.09	t(28)=-3.11, p<0.01**

Table B3: Significant findings before and after across interventions

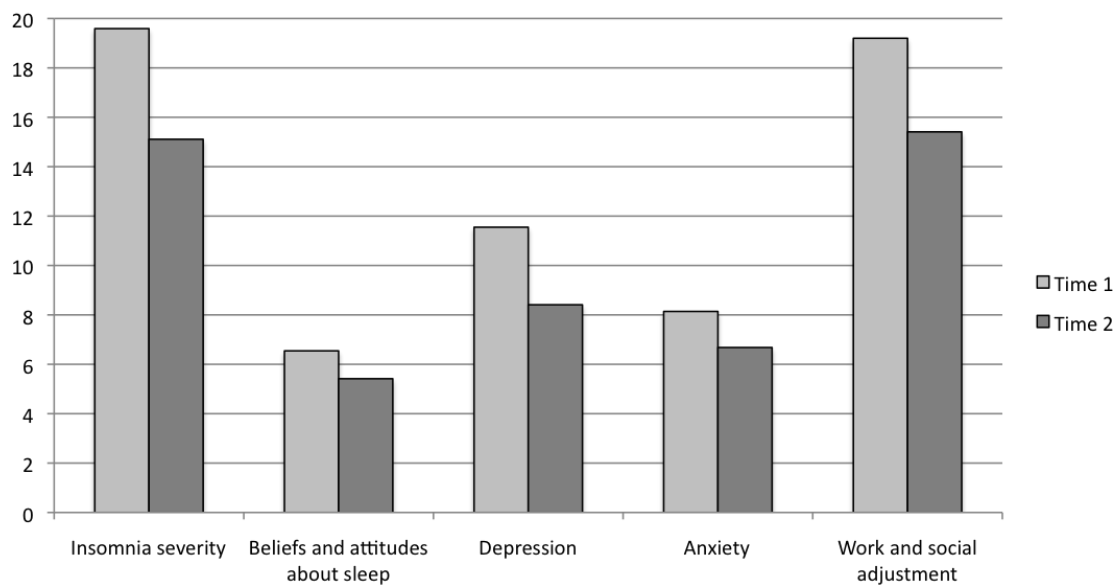


Figure B4: Insomnia severity, beliefs and attitudes about sleep, depression, anxiety, and daytime functioning and health-related quality of life before and after intervention

In terms of clinical severity, the mean score for insomnia at Time 2 was 15.11, which is just over the 15-21 classification of moderate, but is a 4.48 point reduction overall and nearly at the cut off point for inclusion in this research. The mean score for depression was 8.41 which is classified as mild, having shown a 3.14 point reduction from the initial moderate rating; and the mean score for anxiety was 6.68 which is still classified as mild, but is a 1.46 point reduction overall.

Findings for medication use are depicted in Figure B5, which show a reduction in the number of those prescribed and taking medication, and an increase in those not prescribed medication.

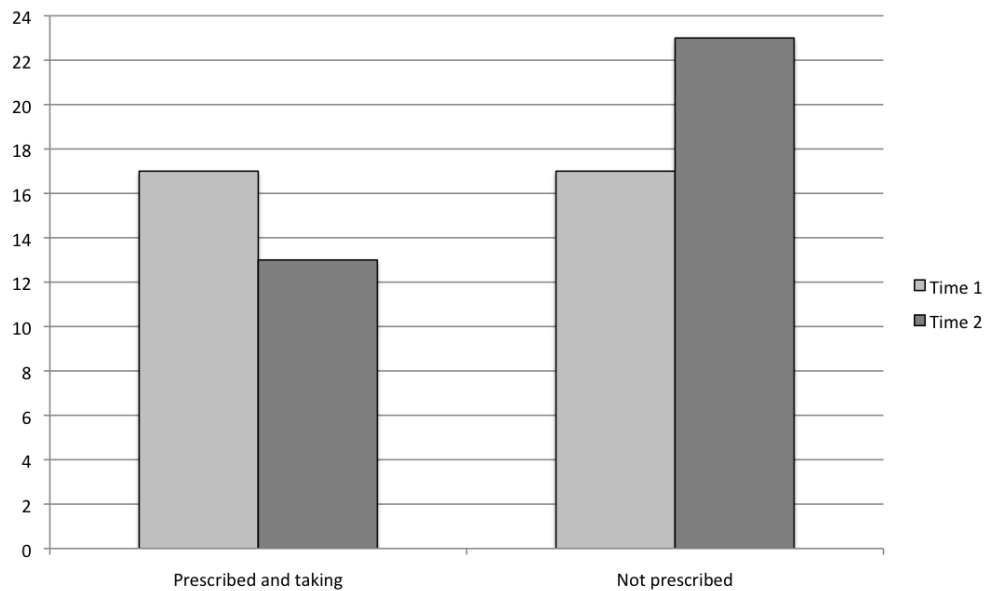


Figure B5: Mental health or insomnia related medication use before and after intervention

Sleep diary data showed reductions for time in bed, sleep onset latency and wakefulness after sleep onset, and an increase in sleep efficiency (See Figure B6).

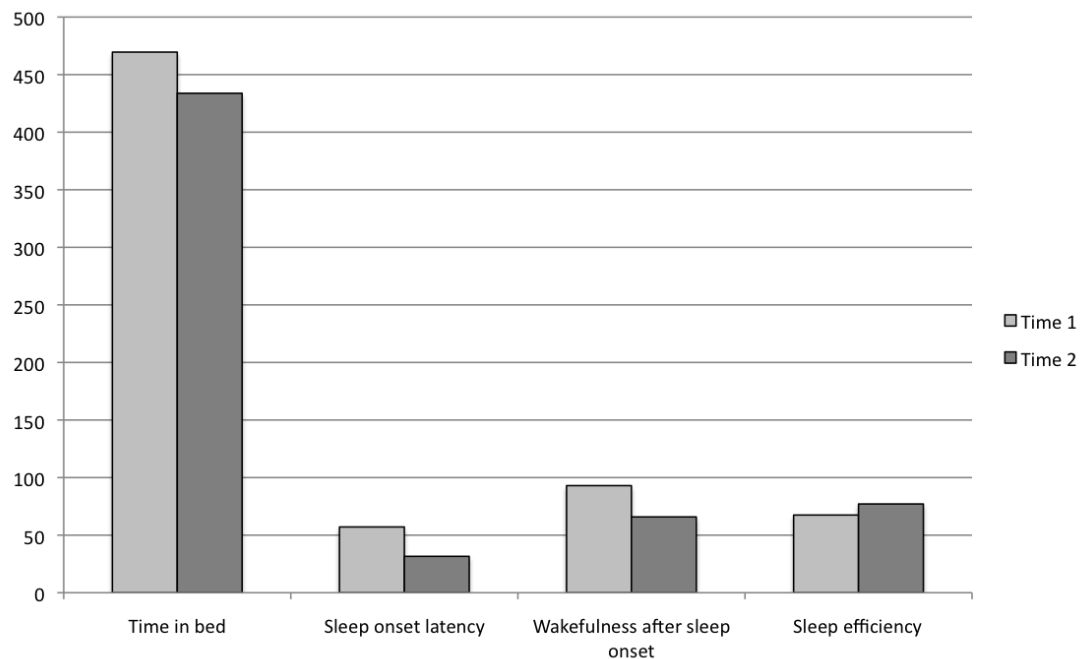


Figure B6: Significant sleep diary outcomes before and after intervention

Before and after for individual items across interventions

Further analysis of individual items of outcome measures before and after across interventions was completed using Paired Sample T-Tests. In order to address any

familywise errors, p values were corrected by multiplying the resulting values by the number of T-Tests completed for each measure.

Insomnia Severity

Findings for insomnia severity are shown in Table B4. Highly significant results were found for questions 1b, 2, 3 and 5. A significant result at $p < 0.01$ was found for question 1a. Questions 1c and 4 were not significant.

Question		Significance
1a	Rate the current (i.e. last two weeks) severity of your insomnia problem(s) – difficulty falling asleep	$t(42)=3.56, p<0.01^{**}$
1b	Rate the current (i.e. last two weeks) severity of your insomnia problem(s) – difficulty staying asleep	$t(42)=4.09, p<0.001^{***}$
1c	Rate the current (i.e. last two weeks) severity of your insomnia problem(s) – waking up too early	$t(42)=1.98, p=0.39$
2	How satisfied/ dissatisfied are you with your current sleep problem?	$t(43)=5.20, p<0.001^{***}$
3	To what extent do you consider your sleep problem to interfere with your daily functioning (e.g. daytime fatigue, ability to function at work/ daily chores, concentration, memory, mood etc)?	$t(43)=4.84, p<0.001^{***}$
4	How noticeable to others do you think your sleeping problem is in terms of impairing the quality of your life?	$t(43)=1.63, p=0.77$
5	How worried/ distressed are you about your current sleep problem?	$t(43)=4.91, p<0.001^{***}$

Table B4: Insomnia severity index

Dysfunctional beliefs and attitudes about sleep

Findings for dysfunctional beliefs and attitudes about sleep before and after across interventions are shown in Table B5. Highly significant ($p < 0.001$) results were found for questions 3, 4, 7, 13 and 14; and significant results at $p < 0.05$ were found for questions 1, 2, 5, 8, 9 and 12. Five items (questions 6, 10, 11, 15 and 16) were not significant.

Question		Significance
1	I need 8 hours of sleep to feel refreshed and function well during the day	$t(42)=3.47, p<0.05^*$
2	When I don't get the proper amount of sleep on a given night, I need to catch up on the next day by napping or on the next night by sleeping longer	$t(43)=3.12, p<0.05^*$
3	I am concerned that chronic insomnia may have	$t(43)=3.95, p<0.001^{***}$

	serious consequences on my physical health	
4	I am worried that I may lose control over my abilities to sleep	t(43)=4.03, p<0.001***
5	After a poor night's sleep, I know that it will interfere with my daily activities on the next day	t(43)=3.64, p<0.05*
6	In order to be alert and function well during the day, I believe I would be better off taking a sleeping pill rather than having a poor night's sleep	t(43)=2.13, p=0.62
7	When I feel irritable, depressed or anxious during the day, it is mostly because I did not sleep well the night before	t(43)=4.38, p<0.001***
8	When I sleep poorly on one night, I know it will disturb my sleep schedule for the whole week	t(43)=3.35, p<0.05*
9	Without an adequate night's sleep, I can hardly function the next day	t(43)=3.20, p<0.05*
10	I can't ever predict whether I'll have a good or poor night's sleep	t(43)=1.21, p=3.76
11	I have little ability to manage the negative consequences of disturbed sleep	t(43)=2.66, p=0.18
12	When I feel tired, have no energy, or just seem not to function well during the day, it is generally because I did not sleep well the night before	t(43)=3.17, p<0.05*
13	I believe insomnia is essentially the result of a chemical imbalance	t(42)=4.33, p<0.001***
14	I feel insomnia is ruining my ability to enjoy life and prevents me from doing what I want	t(43)=3.92, p<0.001***
15	Medication is probably the only solution to sleeplessness	t(43)=3.00, p=0.06
16	I avoid or cancel obligations (social, family) after a poor night's sleep	t(43)=1.17, p=3.97

Table B5: Dysfunctional beliefs and attitudes about sleep scale

Depression

Findings for depression are shown in Table B6. Highly significant results were found for question 3, and significant results at p<0.05 for questions 4. Questions 1, 2, 5, 6, 7, 8 and 9 were not significant.

Question		Significance
1	Little interest or pleasure in doing things	t(43)=2.56, p=0.13
2	Feeling down, depressed, or hopeless	t(43)=1.19, p=2.17
3	Trouble falling or staying asleep, or sleeping too much	t(43)=4.59, p<0.001***
4	Feeling tired or having little energy	t(40)=3.05, p<0.05*
5	Poor appetite or overeating	t(41)=2.65, p=0.11
6	Feeling bad about yourself - or that you are a failure or have let yourself or your family down	t(42)=1.95, p=0.52
7	Trouble concentrating on things, such as reading	t(43)=2.24, p=0.27

	the newspaper or watching television	
8	Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	t(43)=2.55, p=0.14
9	Thoughts that you would be better off dead or of hurting yourself in some way	t(43)=1.63, p=0.99

Table B6: Depression

Anxiety

Findings for anxiety before and after across interventions are shown in Table B7.

Significant results at $p < 0.05$ were found for question 2, but the other six questions were not significant.

Question		Significance
1	Feeling nervous, anxious or on edge	t(43)=2.23, p=0.22
2	Not being able to stop or control worrying	t(43)=2.98, $p < 0.05^*$
3	Worrying too much about different things	t(42)=2.14, p=0.27
4	Trouble relaxing	t(43)=1.55, p=0.91
5	Being so restless that it is hard to sit still	t(43)=0.40, p=4.82
6	Becoming easily annoyed or irritable	t(42)=2.61, p=0.09
7	Feeling afraid as if something awful might happen	t(43)=1.52, p=0.95

Table B7: Anxiety

Daytime functioning and health-related quality of life

Findings for daytime functioning and health-related quality of life (assessed by work and social adjustment scale) are shown in Table B8. Significant results at $p < 0.01$ were found for questions 2 and 4; and significant results at $p < 0.05$ were found for question 5. Two items (question 1 and 3) were not significant.

Question		Significance
1	Affect that insomnia has on ability to work	t(42)=1.12, p=1.34
2	Affect that insomnia has on home management	t(43)=3.48, $p < 0.01^{**}$
3	Affect that insomnia has on social leisure activities	t(43)=1.04, p=1.53
4	Affect that insomnia has on private leisure activities	t(43)=3.53, $p < 0.01^{**}$
5	Affect that insomnia has on family and relationships	t(43)=2.98, $p < 0.05^*$

Table B8: Work and social adjustment scale

Before and after between interventions

ANOVA and Kruskal Wallis (where Levene's test showed unequal homogeneity of variance) analysis established that there was no significant difference between the five-week group, one-day workshop or online programme for insomnia severity [$F(2,41)=2.44$, $p=0.10$], beliefs and attitudes about sleep [$F(2,41)=1.16$, $p=0.32$], depression [$F(2,41)=1.84$, $p=0.17$], anxiety [$F(2,41)=1.09$, $p=0.35$], daytime functioning and health-related quality of life (assessed by work and social adjustment) [$F(2,41)=0.47$, $p=0.63$], medication use [$H(2)=0.55$, $p=0.76$], non-prescription drug use [$H(2)=1.86$, $p=0.39$], alcohol use [$F(2,41)=0.94$, $p=0.40$], sleep onset latency [$F(2,27)=0.78$, $p=0.47$], number of awakenings [$F(2,27)=0.78$, $p=0.47$], wakefulness after sleep onset [$F(2,26)=1.01$, $p=0.38$], total sleep time [$F(2,26)=0.16$, $p=0.85$], or sleep efficiency [$F(2,26)=0.96$, $p=0.40$].

A significant difference was however found for time in bed between interventions ($p<0.05$). On further investigation through post hoc tests, it was determined that the difference lay between the five-week group and the online programme at Time 2. Participants in the five-week group spent an average of ninety-one minutes less time in bed than on the online programme – a different outcome to Time 1 when the difference was between the one-day workshop and the online programme. Participants in the one-day workshop group at Time 1 spent an average of seventy-six minutes less time in bed than on the online programme. Therefore participants allocated to the online programme were generally spending more time in bed before and after the intervention than the other two groups.

Before and after for individual items between interventions

Further analysis of individual items of outcome measures was conducted to determine whether there were any individual items that were significant between groups at Time 2. In order to compare the interventions without increasing the Type 1 error rate above 0.05, the Ryan, Einot, Gabriel and Welsh Q (REGWQ) post hoc comparison procedure was applied, as suggested by Field (2009). Findings for insomnia severity, dysfunctional beliefs and attitudes about sleep, depression, anxiety, and daytime functioning and health-related quality of life are detailed in Table B9-B12.

Insomnia Severity

Question		Significance
1a	Rate the current (i.e. last two weeks) severity of your insomnia problem(s) – difficulty falling asleep	$F(2,40)=1.71, p=0.18$
1b	Rate the current (i.e. last two weeks) severity of your insomnia problem(s) – difficulty staying asleep	$F(2,40)=0.94, p=0.44$
1c	Rate the current (i.e. last two weeks) severity of your insomnia problem(s) – waking up too early	$F(2,40)=1.56, p=0.30$
2	How satisfied/ dissatisfied are you with your current sleep problem	$F(2,41)=1.54, p=0.30$
3	To what extent do you consider your sleep problem to interfere with your daily functioning (e.g. daytime fatigue, ability to function at work/ daily chores, concentration, memory, mood etc)	$F(2,41)=0.94, p=0.45$
4	How noticeable to others do you think your sleeping problem is in terms of impairing the quality of your life?	$F(2,41)=0.62, p=0.54$
5	How worried/ distressed are you about your current sleep problem?	$F(2,41)=3.00, p=0.10$

Table B9: Insomnia severity index

No individual items for insomnia severity were significant.

Dysfunctional beliefs and attitudes about sleep scale

No individual items for beliefs and attitudes were significant.

Depression

Question		Significance
1	Little interest or pleasure in doing things	$F(2,41)=1.84, p=0.20$
2	Feeling down, depressed, or hopeless	$F(2,41)=1.13, p=0.37$
3	Trouble falling or staying asleep, or sleeping too much	$F(2,41)=1.60, p=0.27$
4	Feeling tired or having little energy	$F(2,38)=0.03, p=0.97$
5	Poor appetite or overeating	$F(2,40)=0.90, p=0.42$
6	Feeling bad about yourself - or that you are a failure or have let yourself or your family down	$F(2,41)=2.63, p=0.11$
7	Trouble concentrating on things, such as reading the newspaper or watching television	$F(2,41)=0.15, p=0.86$

8	Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	$F(2,41)=0.39, p=0.68$
9	Thoughts that you would be better off dead or of hurting yourself in some way	$F(2,41)=1.08, p=0.36$

Table B10: Depression

No individual items for depression were significant.

Anxiety

Question		Significance
1	Feeling nervous, anxious or on edge	$F(2,41)=0.31, p=0.74$
2	Not being able to stop or control worrying	$F(2,41)=2.30, p=0.11$
3	Worrying too much about different things	$F(2,41)=0.84, p=0.42$
4	Trouble relaxing	$F(2,41)=1.54, p=0.22$
5	Being so restless that it is hard to sit still	$F(2,41)=0.57, p=0.61$
6	Becoming easily annoyed or irritable	$F(2,41)=0.10, p=0.90$
7	Feeling afraid as if something awful might happen	$F(2,41)=0.60, p=0.59$

Table B11: Anxiety

No individual items for anxiety were significant.

Daytime functioning and health-related quality of life

Question		Significance
1	Affect that insomnia has on ability to work	$F(2,40)=4.09, p=0.06$
2	Affect that insomnia has on home management	$F(2,41)=0.03, p=0.98$
3	Affect that insomnia has on social leisure activities	$F(2,41)=0.35, p=0.75$
4	Affect that insomnia has on private leisure activities	$F(2,41)=1.66, p=0.18$
5	Affect that insomnia has on family and relationships	$F(2,41)=4.05, p=0.80$

Table B12: Work and social adjustment scale

No individual items on the work and social adjustment scale were significant, although question 1 (affect that insomnia has on ability to work) was approaching significance at

0.056. Post hoc analysis showed this potential difference to be between the five-week group and the one-day workshop, where scores for participants in the one-day workshop increased by half a point on average when the other group averages decreased.

Attendance and attrition

The average attendance figure for all weeks of the five-week group was 72.7%, giving an average attendance of 4.7 out of 5 sessions. Access to the online programme was granted for twelve weeks, with the six core weekly sessions plus an optional six weeks. Nine out of ten of those completing the online programme completed all six core sessions, with the remaining participant not completing within their twelve-week account window, or within two account extensions to eighteen weeks. This equates to an average attendance of 5.9 sessions. Two participants completed all twelve sessions that were available, but others either chose not to complete the optional weeks, or took the full twelve weeks to complete the six core sessions, therefore not completing weekly.

Feedback was gathered from participants who chose not to continue with the study. Reasons given for deciding not to continue with the allocated intervention are shown in Table B13. Others were lost to follow up.

Intervention	Status	Reason
Five-week group	Dropped out after week one	Family and work commitments
Five-week group	Dropped out after week two	Stated that all the techniques had already been through or tried
One-day workshop	Offered two dates but declined both and opted out of research to go on standard wait list for five-week group	Work commitments
One-day workshop	Left halfway through the workshop	Stated that not feeling well and the day was too long. Moved to standard wait list for five-week group
Online programme	Redeemed code but did not start	Postponed due to work commitments then informed clinic no longer required
Online programme	Dropped out after two sessions	Not tailored to individual needs

Online programme	Did not start	Moved abroad where planned to complete but did not access and no further contact
Online programme	Dropped out after two sessions	Family and work commitments followed by reporting no positive effect

Table B13: Reason for not completing by intervention and status

Secondary findings - Content Analysis

Five-week CBT-I group

Content analysis was conducted on ten feedback forms received from participants of the five-week group (see Appendix B10). These participants were recruited across six groups, run by three different facilitators.

Question 1: How would you describe your experience?

Overall participants reported a positive experience with learning and reflection to implement changes for the better. Three main categories were identified from sub-categories and codes – ‘group experience’, ‘learning and understanding’, and ‘moving forward’.

Group experience

Participants described their experience in relation to how the group was facilitated, reflecting on delivery, interactivity and structure:

“The doctor was very clear and engaging, and knew his subject well. When you have insomnia it is very difficult to concentrate for long periods of time, but the interactive nature of the classes made it easier to engage and remember the key points” (105)

There was a sense of having a positive group encounter and shared experience. One response given was:

“It felt like a safe environment...Each week was reassuring made more so by other people’s experiences” (132)

One participant reported that some difficult group dynamics were encountered:

“Initially certain members of the group were very disruptive but they did not attend other sessions...but two of us found the sessions very good” (125)

Learning and understanding

Participants also described their experience as having given them knowledge and insight, as well as challenging myths and perceptions:

“Learnt a lot about what causes the insomnia and the effect this can have on you” (112)

"It encouraged me to think about sleep completely differently and helped to release me from some of the myths about sleep" (117)

"It was also interesting to learn from my sleep diary that I actually slept more than I thought I did" (130)

Moving forward

Participants detailed how the practical advice given regarding managing and changing behaviours was impactful when translated into practice:

"Provided a number of different mechanisms to cope with and change reinforced behavioural patterns associated with insomnia" (118)

"Sessions all had applicable advice that would help me in the long term" (129)

Question 2: What did you enjoy most about your experience?

The overall theme to emerge was the importance of facilitation, learning and group experience. Three main categories were identified – 'facilitation, learning and expertise', 'group experience', and 'achievement'.

Facilitation, learning and expertise

Participants emphasised the importance of the facilitator approach and delivery, their expertise, and gaining knowledge and skills, for e.g.:

"Having a number of tools explained to me in a simple, informed and evidence-based way in a classroom format...He was flexible in the way that tools should be used...and was open to feedback throughout the course" (105)

Participants also appeared to enjoy applying their learning practically, and having direct access to an expert in the field, for instance:

"Learning practical ways and coping mechanisms that you can apply in any given setting" (118)

"I enjoyed contact on a regular basis with an expert in the area of sleep..." (134)

Group experience

The feedback for this category focused on shared experience, and enjoyment received from the nature of the group, support, and other perspectives, for e.g:

"The size of the group was perfect for keeping the sessions interactive and supportive, and also getting input from different people's perspectives" (105)

Achievement

Participants described enjoying gaining new perspectives and control, for instance:

“...it has genuinely broadened my mind...I didn’t believe I would get from the sessions what I have” (117)

“I felt positive about keeping the sleep diary...this enabled me to...observe my insomnia in a less emotional and more objective way. It contributed to my feelings of taking control over something that had become out of control, which felt very positive” (132)

Question 3: What did you least enjoy about your experience?

Overall participants highlighted the importance of considering needs of individuals before, during and after the group. Three main categories were identified – ‘needs assessment and patient involvement’, ‘implementation’, and ‘administration’. Two participants reported that there was nothing that they least enjoyed about their experience.

Needs assessment and patient involvement

Participants described their experience in relation to the importance of considering knowledge and information needed, individual need, and the need for interaction and feedback:

“Going over a lot of things that I had already read about, or tried before such as caffeine intake, sleeping environment and other hygiene factors” (105)

“Very little sharing of experience or ‘sense of group’” (118)

“It felt a bit basic and ‘one size fits all’” (122)

“On the last session I would like to have known ‘what next’ in terms of what to expect and how to modify future sleep patterns etc” (132)

Implementation

The feedback focused on the challenges of implementing and changing behaviours in daily life:

“The amount of tasks required before bed-time built up over the 6-week course...I began to obsess about filling in the sleep-diary, the thoughts diary, creating the buffer-zone etc. and sometimes this was anxiety invoking and counter-productive...” (105)

“Whilst I appreciate that there is probably never a right time to do this, I do think some more guidance about what is required would be helpful at the outset...” (118)

"I found it frustrating that some of the techniques are difficult to integrate into life. The sleep scheduling was effective but initially it made me depressed, exhausted and hungry" (134)

Administration

Participants also found the scheduling of group sessions unhelpful when there were gaps for administration reasons:

"The spread of the sessions, consecutive weeks may have been more useful"
(117)

Question 4: Are you likely to use any of the methods learnt to help manage your sleep?

All participants answered 'Yes' to this question and went on to state which methods. Overall feedback was that participants would use the core elements of the programme, alongside benefitting from having had the group experience and managing their expectations going forward. As the majority of comments related to the core elements, categories relating to these were applied in order to structure the feedback. There was therefore no need to generate sub-categories.

Sleep information

Two participants commented on recording sleep, stating that they would be likely to continue to use a *"sleep diary"* (105, 132).

Sleep hygiene and relaxation

One participant specifically mentioned *"sleep hygiene"* (134) as a method that they would use, and four participants stated *"progressive muscle relaxation"* or *"muscle relaxant exercises"* (118, 130, 132, 134) as a technique.

Sleep scheduling

This category was formed from a large number of responses, with feedback focusing on reshaping sleep and the bed-sleep connection:

"Anchoring my bed-time and waking time" (105)

"Not doing anything that isn't related to sleep in the bedroom" (129)

"The 15-minute rule" (132)

Cognitive approaches

Feedback focused on reducing alertness and reducing thoughts and anxiety. This aspect constituted the largest number of responses, with fourteen comments made across the ten participants. Feedback included that participants would use:

“Creating a ‘buffer zone’ before bed-time to relax” (105)

“Visualisation techniques and diary technique” (118)

“Eyes open technique” (134)

Group experience

This category was formed from one response that highlighted reassurance:

“Overall it was the reassuring effect of the group rather than specific techniques that was useful” (122)

Managing expectations

One participant reported on their progress to far in relation to their expectations:

“I have been trying nearly all the methods but so far not managed to fall asleep as quickly as I would like” (125)

Conclusion for five-week group

Views from the ten participants provided constructive and informative feedback about elements of the programme that are working well and areas for improvement.

Participants are learning the key techniques for managing their sleep, as evidenced by the unanimous response to using the methods learnt, and feedback forming categories relating to the core programme.

One-day CBT-I workshop

Content analysis was conducted on all ten feedback forms received from participants of the one-day workshop (see Appendix B10). These participants took part in one of four different workshops delivered by the same facilitator.

Question 1: How would you describe your experience?

Overall participants reported their experience was positive and informative, but the general consensus was that there was a lot of information imparted in one day. Three

main categories were identified – ‘content, facilitation and format’, ‘shared experience’, and ‘outstanding issues’.

Content, facilitation and format

Six participants specifically used the word ‘informative’ in their feedback, hence the importance given to this word in both a code and sub-category. Participants also described their experience in relation to facilitation and format, describing it as practical, theoretical and addressing their needs:

“I found the one-day workshop to be very relaxed and extremely informative...I gained a lot of information that I have found extremely useful...” (120)

“I wasn’t sure what to expect but I thought it was excellent: interesting, informative and well delivered. It took us through the research, dispelled some myths about insomnia and addressed the questions asked by the group. I couldn’t wait to get started” (127)

“I found the workshop well grounded, logical, honest and informative on the topic of sleep in general and insomnia and its treatment in specific” (148)

One participant highlighted the efficiency of the workshop:

“It was pleasing to gain all the information in one go and this was then the enabler to start the ‘sleep diary’ part of the program. This was my preferred option of delivery and I feel it was most beneficial to myself” (120)

However, others found the day overwhelming in receiving all the information in one day, and had other treatment and format preferences, although positives were still identified:

“It’s a lot to take in but the one-day is a good option for me, and from a travel cost point of view” (146)

“I would have preferred the five-week group as the one-day workshop was too tiring and too much to take in, in one day. A choice would have been better but I was given an either/or choice of a nine-month wait or a one-day workshop” (141)

This last participant’s preference before randomisation and allocation was the one-day workshop.

Shared experience

Participants mentioned gaining from others’ experiences and similar conditions:

“It was good to hear experiences from others in the group” (103)

"It was good to be with other people and I think the opportunity to speak with people who have the same thing is invaluable" (146)

Outstanding issues

This category came from one participant who identified an unaddressed need relating to how to address travel and jetlag:

"The one issue I still have is with multi-zone travel and jetlag" (146)

Question 2: What did you enjoy most about your experience?

The overall consensus was that the one-day workshop was a positive and supportive group experience that enabled learning and strategies to change. Three main categories were identified – 'delivery style and content that supports learning', 'optimism', and 'group experience'.

Delivery style and content that supports learning

Participants described the facilitation, and applicability of content and what they learnt:

"It was presented in a relaxed way...handouts are a good reference as well"
(103)

"It was the learning and putting insomnia in the context of wider health issues. It gave me the tools to tackle my long term problem" (127)

"Research and medically grounded (i.e. logical)" (148)

Optimism

This category was formed from one participant's response who reported:

"A reassuring message – if you've got insomnia there is treatment..." (104)

Group experience

This category was drawn from feedback of gaining from the presence of others, namely in having a positive, shared group experience and not being alone:

"The attendees were very friendly and affable within my group. I realised I was not alone in my sleep difficulties" (120)

"Being able to discuss issues with others who understand insomnia" (126)

"Meeting others who experienced similar issues" (143)

Question 3: What did you least enjoy about your experience?

Overall participants highlighted balancing the design and format of the day with individual needs. Three main categories were identified – ‘practicalities and format’, ‘learning resources’, and ‘group dynamics’. Two participants reported that there was nothing that they least enjoyed about their experience.

Practicalities and format

Participants commented on travel, an unsuitable room, and the workshop being a long day:

“...having something closer to home would have been good” (103)

“Room was a bit too small and quite stuffy for number of people on course (not a great aid to concentration for a group of very tired people!)” (143)

“The day was too long and I felt too tired in the afternoon to fully focus on the exercises we had to do” (141)

Learning resources

Feedback focused on support for learning, but comments were balanced:

“The calculations on sleep efficiency – didn’t detract from enjoyment of workshop” (104)

“I would have liked even more handouts. I did take a lot of notes but it’s sometimes better to get sections of the day more documented” (127)

Group dynamics

This category was formed from one participant’s response regarding other members of the group:

“Some of the participants seemed to have rather more serious personal / psychological issues which had them speaking too much...The doctor did manage this well” (148)

Question 4: Are you likely to use any of the methods learnt to help manage your sleep?

All participants answered ‘Yes’ to this question and went on to state which methods. Overall feedback was that participants would use the core elements of the programme. Codes were developed from the data and categories relating to these were applied in order to structure the feedback.

Sleep information

Two participants commented that they would be likely to use a sleep diary and medication, although the programme aims to reduce use of medication:

“Sleep diary” (140)

“Use of medication” (120)

Sleep hygiene and relaxation

Methods that participants stated included elements of sleep hygiene and the avoidance of use of IT at night time:

“Sleep hygiene which I am very conscientious about...” (127)

“Advice on IT at night” (141)

Sleep scheduling

This category was formed from the largest number of responses, with feedback focusing on reshaping sleep and the bed-sleep connection:

“Regular bed times and ‘get up’ times” (120)

“15 minute rule” (140)

“Focus on routine and buffer zone, not just lying in bed if unable to sleep, not trying to go to sleep if not tired” (143)

Cognitive approaches

Feedback in this category focused on reducing alertness and reducing thoughts and anxiety:

“Wind down routine” (104)

“Putting my day to bed – writing down what I need to do the following day” (127)

“Clearing the mind before sleep” (148)

Conclusion for the one-day workshop

Feedback from participants was positive overall, which also included elements that they least enjoyed being balanced with positive feedback. Practical suggestions were made on how to improve the one-day workshop. Once again participants demonstrated that they had learnt and remembered the key techniques.

Online CBT-I programme

Content analysis was conducted on ten feedback forms received from participants of the online programme (see Appendix B10).

Question 1: How would you describe your experience?

Overall participants reported a positive experience with some challenges to implementation. Three main categories were identified – ‘design, format and content’, ‘nature of online’, and ‘negative experience’.

Design, format and content

Participants described their experience in relation to the format, content, support tools and time / travel saving:

“I found the programme easy to follow as each session covered different topics...in small easy to understand steps...I was happy with the online programme, especially as it could be started almost immediately” (102)

“Although initially sceptical...I found the online course very helpful and was also surprised that I was able to maintain a strict adherence to the course principles with the help of the online “Prof”. The whole package...was well designed and conducive to encouraging engagement...” (114)

“I really enjoyed the online programme, I found it both informative and engaging. It was very easy to use and still felt personal even though it was online” (123)

“Online program is great, especially if people can’t get to the courses in person. It helped me understand a lot...” (136)

One participant found the format useful but had some difficulties with completing the Time 1 and Time 2 questionnaires:

“I found the online programme very direct and easy to follow but due to my inadequate computer skills filling in details at onset of course and at end have been frustrating and lengthy” (110)

One participant stated that the support tools available were useful, although he had not utilised them personally:

“Although I did not need to use them I thought the e-mail prompts and online discussion boards a great support idea” (102)

Nature of online

One participant described their experience as positive, but did find some challenges in relation to committing to certain methods perceived to be more challenging:

"I found the online programme convenient to fit into my lifestyle and I definitely benefitted from the advice given. However as I was not 'answerable' to a human being, I think I shirked some of the tougher aspects of the course...which I think I would have gained improvements from" (111)

Negative experience

One participant stated that the programme did not meet their needs, describing the treatment as:

"Very long winded and over complicated" (139)

Question 2: What did you enjoy most about your experience?

The overall experience of the online programme was said to be a positive learning experience, facilitating improvements and accessibility to treatment. Four main categories were identified – 'design', 'improving sleep', 'accessibility', and 'applicability'.

Design

One participant fed back that they most enjoyed the animated nature of the programme in helping to explain the subject matter:

"The cartoon element of the programme which helped greatly in explaining the topics" (102)

Improving sleep

The majority of responses were associated with seeing improvements through perseverance, balanced thinking and hope:

"I learnt that if I put what I was told into practice and persevered with the programme my sleep improved. I have started to have dreams again and feel like I've had a deeper sleep" (110)

"I enjoyed seeing the positive pay-offs in my sleep by incorporating aspects of the course into my sleep schedule...gaining a more relative/proportional balance of my sleep problems" (111)

"The fact that I could see my sleep improving, together with the help of the online diary. The course has also helped me to become less anxious and stressed about those times when I don't sleep very well. I also haven't had a single night of "no sleep at all" which was a frequent occurrence...My sleep still

isn't perfect or consistent, but the course has allowed me to believe that perhaps by persevering with what I have learned so far, this may be possible in the future. In short, it has given me hope!" (114)
"Having more sleep, makes me better and happier person" (136)

Accessibility

This category was drawn from feedback relating to flexibility, ease of access and fitting into daily life:

"It could be accessed almost anywhere which made it ideal for me" (123)
"I enjoyed the fact that I could do it at home – around all my commitments" (138)

Applicability

Within this category, participants described enjoying the individualised approach, with attention to individual cases and relevance to them:

"Even though it was online there was a sense that the professor really knew my case" (138)

Question 3: What did you least enjoy about your experience?

Overall participants highlighted the need for application to individual experiences, and this formed the two main categories of 'content' and 'design'. One participant reported that there was nothing that they least enjoyed about their experience.

Content

Participants described least enjoying completion of the sleep diary and quiz:

"It was quite tedious filling out the sleep diary every day" (123)
"When I've got little time to do the quiz I got frustrated, but it's me and not the quiz I got frustrated with" (136)

One participant struggled a little with the increasing tasks:

"I felt a little overwhelmed by the course as the commitments and tasks significantly increased and I felt a bit of a failure when I decided not to fully embrace the extremely intense sleep restriction aspect of the course" (111)

Other comments focused on sleep restriction and maintenance as the least enjoyable aspect, but improvements were also mentioned:

"The sleep restriction phase was remarkably very difficult especially to begin with... However, because I was able to actually start falling and staying asleep during my "window" – this encouraged me to stick with it, and in some ways grow to enjoy it in the end as I started to feel that it was working!" (114)
"It was not easy to adjust to using a sleep window and sticking to it every night" (123)

Design

Some of the feedback highlighted less helpful aspects of the programme, including lack of human contact and supporting materials, and a sense that the content was not applicable:

"One thing about having insomnia is that your memory is impacted and therefore I think after completing each session you should be given a print out of all the info it contained. This would allow you to review what you need to do to improve your sleep at any given time" (118)
"A lot of the things had no relevance to me and the programme contradicted itself" (134)
"Lack of human side" (135)

Question 4: Are you likely to use any of the methods learnt to help manage your sleep?

Nine out of ten participants answered 'Yes' to this question and went on to state which methods. Overall feedback was that participants would use the majority of the core elements of the programme, apart from recording sleep and sleep processes. Codes were developed from the data and categories relating to these were applied in order to structure the feedback.

Sleep hygiene and relaxation

This aspect was equal to sleep scheduling in the largest number of responses, with participants listing specific methods that they would implement:

"I am walking for an hour daily...using techniques like mindfulness and relaxation to get to sleep..." (110)
"Loads: no caffeine in the afternoon evenings/I have hugely reduced my alcohol intake/I don't do intense exercise in the evenings...I don't eat soon before bed/I have increased my yoga practise particularly in the evenings to relax me before bed" (111)
"No phones, laptop, TV bed time" (136)

Sleep scheduling

This aspect was equal to sleep hygiene and relaxation in the largest number of responses, and contained feedback focusing on reshaping sleep and the bed-sleep connection:

“If I wake up early, I just get out of bed and do stuff” (111)

“Sticking to my “schedule” no matter what amount of sleep I may (or may not) have had the previous night” (114)

“The sleep window” (123)

Cognitive approaches

Feedback in this category focused on reducing alertness and reducing thoughts and anxiety:

“I switch off from mentally challenging chores well before bed to give myself a chance to unwind. I read a lot more in the evenings before bed instead of watching TV” (111)

“I think the “mindfulness” and “paradoxical thinking” approaches have also been very helpful in counteracting anxiety and stress about not sleeping” (114)

“The positive thought” (124)

Finally one participant stated:

“I will try all the strategies mentioned as soon as my family commitments allow me to” (138)

Conclusion for online programme

Feedback received led to a good understanding of participant’s experiences of the programme, which was positive overall, apart from one participant who did not appear to find the programme helpful in meeting their needs. Feedback on the methods that participants might use to help manage their sleep was somewhat sparser than that from the other interventions, but still reflected the core elements.

Secondary findings - Interpretative Phenomenological Analysis

Case study 1 – Philip – five-week CBT-I group

Male, age 58, White British, self-employed

The following analysis explores Philip's (pseudonym) experience of insomnia and the five-week group via examination of three superordinate themes that capture the nature and quality of his experience – 'evolution of insomnia', 'desperation and loneliness', and 'achievements and outcome'. Full quotes, page and line numbers are detailed in Appendix B11.

Evolutions of insomnia

Start of insomnia experience and association of insomnia and cancer

Philip described how his insomnia started, initially on Sunday nights. He identified work as the influencing factor for his insomnia, but this was further impacted upon by a diagnosis of cancer. Philip's diagnosis of cancer at the same time as experiencing insomnia seemed to create a sense that the insomnia was a consequence of having cancer, and that therefore the two were related. He arrived at the assumption that the insomnia would resolve once the cancer had been treated, however it deteriorated. Following his first consultation at the Insomnia Clinic, he reported learning:

"...that whatever precipitated your insomnia...isn't necessarily what perpetuates it...and I'd started to then work out that possibly whatever it was that triggered the insomnia initially it probably wasn't anything to do with cancer...Maybe it was just a set of...coincidences"

Prior to his diagnosis of cancer, Philip described how his insomnia was negatively impacting on day-to-day life. He described how insomnia was impacting 'in every aspect of my life actually...in many ways'.

Desperation, frustration and loneliness

Frustration of waiting for consultation then treatment

Philip described the four months from referral to initial consultation as a long time and this appeared very frustrating to him. He reported feeling grateful for being offered the expertise from the Clinic, and he seemed pleased to be doing something positive and taking control, but '*deeply frustrated and disappointed*' on hearing that the clinic waiting times for treatment would be approximately one year. He stated that he was '*pretty desperate*' by that time.

Preference for the five-week group

Philip expressed reservations about sleeping tablets, having tried one once that did not work. He appeared to feel that they would merely mask the problem as opposed to curing it. He explained that having found out about CBT-based treatment for insomnia, his conclusion was that it seemed an understandable thing to do:

"...when you are not able to sleep what you want is usually just want a quick win...you just want to be able to sleep...but...I didn't want to take any sleeping tablets...cause I knew...that wasn't going to cure anything. That might help a little bit but it's not going to get to the root problem of why I am not sleeping"

His response to being asked about his initial thoughts on being randomly allocated to the five-week group was that this had been his preference from the three interventions. It emerged that Philip saw the five-week group as a more intensive intervention compared with the others, and this seemed to suit him in terms of what he felt that he needed:

"...as far as I was concerned, doing an online course wasn't going to do it for me...coming on a sort of one day seminar, that wouldn't do it for me. I thought I need much more than that. So I was very pleased with the five weeks"

Group dynamics and environment

Whilst reporting liking being in a group, Philip found some of the other members of the group '*really irritating*'. However, these participants left the group and he reported being pleased about this; but their presence appeared to question whether or not he would have been able to stay in the group had they not left:

"I was just becoming quite really quite resentful about the amount of time they were soaking up"

He also seemed to find the physical environment unsatisfactory and the room uncomfortable, particularly as he felt this impacted upon his ability to concentrate. However, Philip stated that he liked the purposeful nature of attending the group at the same place at the same time, as he found that helpful.

Lack of acknowledgement of feelings around insomnia

As the treatment progressed, Philip felt that the feelings people had about insomnia were not fully acknowledged by the facilitator, or discussed in the depth that he would have liked, which he found difficult:

"...you know when...you're a insomniac and when you have nights where you just don't sleep at all and it's just night after night, you feel wretched, I mean you feel really awful. And you're pretty desperate. So...not to acknowledge how you feel is actually not a good thing..."

He described being pleased to be doing the therapy but frustrated by the lack of exploration of the origins of his insomnia. The author reflected on participants being offered a psychological therapy that is focussed on the here and now as a solution, rather than necessarily looking back, to which Philip agreed. It therefore appears to be a sense of acknowledgement of the insomnia experience that was so important to Philip.

Desperation and frustration of gap in sessions and wanting to share experiences

Philip felt the need to move forward quickly and do what he could to improve his insomnia as soon as possible. This was reflected from initial symptoms through to being in the group. It continued once in treatment, as there was a long gap between the first and second sessions. He seemed to feel rather let down by this, which compounded his feelings about the lack of acknowledgement of people's feelings around insomnia:

"...I can't speak for other people but I'm desperate. I haven't slept for three years. I'm pretty desperate. And so, I just want to get on with this. And it doesn't feel like we're getting on with anything. So I was very frustrated"

Philip also highlighted how important it was to him to feel able to share experiences within the group, on top of acknowledging feelings:

“...the people want to talk about their sleeplessness...I wanted to talk about mine and I know other people wanted to talk about theirs but there wasn’t really...either any encouragement or any...incentive to do that, but people were doing it around the margins ...And I just thought...why else would we be in a group? You know what’s the point of having...a group? ...when...you suffer like that...that’s the one thing you want to talk about”

Philip held a strong belief that the point of having a group is to be able to talk to others about sleeplessness. He later suggested that more could be made of people’s experiences. A rationale given for this was due to the feelings of desperation and loneliness, and how important it was to know that he was not alone. This is interesting from the author’s point of view, as the group as an intervention did not specifically aim to bring people together with similar experiences; rather it was a means of increasing accessibility for people to receive CBT-I in an effective way. However, by its very nature, people are likely to want to learn from and support each other, possibly hoping to gain additional benefits than would be available to people treated in an individual format.

Achievements and outcome

Implementation of strategies and routine

Philip was asked which CBT for insomnia strategies had helped or not helped him with his insomnia. In response he highlighted how keeping a sleep diary initially was very helpful, enabling him to work out his sleep efficiency and stick to a routine, as he seemed to like routines. The fifteen-minute rule also appeared helpful, although he stated that he *‘hated it’*. He described those as the core techniques, and whilst not keeping a diary anymore, he maintained the time schedule of going to bed and getting up in the morning. He had also implemented some sleep hygiene and stimulus control techniques, such as keeping anything IT-related out of the bedroom and not reading in bed. He stated generally he was more *‘mindful’* of the *‘triggers’* that kept him awake when he goes to bed. It emerged that Philip felt *‘sad’* about no longer drinking tea or coffee in bed, but he emphasised the importance of establishing and implementing a routine without this.

He stated not finding mindfulness or relaxation particularly helpful, or keeping a to-do list for the following day:

“...the lists before you go to bed...I found that they themselves were making me feel anxious...So...I stopped doing them...and I do do lists but I do them much earlier in the day”

Reflecting back to his original difficulties he was having with his sleep, Philip was asked for his thoughts about CBT as a solution now that he had experienced it as a treatment. It appeared to make sense to him:

“It was definitely about sort of stripping back all that, all the sleep...theory...You go to bed when you're tired an'...I mean...it's quite simple. You can't sleep unless you're tired...it's not rocket science. So you need to be tired...it's bringing discipline back...and that's not easy. It's really hard. And it continues to be...”

At this stage of the interview, the author reflected on the challenges people face regarding the technique of sleep scheduling and of its effect on many different levels. Philip identified with this and outlined how his sleep needs have changed over time.

Seeing improvements and positive changes

A theme that also came through in relation to the impact that the treatment had on his daily functioning and quality of life was gradually seeing improvements as a result of this new routine. However, a certain level of anxiety or fragility around this appeared to be present:

“...cause the sleep although it's improved...I don't feel secure about it. So...every night I go to bed and I'm anxious because I think, I'm not going to sleep tonight...but actually the reality is, is that more often than not, I do...”

This improvement was confirmed in his follow up appointment at the Clinic, and he reflected that the fact that he was having five or six nights out of seven when he was sleeping was *‘just a miracle...I mean, it's remarkable...’*

He seemed to be aware of where problems could arise, e.g. if he had a difficult day or week ahead, but appeared to think that things were beginning to shift for the better. He also reflected on whether the fact that his cancer treatment was over had an influence

on him emotionally. Therefore, the fact that the '*parallel set of activities*' were also positive appeared to have helped.

Need for ongoing support and self-confidence

What appeared to be key for Philip, and his future thoughts on his insomnia, was for this positive state to continue. The provision of some type of ongoing support beyond the treatment phase, such as Philip's attendance at the interview, was important to him. He described the need to maintain a connection:

"...I still want that sort of connection in a way, cause I fear, cause then I've sort of latched on I suppose...because...I have found it helpful and useful...otherwise I wouldn't be here..."

He had also agreed not to be discharged at his follow up appointment and had arranged to have another review with the Clinic team in six months time:

"So I think that's how I feel about it at the moment...So overall, positive. Good...but I'm not confident about it yet"

Case study 2 – Daniel – one-day CBT-I workshop

Male, age 34, White British, full-time employment

The following analysis explores Daniel's (pseudonym) experience of insomnia and the one-day workshop via examination of three superordinate themes – 'development of need to seek help', 'pros and cons of the workshop', and 'implementing and looking forward' (see Appendix B11).

Development of need to seek help

Duration of sleep issues and beliefs about medication

Daniel described experiencing problems with his sleep since he was a teenager. He did not appear initially worried about this, as he stated that teenage sleep is often disrupted; but his concern increased by his late teens when he decided to try sleeping tablets. However:

“...really didn’t get on with them at all...cause I felt like sometimes they’d help me get to sleep but I’d just wake up...a few hours after...a lot groggier the next day...”

He described wanting to minimise his tiredness rather than maximise his sleep, so concluded that taking sleeping tablets was pointless. It emerged that he had been against taking any kind of medication since.

Trigger for seeking help, future aspirations and the referral process

Until seeking help recently, Daniel expressed a certain resignation to the situation, thinking that it was something he just had to live with. However he found that it was beginning to impact further on his day-to-day functioning, as well as future aspirations. He described starting to feel that perhaps he should not accept the situation:

“...it’s one of those things where actually when you sit back and you look at it and think well, ok, I’m used to it...this is normal...but it’s not normal for...most people...”

He appeared to hold the belief that if he could improve his sleep and not be tired, there could be considerable benefits in terms of ‘*efficiency and capability*’, and generally being in a situation that was more ‘*normal*’. There was a real sense of frustration with how things were.

Daniel described a positive process of getting referred to the Insomnia Clinic, following an initial investigation for breathing issues. He seemed to appreciate the personal approach of his GP, highlighting that his GP knew his character and therefore knew that if he was seeking help it was serious. Daniel also seemed to appreciate being referred to a specialist team:

“...there’s a bunch of people who’ve dedicated... their life to learning a lot about sleep and stuff...compared to someone who might be, have read a few websites...I figured they would probably be a better place to help”

Contributing factors

Daniel identified some factors that had negatively impacted upon his sleep problems, such as work pressures, stress, and social activities. In addition, he identified one of the key elements that differentiates chronic and acute insomnia, and emphasised a certain irony in his use of words:

“...there is some kind of residual underlying thing...which is actually when everything’s fine...it’s still a bit of a nightmare to get to sleep. Probably the wrong choice of words!”

Pros and cons of the workshop

Treatment options and thoughts and feelings around study and allocation

Daniel appeared to find discussing different treatment options helpful in understanding how a CBT-based treatment would be best for him. He described being allocated to the one-day workshop as a way to:

“...accelerate it cause there was quite a long wait for the traditional one...which...I think I would’ve felt quite frustrated at...”

He mentioned being interested in science and often wanting to help out with ‘*those sorts of things if possible*’, and that he had reflected on the different interventions that he could have been randomised to. He concluded that the one-day workshop was most suitable as it fitted in with work, unlike ‘*committing to a specific time each week*’ for the five-week group. He also expressed that he had a gut feeling that the online programme was not what he wanted. Therefore his happiness at being allocated to the workshop appeared to link to his busy schedule. He also seemed to like the idea of contact with the team and having the ability to ask questions:

“cos there’s actual contact and you can ask questions. And there’s...different to just being given a bunch of stuff to read”

Understanding insomnia, the reassurance of others and taboos around insomnia

In talking about his experience of the one-day workshop, it materialised that Daniel found learning more about insomnia and techniques that could potentially help very useful. He also described the experience as reassuring in terms of being around other people with insomnia, and therefore no longer feeling quite so ‘*strange for not being able to sleep*’. He also highlighted feelings of a taboo around insomnia:

“...I guess, make you feel less... weird...I don’t know why but there’s a bit of a taboo around....sleep I think and...insomnia. It’s not something I would ever share with my work colleagues...or...anyone but my closest friends...just

because I think it has...connotations of someone who's just... very anxious or worries too...much or something..."

Daniel talked in a self-restricting way, and appeared to have concerns about how others would view him if they knew about his insomnia. He did not elaborate on this, or explain why he felt this way, instead moving onto the next theme quickly and therefore preventing the author from fully exploring this element without re-introducing the subject.

Course structure and information provision

Other elements of Daniel's experience seemed to relate to the structure of the workshop. He reported that the room was small and warm which was not ideal for a group of tired people with insomnia, especially when trying to learn. It emerged that he thought there was 'logic' in covering everything in one day, but also felt that delivery of the workshop over two half days could facilitate learning:

"...maybe splitting it in two would be good...cause then at least you've got half the things and then a few weeks later come back and then you've...already been able to try and implement those first things and ask questions on those as well...and come back and have a bit of a feedback on it...I think that would've been...helpful"

He suggested that a booklet to accompany the workshop would be beneficial to refer to, rather than several separate handouts. He also suggested that access to an online version would be useful, so that people could look back at or repeat learning on certain strategies, especially if they were struggling to maintain concentration on the one-day workshop due to tiredness.

The amount of content covered in the one-day workshop was mentioned a few times by Daniel. He referred to the quantity and volume of information provided, and seemed quite overwhelmed by it. This appeared to be linked with a concern of how to implement it in an already hectic and busy life.

Implementing and looking forward

Interconnectedness of programme and freeing up tension

Whilst reporting that there was a lot of information delivered within the workshop, Daniel also noted a beneficial '*interconnectedness*' to the workshop, as it gave a '*holistic view*' of how the various elements slot together. He also expressed a sense of relief having attended the workshop and learning the strategies, and described this as '*freeing up tension*' as it meant he no longer had to feel guilty for not going to bed and trying to sleep when he knew he would not. The workshop seemed to have given him permission to work his routine around his personal sleep schedule, which highlighted his experiences compared to what he might feel he, or society feels he, should do.

Implementing strategies in daily life

Despite the benefits, Daniel also described the challenges he had experienced in putting the techniques into practice. He seemed to have a concern that it would be '*very difficult to go over the hump of it getting worse before it getting better...*', which appeared to have put him off implementing what he learnt. However, having reflected upon this within the interview seemed to act as a reminder of what could be different and he reported that he wanted to '*give it another shot*' in order to see the benefits. He reported that he found sleep scheduling and the fifteen-minute rule the most challenging strategies to implement. The reason given was that he found resting, even if not sleeping, beneficial. This seemed to be particularly the case if he had something important to do the following day:

"...it always seems like a valid reason, like oh but I can't do it tonight because I need to be fresh for tomorrow for this..."

It appeared that his belief was that getting up if he was not asleep within fifteen-minutes would negatively impact upon his rest as well as his sleep. He also described the difficulty around social functions as well as obligations, as these could disrupt getting into a regular pattern.

Sleep scheduling as a technique appeared to be a significant factor related to implementation. He described this as substantially more challenging than the sleep hygiene techniques. However, he acknowledged that the significance of sleep scheduling could also reflect the fact that it could have the '*most major influence*' on his sleep. He spoke of his general concerns and of the need to dedicate time to gain mastery to enable him to implement this specific technique effectively, elaborating that:

“...maybe I needed a month off work, just to get into the habit...of it...it’s the risking of...having even less sleep was the hardest thing...because ultimately...when life gets in the way sometimes you actually can’t do that”

Daily routine therefore appeared to play a part in Daniel’s ability to put some of the strategies into practice and manage the times when he felt most tired. Napping was part of this, as he described times when he felt better able to sleep than when he was scheduled to sleep. Although having these difficulties in implementing some of the strategies, Daniel described how having options was helpful as:

“...there’s nothing worse than if you’ve tried everything and you still can’t do anything cause....there’s a certain amount of hopelessness or helplessness about it...”

He also appeared to feel more empowered and motivated by being given the tools to change his situation, rather than being resigned to it.

Reflecting on impact of treatment

Daniel’s response to being asked how he would describe the impact the workshop had so far on his daily functioning and quality of life was that there were elements that did help, even if he had not applied them in a *‘coherent and organised way’*. It surfaced that he felt the problem was still there, but he also recognised that he needed to implement the techniques so *‘there’s a chance that it could work’*.

On discussing how day-to-day life felt following the workshop, Daniel reflected on moving forward and beginning to contemplate how he might implement what he had learnt. At this point he described being *‘cautiously hopeful’*. In response to being asked how he saw his future, Daniel reported:

“I’d say I’m cool, yeah, cautiously optimistic. I don’t have a...strong feeling that...if I implement these things I’d definitely be able to sleep...but I think there’s a chance...which is better than before...where I was just...resigned to the fact that I was always gonna sleep really badly and...never reach my full potential as a person!”

Once again, Daniel used irony to describe a clearly very important concern. This kind of light-hearted terminology was used a few times during the interview whilst describing things that were very impactful on his day-to-day life and how he viewed himself. This

may have been as a coping strategy employed to normalise his circumstances. It could also have been that he felt relaxed in the participant-researcher interaction. The conversation continued for forty-five minutes after the interview had been completed, so it could be the latter along with the opportunity to further discuss the issues at hand.

Case study 3 – Gloria – online CBT-I programme

Female, age 52, White British, part-time employment

The following analysis explores Gloria's (pseudonym) experience of insomnia and the online programme via examination of three superordinate themes – 'seeking help', 'impact of insomnia', and 'implementing the programme, new routine and helping myself' (see Appendix B11). Gloria was identified from the waiting list, rather than from her first appointment. In interpreting Gloria's experience, the author has kept to the meaning and words used by the participant, who's first language is not English, in order to reflect the tools that she used to talk about her experience.

Seeking help

Development of severe insomnia, initial referral and being taken seriously

Gloria described having bad sleep for a long time and felt that she was coping with it until it reached crisis point five years ago when:

"...it wrecked my...lifestyle really and people will think, erm, get on with it, it's only sleep, but if people...haven't experienced... sleepless nights...then you know...it's a huge issue actually"

Here she appears to portray not only her own development of severe insomnia, but also her perceptions of what other people think about insomnia. She continued to explain that it was not a quick development, instead *'it crept on, bit by bit'* until it seemed to take over her life, which she found *'awful'*.

Describing her quest for help, Gloria explained that she initially had an overnight sleep test that did not show any problems. She then illustrated her frustration where she felt that her insomnia was doubted and not seen as a genuine problem. She outlined the medical response to this result:

“... unfortunately they can put it down to anxieties...and then...you don’t get any further...because...that’s it and...they say go back to your GP or take antidepressants or whatever but ...I know that I had a genuine problem”

For Gloria, it appears that having a friend who had a similar experience played a key role in her pushing for treatment, in addition to providing her with support. She therefore requested that her GP refer her to Guy’s and St Thomas’s Hospital, and reported being ‘*delighted*’ when this was done. Having her friend and a supportive GP appeared to make all the difference to Gloria’s experience, where previously she was struggling to be taken seriously.

On being asked how she felt about the Guy’s referral and whether she had any expectations, Gloria stated that she was ‘*desperate*’, though not ‘*anxious*’, as she felt that she might get some answers, especially as her friend had done. She therefore seemed to have confidence in this referral, and high expectations as a result. Having been seen at Guy’s, Gloria was referred to the Insomnia Clinic at RLHIM, and also informed of the current waiting list. She reported that the doctor told her there was a six to eight month wait for treatment, but this did not appear to faze her:

“...I said that’s fine I’m desperate, I’m willing to do anything...but...within eight months somebody rang me...”

CBT as an intervention and being shown the right track

Gloria was asked what she thought about being offered a CBT-based treatment, and she described being ‘*really excited*’. She stated that:

“...when somebody’s desperate...they’re willing to do anything...hopefully to help, well for you to help me I have to help myself...and I accept the help. What a privilege because I know...other people maybe their GP...wouldn’t be able to to refer them, but I was so blessed”

Gloria appeared to have a strong sense of her role in improving her situation, and how she could play a part in this. She also recognised that others may not have been given the same treatment options as her, which was insightful given the level of distress about her own insomnia that she described. She reported being ‘*thrilled*’ to be offered the opportunity to both contribute to the study and to receive help herself.

Gloria used the word '*desperate*' throughout her descriptions of seeking help, and this use of the word so frequently helps to understand what she thought and felt prior to receiving treatment, as well as helping to explain why she was so keen to be involved.

Impact of insomnia

Consequences of insomnia on self and family

In talking about her experience of insomnia, Gloria highlighted the impact that her condition had on both herself and her family:

"...I was always tired, it lead to me being irritable, it affected my family too, my children and my husband, you know...it does put pressure on...the family too...I felt bad...you feel a rubbish per...[person], a rubbish...mum"

She illustrated this further with examples of spending sunny days '*lying on the sofa*' or trying to catch up with sleep, feeling that she was '*wasting my days*'. She seemed to feel that everything was impacted upon as a result. Once again she was considering others, and associating the symptoms she experienced and the ways she needed to manage her insomnia with being a '*rubbish mum*'. But this was also a driver for her seeking help. Gloria was asked what she was hoping for by being referred to the hospital. She replied that she was hoping for '*answers...and more quality of sleep...so I can be a better person, you know*'. This links in with her perceptions about what others think, and she went on to elaborate:

"Cause you feel bad, you know...it's not an obvious illness, but it does impact...your life"

Differing views and support of others

Gloria described an instance where she found that others did not understand her insomnia in the way that she would have hoped. In discussing her provision of a CBT-based treatment, she reported that:

"...I mentioned to one friend...what I'm doing and directly she put it to a psychology...she sort of was...not put me down but she was, negative...I mentioned about the programme...and I felt that she was judging me...which I was really disappointed. So I stopped mentioning to friends"

The use of strong words such as ‘*negative*’ and ‘*disappointed*’ in this statement appear to highlight how hurtful this occurrence was to Gloria, which suggests that this could have resulted in her frustrations about insomnia not being ‘*an obvious illness*’ even harder to manage, especially when it caused such distressing symptoms that she felt she could not talk to friends about. She described experiencing a form of stigma. Others, however, were more compassionate and she appeared to feel well supported by her husband, her daughter, and a further friend.

The online programme gave access to a support forum and the author was interested to know whether Gloria felt the need to make use of this. She stated that she did not use the support forum very often but described how her friend provided the support she needed:

“A few...times, I saw what other people, you know chatting, but...I didn’t make the most of it...I was curious to see how other people...would cope with that. But because I’ve got my friend...I had somebody...who’s going through the same thing. So that’s really helpful”

Implementing the programme, new routine and helping myself

Programme format, expectations of treatment and advice from friends

Gloria reported a positive experience with completing the online programme, describing it as ‘*amazing*’ and ‘*very professional*’. She also commented on the content and applicability, highlighting that it was clearly created using research and with the best of intentions for patients.

Gloria expressed surprise related to some of the techniques taught, such as not reading in bed, as she reported thinking that this aided relaxation. She seemed quite disappointed by this news, describing previously enjoying reading in bed. She found that others’ ideas and advice for what might be helpful were also different to the programme recommendations, and she did not appear to find this advice from others’ very useful:

“...friends try to help you...people try to give you an advice...whether it’s, it’s right or wrong ...and some of it...sort of some old people’s...tales...that might be like a tiny, like one percent of the truth...but that’s not gonna...solve your problem totally”

As well as learning new techniques from the programme, this account also appeared to reflect her frustration at other people viewing her insomnia as somewhat trivial and something that can be cured easily. She believed this was more supporting myths.

Positive experience of treatment

In describing her overall experience of the online programme, Gloria reported that she would *'recommend it to ...anybody'*, and that she had shown her friend the programme in action. Gloria stated that it was the knowledge that she found helpful. In addition, she showed enthusiasm to inspire others to tackle their sleep problems, as well as help them from her newfound knowledge:

"And I can benefit other people...so it's just not being naïve...I was thrilled, I accepted the help because some people would just want to put up with it..."

Determination, implementing learning and challenges

Gloria described a feeling of determination in her commitment to the programme:

"I knew...it was a commitment....but I was desperate and I insisted. I'm a very strong person. That I wanted to get help so I insisted to...to finish it all...I wasn't willing to give up"

There was evidence of her determination continuing after completing the programme, within her account of describing being highly *'motivated'* and trying her best to maintain what she has learnt. She reflected on where future problems could arise, as well as recognising her willpower to stick to the programme. Gloria identified several elements that were particularly challenging, including keeping a sleep diary and remembering the content of the programme. She seemed to be concerned about maintaining these, so reported writing things down to help herself. Gloria spoke about the importance of helping herself, which appeared to be an important part of how she explored options, learnt new information, implemented and reviewed her experience.

A part of the programme that she described as challenging but most helpful was finding out about the impact having a *'cat nap'* had on sleep. She viewed *'napping'* in the day and evening as a means to cope and have more time with her family. However, she learnt from the programme about the need to build up a drive for sleep by remaining awake all day, and whilst difficult, she described this as helpful. In fact, Gloria reported not finding any part of the programme unhelpful, although did state that getting up in the night with the fifteen-minute rule, and at a specific time as part of sleep scheduling,

was difficult. Struggling to do these strategies appeared to also challenge the idea that she must help herself, as she took responsibility for not being able to carry these out in stating *'I didn't help myself with that'*.

Noticing improvement

Gloria was asked about the effect the treatment had on her daily functioning and her quality of life. She stated that *'I'll be lying if I say...it's 100%'* but she had noticed improvements in the number of hours and days in a row that she is now sleeping compared to what she had experienced for years. To be able to quantify this improvement seemed to be particularly impactful for her. She also went on to say:

"...I'm much more, in the morning when I wake up I just want to do things. To make the most of the days but I still have...some nights where...I still can't sleep...but compared to before, it's amazing..."

Sticking to routines and avoiding bad habits

Gloria explained that she was noticing occasions when she fell asleep on the sofa and that as a result, by the time she was went to bed she was more alert. She seemed to have found ways to manage this as much as possible. On being asked if there was anything that she felt might be important to share about her experience of the programme, Gloria again identified the need to stick to routines and help herself, even after someone may think they have *'cracked it'*:

"...things will start creeping back to the...old habits and then...things can go back...to being difficult. So, it's not easy to stick to it...but do the best...if I slip into the...old habits...I remember...cause I suffer....the next day...So I think it's all my doing! I have to help myself. So otherwise I can't complain and if I don't stick to it"

Positive impact

Gloria highlighted where she felt that she has had most benefitted from the programme, and this linked back to how she described the impact of her insomnia on herself and family originally:

"Being a lot calmer...It's horrible. Cause I knew I was not nice...irritated with my friends...bit snappy with my husband...I didn't like myself and that is a...vicious circle of...not liking yourself, then feeling guilty that you snapped at your family"

She also described feeling more energetic and having better concentration, and reflected back to how she felt before:

“Cause it’s awful when your concentration goes, I actually feel very embarrassed...cause you feel like an old person who can’t remember things”

Once again, her concern was how she was viewed and what others might think.

DISCUSSION

This study compared the effectiveness of three UK CBT-I treatment delivery interventions, namely a manual-guided five-week group, a one-day workshop, and an online programme, on key outcomes. The secondary aim of the study was to explore participatory experience of patients in each intervention through the completion of a patient experience questionnaire (for all treatment completers), and semi-structured interviews from a purposive sample of one participant from each of the three interventions to form a case study.

Primary findings – statistical analysis

Primary findings across interventions

The findings revealed that CBT-I treatment resulted in a highly significant improvement in insomnia severity, dysfunctional beliefs and attitudes about sleep, depression, and daytime functioning and health-related quality of life (assessed by work and social adjustment) across interventions. There were also significant improvements for anxiety, mental health or insomnia related medication use, time in bed, sleep onset latency, wakefulness after sleep onset, and sleep efficiency. Therefore, it was concluded that the average change in scores was not due to chance, but was a result of participating in a CBT-I intervention. There were no significant differences in non-prescription drug use, alcohol use, number of awakenings, or total sleep time, before and after across interventions.

Primary findings between interventions

No significant differences between the effectiveness of the three CBT-I interventions were found, apart from more time in bed, for the online programme. Therefore, the one-day workshop and the online programme were assessed to be as effective overall on key outcomes as the five-week group.

Through analysis of individual items of outcome measures, a greater understanding of statistical significance across and between interventions was gathered.

Insomnia severity

Across interventions

CBT-I treatment improved a range of insomnia severity outcomes across interventions, except for waking up too early and how noticeable the impairment on quality of life was to others, and the difference was significant overall. CBT-I had the greatest positive impact on difficulty falling asleep, difficulty staying asleep, dissatisfaction with current sleep, daily functioning, and worry/distress about sleep. As highlighted previously, a person experiencing insomnia is likely to view their sleep as unacceptable, often noticing impairments in their daytime functioning, and being very concerned about the unpredictable nature of their sleep (Espie & Kyle, 2009). In addition, as Espie et al. (2007) reported, difficulty initiating or maintaining sleep, or both, can be associated with reduced daytime alertness and productivity, poorer quality of life, higher rates of relationship difficulties, and increased ill-health. Therefore to see highly significant improvements in these outcomes was particularly encouraging given previous research.

Between interventions

There was no significant difference between the five-week group, one-day workshop or online programme for insomnia severity overall or on individual items.

Dysfunctional beliefs and attitudes about sleep

Across interventions

There was an overall significant reduction in intense and frequent unhelpful beliefs and attitudes about sleep across interventions, and eleven of sixteen individual items were significant. This supports previous research by Edinger and Means (2005), which reported that, without intervention, people can make misattributions about the causes of insomnia, develop misconceptions about sleep needs and the effects of sleep loss, have concerns about the consequences of poor sleep, and dysfunctional beliefs about sleep promoting practices. These cognitions have therefore been successfully modified in the interventions.

Between interventions

There were no significant differences between the five-week group, one-day workshop or online programme for dysfunctional beliefs and attitudes overall or on individual items.

Depression

Across interventions

There was a highly significant improvement in depression outcomes across interventions. Roth (2007) reported that approximately forty percent of adults with insomnia also have a diagnosable psychiatric disorder, most notably depression; and that a co-morbid psychiatric disorder such as depression or anxiety may be a consequence, of as well as a risk factor for disrupted sleep. In the present study, ninety-one percent of participants had some form of depression, ranging from mild to severe, with the majority having moderate depression. This was a high figure, but could reflect the fact that participants were identified from the specialist Insomnia Clinic rather than from primary care. However, following CBT-I, the percentage with depression reduced to seventy-seven percent of participants, and mean scores dropped from moderate to mild, which was an important finding.

Previous research found depression severity to be a predictor for early drop-out from treatment (Ong, Kuo & Manber, 2008), but patients who remained in treatment experienced benefits equivalent to those with low depression severity (Manber et al., 2011), which also occurred in the present study. CBT-I treatment therefore appeared to have a positive impact on a range of depression outcomes, and significant differences before and after CBT-I were found for the items 'trouble falling or staying asleep' and 'feeling tired or having little energy'. The item 'medication is probably the only solution to sleeplessness' was also approaching significance. CBT-I was not directly targeting these outcomes, so to have significant results for two items and overall was of particular interest. It may also be helpful to consider baseline depression outcomes in preventing possible drop-out from interventions.

The reduction in score categories for both insomnia severity and depression before and after CBT-I was itself a valid finding, regardless of statistical significance. Thoughts and worries have been commonly reported reasons for sleep problems (Calem et al., 2012; Sleepio, 2012; The Sleep Council, 2014), so there appears to be a bi-directional effect between insomnia and depression; when insomnia symptoms are improved so too are depression symptoms.

Between interventions

There were no significant differences between the five-week group, one-day workshop or online programme for depression overall or on individual items.

Anxiety

Across interventions

There was a significant improvement in anxiety outcomes across interventions. Seventy-point-five percent of participants had anxiety, ranging from mild to severe, with the majority having mild anxiety. This figure reduced to fifty-nine percent after the CBT-I interventions. CBT-I treatment therefore appeared to be positively impacting upon a range of anxiety outcomes, and a significant difference before and after CBT-I was found for the item of 'not being able to stop or control worrying'. Once again, CBT-I is not directly targeting this outcome, so to have a significant individual item and overall is an interesting result. This supports the findings of Pillai, Anderson, Cheung, Bazan, Bostock et al. (2015), who found that CBT-I interventions could improve co-morbid anxiety symptoms among individuals with insomnia.

Between interventions

There were no significant differences between the five-week group, one-day workshop or online programme for anxiety overall or on individual items.

Daytime functioning and health-related quality of life (assessed by work and social adjustment scale)

Across interventions

There was a highly significant improvement in work and social adjustment scores across interventions. CBT-I appeared to improve a range of daytime functioning and health-related quality of life outcomes, specifically home management (for e.g. cleaning, shopping, cooking, looking after home/ children); private leisure activities (for e.g. reading, gardening, hobbies, walking); and family and relationships (for e.g. forming and maintaining relationships with others). There was not a significant change for ability to work, and social leisure activities (for e.g. parties, outings, entertaining), although the outcome overall was significant. As Kyle et al. (2010) suggest, health-related quality of life is helpful in the context of insomnia, as it quantifies the impact of disease or illness on aspects of functioning. The extent of meaningful change in patient's lives has been highlighted previously (Vitiello et al., 2013), and to be able to measure these improvements in this study has enabled further knowledge to be generated.

Between interventions

There were no significant differences between the five-week group, one-day workshop or online programme for this measure overall. However, further analysis showed that the affect that insomnia had on ability to work (question 1) was approaching significance between the five-week group and the one-day workshop participants, where scores for participants in the one-day workshop increased detrimentally by half a point on average when the other group averages decreased. This was an interesting finding, as across interventions there was not a significant change for ability to work, so this eludes to a possible difference between the interventions. Further research would be required to investigate this difference, including the amount of content relating to maintaining the ability to work in both interventions.

Mental health or insomnia related medication use

Across interventions

There was a significant improvement in mental health and insomnia-related medication use across interventions, although numbers of participants included in this analysis were small in considering significance. However, the results showed a reduction in the number of those prescribed and taking medication, and an increase in those not prescribed medication, which is positive. The reduction in medication use also supports the findings by Morgan et al. (2004) who found that psychological treatment for insomnia can improve sleep quality, reduce hypnotic medication use, and improve health-related quality of life. This is particularly pertinent when there are no NICE guidelines to support CBT-I, and it is known that the majority of insomnia patients in routine practice are treated with medication rather than CBT-I (Espie & Kyle, 2009).

Between interventions

There were no significant differences between the five-week group, one-day workshop or online programme for medication use between interventions.

Sleep diary outcomes

Across interventions

There were significant improvements for time in bed, sleep onset latency, wakefulness after sleep onset, and sleep efficiency, but not number of awakenings or total sleep time, across interventions. It should be noted that a reduction of time in bed was

potentially a positive outcome in treatment, as confirmed by an increase in sleep efficiency. Whilst participants were spending less time in bed, the time that they were in bed they were sleeping more, which was a key target for CBT-I interventions. Time in bed would therefore be likely to increase as sleep efficiency increases.

Between interventions

There was no significant difference between the five-week group, one-day workshop or online programme for sleep onset latency, number of awakenings, wakefulness after sleep onset, total sleep time, or sleep efficiency. A significant difference was found for time in bed between interventions. Having investigated this further, it was determined that the difference lay between the five-week group and the online programme at Time 2. Participants in the five-week group spent less time in bed than those on the online programme – a different outcome to Time 1 when participants in the one-day workshop group spent less time in bed than on the online programme. Therefore, participants allocated to the online programme were generally spending more time in bed before and after the intervention than the other two groups. There could be benefits or disadvantages to this at Time 2, depending on whether or not it is a reflection of implementing the strategies or not. One might expect to be initially reducing time in bed in order to increase time asleep in bed and therefore sleep efficiency. The fact that sleep efficiency was not significant between groups implies that spending more time in bed has not impacted sleep efficiency between the online programme participants and the other groups. Further research would be required to fully investigate this difference.

Non-prescription drug use and alcohol use

There were no significant differences in non-prescription drug or alcohol use across or between interventions.

Impact and importance of primary findings

The results support the hypothesis that there would be improvements in key outcomes across interventions, given the effectiveness of the three CBT-I interventions already evidenced from previous research. Of particular note was the drop in clinical severity of insomnia and depression symptoms, as insomnia can be associated with complex

clinical presentations and physical and/ or mental health problems. These findings support previous research that found targeting insomnia through CBT-I was effective for treating co-morbid insomnia and depression (Ashworth et al., 2015; Hsu et al., 2015). Therefore, participating in any one of these three CBT-I interventions would be of benefit to someone experiencing insomnia and related symptoms.

The concept of “clinical significance” is important to consider here. Jacobson, Follette and Revenstorf (1984) first highlighted the need to determine whether or not different mental health therapies were truly effective in helping clients. They suggested that clinical significance is the ability for an intervention to help a client or patient so that they no longer meet the criteria for a diagnosis. It is therefore an assessment of how meaningful the outcome is, and how important it is in a clinical setting (Dempster, 2011). In this study, this would reflect whether CBT-I has been able to treat the insomnia to a level where the patient no longer meets an insomnia diagnosis, or reports that they have returned to a normal level of functioning, regardless of statistical significance. An average score of 15.11 for insomnia severity at Time 2 showed that participants were nearly at the cut off point for inclusion in this study, which was a score of 15 or more on the ISI indicating moderate severity insomnia. This was a clinically significant, as well as statistically significant, drop from Time 1 where the average score was 19.59, at the upper end of the moderate severity category. Morin et al. (2011) investigated ISI sensitivity to detect clinical improvements, comparing baseline to post-treatment change scores with clinical global improvement ratings obtained from an independent assessor. The authors found that a mean change of -4.65 (95% CI: -2.61, -6.69) indicated slight improvement, -8.36 (95% CI: -7.20, -9.53) as moderate improvement, and -9.89 (95% CI: -8.74, -11.04) as marked improvement. The change of -4.48 in this study is therefore a little less than the criteria for slight improvement, but falls within the ninety-five percent confidence interval range. The ISI also specifically assesses the extent to which insomnia interferes with daily functioning, and scores for this question in this study moved from an average of 3.3 (much interferes) at Time 1 to 2.5 (somewhat interferes) at Time 2.

Clinical significance in relation to other elements of key outcomes can also be explored. Average depression scores dropped from the moderate to mild category, and below the recommended cut-off score of 9. Anyone scoring 10 or above could be considered to have clinically significant symptoms of depression (Department of Health, 2011). Therefore a drop from an average of 11.55 to 8.41 would be considered clinically significant. This also applies to anxiety scores, which whilst remaining in the mild category, dropped from an average score of 8.14 to 6.68, which is below the

recommended cut off score of 7 (Department of Health, 2011). Daytime functioning and health-related quality of life (assessed by the work and social adjustment scale) dropped from insomnia 'definitely' affecting the ability to carry out day-to-day tasks, to between 'slightly' and 'definitely'. These results therefore give a good indication of how clinically significant the interventions have been, and provide a useful direction for future treatment.

All participants were informed that should the research show one intervention to be more effective than the others, those previously assigned to the other interventions would be given the opportunity to participate in the most favourable intervention upon completion of the study. As no overall statistically significant differences were found between interventions this was not required, but all participants, regardless of completion, will be given a summary of the study findings.

All three interventions adhered to the core features of CBT-I and have been evidenced to not only improve sleep, but also anxiety, depression, daytime functioning and health-related quality of life. This approach has enabled similar outcomes to be found as per previous research (Espie et al., 2001, 2007, 2012; Bastien et al., 2004; Morgan et al., 2004; Verbeek et al., 2006; Ritterband et al., 2009; Swift et al., 2012; Bothelius et al., 2013; Thorndike et al., 2013; De Bruin et al., 2014; Lovato et al., 2014; van Straten et al., 2014; Blom et al., 2015; Kaldo et al., 2015; Trauer et al., 2015), but this is the first known study to compare these three interventions alongside health-related quality of life and patient experience, and that can be delivered in both primary and secondary care.

Participant demographics

Previous research has suggested that there is an increased prevalence of insomnia in women, older adults, and those who are unemployed or with a lower socioeconomic status (Ohayon, 2002; Roth, 2007; Calem et al., 2012; Sleepio, 2012; The Sleep Council, 2014). The participants recruited to this study were an almost fifty-fifty split in terms of gender, with only slightly more females (52.3%) than males (47.7%). They were also a relatively young sample, with the largest number between the age of 35 and 44. Fifty-seven percent were in full-time employment. Others were self-employed and in part-time work, with much lower numbers unemployed and retired, in addition to a student and a carer. This population does not necessarily reflect previous research, but this was a comparatively small sample that had consented to participate in this

study, compared to the large number of people seeking help from the Clinic. It cannot therefore be entirely generalisable to this patient population. However, outcomes do show external validity by being similar to previously published good quality data from other samples. Future research could compare outcomes between interventions with different demographic groups.

Secondary findings – Content Analysis

Understanding of the experiences of participants in each intervention was gained through content analysis. Constructive and informative feedback about elements of the interventions that worked well and areas for improvement were provided.

Similarities between interventions

Overall participants in all three interventions reported a positive experience. A sense of shared experience and the positives of being in a group came across in the five-week group and the one-day workshop. Participants in the online programme did not mention feeling disadvantaged from not being in a group, although a few participants mentioned that the lack of human contact was difficult at times. The content of the programme, the format in which it was delivered, and the facilitation of strategies were appraised positively across interventions, with accessibility mentioned as a benefit to the online programme. Participants learnt the key techniques for improving their sleep, evidenced by all core elements being mentioned across interventions, and achievements since completing the interventions were reported, with a greater sense of optimism and hope for the future.

Five out of the thirty participants who completed feedback stated that there was nothing that they least enjoyed about their experience. For those that provided comments on this, the themes were similar across interventions and related to the importance of considering individual needs in terms of involvement, format, learning, and implementation, as well as managing the increased tasks that were part of the interventions.

Recording sleep through the use of sleep diaries and sleep processes were fairly similar across the five-week group and one-day workshop, and although not

specifically mentioned by participants of the online programme, this is an key element of the intervention and these participants did mention monitoring patterns in their sleep.

Differences between interventions

The main differences in overall experiences of participants in each intervention were that participants in the five-week group tended to focus more on learning and reflection to implement changes, whereas those in the one-day workshop commented on what they learnt. They also found that there was a lot of information to take in, in one day, and those on the online programme found some challenges to implementing what they had learnt.

The online programme was the only intervention to get any negative feedback, with one participant who did not appear to find the programme helpful in meeting their needs. Feedback on the methods that participants might use from the online programme to help manage their sleep was somewhat sparse compared to feedback received regarding the other interventions. However, they still reflected the core elements and tended to feed back more on their overall experience, commenting on good design, helpful content, encouraging adherence and engagement, and time/travel saving.

Some of the participants in the one-day workshop found it a long day, which impacted on their ability to focus, particularly as the rooms used were reported to not be entirely suitable. In contrast, those in the five-week group had occasional issues with administration and gaps between sessions. Those in the online programme found the ease of it fitting into daily life and accessing the programme from home a benefit.

Cognitive approaches, such as reducing alertness, thoughts and anxiety, formed the largest number of responses from the five-week group for methods that participants would use, followed by sleep scheduling. In contrast, sleep scheduling was reported as the method the majority of participants from the one-day workshop would use, followed by sleep hygiene and relaxation. Participants completing the online programme reported both sleep hygiene and relaxation and sleep scheduling equally in terms of methods that they would use. Consequently, there was a difference in elements of CBT-I that participants found most effective, and further investigation into the weighting of specific topics in each intervention would be required to better understand this difference.

Secondary findings - Interpretative Phenomenological Analysis

Case studies generated from one participant from each of the three interventions revealed an in-depth insight into the perspectives of each participant and their experience of the allocated intervention. They also contribute to an understanding of the clinical significance of these findings for this sample. All three participants described the evolution of their insomnia, with mostly different experiences, yet there were some similarities regarding the impact of insomnia such as work stresses and impact on relationships. There was a sense of frustration pertaining to seeking treatment from all three, but at different time points. The online programme participant had initial frustrations at not being taken seriously; the five-week group participant felt frustrated at having to wait for the treatment but felt that he needed this particular mode of delivery of the intervention; and the one-day workshop participant was pleased with being allocated the workshop as he felt that he would have been frustrated to wait for the five-week group. All three participants appeared to experience a strong feeling of desperation, in terms of how urgent it was for them to get help, to get going once treatment started, and to feel able to share experiences with others who understood. This supports the findings of existing research that found poor sleepers are seven times more likely to feel helpless, and five times more likely to feel alone, compared with good sleepers (Sleepio, 2012).

Findings from all three case studies also support the research by Espie and Kyle (2009), as participants viewed their sleep as unacceptable in terms of quality and pattern. Difficulties reported with regards to concentration, memory, quality of life, and fatigue also support previous research (National Institutes of Health, 2005; Espie et al., 2007; Kyle, Morgan & Espie, 2010; Sleepio, 2012). Furthermore, employment and impact on work was mentioned by all three participants, supporting the reciprocal link suggested by Linton and Bryngelsson (2000), and the role of work in patient narratives about their insomnia experiences (Henry et al., 2008).

Case studies explained reasons for help-seeking for their insomnia in a way that supports previous research (Carey et al., 2005; Morin et al., 2006). Daytime symptoms, such as fatigue, irritability, and reduced work productivity were all described. Participants appeared to reach a threshold of noticeable impact on daytime functioning before seeking medical advice. This study only accessed people who had already sought help for their insomnia, but they did not do so until it had become fairly serious.

If the general population had awareness about CBT-I and treatment options were more available, this could encourage people to seek help sooner and therefore lessen the negative impact that they experience.

Loneliness, taboo and stigma were also common themes identified. However, the five-week group participant's experience of the group helped with this, as he described knowing that he was not alone. However, he also felt that the point of having a group was to talk to others about sleeplessness, which was quite different from the reasons for running a group in clinical practice, namely as a means of effectively increasing accessibility for people to receive CBT-I. Whilst it is accepted that people would be likely to want to learn from and support each other, this is not the main reason for delivering the treatment in this format.

The one-day workshop participant felt reassured being around others with insomnia in the workshop due to the taboo around insomnia; and the online programme participant reported experiencing a form of stigma when she felt judged by a friend for seeking help and having CBT-based treatment. Concern about others views of insomnia was therefore an issue for both of these participants. The one-day workshop participant's concerns about what other people might think about his sleep problems, and the online programme participant's perceptions about insomnia not being an obvious illness, both link with research on invisible illnesses such as arthritis, where the importance of being believed, understood and acknowledged by others is highlighted (Hadert and Rodham, 2008). Experiences also support research conducted by Carey et al. (2010), that found participants felt that the impact insomnia had on their lives was wide-ranging and misunderstood by significant others and those treating their sleep complaints. The perception of insomnia as benign, trivial, or a problem that someone should be able to cope with alone, as described by Stinson et al. (2006) were echoed not by the participants themselves in terms of their experiences, but by how some of the people around them reacted. This confirms the social stigma described by previous research (Stinson et al., 2006; Henry et al., 2013; Morin, 2014) as a barrier for help-seeking.

Interestingly, within their accounts, participants did not raise concerns about some commonly described cognitive elements such as a racing mind (Robatham, 2011), or behavioural aspects such as poor sleep habits or irregular schedules (Morin & Benca, 2012). They also did not specifically mention feeling depressed or anxious before treatment, rather linking this with reasons why others may think they have a problem with their sleep. Anxiety was only mentioned by one participant in relation to post-treatment and still feeling anxious about whether they would sleep, especially if they

were anxious about work. Yet these participants were part of a sample that saw significant improvements in depression and anxiety symptoms, and where CBT-I had improved outcomes, therefore having worked directly on cognitive and behavioural elements. So it may be that this is not automatically raised as an issue in the context of other complaints. Ustinov et al. (2010) stated that reports of insomnia might be related to specific cognitive factors, such as depression and anxiety, which cause individuals to be more distressed with their sleep, and increase their dissatisfaction with daytime functioning. Participants did however associate sleep and bedtime with a range of negative thoughts and feelings, as suggested by Harvey (2002).

All three case studies were very against taking medication for their insomnia, which is the opposite to what some research has shown, in that GPs think patients expect a prescription (Dyas et al., 2010). The relief at accessing specialised care echoes Cheung et al.'s (2014) research, which found participants were relieved to access specialised care after unsuccessful treatment attempts. However, contrary to Cheung et al.'s (2014) other findings that participants were concerned that this specialised care fell under the medical specialty of mental health, none of the participants in this study appeared to be concerned that they were seen by a psychiatry team or offered a psychological therapy.

All three participants revealed preferences, advantages and disadvantages of their respective interventions, which echo the feedback provided in the experience questionnaires. The five-week group participant appeared to find sleep scheduling using a diary the most effective strategy for managing his insomnia, which is similar to the overall feedback from the five-week group participants where sleep scheduling was the second highest response in terms of methods they would use. The online programme participant appeared to find sleep scheduling a key part of improving her sleep, but also mentioned sleep hygiene and relaxation, which echoes the responses from other participants completing the online programme who reported these two elements equally in terms of methods that they would use.

The participants seemed to feel that they had made some progress, particularly the five-week group and online programme participants, who appeared to have embraced the core techniques and seen improvements, though both were still not confident about their sleep. The one-day workshop participant less so, evident in his description of receiving lots of information at one time, and not having the opportunity to try techniques and come back to discuss them. But he was cautiously optimistic about having the tools to make changes that could work, rather than being resigned to not

sleeping. He appeared to think that sleep scheduling would be the method that would have the most impact, which is also reflected in other participant's feedback questionnaires from the one-day workshop.

Participants' reports therefore support the findings of Harvey, Inglis and Espie (2002), in that the use of stimulus control and sleep scheduling were contributing to improvements in sleep onset latency and wakefulness after sleep onset. However, other findings by Harvey et al. (2002) for cognitive restructuring, including altering beliefs about sleep, contributing significantly to reducing wakefulness, were not reported in the case studies, although emerged from the quantitative findings.

Edinger and Means (2005) stated that the ultimate success of CBT depends on patients' willingness, ability, and motivation to learn and implement behavioural changes at home. This includes acceptance of CBT as a potential solution to their sleep difficulties, as well as adhering to recommendations by transferring skills learned to their day-to-day lives. The author believes these participants have done so, and by interpreting their experiences, further insight into their perspectives and experience of the different modes of delivery of the CBT-I interventions has been gained.

Impact and importance of secondary findings

Overall findings provided useful information on participant experience, which in addition to an overall positive treatment effect across all interventions, could provide future options and choice for individuals in determining what would be the most beneficial intervention for them based on their specific needs. This supports the suggestion made by Ritterband and Thorndike (2012), that different people are likely to need different treatment approaches, and the more options available, particularly those that can be made widely available, the greater likelihood that those seeking help can obtain it.

Methodological considerations and lessons learned – primary and secondary findings (participant experience questionnaires)

Part of designing this as a pilot study was to explore feasibility in an applied setting. Whilst research has shown that these CBT-I interventions are efficacious in primary care (Espie et al., 2001, 2007, 2012; Swift et al., 2012), practical problems remain in making CBT widely available (Espie & Kyle, 2009). The reality of carrying out this study was not what was initially expected in terms of recruitment, treatment preferences, and administration of the study. Sample size was an issue, even with the data collection period having been extended from six months to nearly two years. The Lead Clinician reported that the majority of invited patients did not wish to participate, as they did not want to risk being randomised to the online programme. However, despite the small sample size, what is reassuring from these results is that participants in the online programme group had equivalent outcomes, and in some individual items actually better scores than the other two groups.

There was a higher drop-out rate from the online programme in this study than the research by the authors of the programme (Espie et al., 2012), but rates were similar to that of Yeung, Chung, Yan-Yee Ho and Ho (2015). However, neither of these latter studies was in a clinical context, which would be important to consider in future research. In addition, it may be helpful to explore the experiences of other online CBT-I providers and how they have managed this issue.

As many people experiencing insomnia also have other medical or sleep conditions (e.g. pain, sleep apnoea), or mental health problems (e.g. depression), the Clinic is run by a team of psychiatrists in order to offer physical and mental health assessment. Therefore, whilst mitigating for serious mental or physical health conditions in the inclusion and exclusion criteria, the team found that eligible patients did not want to participate as they did not want to be allocated to the online programme. Many reported to the team that they felt their insomnia was too serious a problem not to be dealt with in person, and that they wanted the support of attending the clinic. The author attempted to address this by offering all participants the opportunity to review their participation once they received the results of their treatment allocation, but this did not have much of an impact.

Dyas et al. (2010) emphasised the need to elicit and understand patient preferences and expectations, with educational support for practitioners to enable this. Morin (2014) also confirmed that patient preference and compliance are important considerations. Cvengros (2015) highlighted research by Vincent, Walsh and Lewycky (2010) that found beliefs about control and treatment preferences impacted treatment satisfaction, adherence and treatment outcomes. Although participants in the current study were recruited on the basis of the study being randomised, many expressed a preference for treatment at the point of consent. The one-day workshop was seen as the most appealing to participants, due to needing to take less time off work, increased travel for the five-week group, and a worry about support and self-discipline if completing the online programme. Other treatment preferences related to time of day, day of the week, fitting around holidays and work commitments. These preferences are in contrast to the significant level of need for help that was also articulated. Therefore, some participants felt that they were only willing to commit one day or certain times to addressing their insomnia problem, even though they reported struggling for years and it having a significant impact on their daily life. Whether expectations or lack of receiving preferred treatment impacted on participants satisfaction, adherence and outcomes is hard to say, as not all participants expressed a preference due to the randomised nature of the study, and no intervention was considered more effective than another, but preferences would be an interesting element to include in future research.

A further factor was that the author held an honorary contract with the Clinic, but did not have access to the clinical systems or secure email, and was not involved in the interventions other than the set up and ongoing coordination of those allocated to the online programme. Therefore, the author needed to be in regular telephone contact with the clinic administration team in order to book participants into either a five-week group or a one-day workshop. The five-week group booking was relatively straightforward as this was the standard treatment, but arranging participation in the one-day group involved lengthy arrangements between participants and the Clinic to ensure the majority could attend, a room was booked, and the facilitator released from their clinic, which often took several months to arrange. Following both the one-day workshop and the online programme, the author also had to ensure that participants were recorded as having received treatment, as this was outside the norm, and in order for them to be booked into a follow up appointment. In light of this, if this study were to be replicated, it would be recommended that an internal researcher or clinic staff conduct the research.

The Time 2 follow up, at approximately two months following start of treatment, was relatively short given the potential lifelong nature of insomnia. However, given the difficulties in both recruiting participants and receiving follow up measures, having a long-term follow up may well have created further challenges. It would be an important element to consider in future research, particularly in understanding what success there has been in relieving symptoms or preventing relapses, and because previous research has found that results are usually maintained (Morin et al., 2006). The case studies, however, provided some insight into long-term clinical outcome, as these were at ten months (five-week group), nine months (one-day workshop), and eight-months (online programme) from start of treatment.

In relation to the quantitative findings, treatment effects may have been negatively impacted upon by the use of intention to treat analysis, as some improvements may not have been recorded. However, without this, the study would not have reflected actual clinical practice, including non-adherence to treatment or attendance, and in a study aiming to increase choice and accessibility this reflection is important. The inclusion of sleep diary data also helped to prevent misperception of sleep. Research has found that patients often overestimate their sleep onset latency and underestimate their total sleep time (Harvey & Tang, 2012). Therefore, including sleep diaries alongside measures of insomnia severity, psychological distress, and health-related quality of life and daily functioning, enabled a broader picture to be gathered in evaluating effectiveness of the three interventions.

It is not possible to make generalisations or conclusions that go beyond the information in the data, but the small sample size overall has not limited the usefulness of these findings in considering current clinical practice. The findings suggest that there were improvements in outcomes across interventions, with no overall significant differences between interventions. Therefore, replicating the current study on a larger scale, bearing in mind the learning from this pilot, would provide further evidence for accessibility to a greater range of interventions in future.

Methodological considerations and lessons learned – secondary findings (case studies)

The interviews generated rich data, which allowed the author to gain insight into participants' unique experience of the CBT-I treatment. The inclusion of this aspect of the research via an ethics amendment at the latter stages of the research has provided valuable contextual information. It is important to highlight that the author as researcher may have influenced findings from her own view of the world, alongside the nature of the interaction between researcher and participant. Results are therefore an interpretation of the participant's experience. The author has reflected on personal demographics, which also fitted within the majority of patient demographics for the study for gender, age, ethnicity and employment status. The author noticed that both the one-day workshop and online programme participants continued to interact with the author for up to forty-five minutes after the interview had concluded, compared to the five-week group participant who was happy to debrief and then leave. The author wonders whether this could relate to the one-day workshop participant being closest in age to the author, and the online programme participant being female, whereas the five-week group participant was older and male. However there will always be researcher and participant dynamics, strengths and limitations, to all methodologies, particularly in clinical practice.

Implications for future research and practice

This study developed into a mixed methods design, which has brought richness to the results and learning that will be beneficial to both the understanding and treatment of insomnia, as well as participatory experience in the future. If these CBT-I interventions were incorporated into stepped care, as has been suggested by previous research (van Stratan and Cuijpers, 2009), they could address some of the barriers to implementation. Findings from this research could also contribute to matching individual patient needs to treatment interventions. As research has suggested (Espie et al., 2007; 2009; Kyle et al., 2010; Vitiello et al., 2013), the common co-occurrence of insomnia with depression and anxiety symptoms in primary care could enable different interventions to be applied in an efficient way as an additional intervention in primary care mental health, depending on presenting needs and accessibility. The success of interventions in this pilot study therefore contributes to the ongoing development of

effective stepped-care treatment. Through improving service delivery, funding CBT-I training for health professionals and provision of interventions, savings could also be made by enabling sleep specialists to see only the most severe cases of insomnia, in addition to potential reductions of long-term use of medication in the general population.

A challenge for the future is therefore to disseminate evidence-based therapies to both patients and health care professionals in order to make treatments more widely available and deployable, as well as enable better understanding of current approaches and options. There is a need to raise further awareness, confidence and knowledge of CBT-I amongst GPs and other health practitioners through dissemination of research and training.

CONCLUSION

Sleep is a key issue in maintaining good mental and physical health, but increasingly people are suffering with insomnia and experiencing poor health-related quality of life and daytime functioning as a result. CBT-I has been shown to be effective. However, there has been little research conducted which compares the efficacy of different treatment modalities on health-related quality of life alongside other measures related to patients' experience of insomnia such as daytime functioning, depression and anxiety. Treatments are not widely available or well understood. This original pilot study explored the effectiveness of three UK CBT-I treatment interventions on outcomes and participatory experience. The use of mixed methodology in this study has been able to factor in quantitative findings, patient satisfaction outcomes, and participant experience of the interventions to inform clinical practice. The results have positive implications for improving the management of insomnia for a large number of patients, and thereby improving the well-being, mental and physical health of many people with sleep problems.

Health psychology as a discipline has so far had little involvement in improving the psychological impact of poor sleep and insomnia. However, as the interdependence between mental and physical health is more widely recognised, health psychology could make a very valued contribution to research, training and delivery of CBT-I interventions, therefore improving insomnia symptoms, beliefs and attitudes, depression, anxiety, health-related quality of life and daytime functioning for those experiencing insomnia.

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Appendix B1



**CITY UNIVERSITY
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RESEARCH INVITATION

Dear Patient

I am a doctoral research student on the Professional Doctorate in Health Psychology at City University London. I am conducting a research study with the team at the Insomnia Clinic at the Royal London Hospital for Integrated Medicine (RLHIM) looking at different ways of delivering treatments for improving the symptoms of insomnia. You are invited to take part in the study as part of your treatment at RLHIM.

The study aims to determine which of three proven methods delivers the most effective outcomes in terms of your overall sleep, ability to function during the day and your quality of life:

1. a manual-guided five-week group (standard treatment at RLHIM)
2. a one-day group workshop (occasionally delivered at RLHIM but available through the research)
3. an online programme carried out at home (only available through the research)

As part of the study, you will be asked to complete two questionnaires, along with a feedback form on your experience of the treatment.

A detailed information sheet is provided along with this letter. It explains why you have been invited and what you will do if you decide to take part in the study, as well as your rights during the study. Taking part, or deciding not to take part, will not affect the care you receive.

If you are interested in participating, or would like more information about this study, please contact me:

Tel: [REDACTED]

Email: [REDACTED]

This study has received ethical clearance for conduct in the NHS by the Central London Research Ethics Committee.

Yours sincerely

[REDACTED]

Belinda Hemingway
Professional Doctorate in Health Psychology
City University London, Northampton Square, London, EC1V 0HB

Appendix B2



**CITY UNIVERSITY
LONDON**

Psychology Department
Social Sciences Building
City University London
Whiskin Street
London EC1R 0JD

Telephone: [REDACTED]
Website: <http://www.city.ac.uk>



**Royal London Hospital for
Integrated Medicine**

Insomnia Clinic

Telephone: [REDACTED]
Website: <http://www.uclh.nhs.uk/>

PATIENT INFORMATION SHEET

1. Title of study

Cognitive Behaviour Therapy for Insomnia (CBT-I): a pilot study to explore whether mode of delivery influences sleep outcomes, daytime functioning and health-related quality of life.

2. Invitation

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

3. What is the purpose of the study?

Sleep is a key issue in maintaining good mental and physical health, but increasingly people are suffering with insomnia, either as a short-term condition lasting less than a month, or as a chronic, long-term condition.

A number of treatments have been developed to improve sleep quality, sleep pattern, and daytime functioning. Many of these interventions have been based on Cognitive Behavioural Therapy (CBT). CBT can help to change how someone thinks (cognitive) and what he or she does (behaviour), in order to feel better and improve state of mind.

CBT for insomnia (CBT-I) is a brief, focussed treatment that aims to change factors that maintain insomnia, including behaviours (such as poor sleep habits and irregular sleep patterns), psychological factors (such as worry and unhelpful beliefs), and physical factors (such as tension). It has been shown to not only improve sleep, but also daytime functioning and health-related quality of life.

A range of CBT-I delivery methods have been found to be effective. This study will explore which of three recently developed CBT-I methods is the most effective for improving overall sleep, ability to function during the day and quality of life:

1. a manual-guided five-week group
2. a one-day group workshop, or
3. an online programme carried out at home following your initial appointment

4. Why have I been invited?

You have been invited to take part in the study because you have been referred to the Insomnia Clinic. At least 50 patients will be involved in this study.

5. Do I have to take part?

Participating in the study is voluntary. It is therefore up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form to confirm that you have agreed to take part. You are still free to withdraw at any time and without giving a reason. Taking part, or deciding not to take part, will not affect the care you receive.

6. What will happen if I take part?

Sometimes we do not know which way of treating patients is most effective for particular results. To find out, we need to compare different treatments. We put people into groups and give each group a different treatment. The results are then compared to see if one is better.

Once written consent is received from you, you will be given an ID number that only the researcher will know. Your anonymous ID number will then be put into one of three treatments groups by chance (randomly):

1. a manual-guided five-week group (standard treatment at RLHIM)
2. a one-day group workshop (occasionally delivered at RLHIM but available through the research)
3. an online programme carried out at home (only available through the research)

Being randomly put into one of the three treatment groups means that there are no influences on which treatment you receive. It does also mean that you will not be allocated to a treatment based on your own choice.

The researcher will then contact you to tell you by telephone which treatment you will be participating in and discuss whether to send you the 'before treatment' questionnaire by email or by post. This questionnaire takes around ten minutes to complete. The researcher will inform the Insomnia Clinic of the

group you have been put in so that arrangements can be made for your treatment.

On completion of your treatment, you will be asked to complete the 'after treatment' questionnaire, plus the patient experience questionnaire, which take around fifteen minutes to complete in total. You will also have a follow-up appointment with the Insomnia Clinic two-three months after treatment completion, as per usual practice.

The study is due to end by Autumn/Winter 2015, when the chief investigator will analyse the questionnaires to see if any one of the treatments had more of an impact on participants' overall sleep, ability to function during the day and quality of life.

7. What are the possible disadvantages and risks of taking part?

CBT-I is generally well accepted by patients, although you might find some aspects of the treatment challenging. However previous research tells us that the treatments do work, and you will be supported by the research and clinical team throughout.

If participants require additional support, the research team is able to provide a list of registered agencies that can provide help and advice, and participants will also be encouraged to visit their GP.

8. What are the possible benefits of taking part?

We cannot promise that the study itself will directly benefit you, but you may feel some fulfilment from just participating. Plus the information we get from the study will help improve the treatment of patients with insomnia, and depending on the results of the study may provide evidence for different options being available for them in the future.

9. Will my taking part in this study be kept confidential?

Yes. Your name will not be written on any of the information you give us, only an ID code number. None of the information you give will be linked with your name, as the researcher will be the only person with access to that information.

Consent forms, questionnaires and ID numbers will be confidentially stored in a locked filing cabinet only accessible to the researcher. This information will be destroyed three years after the study has finished.

Should there be a need to break confidentiality due to the identification of risk to yourself or others, you will be informed of this and what will need to happen to ensure your own or others safety.

10. What will happen to the results of the research study?

The results from the study will be used to inform the treatment provided at the Insomnia Clinic in future. The results will also form part of the researcher's doctoral thesis, and be summarised and presented both at medical/psychology conferences and through scientific publications, so health professionals can learn more about the results of the study. At the end of the study you will also be provided with a summary of the study findings. You will not be identified in any report/publication.

11. What will happen if I don't want to carry on with the study?

You are free to withdraw from the study without an explanation or penalty at any time, and this will in no way affect the standard of care you receive. If you wish to withdraw, please inform the researcher who will make any necessary arrangements with the Insomnia Clinic.

Even if you do wish to withdraw from the study, you will still be offered treatment through the standard pathway at the Clinic.

12. What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to the researcher.

If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee. You could also write to the Secretary at: Research Office, E214, City University London, Northampton Square, London, EC1V 0HB, or email Anna.Ramberg.1@city.ac.uk

You may also contact the Patient Advice and Liaison Service (PALS) at University College London Hospitals at: Ground Floor, University College Hospital, 235 Euston Road. London, NW1 2PQ, or telephone 020 3447 3042 or email PALS@uclh.nhs.uk

Alternatively, you can contact the Lead Clinician at the Insomnia Clinic (Dr Hugh Selsick) on [REDACTED].

13. Who is organising the research?

The researcher is a doctoral research student on the Professional Doctorate in Health Psychology at City University London. The research is supported by and will take place at the Insomnia Clinic at The Royal London Hospital for Integrated Medicine (RLHIM), located within University College London Hospitals (UCLH) NHS Trust.

14. Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the Central London Research Ethics Committee.

15. What should I do now?

If you are interested in participating, or would like more information about this study, please either contact the researcher (details below) or ask the Insomnia Clinic to pass on your details to the researcher.

16. Contact for further information

You may obtain more information about this study by contacting the researcher (Belinda Hemingway) on [REDACTED] or [REDACTED]

Alternatively, you can contact the Lead Clinician at the Insomnia Clinic (Dr Hugh Selsick) on [REDACTED].

Thank you for taking the time to read this information sheet.

Appendix B3



**CITY UNIVERSITY
LONDON**

University College London Hospitals
NHS Foundation Trust



**Royal London Hospital for
Integrated Medicine**

INITIAL CONTACT CONSENT FORM

Title of Study:

Cognitive Behaviour Therapy for Insomnia (CBT-I): a pilot study to explore whether mode of delivery influences sleep outcomes, daytime functioning and health-related quality of life.

Please insert your initials in the boxes below to indicate agreement:

1	I confirm that I have been given the invitation letter (dated 29/08/15, version 6) and information sheet (dated 29/08/15, version 6) for the above research study	
2	I confirm that I am interested in finding out more about the research study and potentially taking part	
3	I confirm that the researcher Belinda Hemingway may contact me directly using the contact details given below	

Name of person interested in finding out more about the research study: _____ _____	Contact details: Telephone _____ Email _____ _____	Date: ____/____/2015	Signature: _____
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Appendix B4



CITY UNIVERSITY
LONDON



QUESTIONNAIRES – TIME 1 and TIME 2

Patient Identification Number:

Cognitive Behaviour Therapy for Insomnia (CBT-I): a pilot study to explore whether mode of delivery influences sleep outcomes, daytime functioning and health-related quality of life.

Thank you for taking the time to complete these questionnaires prior to your insomnia treatment at RLHIM as part of the above research study.

1. ABOUT YOU

GENDER

Male _____
Female _____

AGE

EMPLOYMENT STATUS – choose one

Self-Employed _____
Full-Time Work _____
Part-Time Work _____
Unemployed _____
Retired _____
Student _____
Carer _____
Volunteer _____
Other _____

ETHNICITY

White

British _____
Irish _____
Other _____

Asian or Asian British

Indian _____
Pakistani _____
Bangladeshi _____
Chinese _____
Other _____

Black or Black British

Caribbean _____
African _____
Other _____

Mixed

White and Black Caribbean _____
White and Asian _____
White and Black African _____
Other _____

Other Ethnic Group

2. THE INSOMNIA SEVERITY INDEX

1) Please rate the current (ie, last 2 weeks) severity of your insomnia problem(s).

	None	Mild	Moderate	Severe	Very
a. Difficulty falling asleep	0	1	2	3	4
b. Difficulty staying asleep	0	1	2	3	4
c. Problem waking up too early	0	1	2	3	4

2) How satisfied/dissatisfied are you with your current sleep pattern?

Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
0	1	2	3	4

3) To what extent do you consider your sleep problem to interfere with your daily functioning (eg daytime fatigue, ability to function at work/daily chores, concentration, memory, mood etc)

Not at all interfering	A little	Somewhat	Much	Very much interfering
0	1	2	3	4

4) How noticeable to others do you think your sleeping problem is in terms of impairing the quality of your life?

Not at all noticeable	A little	Somewhat	Much	Very much noticeable
0	1	2	3	4

5) How worried/distressed are you about your current sleep problem?

Not at all worried	A little	Somewhat	Much	Very much worried
0	1	2	3	4

Guideline for Scoring/Interpretation

Add scores for all seven items (1a + 1b + 1c + 2 + 3 + 4 + 5) =
Total score ranges from 0-28; if total score falls between:

0-7	=	No clinically significant insomnia
8-14	=	8-14 = Subthreshold insomnia
15-21	=	Clinical insomnia (moderate severity)
22-28	=	22-28 = Clinical insomnia (severe)

3. BELIEFS AND ATTITUDES ABOUT SLEEP SCALE

Several statements reflecting people's beliefs and attitudes about sleep are listed below.

Please indicate to what extent you personally agree or disagree with each statement.

There is no right or wrong answer. For each statement, circle the number that corresponds to your own *personal belief*. Please respond to all items even though some may not apply directly to your own situation.

		Strongly Disagree											Strongly Agree
1.	I need 8 hours of sleep to feel refreshed and function well during the day	1	2	3	4	5	6	7	8	9	10		
2.	When I don't get the proper amount of sleep on a given night, I need to catch up on the next day by napping or on the next night by sleeping longer	1	2	3	4	5	6	7	8	9	10		
3.	I am concerned that chronic insomnia may have serious consequences on my physical health	1	2	3	4	5	6	7	8	9	10		
4.	I am worried that I may lose control over my abilities to sleep	1	2	3	4	5	6	7	8	9	10		
5.	After a poor night's sleep, I know that it will interfere with my daily activities on the next day	1	2	3	4	5	6	7	8	9	10		
6.	In order to be alert and function well during the day, I believe I would be better off taking a sleeping pill rather than having a poor night's sleep	1	2	3	4	5	6	7	8	9	10		
7.	When I feel irritable, depressed or anxious during the day, it is mostly because I did not sleep well the night before	1	2	3	4	5	6	7	8	9	10		
8.	When I sleep poorly on one night, I know it will disturb my sleep schedule for the whole week	1	2	3	4	5	6	7	8	9	10		
9.	Without an adequate night's sleep, I can hardly function the next day	1	2	3	4	5	6	7	8	9	10		
10.	I can't ever predict whether I'll have a good or poor night's sleep	1	2	3	4	5	6	7	8	9	10		
11.	I have little ability to manage the negative consequences of disturbed sleep	1	2	3	4	5	6	7	8	9	10		
12.	When I feel tired, have no energy, or just seem not to function well during the day, it is generally because I did not sleep well the night before	1	2	3	4	5	6	7	8	9	10		
13.	I believe insomnia is essentially the result of a chemical imbalance	1	2	3	4	5	6	7	8	9	10		
14.	I feel insomnia is ruining my ability to enjoy life and prevents me from doing what I want	1	2	3	4	5	6	7	8	9	10		
15.	Medication is probably the only solution to sleeplessness	1	2	3	4	5	6	7	8	9	10		
16.	I avoid or cancel obligations (social, family) after a poor night's sleep	1	2	3	4	5	6	7	8	9	10		

4. PHQ-9 AND GAD-7

PHQ-9

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?

		Not at all	Several days	More than half the days	Nearly every day
1.	Little interest or pleasure in doing things	0 ☐	1 ☐	2 ☐	3 ☐
2.	Feeling down, depressed, or hopeless	0 ☐	1 ☐	2 ☐	3 ☐
3.	Trouble falling or staying asleep, or sleeping too much	0 ☐	1 ☐	2 ☐	3 ☐
4.	Feeling tired or having little energy	0 ☐	1 ☐	2 ☐	3 ☐
5.	Poor appetite or overeating	0 ☐	1 ☐	2 ☐	3 ☐
6.	Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0 ☐	1 ☐	2 ☐	3 ☐
7.	Trouble concentrating on things, such as reading the newspaper or watching television	0 ☐	1 ☐	2 ☐	3 ☐
8.	Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0 ☐	1 ☐	2 ☐	3 ☐
9.	Thoughts that you would be better off dead or of hurting yourself in some way	0 ☐	1 ☐	2 ☐	3 ☐

PHQ-9 total score

GAD-7

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?

		Not at all	Several days	More than half the days	Nearly every day
1.	Feeling nervous, anxious or on edge	0 ☐	1 ☐	2 ☐	3 ☐
2.	Not being able to stop or control worrying	0 ☐	1 ☐	2 ☐	3 ☐
3.	Worrying too much about different things	0 ☐	1 ☐	2 ☐	3 ☐
4.	Trouble relaxing	0 ☐	1 ☐	2 ☐	3 ☐
5.	Being so restless that it is hard to sit still	0 ☐	1 ☐	2 ☐	3 ☐
6.	Becoming easily annoyed or irritable	0 ☐	1 ☐	2 ☐	3 ☐
7.	Feeling afraid as if something awful might happen	0 ☐	1 ☐	2 ☐	3 ☐

GAD-7 total score

5. WORK AND SOCIAL ADJUSTMENT

Work and Social Adjustment

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems look at each section and determine on the scale provided how much your problem impairs your ability to carry out the activity.

1. **Work** – if you are retired or choose not to have a job for reasons unrelated to your problem, please tick N/A (not applicable)

0	1	2	3	4	5	6	7	8	N/A
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all		Slightly		Definitely		Markedly		Very severely, I cannot work	

2. **Home management** – cleaning, tidying, shopping, cooking, looking after home/children, paying bills etc

0	1	2	3	4	5	6	7	8
☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all		Slightly		Definitely		Markedly		Very severely

3. **Social leisure activities** – with other people, e.g. parties, pubs, outings, entertaining etc

0	1	2	3	4	5	6	7	8
☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all		Slightly		Definitely		Markedly		Very severely

4. **Private leisure activities** – done alone, e.g. reading, gardening, sewing, hobbies, walking etc

0	1	2	3	4	5	6	7	8
☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all		Slightly		Definitely		Markedly		Very severely

5. **Family and relationships** – form and maintain close relationships with others including the people that I live with

0	1	2	3	4	5	6	7	8
☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all		Slightly		Definitely		Markedly		Very severely

6. MEDICATION, NON-PRESCRIPTION DRUGS AND ALCOHOL

Use of mental health related or sleep medication

Prescribed and taking	☐
Prescribed but not taking	☐
Not prescribed	☐
Not stated	☐
Unknown	☐

Type of medication.....

Use of non-prescription drugs

Yes	☐
No	☐

If yes, please specify.....

Use of alcohol

Yes	☐
No	☐

If yes, approximate number of units per week.....

MANY THANKS FOR COMPLETING THIS QUESTIONNAIRE

Appendix B5**SLEEP DIARY – TIME 1 and TIME 2****Patient Identification Number:**

Week starting:	Last night I went to bed at:	This morning I got up at:	So I was in bed for (minutes):	It took me ? minutes to fall asleep:	I woke ? number of times:	During the night I was awake for (minutes):	In total I think I slept for (minutes):	Other info:
Night 1								
Night 2								
Night 3								
Night 4								
Night 5								
Night 6								
Night 7								
Total								
Average in minutes			<u>B</u>				<u>A</u>	
Average in hours and minutes							<u>C</u>	

A divided by B x 100 = Sleep Efficiency A____/B____x100 = ____**Your chosen rising time minus your average time asleep in hours and minutes (C) = your Threshold Time****_____ - _____ = _____**

Appendix B6



**CITY UNIVERSITY
LONDON**



PATIENT EXPERIENCE QUESTIONNAIRE

Patient Identification Number:

Cognitive Behaviour Therapy for Insomnia (CBT-I): a pilot study to explore whether mode of delivery influences sleep outcomes, daytime functioning and health-related quality of life.

Thank you for taking the time to complete this questionnaire following your insomnia treatment at RLHIM as part of the above research study.

- 1. How would you describe your experience of either: 1) the five-week group; 2) the one-day workshop; or 3) the online programme?**

- 2. What did you enjoy most about your experience?**

- 3. What did you least enjoy about your experience?**

- 4. Are you likely to use any of the methods learnt to help manage your sleep?**

If so, which?

Yes

No

Appendix B7



**CITY UNIVERSITY
LONDON**



CONSENT FORM

Patient Identification Number:

Title of Study:

Cognitive Behaviour Therapy for Insomnia (CBT-I): a pilot study to explore whether mode of delivery influences sleep outcomes, daytime functioning and health-related quality of life.

Name of Researcher: Belinda Hemingway

Please initial box

1. I confirm that I have read and understand the information sheet (dated 29/08/15, Version 6) for the above study and have had the opportunity to ask questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected

3. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party

4. I agree to take part in the above study

Name of Patient

Signature

Date

Researcher

Signature

Date

Name of Person taking consent
(if different from researcher)

Signature

Date

1 copy for patient; 1 copy for researcher; 1 copy to be kept with hospital notes

Appendix B8



**CITY UNIVERSITY
LONDON**

Psychology Department
Social Sciences Building
City University London
Whiskin Street
London EC1R 0JD

Telephone: 020 7040 8500
Website: <http://www.city.ac.uk>



Telephone: [REDACTED]
Website: <http://www.uclh.nhs.uk/>

SUPPLEMENTARY INFORMATION SHEET AND CONSENT FORM

1. Title of study

Cognitive Behaviour Therapy for Insomnia (CBT-I): a pilot study to explore whether mode of delivery influences sleep outcomes, daytime functioning and health-related quality of life.

2. Invitation

We would like to invite you to take part in an additional element to this research study. Before you decide whether you would like to take part it is important that you understand why this additional research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

3. What is the purpose of the additional element to this study and why have I been invited?

The original study aimed to explore which of three recently developed CBT for Insomnia methods was the most effective for improving overall sleep, ability to function during the day and quality of life:

1. a manual-guided five-week group
2. a one-day group workshop, or
3. an online programme carried out at home following your initial appointment

The research team is conducting an additional element to the study to further explore the experience element of the research, through carrying out interviews of participants who have already completed their treatment in order to give us more insight.

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign the consent section at the end confirming that you have agreed to take part. You are still free to withdraw at any time and without giving a reason.

5. What will happen if I take part?

Once written consent is received from you, the researcher will arrange a time to meet with you or telephone you to carry out the interview. This interview will take around 30 minutes and be either in person at a location convenient to you, or over the telephone.

The interview will be semi-structured in the sense that the researcher will be asking particular questions, but will also encourage you to talk about your experience such as how you came to seek treatment, completing your allocated treatment, and whether CBT for your insomnia has helped. The interview will be audio-recorded for later transcription and analysis by the researcher.

You will receive a £10 voucher for taking part in the study.

6. What are the possible disadvantages and risks of taking part?

We do not believe there are any disadvantages for you in taking part in this additional part of the study.

7. What are the possible benefits of taking part?

We cannot promise that this additional part of the study itself will directly benefit you, but you may feel some fulfilment from just participating in the interview and having the opportunity to talk about and reflect on your experience. Plus the information we get from the study will help improve the treatment of and options for patients with insomnia in the future.

8. Will my taking part in this study be kept confidential?

Yes. Your name will not be written on any of the information you provide to us. The researcher will only use your original ID code number. None of the information you give will be linked with your name, as the researcher will be the only person with access to that information.

Signed consent, interview transcriptions and ID numbers will be confidentially stored in a locked filing cabinet only accessible to the researcher. This information will be destroyed three years after the study has finished.

Should there be a need to break confidentiality due to the identification of risk to yourself or others, you will be informed of this and what will need to happen to ensure your own or others safety.

9. What will happen to the results of the research study?

The results from the study will be used to inform the treatment provided at the Insomnia Clinic in future. The results will also form part of the researcher's doctoral thesis, and be summarised and presented both at medical/psychology conferences and through scientific publications, so health professionals can learn more about the results of the study. At the end of the study you will also be provided with a summary of the study findings, if you wish to receive this. You will not be identified in any report/publication.

10. What will happen if I don't want to carry on with the study?

You are free to withdraw from the study without an explanation or penalty at any time, and this will in no way affect the standard of any future care you receive. If you wish to withdraw, please inform the researcher who will make any necessary arrangements with the Insomnia Clinic.

11. What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to the researcher.

If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee. You could also write to the Secretary at: Research Office, E214, City University London, Northampton Square, London, EC1V 0HB, or email Anna.Ramberg.1@city.ac.uk

You may also contact the Patient Advice and Liaison Service (PALS) at University College London Hospitals at: Ground Floor, University College Hospital, 235 Euston Road. London, NW1 2PQ, or telephone 020 3447 3042 or email PALS@uclh.nhs.uk

Alternatively, you can contact the Lead Clinician at the Insomnia Clinic (Dr Hugh Selsick) on [REDACTED].

12. Who is organising the research?

The researcher is a doctoral research student on the Professional Doctorate in Health Psychology at City University London. The research is supported by the Insomnia Clinic at The Royal London Hospital for Integrated Medicine (RLHIM), located within University College London Hospitals (UCLH) NHS Trust.

13. Who has reviewed the study?

This study amendment has been given a favourable ethical opinion for conduct in the NHS by the Central London Research Ethics Committee.

14. What should I do now?

If you are interested in participating, or would like more information, please contact the researcher (details below).

15. Contact for further information

You may obtain more information about this study by contacting the researcher (Belinda Hemingway) on [REDACTED] or [REDACTED]

Alternatively, you can contact the Lead Clinician at the Insomnia Clinic (Dr Hugh Selsick) on [REDACTED].

Thank you for taking the time to read this supplementary information sheet.

CONSENT

Please initial box

- | | |
|--|--------------------------|
| 1. I confirm that I have read and understand this supplementary information sheet (dated 24/04/16, Version 2) for the above study and have had the opportunity to ask questions | ☐ |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected | ☐ |
| 3. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party | ☐ |
| 4. I agree to take part in this additional element of the above study | ☐ |

_____	_____	_____
Name of Patient	Signature	Date
_____	_____	_____
Researcher	Signature	Date

1 copy for patient; 1 copy for researcher; 1 copy to be kept with hospital notes

Appendix B9



**CITY UNIVERSITY
LONDON**

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INTERVIEW GUIDE

1. Introductions and aim//format of the interview

Aim – to explore your experiences of treatment in order to give us more insight and better understand the different treatments in addition to the questionnaire analysis.

Format – a series of semi-structured questions built around themes to help answer the research question

Similar questions will be asked of all interviewees, although additional questions may be asked as appropriate. Interviewees can respond however they would like.

2. You were initially referred to the Insomnia Clinic – can you tell me about what led to your seeking help and your insomnia experience?

Prompts –

What made you seek help at that particular time?

Were there any delays to getting a referral?

3. What did you hope to gain from this referral?

Prompts – details, examples

4. What did you think about being offered a therapy-based (CBT) treatment for your insomnia?

Prompts –

Explore their thoughts around being offered a psychological intervention for what they may view as a physical problem previously dealt with by medication

5. You were a participant in the five-week group / one-day workshop / online programme “Sleepio” – what did you think about being allocated to this treatment?

Prompts –

Initial expectations around treatment

Any preferences to treatment delivery method

6. How would you describe your experience of your allocated treatment?

Prompts –

Sleepio – experience of online participation

One-day workshop – experience of learning strategies in one full day with others

Five-week group – experience of regular attendance at clinic with others

7. Which CBT-I strategies have helped / not helped and why?

Prompts –

Willingness / ability / motivation to learn

Acceptance of CBT-I as a solution to their sleep difficulties

8. How did you find implementing what you learnt at home after your treatment?

Prompts –

Confidence in implementing behavioural changes outside treatment

Adherence to recommendations by transferring skills to day-to-day life

9. What sort of impact has your treatment had on your day-to-day functioning and quality of life?

Prompts –

Areas of life that most / least benefitted

Which element of treatment was most impactful

10. Is there anything else you feel is important to share or you would like to say about your experience of the five-week group / one-day workshop / online programme “Sleepio”?

Prompts –

Future thoughts on their insomnia

Appendix B10 – Content Analysis

Five-week group – question 1: How would you describe your experience?

Theme	Overall positive experience with learning and reflection to implement change for the better							
Category	Group experience				Learning and understanding		Moving forward	
Sub-category	Facilitation	Positive group encounter	Shared experience	Difficult group dynamics	Learning experiences	Insight	Practical advice	Impact
Codes	Delivery Interactivity Structure	Environment Atmosphere	Experience of others	Disruption from others	Understanding Learning Challenge perceptions/myths	Importance of cognitions	How to manage and change behaviours	Future outlook
Meaning unit	• Well run (105) • Very useful (112) (117) • Very helpful (105) (132) • Doctor was very clear and engaging, and knew his subject well. When you have insomnia it is very difficult to concentrate for long periods of time, but the interactive nature of the classes made it easier to engage and remember the key points (105) • Excellent group leader. Very helpful and encouraging (122) • Very positive, felt that all the sessions were suitably interactive (129) • Sessions were engaging (130) • Facilitator was professional but empathic to the right degree (132) • Well structured and delivered (134)	• Positive, trusting environment (105) • Safe environment (132) • Each week was reassuring made more so by other people's experiences (132) • Reassuring (134)	• Sharing experiences and concerns with a group of people experiencing the same issues (105)	• Initially certain members of the group were very disruptive but they did not attend other sessions. Remaining members very quiet and did not respond much but two of us found the sessions very good (125)	• Learnt a lot about what causes insomnia and the effect this can have on you (112) • Also good to understand the different types of insomnia (112) • Encouraged me to think about sleep completely differently and helped to release me from some of the myths about sleep (117) • Informative (118) • Some useful techniques learned – but as a hardcore insomniac I had encountered most of them before (122) • Learnt interesting facts about insomnia (130) • Interesting to learn from sleep diary that I actually slept more than I thought I did (130) • Interesting and useful to find out more about the science of sleep (132)	• Very insightful (117) • Realised how important it is to recondition my mind in order to improve my sleep pattern (130) • Very insightful and useful (134)	• Provided a number of different mechanisms to cope with and change reinforced behavioural patterns (118) • Very happy to get so many practical tips on managing my sleep and sleep problem. I find the PMR recording particularly useful (130) • The key components of CBT-I made sense and were relatively straightforward to implement (132)	• Sessions had applicable advice that would help in the long term (129) • It is still work in progress but I feel more relaxed about rough nights (130)

Five-week group – question 2: What did you enjoy most about your experience?

Theme	Importance of facilitation, learning and group experience				
Category	Facilitation, learning and expertise			Group experience	Achievement
Sub-category	Importance of approach / delivery	Knowledge and skills	Expertise	Shared experience	New perspectives
Codes	Delivery style Format Evidence-based	Learning Application Practicality	Contact Knowledge and understanding	Nature of the group Support Other perspectives	Gaining control Unexpected outcomes
Meaning unit	• Having a number of tools explained in a simple, informed and evidence-based way in a classroom format (105) • I like the way the doctor introduced the subjects, and gave evidence-based analyses about what things did and didn't work for different people before explaining the tools clearly (105) • Careful to treat us like adults and not be patronising (105) • Flexible in the way that tools should be used (everyone is different) and was open to feedback throughout the course (105) • X's positive and optimistic approach (122) • Dr X is a very good lecturer and has a good sense of humour. I really enjoyed the sessions! (130) • I enjoyed the regularity and routine nature of attending the clinic (132)	• Learning more about sleep problems (105) • Learning practical ways and coping mechanisms that you can apply in any given setting (118) • Found some tips were very useful (125) • CBT is a very practical approach and I am really happy I have been taught techniques by which I can manage my sleep problem alone. Busting myths about sleep was also very useful (130)	• Enjoyed dealing with an expert in the field and having face to face interaction, it was beneficial to have someone with vast experience in the area (129) • Enjoyed contact on a regular basis with an expert in the area of sleep and others with the same problem (134)	• Size of the group was perfect for keeping the sessions interactive and supportive, and also getting input from different people's perspectives (105) • Being with other people meant you could share your experience (112) • Meeting others with similar challenges (122)	• The fact that it has genuinely broadened my mind in terms of being in control of subconscious activities. I didn't believe I would get from the sessions what I have (117) • Felt positive about keeping the sleep diary and working out the various algorithms to monitor my sleep patterns. In some way this enabled me to distance myself from my experience and observe my insomnia in a less emotional and more objective way. It contributed to my feelings of taking control over something that had become out of control, which felt very positive (132)

Five-week group – question 3: What did you least enjoy about your experience?

Theme	Importance of considering needs of individuals before, during and after the group					
Category	Needs assessment and patient involvement			Implementation	Administration	Nothing
Sub-category	Importance of considering knowledge / information needed	Consideration of individual need	Need for interaction and feedback	Challenges of implementing	Group scheduling	
Codes	Covering basics of sleep education Need for what to expect in future	Basic level Not individually applied	Lack of involvement Need for group feedback	Implementing tasks / changing behaviours in daily life	Scheduling of group sessions	
Meaning unit	• Going over a lot of things that I had already read about, or tried before such as caffeine intake, sleeping environment and other hygiene factors (105) • On the last session I would like to have known 'what next' in terms of what to expect and how to modify future sleep patterns etc (132)	• It felt a bit basic and "one size fits all" (122)	• Very little sharing of experience or "sense of group" (118) • I know that the sessions were not 'therapy sessions', however, I think more could have been made of fellow course members' responses to the various exercises. I found some of them difficult to do and maintain (and continue to do so) (132)	• The amount of tasks required before bedtime built up over the 6-week course and became administratively burdensome. I began to obsess about filling in the sleep-diary, the thoughts diary, creating the buffer-zone etc. and sometimes this was anxiety invoking and counter-productive (made me dread bedtime even more than before) (105) • The complete change in lifestyle (112) • Whilst I appreciate that there is probably never a right time to do this, I do think some more guidance about what is required would be helpful at the outset – having just moved house, into a shared flat, the reality of either staying awake and active until late into the night or removing yourself from the bedroom for the "15 minute rule" was very difficult when there are others to consider. I therefore found it difficult to put everything that was needed into action. However it is still very useful in terms of techniques which I can hopefully apply at a later date (118) • I found it frustrating that some of the techniques are difficult to integrate into life. The sleep scheduling was effective but initially it made me depressed, exhausted and hungry (134)	• The spread of the sessions, consecutive weeks may have been more useful (117) • Little – however it was tight for time attending the course and would have to leave work on a tight time schedule (129) • I found the start of the course frustrating. There was a large time interval between session one and session two, so it seemed like nothing was happening and I felt rather let down (such was my desperation to do something about my insomnia) (132)	• Nothing (125) • N/A (130)

Five-week group – question 4: Are you likely to use any of the methods learnt to help manage your sleep?

- All participants answered Yes

Theme	Core elements of the programme alongside group experience and managing expectations									
Category	Sleep information		Sleep hygiene and relaxation		Sleep scheduling		Cognitive approaches		Group experience	Managing expectations
Codes	Recording sleep	Sleep processes	Sleep hygiene	Relaxation	Reshaping sleep	Bed-sleep connection	Reducing alertness	Reducing thoughts and anxiety	Reassurance	Expectations
Meaning unit	• Sleep diary (105) • Continuation of sleep diary – intending to keep diary but find this the most difficult (132)	• Session related to the Broca's area of the brain (117)	• Sleep hygiene (134)	• Muscular relaxation (118) • Progressive muscle relaxation (130) (134) • Muscle relaxant exercises (132)	• Anchoring my bed-time and waking time (105) • Condensing sleep time (112) • Restricted time spent in bedroom (117) • Trying to reduce time awake in bed (118) • Sleep threshold and anchor time (122) • Core methods of 'threshold' & 'anchor' times (132) • Sleep scheduling (134)	• Not doing anything that isn't related to sleep in the bedroom (129) • 15 minute rule (132)	• Creating a 'buffer zone' before bed-time to relax (105) • Visualisation techniques (118) • Bath pre-bed (129) • Imaging surroundings when trying to sleep (129) • Thought stopping (130) • Working to improve the 'buffer zone' whilst acknowledging how important it is (132) • Thought interruption (134) • Eyes open technique (134)	• Keeping a to-do list (105) • Thoughts diary before bed (105) • Diary technique (118) • Mind-dump / diary (122) • Writing lists (129) • Constructive worry (130)	• Overall it was the reassuring effect of the group rather than specific techniques that was useful (122)	• I have been trying nearly all the methods but so far not managed to fall asleep as quickly as I would like (125)

One-day workshop – question 1: How would you describe your experience?

Theme	Overall positive and informative experience but a lot of information in one day				
Category	Content, facilitation and format			Shared experience	Outstanding issues
Sub-category	Informative	Facilitation	Format	Group experience	Unaddressed need
Codes	Informative Practical Theoretical Addressed needs	Provision of knowledge and confidence	Efficient Overwhelming Preferences	Others experiences Similar conditions	Travel and jetlag
Meaning unit	• It was very informative and a lot of very practical things were discussed (103) • Positive, was informative and presentation covered caffeine use, late night computer use etc. Helpful information-wise (104) • Found the one-day workshop to be very relaxed and extremely informative...I gained a lot of information that I have found extremely useful in the improvement of my sleep difficulties (120) • Very informative, detailed and theory-based (126) • I wasn't sure what to expect but I thought it was excellent: interesting, informative and well delivered. It took us through the research, dispelled some myths about insomnia and addressed the questions asked by the group. I couldn't wait to get started (127) • Excellent workshop. Found the material extremely interesting (140) • Generally felt very positive about the workshop, was a good mix of practical and theoretical information (143) • Very good (146) • I found the workshop well grounded, logical, honest and informative on the topic of sleep in general and insomnia and its treatment in specific (146)	• Dr X is very knowledgeable and instilled confidence (103)	• It was pleasing to gain all the information in one go and this was then the enabler to start the 'sleep diary' part of the program. This was my preferred option of delivery and I feel it was most beneficial to myself (120) • Long day (126) • I would have preferred the five-week group as the one-day workshop was too tiring and too much to take in, in one day. A choice would have been better but I was given an either/or choice of a nine-month wait or a one-day workshop (141) • There was a lot of information and techniques to try, but this could be a bit overwhelming for some (143) • It's a lot to take in but the one-day is a good option for me, and from a travel cost point of view (146)	• It was good to hear experiences from others in the group (103) • It was good to be with other people and I think the opportunity to speak with people who have the same thing is invaluable (146)	• The one issue I still have is with multi-zone travel and jetlag (146)

One-day workshop – question 2: What did you enjoy most about your experience?

Theme	Positive and supportive group experience that enabled learning and strategies to change			
Category	Delivery style and content that supports learning		Optimism	Group experience
Sub-category	Applicability	Facilitation	Reassurance	Gaining from the presence of others
Codes	Learning Applicable content Research evidence	Delivery style Format	Reassurance Hopefulness	Positive group dynamics Not alone Shared experience
Meaning unit	• Content was very good (103) • It was the learning and putting insomnia in the context of wider health issues. It gave me the tools to tackle my long term problem (127) • Learning about sleep patterns (140) • In-depth info about strategies to follow to improve sleep (140) • Increased understanding of sleep problems, what causes them (143) • Research and medically grounded (i.e. logical) (148)	• It was presented in a relaxed way (103) • Handouts are a good reference as well (103) • Dr X has a very engaging delivery style of teaching (127) • Being able to ask questions (146)	• A reassuring message – if you've got insomnia there is treatment, a sense of reassurance (104)	• The attendees were very friendly and affable within my group. I realised I was not alone in my sleep difficulties (120) • Meeting other people who have similar experiences of insomnia (126) • Being able to discuss issues with others who understand insomnia (126) • My experience was positive from meeting others who shared similar problems from lack of sleep (141) • Meeting others who experienced similar issues (143) • Speak to others, listen to others (146) • Hearing the experiences of others in the group (148)

One-day workshop – question 3: What did you least enjoy about your experience?

Theme	The balance of design and format of the day with individual needs					
Category	Practicalities and format			Learning resources	Group dynamics	Nothing
Sub-category	Travel	Unsuitable room	Long day	Support for learning	Different needs	
Codes	Travel Ideally closer to home	Room too small Room not appropriate	Day too long Too tiring to focus in the afternoon	Sleep efficiency calculations Not enough handouts	Varying needs of the group People speaking too much	
Meaning unit	• I was travelling in from Watford so having something closer to home would have been good (103) • The journey – but it had to be undertaken only once! (Bonus) (120)	• Nothing really. A minor point is that the room was a little small and it was difficult to write down all the information delivered – which I wanted to do. We needed writing desks or at least A4 boards – although I appreciate that is not for everyone (127) • Room was a bit too small and quite stuffy for number of people on course (not a great aid to concentration for a group of very tired people!) (143)	• Long day (126) • The day was too long and I felt too tired in the afternoon to fully focus on the exercises we had to do (141)	• The calculations on sleep efficiency – didn't detract from enjoyment of workshop (104) • I would have liked even more handouts. I did take a lot of notes but it's sometimes better to get sections of the day more documented (127)	• Some of the participants seemed to have rather more serious personal / psychological issues which had them speaking too much...The doctor did manage this well (148)	• Nothing comes to mind (140) • There was nothing negative as far as I'm concerned (146)

One-day workshop – question 4: Are you likely to use any of the methods learnt to help manage your sleep?

- All participants answered Yes

Theme	Core elements of the programme							
Category	Sleep information		Sleep hygiene and relaxation		Sleep scheduling		Cognitive approaches	
Codes	Recording sleep	Sleep processes	Sleep hygiene	Relaxation	Reshaping sleep	Bed-sleep connection	Reducing alertness	Reducing thoughts and anxiety
Meaning unit	• Sleep diary (140)	• Use of medication (120)	• Sleep hygiene (103) • No caffeine drinking (104) • Sleep hygiene which I am very conscientious about – food, drink, temperature in room etc (127) • Advice on IT at night (141) • Reduction in caffeine and other stimulants in the evening (148)	• Progressive muscle relaxation (103) (126) • Relaxation techniques (141) • Recorded CD (146)	• Regular bed times and 'get up' times (120) • Anchoring waking time (126) • Working out the best time to go to bed taking account of my getting up time (127) • Focus on routine and buffer zone (143) • Sleep time management (146) • Rigid bedtimes (148)	• Staying out of the bedroom more than I did before! (127) • 15 minute rule (140) • Not just lying in bed if unable to sleep, not trying to go to sleep if not tired (143) • Time in the bedroom (148)	• Wind down routine (104)	• "No technique" (126) • Putting my day to bed – writing down what I need to do the following day (127) • Clearing the mind before sleep (148)

Online programme – question 1: How would you describe your experience?

Theme	Overall positive with some challenges to implementation			
Category	Design, format and content		Nature of online	Negative experience
Sub-category	Format and content	Support tools	Commitment challenges	Did not meet patient needs
Codes	Good design / format Helpful content Quick treatment start Difficulties with research documents Encourages adherence and engagement Time / travel saving	Email prompts Discussion boards	Non-human contact limiting commitment to certain methods	Wordy Complex
Meaning unit	• I found the programme easy to follow as each session covered different topics that effected insomnia in small easy to understand steps... The online programme is a remote based CBT programme which some people might not like preferring a more personal, group based approach. I was happy with the online programme, especially as it could be started almost immediately (102) • I found the online programme very direct and easy to follow but due to my inadequate computer skills filling in details at onset of course and at end have been frustrating and lengthy. My husband had to help me on various occasions with technical detail (110) • Although initially sceptical (as nothing else I had tried in over 15 years seemed to have any effect on improving my sleep), I found the online course very helpful and was also surprised that I was able to maintain a strict adherence to the course principles with the help of the online "Prof". The whole package of sessions with the "Prof", tools, sleep diary and scheduling was well designed and conducive to encouraging engagement with all aspects of the Sleepio philosophy. The course also provides enough flexibility to allow participants to find an appropriate "method" from a selection of tools, tailored to particular preference(s), thus increasing the likelihood of sticking to the program (114) • I really enjoyed the online programme, I found it both informative and engaging. It was very easy to use and still felt personal even though it was online (123) • Very good experience for taking the online programme. It help me understanding about the sleep hygiene...and especially about the positive thought, less stress to help for my sleep...and also with online course, I access to the lesson anytime, save time to travel to the workshop (124) • Online program is great, especially if people can't get to the courses in person. It helped me understand a lot about habits and sleep patterns (136) • I did the online programme and found it very informative. I liked the fact that each session was quite short which meant you could fit it into a busy schedule (138)	Although I did not need to use them I thought the e-mail prompts and online discussion boards a great support idea (102)	• I found the online programme convenient to fit into my lifestyle and I definitely benefitted from the advice given. However as I was not 'answerable' to a human being, I think I shirked some of the tougher aspects of the course, such as 'sleep restriction' which I think I would have gained improvements from, if I had been more committed to it. I think a human-led 5 week group would have made me more driven and committed to these harder aspects of the CBT course (111) • Hard to stick to but the limiting sleep worked ok. Rest didn't work (135)	Very long winded and over complicated (139)

Online programme – question 2: What did you enjoy most about your experience?

Theme	Positive learning experience facilitating improvements and accessibility to treatment			
Category	Design	Improving sleep	Accessibility	Applicability
Sub-category	Format	Seeing improvements through perseverance	User-friendly	Individualised approach
Codes	Animated nature of programme helpful	Perseverance Sleep improvements More balanced thinking Hope	Ease of access Fit into daily life	Attention to individual case Relevance
Meaning unit	The cartoon element of the programme which helped greatly in explaining the topics (102)	- I learnt that if I put what I was told into practice and persevered with the programme my sleep improved. I have started to have dreams again and feel like I've had a deeper sleep (110) - I also enjoyed seeing the positive pay-offs in my sleep by incorporating aspects of the course into my sleep schedule. I enjoyed gaining a more relative/proportional balance of my sleep problems (111) - The fact that I could see my sleep improving, together with the help of the online diary. The course has also helped me to become less anxious and stressed about those times when I don't sleep very well. I also haven't had a single night of "no sleep at all" which was a frequent occurrence prior to enrolling on the Sleepio course. One morning I even slept through my alarm – and I don't remember ever having done that before. My sleep still isn't perfect or consistent, but the course has allowed me to believe that perhaps by persevering with what I have learned so far, this may be possible in the future. In short, it has given me hope! (114) - Having more sleep, makes me better and happier person (136) - Some new techniques (139)	- I enjoyed the fact that I could do the course sat on my sofa with a cup of tea and my dog on my lap/ totally relaxed! (111) - It could be accessed almost anywhere which made it ideal for me (123) - I enjoyed the fact that I could do it at home – around all my commitments (138) - Flexibility (135)	- The prof talking about my sleep diary (124) - Even though it was online there was a sense that the professor really knew my case (138)

Online programme – question 3: What did you least enjoy about your experience?

Theme	Need for application of content and design to individual experiences						
Category	Content			Design			Nothing
Sub-category	Administration	Challenges	Sleep scheduling	Format	Resources	Applicability	
Codes	Sleep diary Quiz	Overwhelmed Increasing tasks Failure for not trying techniques	Sleep restriction Surprise at difficulty but saw improvements Maintenance	Gap between sessions No human contact	Lack of supporting materials	Irrelevant Contradicting	
Meaning unit	• Having to write a sleep diary (110) • It was quite tedious filling out the sleep diary every day (123) • When I've got little time to do the quiz I got frustrated, but it's me and not the quiz I got frustrated with (136)	• I felt a little overwhelmed by the course as the commitments and tasks significantly increased and I felt a bit of a failure when I decided not to fully embrace the extremely intense sleep restriction aspect of the course (111)	• The sleep restriction phase was remarkably very difficult especially to begin with. This surprised me as I usually spent so much of my time awake at night that I didn't think it would be so hard – but it was! However, because I was able to actually to start falling and staying asleep during my “window” – this encouraged me to stick with it, and in some ways grow to enjoy it in the end as I started to feel that it was working! (114) • It was not easy to adjust to using a sleep window and sticking to it every night (123)	• I have to wait for 7 days to have the next lesson (124) • Lack of human side (135)	• One thing about having insomnia is that your memory is impacted and therefore I think after completing each session you should be given a print out of all the info it contained. This would allow you to review what you need to do to improve your sleep at any given time (138)	• A lot of the things had no relevance to me and the programme contradicted itself (139)	• Nothing (102)

Online programme– question 4: Are you likely to use any of the methods learnt to help manage your sleep?

- Nine out of ten participants answered Yes

Theme	Core elements of the programme apart from recording sleep and sleep processes						
Category	Sleep hygiene and relaxation		Sleep scheduling		Cognitive approaches		All
Codes	Sleep hygiene	Relaxation	Reshaping sleep	Bed-sleep connection	Reducing alertness	Reducing thoughts and anxiety	
Meaning unit	• I am walking for an hour daily (110) • I don't have caffeine after 6pm (110) • Loads: no caffeine in the afternoon evenings/I have hugely reduced my alcohol intake/I don't do intense exercise in the evenings/I don't eat soon before bed (111) • The bedroom: light, noise... (124) • No phones, laptop, TV bed time (136)	• Using techniques like mindfulness and relaxation to get to sleep (110) • I have increased my yoga practise particularly in the evenings to relax me before bed (111)	• Sleep restriction (102) • Sticking to my "schedule" no matter what amount of sleep I may (or may not) have had the previous night (114) • Reverting back to using sleep restriction if my sleep patterns begin to deteriorate or regress in any way (114) • The sleep window (123) • Limit sleep (135)	• Making sure I go to bed when really tired (110) • If I wake up early, I just get out of bed and do stuff (111) • Not staying in bed if I have been awake for too long (to maintain the bed/sleep association) (114)	• I switch of from mentally challenging chores well before bed to give my self a chance to unwind. I read a lot more in the evenings before bed instead of watching TV (111) • Imagery (123)	• I think the "mindfulness" and "paradoxical thinking" approaches have also been very helpful in counteracting anxiety and stress about not sleeping (114) • The positive thought (124)	• I will try all the strategies mentioned as soon as my family commitments allow me to (138)

APPENDIX 11 - Interpretative Phenomenological Analysis

Participant 132 - five-week group - full quotes from themes

Superordinate themes	Sub themes	Quotes	Page and line numbers
Evolution of insomnia	Start of insomnia experience and association of insomnia and cancer	Erm, my insomnia started...just after three years ago now...started off initially being just Sunday nights when I didn't sleep...terribly well. Some Sunday nights when I didn't sleep at all...But as the year progressed that got steadily worse...but then, er, sadly I became very ill and erm I was diagnosed with cancer. So, er, in my mind I had worked out that therefore the...insomnia...was as a consequence of cancer...So in my mind...at least I had worked out that was that those two things were related erm and essentially I was treated for cancer from 2013...right the way through to very recently...I'm now clear which is a good thing. So, erm, it impacted quite severely in terms of my err work, certainly in terms of my relationship, erm and yeah I'd say in every aspect of my life actually...in many ways. I had a parallel set of things going on then, once I'd been diagnosed...and once I was been treated err, for cancer ...then I had assumed that once all that was out of the way then...everything would go back to... but it really didn't and in fact it got worse erm and so...what was very refreshing was coming here and actually it was the session that Doctor X ran and he said that whatever precipitated your insomnia...isn't necessarily what perpetuates it...and I thought ah that makes sense...for me. Erm and I'd started to then work out that possibly whatever it was that triggered er the insomnia initially it probably wasn't anything to do with cancer...Maybe it was just a set of er.. coincidences. Erm, and, but I'm sure that's what then precipita...you know...contin...what then made it continue...beyond.	Page 1, lines 20-31 Page 1, lines 35-47 Page 2, lines 32-40 Page 2, lines 41-48 – page 3, lines 1-13
Desperation and loneliness	Frustration of waiting for consultation then treatment	... but then of course I had to wait a very long time...from February through to, I think it was June before I actually got a consultation with Doctor X which was deeply frustrating ...and it was deeply disappointing of course coming along here and having that initial conversation with Doctor X and finding in fact that erm I'd still have to wait another year until I could have treatment. So I was pretty desperate by this time because the previous years had been pretty 'orrible...sooo when the offer came to be part of a trial, err, in this, then I said yeah, absolutely, I'll do it. So that's what lead me to this so it was er a whole catalogue of things which lead to this... I was really grateful...that I had been accepted onto this trial so I thought I'm doing something positive...I'm actually doing something about this. I'm trying to take control of it. Erm, so I, you know I felt good because I was trying to do something about it, but <i>deeply</i> frustrated that it was taking so long.	Page 2, lines 10-22 Page 3, lines 43-45 – page 4, lines 1-3
Desperation and loneliness	Lack of acknowledgement	...but there were points on the course where I actually felt quite angry because I just thought, erm, the acknowledgement of some of the feelings you have around insomnia is really important and I didn't think we did enough of that...And I felt	Page 4, lines 4-22

	of feelings around insomnia	sometimes that they were dismissed...too lightly. Err, and I, I got very angry and I think I did actually say one session. I said, you know when you're a, when you're an insomniac and when you have nights where you just don't sleep at all and it's just night after night, you feel wretched, I mean you feel really awful. And you're pretty desperate. So, erm not to acknowledge how you feel is, is actually not a good thing, just, just to sort of...I'm not saying that... it was not acknowledged but it just wasn't, I didn't think it talked about stuff... sufficiently deeply or well enough. I was pleased to be doing the therapy but if, if I'm really honest I thought the therapy would have looked more at why I wasn't sleeping rather than just dealing with a sleeplessness...And Doctor X was very clear about that, when I saw him at the very beginning...of that initial consultation and I was a little bit frustrated by that cause I told him my story...and er he wasn't intere... I mean on the one hand it was quite refreshing becau...because he really wasn't interested in that...erm, but at the same time I thought, it, it has to have some bearing on this. You can't dismiss something that is so, erm, life changing and not to acknowledge that that possibly could have, or is continuing to have this, this effect on your sleep.	Page 5, lines 25-39
Desperation and loneliness	Preference for the five-week group	...when you are not able to sleep what you want is usually just want a quick win, you know, you just want to be able to sleep. So, erm, but one thing I was quite clear about was, I didn't want to take any sleeping tablets....I think I took one once ac... It just didn't work. So, erm, so I, I really didn't want, cause I knew, for me I just knew that wasn't going to cure anything. That might help a little bit but it's not going to get to the root problem of why I am not sleeping. ...over my life I've always been very keen to try lots of different things if I think they'll help me. So, I've always been sort of very open to that. So I've never done CBT before but it seemed like an obvious thing to do...when I read about it. I was very pleased, cause out of the three options then that was the one that I wanted to do anyway because, I just, in my mind erm, as far as I was concerned er, doing an online course wasn't going to do it for me. I'd already worked that out...coming on a sort of one day seminar, that wouldn't do it for me. I thought I need much, I need ...much more than that...So I was very pleased with the five weeks...I think in my mind I'd worked out that I'd needed something much more intense.	Page 5, lines 16-24 Page 5, lines 40-44 Page 6, lines 21-34
Desperation and loneliness	Group dynamics and environment	I liked being in the group. I found on the very first session, I found some people really irritating. Really irritating. Irritating to the point of distraction...they left interestingly, the ones that irritated me...and I was pleased, I was really pleased cause...I think had they continued to come back...I probably would have not, I don't know whether I would have left...but I think, erm, by the second session, err, I was just becoming quite really quite resentful about the amount of time they were soaking up...It's, it's, it's really hard and I understand that. And I think it's partly to do too, you know with just the physical layout, because you know, you're sitting in a room like this and it's not a very tidy room, it's not a very....comfortable room... Maybe they don't bother other people but they bother me because I just think they're...they're a distraction....And I'm very aware of it but they become a distraction to me. Erm, and I then, then I realise how precious this time is so, erm, I start to lose concentration... Erm, I like coming here. I like going to somewhere. I like coming here today. I, I, I, you know, it feels very purposeful...so I like that aspect of the, of the course and of the therapy. Erm, no so I do like being in the same place at the same time as er, I, I, I find that very helpful.	Page 7, lines 3-42 – page 8, lines 1-24 Page 8, lines 35-37

Desperation and loneliness	Desperation and frustration of gap in sessions	... I think there was a really long time lag between the first session and the second session. And that was very unfortunate. It's not typical apparently, but I, but it was far too long. Errrm, because actually, you know, we'd all come, me particularly, I don't know about the others, to help with our sleeplessness but on that first session it's all about sleep...And I'm thinking and so when are we going to get to the stuff that's going to help me because this isn't helping me at all. Certainly interesting but it's not helping me. So I was very frustrated by that and it was compounded by the fact that we then had to wait a very long time until the next session...And I think it was during the second session...that's when I got a bit cross. Because I spoke about, sort of don't dismiss people's feelings...which I've said to the tutor because err, you said I can't speak for other people but I'm desperate. I haven't slept for three years. I'm pretty desperate. And so, I just want to get on with this. And it doesn't feel like we're getting on with anything. So I was very frustrated.	Page 8, lines 37-44 – page 9, lines 1-22
Desperation and loneliness	Acknowledgment of desperation and wanting to share experiences	The other thing too that, err, possibly wasn't done, ah maybe it's done for good reasons but the people want to talk about their sleeplessness as well. I mean, I wanted to talk about mine and I know other people wanted to talk about theirs but there wasn't really...either any encouragement or any...incentive to do that, but people were doing it around the margins even if before...or afterwards...And I just thought, cause actually...why else would we be in a group? You know what's the point of having...a group? What's the, yeah what's the point? I mean you're sharing experiences about how useful the techniques have been the following week. But actually about the sleeplessness. Which is the, which is the one thing that brought us all there in the first place...And yet actually when you are sle', when you suffer like that...that's the one thing you want to talk about. It just seemed like a bit of a waste. I'm, I'm not then saying you should then spend a large part of the session sort of talking in an angst ridden way...about how awful this is, but I don't know, something...something can be done.	Page 16, lines 24-45 – page 17, lines 1-25 Page 17, lines 30-33
Achievements and outcome	Implementation of strategies and routine	...definitely keeping that sleep diary initially was very helpful...errrm, working out all those, which I was religious about, you know, those er, those, your sleep efficiency and all the rest of it...so I found that very good, cause I, again I like the routine and actually what I realise is I just like routines probably. So, erm, for me, identifying a time, err, err, a time to go to bed and a time to wake up in the morning, erm, then that's and I can continue to do that now. So that's been very helpful. You know, the whole sort of fifteen minute rule...I was, I hated it, but I did it. And I still do it. If I need to. And I still use it now, so I use that. Other techniques, so they're the core ones. And I've, I, I continue to use tho...well I don't, I don't keep the diary anymore but I keep to the time of going to bed and...getting up in the morning. Erm, other things errrm, like the lists before you go to bed, I was talking to Dr X about this. For me I found that they themselves were making me feel anxious...So, so I stopped doing them. Err, and I do do lists but I do them much earlier in the day. Because I thought, god I can't do this. If I got to just half an hour before going to bed start to dredge up all this stuff. I don't want to for a start and also it doesn't, it's sort of, it re...it really wasn't helping, so I started to get an... quite anxious jus... just about that. So I sto... I just stopped doing that. Errrm, other sort of techniques that we spoke about, you know, the mindfulness, I wasn't very good at those to be honest. I did try though, listening to Dr X's voice...and relaxation. I didn't find that particularly helpful actually. Erm, so erm, so a lot of them I haven't used...but some of them I have and continue to and they for me are the key ones that make it useful. What I'm much better at now is being much more mindful about erm, I suppose the triggers, to...to sort of making me feel more awake at night when I go to bed...I don't, sad thing, erm drink tea or coffee anymore in bed... in the morning which I used to like doing, so you know I, so I, I'm pretty errrm, strict about all that, about all that sort of stuff.	Page 9, lines 29-45 – page 10, lines 1-41

		It was definitely about sort of stripping back all that, all the sleep...theory, you know, none of these in the bedroom...you know, beds are just for sleeping in. You go to bed when you're tired an'...I mean, I always remember Dr X saying, it's quite simple. You can't sleep unless you're tired...It's not, it's not rocket science. So you need to be tired...you know, it's bringing discipline back to...training and that's not easy. It's really hard. And it continues to be cause I still have some nights when I'm like that...	Page 14, lines 31-45 – page 15, lines 1-31
Achievements and outcome	Seeing improvements and positive changes	That routine I've found is just part of what I do now, so...it's er, it's embedded. So, I, I, you know so that's just what I do. I find it more difficult probably getting up in the mornings. Sometimes. Erm, cause the sleep although it's improved, and it has improved, it's n', it's, I don't feel secure about it. So I still, I get every night I go to bed and I'm anxious because I think, I'm not going to sleep tonight. Erm, but actually the reality is, is that more often than not, I do...And it was very helpful coming to see Dr X a couple of weeks ago where he just said, you know, if my trajectory had just been just sort of in a straight line then he'd have been more worried... but the fact I sort of go up, come down a bit, go up again...but if the general line is one of improvement, then that's a good thing...And it is happening and I'm really, you know, pleased with that over all because there was a time when, maybe I'd have two nights out of seven, that would be ok, in terms of, you know, I'd sleep but they were usually because I was completely exhausted...and you know, you would get to sleep but they weren't consecutive nights. Then I started to have a couple of consecutive nights and then it moved to three consecutive nights...so I get three out of seven, but now I'd say it's completely switched and it's probably, it's more like sort of five or six nights that's where I'm sleeping. Out of seven. So for me that's...that's just a miracle...I mean, it's remarkable, erm, it it, the nights don't always, I wake up sometimes, I wake up early, but my sleeplessness had got to the point where I just wasn't going to sleep...you know, I just wasn't sleeping at all. So...I'm probably, on the nights now having more nights where I'm probably sleeping sort of five-ish sort of hours....so again, it's, it's steadily improving...Which is always fantastic news. It's brilliant. Well, I mean, overall, then it's, it's had a positive impact because erm, I still do have sleepless nights and if I have work related er, anxiety which happens quite a lot with me, then err, then I still get sleepless nights but I, but I also have nights now where, erm, I do sleep...before I have a particularly difficult day or, or, the thought of a difficult...week ahead. So there is no doubt that erm, things are beginning to shift and change there. I wouldn't, they're not...they're not, they're not where I want them to be yet...but overall I'd say it's been positive...I think emotionally I'm better, erm, I'm sort of on a more even keel. Erm, but you see part of this is also to do with the cancer diagnosis, as well...if I'm really honest. And so, erm, you know, I can't ignore that because it's a parallel set of activities going on there...so I can't disassociate...that from that...and because that track of activities is also positive and, err, then I think that's, is also having an influence on me emotionally...I know, I know it is...cause I feel more confident.	Page 11, lines 2-45 – page 12, lines 1-38 Page 13, lines 38-45 – page 14, lines 1-16
Achievements and outcome	Need for ongoing support and self-confidence	I don't feel confident. Erm and I think part of me coming along today is cause I still want that sort of connection in a way, cause I fear, cause then I've sort of latched on I suppose. Err, because I ha', I have found it helpful and useful. Because otherwise I wouldn't be here...so that's one of the reasons why, when Dr X said it's sounds, you know, you're doing really well so maybe, you know, we can, we can now dis... discharge you...So I said, w.w...well, he really sort of sensed that I wasn't too happy about that, but he said to me on the other hand in six months' time it would be helpful for you just to know, know that you can come back...then that's equally fine. So I think that's how I feel about it at the moment...So overall, positive. Good, but I'm, but I'm not confident about it yet.	Page 17, lines 38-45 – page 18, lines 1-12

Participant 143 - one-day workshop – full quotes from themes

Superordinate themes	Sub themes	Quotes	Page and line numbers
Development of need to seek help	Duration of sleep issues and beliefs about medication	I've basically, erm had probably issues with sleep erm, I think as far back as, like secondary school...Erm, but at the time, I, I think I didn't really worry too much about it...because it's quite a typical thing that teenagers tend to...sort of stay up late and they have a different internal clock and you know...it's kind of studies and things that show that...So, it's sort of, I wasn't that..kind of worried about it.	Page 1, lines 15-27
		...when I was eighteen nineteen I started getting a bit more kind of, you know, I tried erm, tried sort of sleeping tablets at one point but really didn't get on with them at all...cause I felt like sometimes they'd help me get to sleep but I'd just wake up sort of a few hours after I still didn't just feel, like a lot groggier the next day...and it's the idea of not to maximise sleep but it's to minimise tiredness...it just seemed like, like a bit pointless and it's why I've been quite against medication since then really.	Page 1, lines 28-39
		...I kind of made it clear I didn't want any kind of medication...erm, because...er.. my experience of that previously had been, well it had just made things worse	Page 5, lines 1-3
	Trigger of seeking help and future aspirations	...so it's just something I think I just, kind of live with, really. Erm and just thought well, this is just kind of how it has to be...I found you know a, a lot of the time I would have you know, quite poor, very poor sleep and I'd just be tired the next day and just learn to function being tired but as I kind of got more senior in working in roles...it just became, more and more difficult to operate on kind of a reduced mental capacity...and operate on that level and you know, I...I just felt I was getting to a point where it was actually going to hold me back, erm, career wise and just generally in life.	Page 1, lines 39-48
		Erm, and also it's just one, it's one of those things where actually when you sit back and you look at it and think well, ok, I'm used to it, that's why I just think, well this is normal...but it's not normal for, for most people...	Page 1, lines 48-51
		...I think my life could be improved you know, massively. Probably the biggest thing that would improve my life would just be, not being tired, like exhausted all the time...Er, like everyone's tired some of the time, but just as a, as a kind of standard matter of course. Cause, you know on the days on which I'm not tired I can feel, erm, you know, my brain works much better and then I can do things much more quickly and then, I, you know, just more, the more intelligent the better and stuff...and I'm just like, well you know, wouldn't it be great if I could get to a situation where that was more the kind of a normal. Erm, so that was really, the motivation for it.	Page 2, lines 1-14
		...it frustrates me...it reduces my, kind of efficiency and capability, erm and yeah, so it's always something that has kind of irritated me.	Page 16, lines 50-51 – page 17, line 1
	Positive referral process	... I explained my, the history of it...and the', then, an ongoing thing...and actually, you know, years before I'd had, you know kind of er, er, gone to a GP and not, it, it, never really been resolved...Erm, so actually he was pretty really good	Page 2, lines 33-39

		...but my GP is very good. Erm, he sort of takes things quite seriously, you know...it's more of an old fashioned GP so someone I've known for...a while and, erm, so you're not really just treated as a kind of erm, you know, like a set of symptoms. I think, you can, because he knows me and my character and things like that. Erm, It kind of makes, makes it easier to decide on... I'm not sure... Yeah, because I don't tend to, yeah, er, it's not, I don't tend to be someone who is always like, yes I must always have this treatment...yes I must have that treatment...I tend to like to, things to try to get better on their own if possible, I don't really like using antibiotics...you know, I don't, from that kind of, I'm generally anti using medication unless it is really...necessary. Erm, so I think yeah, I kind of, I just, if I say that then...it's a real issue so yeah. To not be tired. Basically, yeah, to sort of, I guess gain more control over my ability to sleep...errm, and to get to a situation where I'm not tired most days, erm, yeah. Erm, I guess, well, you first...there's a bunch of people who've dedicated... their life to learning a lot about sleep and stuff...compared to someone who might be, have read a few websites...I figured they would probably be a better place to help.	Page 3, lines 36-50 Page 4, lines 5-11 Page 4, lines 16-18 Page 4, lines 24-27
	Contributing factors	there's certainly lots of variables which kind of, I mean there's kind of an underlying issue which is when I'm completely fine...and not stressed and not worried and, you know, don't have any work...and I'm on holiday I can...still have issues sleeping. Erm, they do...get exacerbated by, if I have, you know pressure work wise...if I'm stressed about anything else, you know, in my, my life. Erm, so that does definitely impact, but there, is, there is some kind of residual underlying thing...which is actually when everything's fine. I can, it's still a bit of a nightmare to get to sleep. Probably the wrong choice of words!	Page 3, lines 3-12
Pros and cons of workshop	Treatment options and no expectations	I think Doctor X did sort of discuss different options...as well so it did feel like it was, erm, it wasn't erm just, you should have this, it was more of a discussion which is good. Yeah I think sometimes...that's lacking...It was nice to be part of a discussion...of what treatment would be best...and things in that respect. Erm, and erm, I guess I, cause I didn't really know what, sort of, I wasn't really expecting any particular type of treatment, so it wasn't really...so I wasn't surprised to be offered a therapy based treatment.	Page 4, lines 41-49
	Thoughts and feelings around study and allocation	I mean firstly I was happy that that, there was a way to accelerate it cause there was quite a long wait for the traditional one...which would've, I think I would've felt quite frustrated at...so the fact that it brought forward the date which I could be seen I was happy about. So, yeah just keen to take part for that reason really. Secondly I guess, I, I did a science degree and I've always kind of been interested in science, so....I have a sort of default thing of, of wanting to help in those sorts of things if possible...In terms of being allocated to the one day one, I guess my gut feeling was I didn't really want to be internet based one. Erm, I didn't really analyse why that was. The one day one probably for me, I was quite excited by having that one rather than the, er, I think I would have preferred th, that one rather than erm, individual one, just cause at that time I was working full time and...it would've, it was easier to have one day off and do it like that rather than it being erm, kind of committing to a specific time each week. Just cause work was very busy.	Page 5, lines 23-27 Page 5, lines 28-38

		I think back to my mind it was that one first. Cos there's actual contact and you can ask questions. And there's...different to just being given a bunch of stuff to read. The individual ones, you know sort of separated out second, cause there's still the kind of the contact. Erm, but, it was probably less convenient than... The preferences. The one day...and then the separate ones...and then the erm...internet one.	Page 6, lines 18-33
	Understanding insomnia and techniques to help	I was kind of pleased...to learn more about it... I thought that was something definitely as a take out from the day...it wasn't just a specific of this is what you need to do it was also but why. Erm, a bit of history around it and I find that, it made it more interesting...but also just as someone who doesn't sleep very well at all, it's really interesting to understand...why that is or, you know, have, how other people erm, have similar experiences... it was useful, it was good to get, errrrm, it was good to get actual kind of tips an', and structured programmes etc on, on what to do...Erm, you know they give you something tangible that can potentially help.	Page 7, lines 5-13 Page 7, lines 28-35
	Reassurance of others and taboo around insomnia	...it was kind of reassuring that there's other people...erm, you know, just in similar situations and you don't feel quite as...strange for not being able to sleep...because then you can see how people who, who really do have those kind of similar issues, and erm and going through similar things erm, so in itself that sort of, I guess, make you feel less...weird...because it can be a bit of a... I don't know why but there's a bit of a taboo around....sleep I think and erm and insomnia. It's not something I would ever share with my work colleagues...or any, anyone but my closest friends really. Errm, just because I think it has a...sort of, many connotations of someone who's just had, someone who's very anxious or worries too...much or something so...erm, so yeah. I guess, probably some kind of psychological thing in me is erm... you know it helps them to see other people in that similar situation...	Page 7, lines 14-27
	Course structure issues	...there's a few kind of errrrm, adminny bits maybe or just on the structure of the course...that, it was, it was in quite a small room...with quite a lot of people...and, it was quite warm. If you put sort of twelve, erm, people who don't sleep very well...in a warm stuffy room. A lot of people were, I think, kind of dozing or snoozing. Like, you know you could see that people were very very...It was sort of exacerbated by the tiredness...you know when you're trying to learn things as well...that's quite err, a difficult errrrm, thing. ...there's a sort of logic in it all being at the same time, but I, I think, I, er, I think maybe there's an in between, maybe splitting it in two would be good...cause then at least you've got half the things and then a few weeks later come back and then you've kind of by that point have already been able to try and implement those first things and ask questions on those as well...and come back and have a bit of a feedback on it, erm, so maybe if it was just even split into two, I think that would've been, that would've been helpful. The other thing as well as...well there was kind of a handout for this and a handout for that and scribbles and notes for this and then, er, you know, whereas actually if it's a programme it's a programme, it would be quite nice to have it all, all in one...book and then I think it would be easier just to refer to and you can have lots of blank bits of...in the end in which you can then kind of write your own notes and things like that, but it just, in terms of...making it easy for you to go back to it...because there is a lot to learn and so if, if it's all in one place I think it's just easier than bits of paper...scattered. It's fine if you're very organised, like most people aren't.	Page 7, lines 35-44 Page 8, lines 41-49 Page 8, lines 49-51 – page 9, lines 1-10

		I think it, yeah, could also be useful if there is an online version...if they've done a day course but maybe we go back if to refer or repeat certain sections if there's no additional cost to per, per unit on doing that. Erm, and especially if, you know if people are tired and can't put everything on that day.	Page 16, lines 13-23
	Overwhelming amount of information in one go	...there was a lot of information. That was the...other thing. It was erm, you know, I guess as you'd expect it's a, a whole day's course but it's erm, I'm quite good at taking information in with, I'm quite academic, I'm quite good at, like...retaining information but, I, I found it a, a challenge probably to remember all of it, I mean, there were kind of hand-outs and...things like that...and you obviously know. So it's stuff you can go back to, but I just, I do sort of maybe worry that there's too much all in one go, for an entire day. Errm, because it can be a bit overwhelming and I'm not sure if, uh, maybe if there's a further question but if in terms of, then trying to implement that stuff...all in one go, was quite difficult and, and just because it's, err, like a massive shock...to the system,...And that's obviously, you know, so, it's how to slot that into an already quite like, hectic...and busy life, it's, it's maybe a bit overwhelming all at once. ...the fact that there's no, then feedback in terms of going and asking questions about the stuff which....you've already tried erm and it can be a bit much, potentially taken in all that information at once.	Page 8, lines 3-30 Page 16, lines 40-43
Implementing and looking forward	Interconnectedness of programme	...definitely, there's an interconnectedness....to do with it, you know and when you think about how the, the sort of programme works and...and it kind of culminates into a whole 24 hours and we should do, things like that Erm, in terms of it being a one day-ness about it, I'd say there's certain benefits about it and drawbacks and benefits...around, well it gives you more of an holistic view and it shows you the things that kind of in combination and it's an approach that they all, sort of slot in together...rather than being separate, kind of, individual things of...to do and you know, so it shows you that whole kind of whole approach type thing...	Page 8, lines 38-41 Page 16, lines 31-37
	Freeing up tension	I'd say there's a certain kind of not feeling guilty about not going to bed...you know, not feeling that actually cause you're not tired and you're staying up til one, or, or two or whatever...that's in some way bad...erm, but you should just be going to bed, cause this is crazy, you need to sleep kind of thing. Erm, so it's sort of like a freeing up of that kind of tension.	Page 9, lines 19-24
	Difficulties implementing in busy life	Erm, I still do have, you know, find it very difficult and I kind of, it was very difficult to go over the hump of it getting worse before it getting better...so I haven't really been able to properly implement a lot of things that I tried for several months, but it was fairly difficult to keep up, an' you know I tend to go back and try and do that...again. Errm, now that I've got a little bit more time and things and work erm, so in some ways I think, I'm going to just give it another shot but I haven't really seen much in the benefit of it... The hardest bits, are I think around erm, just keeping to the programme, er, of going to bed and then waking up at a specific time...each morning. Erm, and getting out of bed when you're not sleeping because sometimes you know it, it can be, you can feel restful at least to sleep, to, to just sort, if you're not sleeping at least...close your eyes and your, you'll get some kind of benefit from that rest...even if it's not the same. And so that's, it's always the temptation it's, is to do that.	Page 9, lines 26-35 Page 9, line 51 – page 10, lines 1-7

		... and especially if you've got something the next day...so it always seems like a valid reason, like oh but I can't do it tonight because I need to be fresh for tomorrow for this...and, and also there's another bit around, it's quite difficult, erm, you know for social functions and things like that, erm because it sort of disrupts the whole, like idea of it is getting into a regular patterns...so it is a kind of mesh of...clockwork...with how life actually happens, which is a bit more...kind of random and you know, your obligations...are not always going to be so easy...	Page 10, lines 19-40
	Implementing sleep hygiene vs sleep scheduling	Yeah and, so most things, I thought were quite useful just as a...reminder and the, the main thing I think was erm, the things which stood out as being like, something that will, could potentially radically change the way in which you do it, erm approach to sleep is, the thing for me it was just the clock. In terms of having a specific time each day and tracking your sleep and then adjusting your, the time which you go to sleep and then waking up at, the, that same time every, every morning, erm...and getting that kind of rigidity, to and the idea that you don't, so, you know, you get up if you're not sleeping and you do something and then, er, I think...but to me it would seem like the biggest...change in approach, that could maybe have the most major influence on it. ...some things were obviously easier than others...and also, getting up in the middle of the night, that was the, certainly the hardest to implement...along, it felt like maybe I needed a month off work, just to get into the habit...of it...it's the risking of massive amount, you know the risking of having even less sleep was the hardest thing...because ultimately you've, when life gets in the way sometimes you actually can't do that.	Page 12, lines 3-30 Page 13, lines 8-33
	Having options and feeling empowered	...I think it does kind of underlie, it gives you a sense of at least there are tools available...that you can try, I mean, you have options which I haven't kind of, there's nothing worse than if you've tried everything and you still can't do anything cause....there's a certain amount of hopelessness or helplessness about it. ...it gave you a feeling of a bit more of empowerment that there were potentially tools you could use...to change the situation, a situation what you, er, personally I sort of felt a little bit resigned to, erm, so in that respect it was quite motivating when I came out of it, feeling, you know, excited by there potentially being stuff that could help.	Page 9, lines 35-45 Page 12, lines 44-49
	Reflecting on impact of treatment	...it is very hard to...to sort of judge when you're comparing to...it's very subjective things...there's probably certain things which have kinda helped, like with the, you know, that's stopped me having caffeine and there's certain bits which are kind of still, if not in a coherent and organised way I probably still have picked some bits out, which do help...a little bit. I'd say the problem, is still there. Erm, that almost kind of mentally, still having that thought that, well then there may still be an option, you know, I just need to sort myself out and make sure I actually do the stuff. Erm, and then that may make it better. It takes away that feeling of... like fed-up-ness but it's just you that's going to have to put up with it...Yeah and there's a chance that it could work.	Page 14, lines 43-51 Page 15, lines 1-12
	Cautiously hopeful / optimistic	I've kind of recently gone freelance and I think that's a good time to, you know, I can a bit more in control of my workload, so...I can fully take the time or to actually to implement these things, erm, so, erm cautiously hopeful. I'd say I'm cool, yeah, cautiously optimistic. I don't have a kind of, a strong feeling that yeah, if I implement these things I'd	Page 15, lines 26-29 Page 17, lines 1-

		definitely be able to sleep. Erm, but I think there's a chance, that it can make it better...Maybe not a 100% better but just, erm, a bit better than it is now. Erm, so, yeah, I'd say, which is better than before the whole course where I was just...resigned to the fact that I was always gonna sleep really badly and never be erm... never reach my full potential as a person!	12
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Participant 136 - online programme – full quotes from themes

Superordinate themes	Sub themes	Quotes	Page and line numbers
Seeking help	Development of severe insomnia	...in the beginning...I was coping with it but it came to a stage maybe, sort of five years ago, er, that it wrecked my...lifestyle really and people will think, erm, get on with it, it's only sleep, but if people don't go, haven't experienced, erm, sleepless nights...then erm, then you know that, it's a, it's a huge issue actually. it wasn't like suddenly it happened it crept on, bit by bit...bit by bit and it got worse and worse and it became really part of my life really, which...was awful, so yeah, but from five years ago it became ridiculous...you know. But I was probably, will say, I can't even remember how long I had it. Yeah. A long, a long time ago.	Page 1, lines 25-30 Page 1, line 51 – page 2, lines 1-4
	Initial referral and being taken seriously	I only got that...over night...and that er, unfortunately that, or maybe I can say fortunately... sometimes things happen for the best. It came, erm, that it didn't show a major problem and fortunately maybe that's happened and then I was referred to [hospital] where I got really, errrm, the expertise there. So he, that, the person, the doctor in [town] he dismissed err, what I said but unfortunately and this is my experience when erm, somebody, erm, like a doctor doesn't sort of, erm, not doesn't, doubts...whether insomnia is a genuine problem and insomnia, or some doctors unfortunately they can put it down to anxieties...and then they say, it's anxieties and once it's put down as an anxiety then you don't get any further...because errrm, that's it and then they say go back to your GP or take antidepressants or whatever but I had, I know that I had a genuine problem. And...I said a friend of mine, erm, experienced exactly the same thing...he's been referred to [hospital], erm, and I had all the details...he was just like, no problem, I'm sorry about your bad experience in the local hospital and you need to be sorted. Yeah. I've got an amazing GP.	Page 2, lines 27-43 Page 2, lines 48-51 – page 2, line 1
	Referral process and expectations	I, I was desperate, I was...so delighted. I wasn't anxious...or anything. I felt that yes, I'm getting an answer there. Erm, yeah and yeah...so it was really exciting. I: Ok. That's good. And, so no particular expectations or...	Page 3, lines 36-38

		P: Errrm, well I did, I tell you the truth. But because I've been, I've had a friend before me who...got some answers...so my expectations were high...because of a friend's, who's been referred six months before me. So yeah. And, then they referred me to...the hospital...which I went and I saw an amazing doctor...who does the course...and he suggested I'll go there, but er, ah, he said the waiting, they were like something like I remember the number, 163 people...on the waiting list and he said you're not going to get in very quickly, expect anything from six to eight months wait. Er, I said that's fine I'm desperate, I'm willing to do anything, he said, suggested a book to read, errm, but, by then within eight months somebody rang me...	Page 3, lines 42-45 Page 4, lines 11-32
	CBT as an intervention and being shown the right track	...I didn't think much about it myself. I was really excited because when somebody's desperate...they're willing to do anything...hopefully to help, well for you to help me I have to help myself...and I accept the help. What a privilege because I know...other people maybe their GP maybe wouldn't be able to spend...the money to come out from their budget....to refer them, but I was so blessed ...I was really thrilled to....be picked, you know and to contribute and erm, to be helped, you know...because when you're so desperate you just need anybody who can erm, show you the right track...if you know what I mean, put you on the right path and say this is what you can do to improve, to improve your sleep.	Page 5, lines 29-35 Page 6, lines 25-30
Impact of insomnia	Consequences of insomnia on self and family	...I was always tired, it lead to me being irritable, it affected my family too, my children and my husband, you know, erm, yeah, so it does put pressure on erm, the family too...so it's not just involved with me. It's the entire family. ...irritable, a bit snappy, I was teary, I felt bad that I wasn't a good mum, sooo, it just...erm, you know and you feel a rubbish per', a rubbish...mum. I was up most of the night, like a nice sunny day...just spending it lying down on the sofa or trying to catch up with sleep. And I felt that, I'm wasting my days really just being lethargic...and erm, and yeah my house suffered, everything suffered. I was hoping for answers obviously...and more quality of sleep...so I can be a better person, you know. Cause you feel bad, you know, even...it's not like a, an obvious to people...it's not an obvious illness, but it does impact...your life, so yeah, I wanted to have a better quality, errm, I didn't want to be lethargic on all these things and...and spend more time with my children and not snap at my husband, as soon as he comes back from work.	Page 1, lines 34-37 Page 3, lines 14-20 Page 3, lines 25-31
	Differing views and support from others	...what was disappointing, I mentioned to one friend or a couple of friends what I'm doing and directly she put it to a psychology, she started telling me, oh that, do you know that psychological and do you know that cognit' and so she sort of was erm, not put me down but she was, negative...I mentioned about the programme...and I felt that she was judging me, as...you know what I mean? Which I was really disappointed. So I stopped mentioning to friends. Because I was so disappointed...with her. ...my husband was very supportive...my daughter was really supportive and er one more friend who's a midwife...er she got medical background, she was really supportive.	Page 5, lines 36-51 Page 6, lines 3-5

		A few...times, I saw what other people, you know chatting, but...erm, not really no. I didn't make the most of it. No a few times...I was curious to see how other people...would cope with that. But because I've got my friend who's...so we were chatting all the time of how he's doing, I was doing, so I had somebody...like a friend...who's going through the same thing. So that's really helpful.	Page 10, lines 18-31
Implementing programme, new routine and helping myself	Programme format	I can say that the programme whoever done it is so amazing...and so professional. I think it was all, done with, erm, very good research and then app'...you know what I mean? So, it was done with the best...intention with lots of research was the best for the patients.	Page 5, lines 13-14 Page 9, lines 14-16
	Expectations of treatment	No actually I was very surprised about some of the things I had to do...to change things. I had in my mind I had totally different ideas! I thought that when you read you start falling to sleep. It makes you sleepy and then you drop the book on the floor and then you fall to sleep. I was really shocked really...I thought it just calms you down...and prepare you to bedtime. To say that you can't read, I was a bit disappointed. Cause I love reading in bed. .	Page 6, lines 35-37 Page 7, lines 11-19
	Unhelpful advice from friends	People like errrm, people try, friends try to help you from their, er, from their ex', you know from, erm, people try to give you an advice...whether it's, it's right or wrong you know what I mean? And some of it I'm sorry to say sort, sort of some old people's...tales you know? Like have a bath and a glass of milk...you know? That might be like a tiny, like one percent of the truth, you know...but that's not gonna, if you still don't follow what been advised to you that's not gonna, a glass of hot milk is not gonna...solve your problem totally.	Page 6, lines 42-51 – page 7, lines 1-6
	Positive experience of treatment	...I would say it was amazing but genuinely not just...to let you hear that...because you're here. It would genu', I would have recommend it to...anybody. Actually a couple of times I put another friend on and I said come and see who's talking to me...the professor and what advice, you know what I mean and so I shared a little bit with another friend...who was supporting me. Just maybe knowledge. Knowledgeable. Yeah. Educated now. And I can benefit other people, so erm yes, so it's just not being naïve before I would...say about the whole thing and what I was thrilled, I accepted the help because some people would just want to put up with it...	Page 7, lines 29-34 Page 7, lines 39-43
	Determination	I knew... when I agreed to it, that it was a commitment....ten to fifteen minutes a day, including weekends. So...but I was desperate and I insisted. I'm a very strong person. That I wanted to get help so I insisted to...erm, yeah, to, to finish it all...I wasn't willing to give up. I hope I'll be er, very motivate', still motivated...to stick to my, you know, I'm determined, but sometimes that human nature, you know? Just slip back into the old habits but hopefully I recognise what's right and what's wrong...and I go back on the right track and I er tackle it from the beginning...rather than let it slip for a long time.	Page 7, lines 49-51 – page 8, lines 1-6 Page 13, lines 37-41

	Implementing learning and challenges	The diary, oooh that was...yeah, I learned as the weeks go that I had to do it when I wake up. Otherwise life is busy and...So it was difficult to remember, so I advise anybody to do it there and then. ...I've got a diary that...I couldn't remember everything that professor was saying...so I had to start writing things down...and when he was asking me questions I had to go over what I've written. And so I wanted to help myself. Not sleep during the day. Yeah, that is definitely, but literally I was like a baby....I was cat nap, you know and I would sleep I think, sleep, grab twenty minutes during the day...better than nothing. Erm, do a little bit in the evening and then er, so it would give me more time with my family, with my husband when he comes back...from work or when it's nine o'clock, have couple of hours, that will be a bonus...but now it's clearer that napping during the day...is not good. ...when you don't sleep during the day, at night then it's really then the most wanted I got sleep was from half four, five o'clock and I couldn't get up in the morning, erm, but I sometimes forced myself...to get up on specific time. Yeah, that was really hard. Erm, I just found it extremely helpful and I...I was so positive about it that I'm going to get somewhere. A couple of times I thought this is hard work...can't, I want, napping during the day was my most erm, when I can't even, err, function or do, or I teach, I couldn't, concentration was absolutely, my concentration was all over the place. One thing I couldn't do, is, if you can't wake up more than fifteen minutes...fifteen minutes you have to go to another room. I couldn't do that, because my body is absolutely exhausted...but my mind is alert and I couldn't, have done that a couple of times maybe, but that was the hard, I think that was the hardest thing to do. I think erm, yeah I didn't help myself with that.	Page 8, lines 18-22 Page 8, lines 30-36 Page 8, lines 48-51 – page 9, lines 1-4 Page 9, lines 23-27 Page 9, lines 48-51 – page 10, lines 1-5 Page 12, lines 36-42
	Noticing improvement	...I'll be lying if I say...it's 100% from...right? That is not the case, but compared to what I had for years...my sleep during the night was two and a half hours to two hours forty-five minutes...then I was grabbing sleep during the day to compensate now my sleep is maybe errrm, four and half to five and a half, six hours maximum....So for me that is quite an achievement. Six hours is like amazing! Yeah. ...I'm much more, in the morning when I wake up I just want to do things. To make the most of the days but I still have got of course some nights where...i still can't sleep. Errm, but compared to before, it's amazing, but I would say it's improved erm, 75 to 85 percent. Which, 85% is massive for me. Before, it was...two nights good or one night or nothing...and now it's like five nights good and two nights in a row. I don't know why...it's becoming a habit...two nights in a row maybe not good and then I'll catch up...and start sleeping better.	Page 10, lines 37-46 Page 10, line 51 – page 11, lines 1-4 Page 11, lines 9-12
	Sticking to routines and avoiding bad habits	I found out what my downfall is, because...I learnt to have bedtime, the room is only for sleep. So I was watching TV, chatting to my husband about everything and anything on the sofa. I feel really tired and then instead of taking myself to bed, I got overtired and I start, I'm like not thinking about it, I drift to sleep...on the sofa for ten minutes and then my husband would say, oh you're falling asleep...but by the time I gone to bed, I'm more alert, that's it. So now I get ready to bed and as soon as I start falling asleep on the sofa I take myself upstairs and so I found out ways to help myself.	Page 11, lines 17-27

		But still I haven't got rid of this habit totally. And that's why I had two bad nights, beginning of the wee', oh last week, actually...cause I couldn't literally get myself erm, up from the sofa to go to bed. So, even twenty minutes, can just that's it. Do the best to stick to it...and then things can slip and I experienced that. Yeah, because you think you, er, how do you say in English, you cracked it and that's it. And you think oh well a little bit reading...ten minutes, that's, that's it, I've gone into routine, it's not going to make a huge difference, you know, instead of reading forty minutes, I'll read ten minutes or well instead of having a forty minutes nap I can have ten. So things will start creeping back to the...old habits and then you become into the old days...where things can go back...to being difficult. So, it's not easy to stick to it...But do the best. ...if I slip into the back, erm, bad habits or the old habits, er, I remember...cause I suffer....the next day...So I think it's all my doing! I have to help myself. So otherwise I can't complain and if I don't stick to it.	Page 12, lines 14-17 Page 13, lines 13-25 Page 13, lines 30-33
	Positive impact	Being a lot calmer, you know and not an er, irritated, agitated person. It's horrible. Cause I knew I was not nice, well irritated, not nice, irritated with my friends...bit snappy with my husband because he's the one that's got to put up with me, but I didn't like myself and that is a circ', a vicious circle of...not liking yourself, then feeling guilty that you snapped at your family. And you think why am I doing this and then, erm, yeah. In the day, yeah, more just, more energetic, more concentration is better. Cause it's awful when your concentration goes, I actually feel very embarrassed...cause you feel like an old person who can't remember things....that really annoyed me, my concentration to go.	Page 12, lines 26-32 Page 12, line 51 – page 13, lines 1-7

Research Supplementary Paper 1

Becoming a health psychologist – the story so far

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Health psychologists still struggle to be fully understood by those outside the field, so championing and promoting the contribution health psychology can make to a range of services seems an important activity.

I currently work as a team leader for two complementary services in Surrey – a mental health promotion service and an IAPT Step 2 service - but my journey started at school when I developed an interest in studying the mind and behaviour. Unfortunately my school decided I didn't meet the entry requirements for psychology A-level but I successfully got onto a BPS recognised honours degree after my A-levels.

The only careers routes mentioned during my degree were clinical, forensic and occasionally occupational psychology. I decided clinical would give me an all round view, enabling me to specialise in the future if I wanted to. I had already gained experience of mental health issues by volunteering at a MIND centre supporting centre users. But, once again, I was diverted by educational advice. A university careers advisor regaled me with tales of students who'd failed to get onto clinical training, and more or less suggested I pursue other options such as HR. This didn't appeal and I left university not really knowing what to do next.

I spent three years travelling, working in temporary jobs and exploring other training options, including occupational therapy. My sister heard about the new MSc in health psychology from some friends and realised it fitted with my developing interest in applying psychology to physical health. It focussed on the promotion and maintenance of health and the prevention of illness, as well as on improving the psychological impact of acute and chronic health conditions. I got a place on the course and completed in a year. Whilst studying, I volunteered for a sexual health promotion project where I ran the drop-in service, providing students and staff with advice and information on sexual health. This provided me with a focus for my MSc dissertation.

My cohort qualified just before the Stage 2 competencies were introduced and we thought that, as the MSc counted as Stage 1 of the qualification, Stage 2 would involve a similar amount of work. We were shocked to find out it meant doing the equivalent of a PhD!

Building up work experience

Faced with this obstacle, I decided to build up my work experience. I temped in local hospitals for several months and in 2002 gained valuable experience of working with multi-disciplinary teams on a variety of projects through a temporary role in a clinical audit team. After six months I began working as a permanent research fellow in cancer care within a large research and development department. I managed two sizeable projects focusing on the assessment and alleviation of symptoms and problems in cancer. I also volunteered to help run a cognitive behavioural therapy course for adults experiencing anxiety, depression and low self-esteem. These experiences re-inspired me to pursue a psychology qualification. I thought about the Stage 2 route but it still felt like a lot of investment for not much gain, so once again I abandoned the idea.

I wanted to explore how health psychology could help in cancer and other life-threatening conditions. The new graduate primary care mental health worker roles seemed a great opportunity to gain both experience and a qualification in primary care mental health, plus a chance to increase my knowledge and skills in therapeutic work. I secured one of these roles but it wasn't for me. The patient work had little structure and I felt GPs didn't use our expertise well.

A new position in the same department built up my experience in health promotion by developing, delivering and evaluating health projects in partnership with local agencies,

to improve health and reduce inequalities for young people. Over three years, I worked in schools and youth centres, created and delivered training for professionals, and championed young people's participation in service delivery. This was followed by a year spent developing and delivering a range of behaviour change programmes for a children and young people's healthy living and obesity prevention organisation. I had a lucky break when I was offered an NHS maternity cover position in health promotion strategy. This experience in health promotion, behaviour change, training delivery and project management to improve health outcomes, re-confirmed my passion for health psychology.

Health psychology's contribution

My current role (see above) has enabled me to put everything that I have learnt on my journey so far into practice. It involves leadership, clinical supervision, and coordinating the work of the teams to ensure the effective running of both services. I work alongside a counselling psychologist, occupational therapists, psychology graduates, and social care professionals. As part of the mental health promotion service, I contribute to and advise on the development, implementation and evaluation of evidence-based health improvement programmes and resources promoting self-management. Then as part of the IAPT service, I provide specialist assessment, formulation and one to one or group cognitive behaviour therapy-based interventions for patients with mild/moderate mental health and emotional difficulties. My role also specifically leads on projects relating to the interaction between physical and mental health, such as rehabilitation programmes and psycho-educational groups. This is where health psychology can play a part. During my time in this role and ten years after completing my MSc, I began my Stage 2 training in health psychology by gaining a place on the professional doctorate at City University London.

I have heard people say that they can't really see how health psychology is relevant in mental health, but working psychologically in this way with those presenting with physical health problems, can make a big difference - think of managing the emotional impact of diabetes, heart disease, chronic pain, HIV, and respiratory disease. As an example of this, a couple of years ago I was contacted by a respiratory physiotherapist requesting psychological input into their rolling pulmonary rehabilitation programmes for patients with Chronic Obstructive Pulmonary Disease (COPD). COPD is still the fifth biggest cause of mortality in the UK. It's also associated with other conditions: about forty percent of people with COPD also have heart disease, and significant numbers

have depression and/or an anxiety disorder. Key issues for this particular programme were helping with the adjustment to chronic respiratory disease, and providing strategies to manage stress and anxiety. We developed a one-hour session based on health psychology theory, delivered in a cognitive behavioural therapy format, to identify factors that help or hinder the management of stress and anxiety, using motivational interviewing techniques to explore patients' own personal motivations for change.

Patients have fed back that the sessions gave them permission to listen and talk about emotions, to talk to someone who understands, let them know it was quite normal to be anxious with a lung disease, informed them what to do to relieve stress, therefore helping them to overcome anxieties, frustrations and find where difficulties arise, discovering that they are not alone in their struggles to manage their condition and its impact.

The current health agenda is somewhat dominated by a mental health focus but there is also recognition of the interdependence between mental and physical health, as well as an undercurrent of prevention, early intervention and health promotion. Health psychology isn't explicitly on the agenda, but health psychologists are in an excellent position to develop the current focus.

What I've learnt about getting qualified

Anyone wanting to become chartered as any kind of psychologist must keep resilient, motivated and creative in building their experience, especially in health psychology. It takes a minimum of six years to qualify as a health psychologist and most people take longer than this. This is similar in other areas of psychology, so getting chartered as a psychologist is akin to training in medicine. I hadn't appreciated that when I started.

Improved vocational guidance at school and university might have made me more focused on achieving a professional qualification at the start. If I were to do anything differently, I would have pursued the professional qualification earlier. I am still certain however that this is the career for me, and it's been worth the challenges. I hope my role will continue to enable me to support the development of my two services into new and exciting areas of work that are key to the current health agenda. I also look forward to qualifying within a year and finally becoming a chartered health psychologist!

Research Supplementary Paper 2

How health psychology can contribute to improving symptoms, health-related quality of life, and daytime functioning for those experiencing insomnia

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Sleep is a key issue in maintaining good mental and physical health, yet health psychology as a discipline has so far had little involvement in improving the psychological impact of poor sleep and insomnia. This article explores the important role health psychology has to play in the treatment of insomnia – a rapidly growing field of interest across health care.

Insomnia remains an area dominated by clinical psychology and psychiatry. There are good reasons for this, in that many people experiencing insomnia also have other medical conditions (e.g. pain) or mental health problems (e.g. depression), and therefore may require mental health or psychiatric assessment – particularly if other sleep conditions need to be considered (e.g. sleep apnoea). Insomnia is also listed in the Diagnostic and Statistical Manual (DSM-V), the manual used by clinicians and researchers to diagnose and classify mental illnesses; so as a result is often viewed as a purely psychiatric condition. However, if after assessment, other sleep or psychiatric disorders have been ruled out, for those presenting with the most common type of insomnia – psychophysiological insomnia – health psychology could make a very valued contribution.

Psychophysiological insomnia is a combination of thoughts, behaviour and physiology, associated with arousal of our mind and body (Robatham, 2011). Typically people complain of a racing mind and fall into a cycle of poor sleep, which can lead to them having concerns about their sleep. Such patterns of thoughts and behaviour then perpetuate the cycle (Robatham, 2011). People with insomnia typically experience higher rates of relationship difficulties, poorer health-related quality of life and perception of lifestyle choices, depressed mood, elevated anxiety and fatigue, reduced daytime functioning, inability to concentrate, and impacts on memory and attention (Espie et al., 2007; Kyle & Espie, 2010; Mental Health Foundation, 2011).

The perceived impact this has on the individual's daytime functioning, rather than simply the perceived sleep loss, appears to serve as an important factor in driving help-seeking behaviour (Morin et al., 2006). This is where health psychology becomes of importance. For example, using evidence-based techniques to promote health and support behaviour change, improvements can be made to reduce the psychological and physical impact of this acute and chronic condition – in the same way that psychological input is recommended in physical health rehabilitation, such as cardiac (British Association for Cardiovascular Prevention and Rehabilitation, 2012) and pulmonary rehabilitation (Department of Health, 2012) programmes.

One of the current interventions for insomnia is Cognitive Behavioural Therapy (CBT). CBT is a way of talking about how someone thinks about themselves, the world and other people, as well as how what they do affects their thoughts and feelings. CBT can help to change how someone thinks (cognitive) and what he or she does (behaviour), in order to feel better (Royal College of Psychiatrists, 2013). Unlike other therapies which focus on the causes of distress or symptoms in the past, CBT focuses on present problems and difficulties, and looks for ways to improve state of mind now (Royal College of Psychiatrists, 2013). CBT for insomnia (CBT-I) is a brief, focussed and multimodal intervention (Morin & Espie, 2003; Edinger & Carney, 2008), which has the objective to change factors that perpetuate insomnia, including behavioural factors (such as poor sleep habits, irregular sleep schedules), psychological factors (such as unrealistic expectations, worry, unhelpful beliefs), and physiological factors (such as tension) (Morin and Benca, 2012).

Espie and Kyle (2009) describe the key components of CBT for insomnia (CBT-I) in clinical practice as sleep education and sleep hygiene, stimulus control treatment, sleep restriction therapy, cognitive control, thought suppression, imagery and relaxation, cognitive restructuring and paradoxical intention. These components have

been shown to not only improve sleep, but also daytime functioning and health-related quality of life (Espie and Kyle, 2009). These are all areas in which health psychology expertise in improving coping and self-management, and health promotion, behaviour change and motivational techniques, can enhance treatment - even from the starting point of sleep education and sleep hygiene, where the impact of caffeine, nicotine, alcohol, diet and physical activity can be explored.

It has been suggested (Kyle, Morgan & Espie, 2010) that the future research agenda should include the comparison of different treatment modalities on health-related quality of life outcomes within the same study. My own pilot study, as part of a Professional Doctorate in Health Psychology, is comparing the effectiveness of three recently developed evidence-based CBT-I treatment delivery interventions – a manual-guided five-week group, a one-day workshop, and an online programme – on insomnia severity, daytime functioning and health-related quality of life.

The research, underway following research ethics committee and research and development approval in May 2014, is currently recruiting, consenting and randomising participants to the treatment interventions. The study is employing mainly quantitative questionnaire measures to assess insomnia severity, daytime functioning and health-related quality of life (Insomnia Severity Index, Dysfunctional Beliefs and Attitudes about Sleep Scale, Patient Health Questionnaire 9, Generalised Anxiety Disorder 7, and Work and Social Adjustment Scale), with a small qualitative aspect to explore patient's experience of participating in the different interventions. This study aims to recruit at least fifty patients over the six-month period of data collection in order to meet the study objectives, and to determine whether a full-scale study is warranted.

Should this study show that one intervention is more effective, or participatory experience varies across interventions, this may provide evidence for different options being available in the future. Different people may require different treatment approaches, and the more options available; particularly those that can be made widely accessible, the greater likelihood that those seeking help can obtain it (Ritterband & Thorndike, 2012).

As the interdependence between mental and physical health is more widely recognised, health psychology can therefore make a valued contribution to improving symptoms, health-related quality of life and daytime functioning for those experiencing insomnia.

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Research Supplementary Paper 3

Improving emotional well-being for respiratory patients

Published as:

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Enhancing quality of life and self-management for respiratory patients is essential, and therefore understanding of strategies to maintain physical and psychological health are extremely beneficial. Improving and Integrating Respiratory Services (IMPRESS) guidance (2011) supported this position by stating the importance of having at least one session of pulmonary rehabilitation focused on addressing psychological issues. More recently, the Department of Health (2012) has suggested that psychological and behavioural interventions are recommended as part of the pulmonary rehabilitation process, and that staff with competencies appropriate for psychological input should be supporting specialists in chronic respiratory care in delivery of “psychological impacts and minimising their effects” (Department of Health, 2012: 17). However, these recommendations are often challenged by limited capacity and funds.

As a mental health promotion service, First Steps previously worked with the East Surrey pulmonary rehabilitation team, who recognised the need for psychological intervention and wanted to improve the service given to their respiratory patients. They identified the link between stress and anxiety and breathlessness, as well as patients adjusting and adapting to their lung disease and its associated complications. First Steps therefore developed, delivered and evaluated an education session for each of the two eight-week rolling programmes that were run.

The objectives were:

- For patients to perceive the information provided as useful in improving their emotional well-being
- To facilitate a change in knowledge of a range of strategies to manage emotional well-being with a chronic respiratory disease
- For patients to show intention to use the strategies discussed

The challenge for this intervention was to provide patients with the opportunity to reflect on their attitudes and beliefs in a group setting, and provide knowledge on, and encourage intention to use the strategies discussed in a one-hour timeframe.

A session was developed using psychological theory, delivered in a cognitive behavioural therapy format, to identify factors that help or hinder the management of stress and anxiety, using motivational interviewing techniques to explore patients' own personal motivations for change. The overall goal in the formulation of this intervention was to improve quality of life, promote self-management, and lessen the psychological impact of their chronic disease.

To determine the efficacy of the intervention, the outcomes were evaluated through patient evaluation forms and feedback from the rehabilitation team. In the eighteen months that this intervention was delivered, one hundred and fifty-six patients participated and one hundred and thirteen completed evaluations

The majority of patients reported finding the information provided useful in improving their emotional well-being – see Table B14. The rehabilitation team described the groups as varying with regards to their needs, perception and acceptance of their condition, sometimes depending on whether they are newly diagnosed or had been living with the condition for some time, which may in turn impact on their perception of the usefulness of the information.

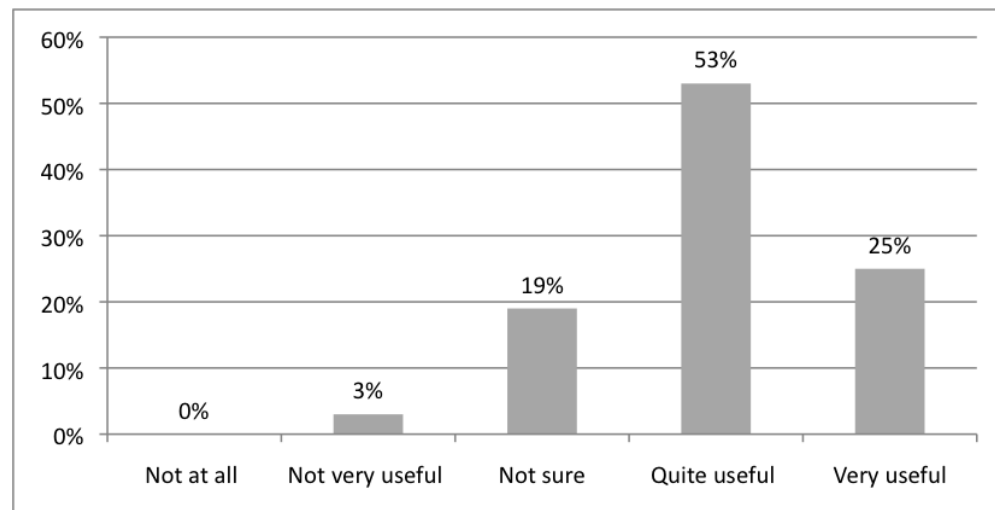


Table B14: How useful has the information from this session been in improving your emotional well-being?

The before and after knowledge score helped to assess knowledge change – see Table B15. In total the knowledge score before the session was 123, and after the intervention was 244, which is almost double.

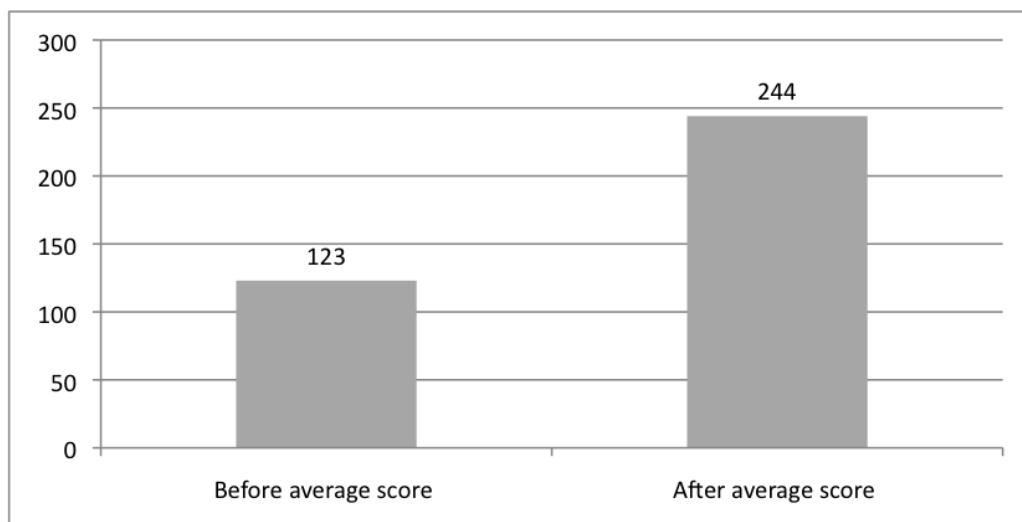


Table B15: Please score your knowledge before and after attending this session on a scale of 0 (no knowledge) to 10 (expert)

In terms of whether the patients were likely to use any of the strategies discussed and if so which, the majority of patients said that they intended to use the strategies discussed. Intended strategies reported included ways to manage stress and anxiety, setting goals, giving themselves more time to relax, and thinking more about dealing with problems and situations in the context of managing their condition.

The analysis of the data derived from the evaluation forms also provided useful feedback relating to the experience of patients in being part of the session. Patients fed back that the sessions gave them permission to listen and talk about emotions, to talk to someone who understands, let them know it was quite normal to be anxious with a lung disease, informed them what to do to relieve stress, therefore helping them to overcome anxieties, frustrations and find where difficulties arise, discovering that they are not alone in their struggles to manage their condition and its impact.

As the principal cause of COPD is smoking, many of these patients may well have used smoking as a means of coping prior to their diagnosis, or may still smoke, so opportunities to learn new ways of managing their emotional well-being appear to be especially helpful.

Overall, the intervention met the objectives and as a result patients gained considerable awareness and support around managing their emotional well-being. Unfortunately, due to organisational changes, delivery of this session came to an end, and to our knowledge has not been replaced. So the question remains as to how NHS services can evidence the need for providing psychological support to respiratory patients, in a climate where resources are stretched, yet very real behavioural changes could be made by patients with the right support and knowledge.

Future directions

As part of my own Professional Doctorate in Health Psychology, I am now working with the West Surrey respiratory care team in carrying out a service improvement project looking at the relationship between patient activation and outcome in pulmonary rehabilitation. The term “activation” describes a patient’s knowledge, skill, and confidence regarding the management of their own health and health care (Hibbard, Greene & Tusler, 2009).

Finding effective ways to engage and support patients in their own care and self-management, through identifying their level of activation, could therefore determine whether there are behaviours that patients are more or less likely to use as a means of coping at different stages. This in turn, will provide health professionals with guidance on how to adapt their practice for particular groups of patients, and improved patient and service outcomes in terms of predicting engagement in services and adherence to treatment. I hope to be able to make the results of this available by Autumn 2015.

First Steps Surrey

To find out more about the work of the First Steps team in Surrey, or if you would like the team to come to one of your local events to promote emotional health or provide training in Surrey, contact us on 0808 8010325 or email first.steps@nhs.net.

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Research Supplementary Paper 4

Patient activation and outcome in pulmonary rehabilitation

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Hemingway, B. (2016). Patient activation and outcome in pulmonary rehabilitation. *Health Psychology Update*. 25, 2, 3-12.

Background: This respiratory service improvement project explored the relationship between patient activation and outcome in pulmonary rehabilitation.

Method: Activation was assessed using the Patient Activation Measure (PAM), as part of pre- and post- assessment questionnaires. Measures of depression (PHQ-9) and anxiety (GAD-7) routinely given were also included. Baseline scores for those that completed pulmonary rehabilitation were compared with those that did not.

Findings: Results showed a significant difference in pre- and post-assessment PAM scores for patients completing ($p < 0.001$). However, there were no significant differences between those completing and those who did not. Significant differences were found for pre- and post-assessment scores for depression ($p < 0.001$) and anxiety ($p < 0.05$), and those not completing were significantly more depressed ($p < 0.005$) and anxious ($p < 0.05$) than those completing the programme.

Discussion: This project, therefore, found that completion of pulmonary rehabilitation can improve outcomes for patient activation, depression and anxiety. The PAM was not able to predict whether a patient will complete pulmonary rehabilitation, but currently used measures for depression and anxiety were. Further research is needed to understand the mechanisms of action, but this project could help inform the development of targeted psychological interventions to support respiratory patients.

Introduction

Patient activation is defined as *“having the knowledge, skill, and confidence to manage one’s health and health care”* (Hibbard, Greene, Shi, Mittler & Scanlon, 2015: 325).

This is particularly relevant to patients with long-term health conditions, who must often follow challenging treatment routines, make lifestyle changes, and monitor their condition so that they are able to make decisions about when they need to seek professional help or can handle a problem on their own (Hibbard, Mahoney, Stockard & Tusler, 2005). The Patient Activation Measure (PAM) considers the knowledge, skills, beliefs and behaviours that a patient needs to manage a chronic illness (Hibbard, Stockard, Mahoney & Tusler, 2004), and thus can assist in supporting self-management.

The PAM segments people into one of four progressively higher levels of activation. Each level addresses a broad range of self-care behaviours and offers insight into the characteristics that drive health activation:

- Level 1 – may not yet believe that the patient role is important. Individuals do not feel confident enough to play an active role in their own health, and are predisposed to be passive recipients of care.
- Level 2 – lacks confidence and knowledge to take action. Individuals lack confidence and understanding of their health or recommended health regimen.
- Level 3 – beginning to take action. Individuals have the key facts and are beginning to take action but may lack confidence and the skills to support their behaviours.
- Level 4 – has difficulty maintaining behaviours over time. Individuals have adopted new behaviours but may not be able to maintain them in the face of stress or health crises.

(Insignia Health, 2013)

It is likely to be important to achieve the basic knowledge and beliefs reflected in early stages of activation for building a sense of efficacy for the self-management tasks involved in the later stages (Hibbard et al., 2005). Therefore patients might move sequentially through stages, and as they progress the type of interventions that will be helpful to them may also change (Hibbard et al., 2004).

The guidelines for using the PAM to tailor care emphasise the objective to move from a style of interaction that is health professional directed and focuses on compliance, to one that supports patient autonomy, matches patients’ level of activation, and

ultimately increases activation. The authors suggest using information from the PAM to help guide discussions and action plans using motivational interviewing (Miller & Rollnick, 2002) techniques (Insignia Health, 2013). The PAM may also be useful for designing interventions, as well as having the potential to evaluate and compare the efficacy of interventions and health care delivery systems as an indicator of performance (Hibbard et al., 2004).

Higher levels of patient activation have been related to positive health behaviours and clinical outcomes, reduced health care utilisation/costs and improved patient experiences. Therefore patients with higher activation are more likely to engage in preventative behaviours, adhere to treatment and effectively self-manage (Hibbard & Gilbert, 2014). Evidence also suggests that patients' activation levels can be modified and that improvements in activation levels can be maintained over time (Hibbard et al., 2015). Therefore, knowing a patient's level of activation provides the individual and the health care team with the best starting point for working towards success in self-management of a chronic condition (Terry, 2010).

Why patient activation might be of interest in pulmonary rehabilitation

Pulmonary rehabilitation is an important element of the long-term management of chronic respiratory conditions and the route to maximise individuals' potential (Department of Health, 2012). The National Institute for Health and Care Excellence (NICE) guidelines on chronic obstructive pulmonary disease (COPD) recommend that pulmonary rehabilitation programmes include multi-component, multidisciplinary interventions, which are tailored to the individual patient's needs (NICE, 2010). It is also recommended that the pulmonary rehabilitation process incorporates a programme of physical training, disease education, and nutritional, psychological and behavioural intervention (Department of Health, 2012).

The pulmonary rehabilitation patient group can have a variety of complex needs. Patients often decline or drop out of pulmonary rehabilitation programmes for a wide variety of reasons including illness, bad weather and transport issues (Department of Health, 2012). Providers should be able to demonstrate how they are assisting patients to fully engage and complete the course. Patients live with their condition daily and need to be supported in understanding that the more they do to manage the impact of it on their life, the less reliant they will be on health services. Self-management is not just about developing an action plan, but also about the process of planning and understanding the requirements and aspirations of the patient (NHS Improvement, 2012). Health professionals need to understand their motivations,

aspirations, fears and behaviours in order to initiate change (Department of Health (2011a).

The design of pulmonary rehabilitation does support patients to make small steps while working to a larger goal, thus enabling "...a sense of mastery and efficacy, in part, by experiencing a series of small successes" (Hibbard & Tusler, 2007b: p.2). This is in line with the PAM premise, that by developing knowledge, skills and confidence in their abilities, patients might be more likely to increase their activation and make behavioural changes.

Hibbard and Tusler (2007b) explored whether there are behaviours that are more or less likely to be adopted at different stages of activation, for example patients with asthma or COPD. Self-management behaviours would include not smoking, knowing what to do during an asthma attack, and managing stress. The authors found that tobacco use was unrelated to activation stage, but knowing what to do during an asthma attack and being able to manage stress were significantly linked with higher activation stages. This research indicated that activation stage is correlated with disease-specific behaviours, and that certain behaviours are realistic for patients at different stages. Therefore a potentially effective strategy may be to assess patients' stage of activation and encourage, tailor and support actions that are realistic given their level of knowledge, skills and confidence. This in turn could provide understanding regarding behaviours such as why patients may decline or not complete pulmonary rehabilitation, cancel clinic appointments, or struggle to give up smoking, for example. In addition, issues of uncertainty (Lewis, Bruton & Donovan-Hall, 2014) about the management of their condition and the major symptom of breathlessness, which can be exacerbated by stress, anxiety and panic, could be intensified if a patient does not feel they have the knowledge, skills and confidence to be in control.

The needs of local Surrey programmes and background to this service improvement project

The West Surrey respiratory care team received referrals from GPs, community matrons, therapy teams, hospital consultants (if a patient had been admitted) and self-referrals. Initial clinic appointments were for one hour, and in that time an assessment was completed and a treatment plan made, for example to register onto pulmonary rehabilitation, stress/anxiety management session with an occupational therapist, home visit for breathing control techniques, or an oxygen clinic. The occupational therapists also telephoned some patients to assess their motivation, as there was often a wide-range of needs, and patients may or may not have self-managed their

condition. Between referral to clinic, and clinic to pulmonary rehabilitation, there was no intervention and there could be significant waits at each stage, if pulmonary rehabilitation was recommended and taken up. This could have increased uncertainty and may have impacted upon motivation.

At the time of this project, staff in the respiratory care team reported trying many different techniques to support the wide-ranging needs of their patients. Staff stated that it would be helpful to be guided in what might work with certain groups of patients so that interventions can be tailored to specific need. The team described patients with COPD as a distinct group. As the principal cause of COPD is smoking, many of these patients had a history of smoking, or may have still smoked. The team stated that anecdotally, COPD patients can feel guilty at not self-managing, which makes them feel less deserving of health care support and they therefore worried about the impact of their health condition on others. This guilt then acted as a barrier to contacting their GP or respiratory team when showing the early warning signs of, e.g. an infection. This highlighted the challenges associated with cultivating the self-management approach in the absence of addressing the health beliefs of these patients. However, if a health professional was able to support a patient into pulmonary rehabilitation, the programme would challenge health beliefs such as “breathlessness is dangerous”, or “it doesn’t matter if I smoke, or don’t do exercise, as it won’t change anything”.

The pulmonary rehabilitation programmes required attendance twice a week for eight weeks. There were ten to twelve people enrolled per programme. Patients also attended sessions for assessment before and after, including completion of outcome measures. To be classed as completing the programme, patients must have attended more than nine of the core sessions.

The local needs therefore appeared to reflect the national pulmonary rehabilitation service specification objectives (Department of Health (2012), which included:

- To improve understanding amongst health professionals of which patients will benefit and should be referred to pulmonary rehabilitation
- To improve completion rates from pulmonary rehabilitation for eligible patients
- To provide a cost-effective, quality assured pulmonary rehabilitation programme that meets the patient’s personal needs
- To improve confidence in the self-management of their conditions, resulting in appropriate use of other healthcare resources

This project was therefore set up to explore any relationships between patient activation and pulmonary rehabilitation outcomes, by adding the PAM into assessment for all programmes. The aim was to provide health professionals with guidance on how to adapt their practice for particular groups of patients; therefore potentially enabling improved patient and service outcomes in terms of predicting engagement in services and adherence to treatment, as well as highlighting the importance of considering psychological measures/activation in service delivery.

Service improvement questions:

- Is the PAM a useful tool to measure outcome of pulmonary rehabilitation?
- Can the PAM predict whether a respiratory patient will complete pulmonary rehabilitation?
- Could the PAM guide practice to improve outcomes for respiratory patients?

Method

Design and sample

As this was a service improvement project, all patients attending the twenty-four West Surrey respiratory care team pulmonary rehabilitation programmes during the two-year duration of this project were asked to complete the PAM, as part of their routine pre and post assessment questionnaire measures. 284 patients with pre and post scores for each measure were included. Gender, age, diagnosis and completion rates were also gathered.

Outcome measures

Patient activation was assessed using the Patient Activation Measure (PAM) (Hibbard et al., 2005) as part of pre and post assessment questionnaires at pulmonary rehabilitation. An academic study research licence was gained from Insignia Health to use the measure from 2013-2015. Insignia Health (2013) suggest that patients who are depressed or have sub-clinical depression are less likely to get activated until the depression is addressed. They recommend screening for depression prior to any attempts to activate patients.

Measures of depression and anxiety were already routinely given to those attending pulmonary rehabilitation programmes, so were also therefore included in the analysis, specifically the Patient Health Questionnaire (PHQ-9) and Generalised Anxiety Disorder (GAD-7). The PHQ-9 (Department of Health, 2011b) is the nine-item version

of the Patient Health Questionnaire, which was designed to facilitate the recognition and diagnosis of depression in primary care patients. It can be used to monitor change in symptoms over time and provides a depression severity index score as follows: none (0–4); mild (5–9); moderate (10–14); moderately severe (15–19); and severe (20–27). The GAD-7 (Department of Health, 2011b), though designed primarily as a screening and severity measure for generalised anxiety disorder, also has moderately good operating characteristics for three other common anxiety disorders – panic disorder, social anxiety disorder, and post-traumatic stress disorder. The index scores are as follows: none (0–4); mild (5–10); moderate (11–15); severe (15–21).

Baseline scores on all measures for those that completed pulmonary rehabilitation were compared with those that did not.

Data analysis

The respiratory team input PAM data alongside standard data into an Excel database. This was anonymised for transferring to the researcher for analysis, in order to safeguard confidentiality. The data gathered was analysed statistically using SPSS for Windows software package. Paired Samples T-Tests and Independent Sample T-Tests were used respectively to compare the means of pre and post measures taken from a single participant, and to compare the differences between baseline measures for those that completed and those that did not.

Results

Patient descriptive statistics

52% of the 284 patients included in the analysis were male and 48% were female. Ages ranged from 29 to 92, with the largest number of patients between the age of 65 and 74. The main diagnosis was COPD (69%). See Table B16 for details.

Descriptive	Type	N	%
Gender	Male	148	52
	Female	136	48
Age			
	25-34	1	0.4
	35-44	2	0.7
	45-54	19	6.7
	55-64	43	15.1
	65-74	110	38.7

	75-84	93	32.7
	85+	13	4.6
	Not recorded	3	1.1
Diagnosis	Asthma	23	8.2
	Asthma and bronchiectasis	1	0.4
	Bronchiectasis	13	4.6
	Chest wall deformity	1	0.4
	COPD	196	69
	Interstitial disease – non-specific interstitial pneumonia	1	0.4
	Interstitial disease – usual interstitial pneumonia	8	2.8
	Interstitial disease – other	17	6
	Interstitial disease – unknown type	16	5.7
	Sarcoidosis	2	0.7
	Other	2	0.7
	Unknown	3	1.1

Table B16: Patient descriptive statistics

Completion rates

85% of the 284 patients completed pulmonary rehabilitation. Of the 15% that did not, the main reason given was due to being medically unfit (25.6), followed by unknown reasons (23.2%). See Table B17 for details.

Descriptive	Type	N	%
Completed	Yes	241	85
	No	43	15
Reason if no	Admitted to hospital – exacerbation	3	7
	Admitted to hospital – other	4	9.3
	Medically unfit (no-respiratory)	11	25.6
	Motivational reasons	6	14
	Social reasons	8	18.6
	Transport	1	2.3
	Unknown	10	23.2

Table B17: Completion rates

Patient activation

In this sample of 240 participants that had both pre and post assessment patient activation scores, scores increased from 54.91 (Level 2 – range 47.1 to 55.1),

(SD=13.29) to 62.43 (Level 3 – range 55.2 to 67.0), (SD=16.43) – see Figure B7. This was highly significant [$t(239)=-7.98$; $p<0.001$]. Therefore it was concluded that the average change in patient activation score was not due to chance, but was a result of pulmonary rehabilitation.

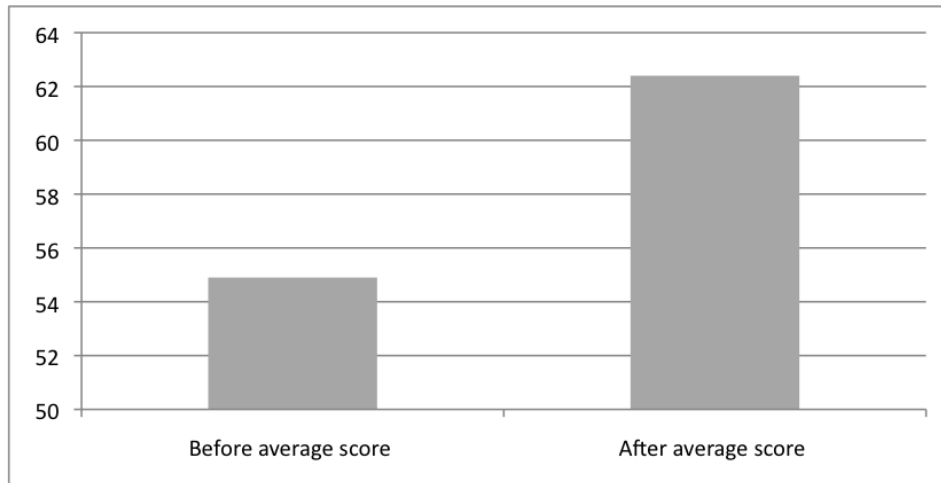


Figure B7: PAM scores before and after pulmonary rehabilitation

An Independent Sample T-Test was used to compare the differences between baseline pulmonary rehabilitation patient activation scores of completers and non-completers of pulmonary rehabilitation. No significant difference on baseline scores [$t(275)=1.69$; $p>0.05$] was found between the 234 completers (mean baseline PAM score = 55.07; SD=13.24) and 43 non-completers (mean baseline PAM score = 51.45; SD=11.19).

Depression

In this sample of 244 participants that had both pre and post assessment depression scores, scores decreased from 5.87 (mild) (SD=5.51) to 4.49 (none-mild) (SD=5.03) – see Figure 2. This was highly significant [$t(243)=5.28$; $p<0.001$]. Therefore it was concluded that the average change in depression score was not due to chance, but was a result of pulmonary rehabilitation.

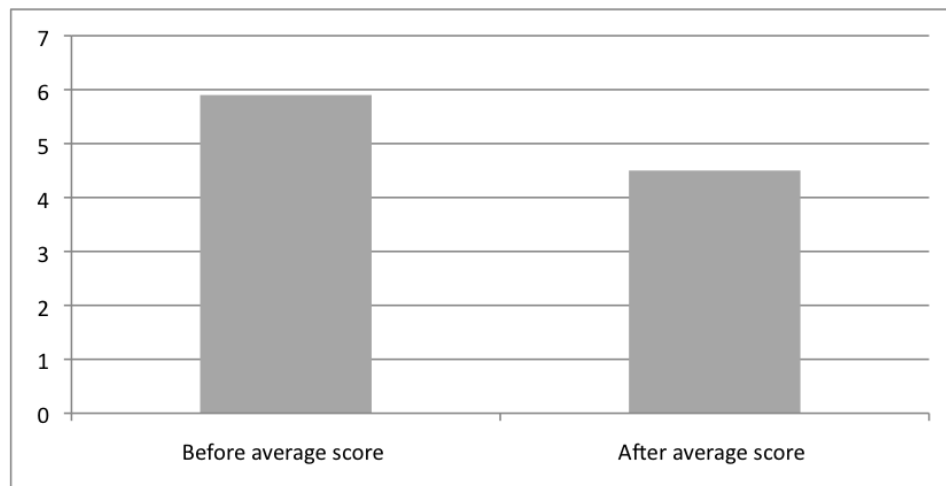


Figure B8: PHQ-9 scores before and after pulmonary rehabilitation

An Independent Sample T-Test was used to further investigate and compare the differences between baseline pulmonary rehabilitation depression scores of completers and non-completers of the programme. For this measure, a significant difference was found for Levene's Test for Equality of Variances between the 236 completers (mean baseline PHQ-9 score = 5.48; SD=5.26) and 43 non-completers (mean baseline PHQ-9 score = 8.72; SD=6.49). This implies that differences exist between the means of the two groups. Therefore a Mann-Whitney U non-parametric test was carried out. This found a significant difference in baseline depression scores between the completers and non-completers ($p < 0.005$) therefore rejecting the null hypothesis. This suggested that those not completing pulmonary rehabilitation were significantly more depressed than those completing, although a score between 5 and 9 on the PHQ-9 is classified as mild.

Anxiety

In this sample of 241 participants that had both pre and post assessment anxiety scores, scores decreased from 4.21 (none-mild) (SD=4.97) to 3.61 (none) (SD=4.85) – see Figure B9. This was significant [$t(240)=2.39$; $p < 0.05$]. Therefore it was concluded that the average change in anxiety score was not due to chance, but was a result of pulmonary rehabilitation.

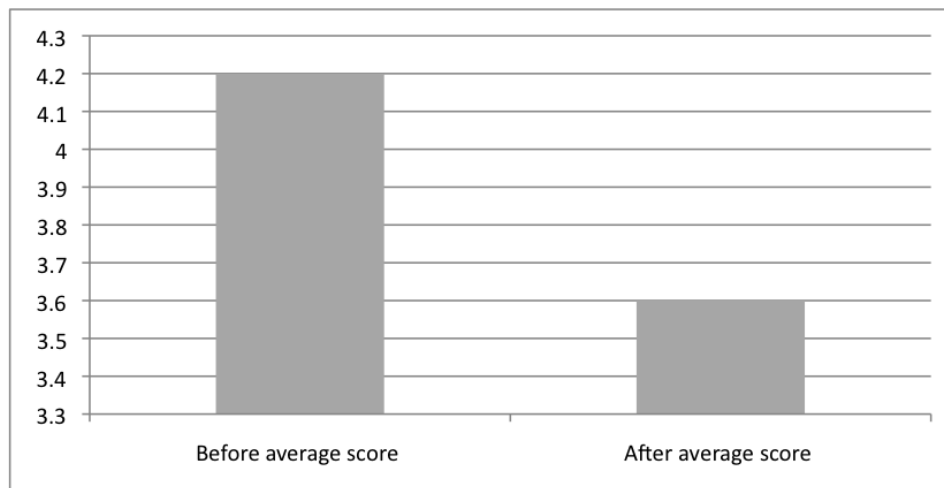


Figure B9: GAD-7 scores before and after pulmonary rehabilitation

An Independent Sample T-Test was therefore used to compare the differences between baseline pulmonary rehabilitation anxiety scores of completers and non-completers of the programme. For this measure, a significant difference was also found for found for Levene's Test for Equality of Variances between the 238 completers (mean baseline GAD-7 score = 3.97; SD=4.74) and 43 non-completers (mean baseline GAD-7 score = 6.93; SD=6.78). Therefore a Mann-Whitney U non-parametric test was carried out on this data. This also found a significant difference in baseline anxiety scores between the completers and non-completers ($p < 0.05$) therefore rejecting the null hypothesis. This suggested that those not completing pulmonary rehabilitation were significantly more anxious than those completing, although a score between 5 and 10 on the GAD-7 is classified as mild.

Age, gender and diagnosis

No significant differences were found between age [$t(279)=0.51$; $p > 0.05$], gender [$t(282)=-0.47$; $p > 0.05$] or diagnosis [$F(11,272)=0.47$; $p > 0.05$] and completion rates for pulmonary rehabilitation.

Discussion

This service improvement project set out to investigate whether the PAM is a useful tool to measure outcome of pulmonary rehabilitation; whether the PAM can predict if a respiratory patient will complete pulmonary rehabilitation; and whether the PAM has potential to guide practice to improve outcomes for respiratory patients.

Is the PAM a useful tool to measure outcome of pulmonary rehabilitation?

In this sample, a significant difference was found between scores, increasing from Level 2 (lacks confidence and knowledge to take action), to Level 3 (beginning to take action). There were therefore elements of the pulmonary rehabilitation programme that were providing the knowledge and skills, challenging beliefs and recommended behaviours that a patient needs to manage their respiratory condition, and thus can assist in supporting self-management through activation.

It is interesting that patients attending pulmonary rehabilitation were already at the higher end of Level 2. It might be that they already understood that the patient role is important, but were lacking the confidence and knowledge to take action. Pulmonary rehabilitation appears to increase the average post assessment score, fitting just above the halfway point of Level 3 - enabling patients to begin to take action, having gained the key facts, but may still lack confidence and the skills to support their behaviours.

Hibbard, Mahoney, Stock & Tusler (2007a) proposed that what will help a patient move from Level 1 to 2 is a different intervention than moving from Level 3 to 4. For this sample, understanding how the content of pulmonary rehabilitation enabled patients to move from Level 2 to 3 would help inform future interventions. It might therefore be possible to be more targeted in supporting patient self-management (Hibbard et al., 2007a)

In addition, the completion figures for the programmes included in this project were high. There may therefore be elements of the West Surrey pulmonary rehabilitation programmes that encouraged attendance. Given that there were often long waits between referral to clinic, and clinic to pulmonary rehabilitation, it would be useful to know how many potential pulmonary rehabilitation participants declined due to the waiting times and were therefore not reflected in the patient activation scores. Further research is required to explore use of the PAM in those that declined pulmonary rehabilitation, or were not considered suitable. It would be helpful to better understand why these pulmonary rehabilitation patients already started off at Level 2; were they more motivated than those who declined, or was there something else going on in the waiting period? Did their expectations of treatment or perception of need differ? Could their scores at clinic have been different, and how did waiting for the programme impact? Would some form of early intervention make a difference?

Further research is also needed to understand the specific elements of pulmonary rehabilitation that increased activation. Could those elements be incorporated into

treatment for patients not participating in pulmonary rehabilitation, thus potentially improving outcomes and service time? Due to the scale of this project, and quantity of assessment outcomes measured and inputted by the respiratory team, the raw data from individual items of the PAM was not gathered. This data could have potentially assisted in exploring any particular mechanisms of action of the programme.

Future research could consider whether the nature of participating in a formal group intervention such as pulmonary rehabilitation in itself is a motivational factor for completing the programme that also aids non-formal learning. Support or community groups can facilitate the development of self-efficacy and health-enhancing behaviours, alongside health professionals, as patients learn incidentally from one another through meaningful exchanges with others in the same community (Stevens, O'Donnell & Williams, 2015). However a randomised controlled trial may be required to assess this, with a group of patients receiving a basic intervention versus those participating in pulmonary rehabilitation, which may be difficult to justify given the merits of pulmonary rehabilitation.

The PAM was accordingly also assessing the effectiveness of pulmonary rehabilitation as an intervention. It therefore has potential to be used as a performance measure against which individual provider or health system performance could be assessed (Hibbard & Gilbert, 2014 in Brewster, Tarrant & Armstrong, 2015).

Can the PAM predict whether a respiratory patient will complete pulmonary rehabilitation?

No significant difference was found between baseline PAM scores for the completers and non-completers. Therefore the PAM did not predict completion of pulmonary rehabilitation in this sample. However, the reason given by the majority for not completing was because they were too unwell to continue. This may help to explain why the PAM did not predict completion.

Additional findings of this project can provide an insight into other reasons for non-completion. Significant improvements in both depression and anxiety scores were found between pre and post assessment scores for those completing the programme, therefore showing that changes were not due to chance. When further investigated, the analysis found a significant difference for baseline scores on the PHQ-9 and the GAD-7 between the completers and non-completers. This suggests that those not completing pulmonary rehabilitation were significantly more depressed and anxious than those completing, although scores were within the mild categories.

Further investigation into why people do not complete pulmonary rehabilitation would be useful. In this sample, it was mostly for medical reasons, but national research cites a wide variety of reasons including illness, bad weather and transport issues (Department of Health, 2012). In addition, given that those not completing pulmonary rehabilitation in this study were significantly more depressed and anxious than those completing, could there be more to it than the medical reasons given?

Could the PAM guide practice to improve outcomes for respiratory patients?

The results of this project support Insignia Health's recommendations that screening for depression is necessary to enable the right support to be given to patients who are depressed. In this case, screening for both depression and anxiety could enable patients with high scores for these measures to be linked in with other support instead of completing pulmonary rehabilitation, where they may be more likely to drop out than patients with lower scores.

In this project, the PAM was applied as an outcome measure. Using the PAM as an additional screening tool at clinic, and analysing it there and then as the developers suggest, could additionally inform the treatment plans for individual patients, for instance including referral to psychological therapies or practical support. This could be especially useful for the West Surrey team as they stated that it would be helpful to be guided in what might work with certain groups of patients so that interventions can be tailored to specific need. This may require staff training, for instance in motivational interviewing techniques, in order to adapt practice and maximise benefit.

PAM scores also need to be visually scanned or analysed at the beginning of pulmonary rehabilitation to assess any change and to ensure the patient is likely to feel able to complete the programme. Hibbard et al. (2005; 2007a) suggest using this as an opportunity to begin a conversation with a patient around where their responses may have changed, and using the PAM as a basis for designing care plans as well as assessing progress over time.

Further research could explore the similarities and differences of the concept of the PAM with health locus of control and health literacy. Individuals differ as to whether they regard events as controllable by them (an internal locus of control) or uncontrollable by them (an external locus of control). Health locus of control (Wallston & Wallston, 1982) has been shown to be related to whether an individual changes their behaviour, and the communication style of the health professional in facilitating this (Ogden, 2007). Health literacy has been described as the cognitive and social skills

which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health (Nutbeam, 1999). Health literacy is needed for patients and the public to understand and act upon health information, to become active and equal partners in achieving good health, and to take control of their health through increasing confidence and skills to enable decision-making that is shared between doctors and patients to help to shape health environments and health services for themselves, their families and their communities (Royal College of GPs, 2014). There are therefore overlaps in the aims and applications of the three concepts in promoting self-management and self-efficacy.

Limitations of this project

It is possible that patients may shift between PAM levels as their condition changes, e.g. moving from a lower level to a higher level as their condition improves, or a higher to a lower level of activation as their condition worsens or their treatment changes. For some patients, maintaining their PAM score at its current level, rather than increasing it may be a positive outcome (Brewster, 2015), and re-measuring if a patient has a significant event, for example an exacerbation, may be required. There is also a risk that the PAM itself may act as an intervention, particularly if it is completed as part of a consultation or referred to by health professionals as part of routine care to support self-management. This could compromise its usefulness as an outcome measure (Brewster et al., 2015).

Finally, the introduction of the PAM to pre and post assessment questionnaires as an outcome measure presented its own challenges, as there were already several other outcome measures in the assessments. Only cases with pre and post assessment PAM scores could be included in this analysis, thus patients attending programmes during the project time period but without PAM scores had to be excluded. The team reported that some measures may have been missed and a few patients declined to complete them. They did not get the opportunity to input the measures until later in the programmes so were not aware when outcomes were missed. Also, some patients were considered not to have officially completed as they did not attend enough exercise sessions, but were present at the end assessments and therefore completed the post PAM score but were not able to be included in this analysis due to not completing the programme.

Other considerations

Further research is required to understand how a patient might achieve Level 4 of the PAM, which categorises an individual as having adopted new behaviours, but may not

be able to maintain them in the face of stress or health crises. Further interventions may be required to enable the maintenance of behaviours over time, or the PAM could be used as part of a follow-up process with patients either under the respiratory team or general practice.

Conclusion

Completion of pulmonary rehabilitation has been found to improve outcomes for patient activation, depression and anxiety. The use of the PAM as a tool to measure patient activation in pulmonary rehabilitation found positive results for programme outcomes. This is in line with the PAM premise, that by developing knowledge, skills and confidence in their abilities, patients might be more likely to increase their activation and make behavioural changes. The PAM was not able to predict whether a respiratory patient will complete pulmonary rehabilitation, but currently used measures for depression and anxiety were. Areas for further research have been identified.

Methods for using the PAM to guide practice to improve outcomes for respiratory patients have been explored and show potential. This project could therefore help inform the development of targeted psychological interventions to support respiratory patients. The project could also be replicated to explore the potential for supporting the prevention, education and self-management of a wide range of long-term health conditions.

This project provides evidence of the need for health psychology interventions to support patient self-management and for possible team training. It also has the potential to assist services in meeting the objectives of the national pulmonary rehabilitation service specification (Department of Health (2012) to: improve understanding amongst health professionals of which patients will benefit and should be referred to pulmonary rehabilitation; improve completion rates from pulmonary rehabilitation for eligible patients; provide a cost-effective, quality assured pulmonary rehabilitation programme that meets the patient's personal needs; and improve confidence in the self-management of their conditions, resulting in appropriate use of other healthcare resources. Tools such as the PAM used alongside techniques such as motivational interviewing may help bring a more client-centred approach to patients participating in rehabilitation programmes as well as those who decline.

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SECTION C

PROFESSIONAL PRACTICE

Generic Professional Skills - A Case Study

This case study will describe and reflect on my professional practice as a health psychologist in training. It details how my supervised practice as a Health Promotion Strategist in Behaviour Change for Whittington Health NHS Trust, and a Team Leader for First Steps mental health promotion service and Healthy Minds Surrey psychological therapy service, has enabled me to develop and meet the required generic professional skills competencies.

Implement and maintain systems for legal, ethical and professional standards in applied psychology

Establish, maintain and review systems for the security and control of information

In my Team Leader role, I am responsible for the development and maintenance of systems for security and control of information. This includes: implementing and reviewing risk protocols, e.g. the identification and management of risk on the client phone line for First Steps, and at assessment and treatment for Healthy Minds Surrey, an Improving Access to Psychological Therapies (IAPT) service (Department of Health, 2007); evaluating clinical governance practices for the team and safeguarding of patients, e.g. ensuring the team are up to date on mandatory training, and report incidents where required; and ensuring correct procedures for access to patient records across both services.

Ensure compliance with legal, ethical and professional practice for self and others

My management responsibilities have increased from three to eight staff, including mental health advisors (one of whom was also a trainee health psychologist), psychological well-being practitioners, and administrators. I have also line managed and supported the development of a volunteer who worked with the team for a year. I provide leadership, coordinating the work of the team to ensure this is evidence-based and effective.

There have been challenges along the way, for example balancing my approachable and open style to empower people to take control of their own work, with the need to

have difficult conversations around performance when this has not met the required standards, and agree action plans based on policies and procedures as a result. Seeking support from my own supervisor has assisted this, alongside attending training on performance management, leadership development and coaching skills.

As part of the IAPT service, I facilitate individual and group clinical supervision, and case management supervision. To support this supervisory development, I attended five days of supervisors training at the University of Surrey from May to October 2013, facilitated by the team that also run the IAPT training programmes. This training explored and enabled me to reflect on the generic and therapeutic skills I already have, learning more specific supervision competencies for case management, clinical and group skills supervision, as well as how to support yourself as a supervisor. It provided me with the opportunity to review my previous experience in primary care mental health and apply this to the IAPT model, enabling supervisees to use theory to formulate and link to practice, as well as creating an environment of trust and reflection. I also put into place outcomes for both services as a result of this training, such as setting up supervision contracts. The training also provided confirmation as to how important supervision is to receive feedback and as a restorative function. This all ensures that the team comply with treatments in line with the protocols recommended by National Institute for Health and Clinical Excellence (NICE) (2011) and the Department of Health (2011), and to ensure patient and staff safety by regular review of patient risk and developing staff clinical practice.

In order to support the ongoing professional development of the team, I have provided a number of skills development and training sessions, for example group work skills, Motivational Interviewing (MI) (Miller & Rollnick, 2002), Cognitive Behaviour Therapy (CBT) for insomnia, a team stress prevention session, and cascaded "Type coach" training on practical applications of personality types in the workplace. I have also arranged for external facilitators to provide training, for instance telephone skills training, and training on self-harm and suicide awareness. These sessions have been a collaborative way of developing strategies for issues impacting upon the team. I have also championed the introduction of ground rules for these sessions as well as team meetings, based on feedback I have received from supervisees and in order to allow everyone to feel that they can contribute.

Establish, implement and evaluate procedures to ensure competence in psychological practice and research

During this time, I have built on my range of previous work experience in research, primary care mental health, health promotion and behaviour change. My practice has helped to shape my competencies, as well as my desire to develop research that would contribute to clinical practice. This led to the investigation of insomnia as a research field, following completion and application of an MSc module in psychological treatments in behavioural sleep medicine in 2012, and proactively contacting key figures in the field to assess the need for research where health psychology could contribute.

I have however experienced delays and challenges in my main research. It took eleven months to submit and receive clearance from ethics and research committees, and then twenty-three months to recruit forty-eight out of the required fifty participants, rather than the original estimate for data collection of six months. Whilst data collection was ongoing, there were also increasing drop-outs and lack of completion of follow up measures. In order to meet doctoral research requirements, recruitment was stopped and an NHS ethics amendment was submitted and approval given to further investigate the experience element of the research, through carrying out semi-structured interviews of a sample of participants who had completed their treatment.

Working with an external clinic created difficulties when trying to contact members of the team, booking participants into treatments, and the level of involvement I had to have on an ongoing basis with participants was substantial. I have, however, enjoyed working with the team and participants, and have also learnt a great deal throughout this process that would be applicable to future research projects in the NHS. For instance, the process of applying for ethics and research clearance encouraged me to: objectively view my research, consider the ethical, legal, scientific and management issues arising from the study; develop supporting documents; and ensure that the study met the necessary standards. I was also required to attend the original ethics committee meeting to present my application and answer any questions. Throughout the study I have maintained processes for the research to continue to be conducted ethically, through ensuring informed consent, maintaining confidentiality, assessing risk, and having regular meetings with the external team.

I have applied The British Psychological Society (BPS) Code of Ethics and Conduct (2009), and the Health and Care Professions Council (HCPC) Standards of Conduct, Performance and Ethics (2015), across my practice as a trainee health psychologist.

Contribute to the continuing development of self as a professional applied psychologist

Establish, evaluate and implement processes to develop oneself professionally

In my Health Promotion Strategist role, I coordinated and delivered a programme of health promotion and behaviour change training for health and social care professionals. Part of this was embedding learning on psychological theories and interventions for teams to promote and protect health. This has been documented in my first teaching and training case study.

The skills I have learnt are transferable and I apply them within my Team Leader role, where I am continuously developing my professional skills. I contribute to and advise on the development, implementation and evaluation of evidence-based health improvement programmes, empowering individuals to manage their own mental health and emotional well-being. As part of this, I lead on programmes and groups relating to the interaction between physical and mental health; and provide assessment, formulation and one-to-one or group CBT-based interventions for people with mild/moderate mental health and emotional difficulties, such as anxiety, stress, depression, anger, and sleep problems.

Elicit, monitor and evaluate knowledge and feedback to inform practice

I have implemented new ways of eliciting information by amending training and workshop feedback forms to include knowledge change scores and behaviour change intentions. It has also been useful to reflect on training and workshop delivery, and any improvements that could be made. This feedback forms part of performance monitoring and reporting, enabling the team to continuously develop and improve our delivery. It has also enabled me to effectively evaluate the work I completed for my second teaching and training case study and behaviour change interventions case study, as well as cascade learning to other team members for their professional development.

Organise, clarify and utilise access to competent consultation and advice

I make good use of supervision, peer support and reflection. In terms of my own professional practice, my work supervisor has allowed me to use my independence and ability to manage a well-respected team whilst being available to me should I need support. Building on my past experience, this has further enabled me to build my skills as an autonomous practitioner.

I have also provided consultation and advice to other health professionals, e.g. when I undertook a formal piece of consultancy work for a public health department to produce a series of mental health podcasts. I have also developed and delivered training and guidance to physical health teams and GPs in order to enhance health and well-being for patients and their families/carers, e.g. a workshop on emotional well-being and cancer for Macmillan, and development of MI and CBT training for musculoskeletal physiotherapy teams.

Develop and enhance oneself as a professional applied psychologist

During my supervised practice, I have also sought to explore development outside of my core work responsibilities. I have attended training on CBT-based self-help and a one-day training course on CBT in the management of long-term conditions provided by the BPS. Both of these were useful reflective experiences for me in confirming my current practice, but also for ways in which I could develop my own and the team's practice. I have shadowed a pulmonary rehabilitation session and a respiratory clinic to better understand the needs for my service improvement project. I have met with a clinical health psychologist at a local centre for pain education, followed by shadowing a pain management session a few weeks later, which enabled me to promote the health promotion service I work for, as well as giving me the opportunity to learn more about managing pain.

I attended the Kent Surrey and Sussex applying health psychology in the NHS and other settings conference in 2013. It was encouraging to see how health psychologists can advance the current health agenda, including developing targeted psychological interventions for physical health patients. I also attended the CBT for insomnia disorder conference at the Royal Society of Medicine, which provided the latest updates on practice in my main research area, as well as the opportunity to hear from sleep experts. Attending a participant workshop as part of my research in May 2015 also gave me a useful refresher, and I learnt further strategies to describe how insomnia can arise and be perpetuated.

Incorporate best practice into one's own work

Attending the University CPD workshops as part of the DPsych has also enabled me to review my current practice whilst receiving up-to-date training and guidance. The annual reviews and further reading on professional and research practice, such as Michie and Abraham (2004) and Dempster (2011), has been helpful for reflecting on my progress across the competencies, enabling me to pull together my knowledge, skills and experience as a health psychology practitioner. I have reviewed where

challenges have arisen in juggling the DPsych alongside increasing work commitments and research delays, and taken learning from these. I also presented two posters at the Division of Health Psychology conference in 2015, one on my respiratory service improvement project, and one on my main research into CBT for insomnia. This was a useful and interesting opportunity to present my work, as well as offering a forum for networking. It also enabled me to see how I might make a case for health psychology input in physical health, with my clinical skills and experience in areas such as supervision and therapeutic interventions.

I have completed the required supplementary research manuscripts, and these have all been published: a careers article in *The Psychologist* (May 2014); how health psychology can contribute to improving insomnia in *PsyPAG Quarterly* (December 2014); improving emotional well-being for respiratory patients in *Breathing Matters* magazine (March 2015); and my respiratory service improvement project in *Health Psychology Update* (Autumn 2016 edition).

Provide psychological advice and guidance to others

Assess the opportunities, need and context for giving psychological advice

My Health Promotion Strategist role enabled me to apply psychology in multicultural contexts, where the importance of culturally relevant psychological advice and information, alongside the understanding of potential barriers to change, was vital to support the professionals I was training.

The First Steps service provides mental health promotion to the population of Surrey. The specification includes: developing capacity; awareness raising, training and anti-stigma campaigns; interventions such as workshops and self-help booklets; and phone line support, signposting, advice and information. I am responsible for all of these activities, overseeing the work of the team as well as being involved in delivery, evaluation and performance reporting.

Provide and evaluate psychological advice

Through my work roles I have provided and evaluated training including CBT-based self-help, workplace well-being, and supporting patients with a physical health condition. I have also provided expertise to physical health teams on working with patients in emotional distress, and psychoeducational group-based interventions in the community. All workshops and training sessions are based on the latest guidelines and

evidence-based practice such as: NICE guidelines on anxiety (2004), depression (2009) and behaviour change (2007); and Department of Health strategies on public health (2010) and mental health (2011).

Reflecting on delivery of these sessions during my supervised practice has been a helpful process personally and professionally. It has enabled me to see the positive impact my practice has had and how my skills have improved across the years. For instance, due to a desire to deliver to a high professional standard, I would sometimes worry about delivering workshops or training to new or unique audiences, which was exacerbated by limited time to prepare in work hours. However, sessions have always gone better than I had expected, including when I have found myself in particularly challenging situations or had to deal with the unexpected, e.g. participant emotional distress or co-facilitator sickness. I have continuously adapted and improved content based on health psychology theory, my own development opportunities, feedback, collaboration, and to work with the needs of diverse audiences through a range of delivery styles and techniques to enable learning and understanding. As part of this I have borne in mind Kolb's (1984) learning styles. This has helped me to understand different individual learning preferences, as well as highlighted the importance of experiential learning.

I have encouraged the team to reflect on their learning following training and skills sessions. I have done this through the use of MI skills, and at times I have utilised the CBT model to identify themes and patterns for particular situations, to clarify thinking, and setting action plans. Otherwise there has been a tendency for the team to request training on certain topics, then having received this not to change practice as a result, or state that they need more training. I have therefore had to balance the support given to the team with an encouragement to utilise learning opportunities already provided and develop their practice.

The CBT-based group interventions for COPD, cancer, cardiac rehabilitation and insomnia that I have developed and delivered in my role, alongside coordinating the development of a range of self-help booklets for physical health conditions, has enabled me to better understand the needs and difficulties of people with physical health conditions, and work collaboratively to enable adjustment and adaptation. I also understand the impact of complex biopsychosocial problems, such as health, housing and family support, and the importance of enabling people to make informed choices and access support services to meet their needs.

For Healthy Minds I am required to make informed professional judgements on complex issues, using disorder-specific measures to guide decision-making, treatment plans and evaluation. I have been able to utilise my previous experience of working one-to-one with patients, further developing my therapeutic skills, as well as understanding the boundaries of my competence and when I need to make an onward referral. Anonymous patient evaluation questionnaires allow for evaluation of the service and contribute to ongoing performance management.

Provide feedback to clients

Evaluate feedback needs

As Team Leader, I provide psychological advice and guidance to team members, other teams and organisations, as well as the general public, through development and review of self-help resources; developing and reviewing training through evaluations and feedback, latest research, reflection and group discussion.

Prepare and structure feedback

Feedback may come in a variety of ways, including formal evaluation, verbal communication or service user consultation, depending on the needs of clients. For instance, our First Steps commissioners require feedback through performance reporting and collation of evaluation reports. I organise, prepare and structure this feedback to ensure that it reflects the work delivered within our service specification and learning points moving forward. Service user involvement is a core part of our service specification and we select methods of communicating feedback such as in newsletters, press releases, and internal reporting.

Select methods of communicating feedback

Through my experience, I have developed an even greater awareness of how feedback might be given in different formats. E.g. I have had many discussions with teams regarding patient 'engagement' and the focus for health improvement being on the patient and whether or not they engaged in treatment. However, it could be that a health professional is not being person-centred and therefore a patient is not being empowered to manage their condition, subsequently not being in a position to begin making behaviour changes. This in itself is feedback, and through cascading of training such as MI, a better understanding can be gained for effective clinical practice.

Present feedback

Feedback is also a core part of my staff supervision, helping supervisees to clarify thinking, critically evaluate their work, and identify themes and patterns in work to increase effectiveness. As part of my own supervision, I have always found feedback helpful, and it was reassuring to see from the IAPT supervisors training that my methods of providing feedback in supervision are constructive and appropriate. It was also interesting to consider that most supervisees want honest feedback yet are fearful of it, which links back to the importance of developing therapeutic skills in supervision as well as patient work.

Conclusion

My work roles have changed quite considerably during my supervised practice. However, with increased work responsibilities have come further opportunities to develop my skills as a practitioner. I now regularly use MI and behaviour change skills, mindfulness approaches, and CBT-based interventions across my practice. I have developed a somewhat unique role for myself as a health psychologist working in mental health promotion and psychological therapy. Keeping a reflective diary for reviewing key events and experiences has enabled me to reflect, learn and develop action plans relating to my professional practice, utilising key themes from over 100,000 words of reflections.

I look forward to my career in health psychology, continuing to develop as a reflective scientist-practitioner, and making a difference in physical and mental health care.

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Teaching and Training of Health Professionals -

A Case Study

In my role as Health Promotion Strategist at Whittington Health I was responsible for a programme of health promotion and behaviour change skills training for health and social care frontline staff, for which I have used concepts and evidence from health psychology. This case study will look at the planning, design, delivery, assessment and evaluation of this programme of training over six months between September 2011 and March 2012.

Planning and designing the training programme to enable health professionals to learn about psychological knowledge, skills and practice

Assessing training needs

From 2010 to 2011, I delivered and co-ordinated the roll-out of two health promotion and behaviour change training programmes. Evaluations of these training courses showed that participants found the mix of information giving, discussion and activities an effective way to learn new skills. Most participants felt that they had a good knowledge of health promotion and behaviour change techniques, and valued the learning and practice of Motivational Interviewing skills. However, we were faced with issues of cost and capacity in running two training programmes, and low attendance on one which ran over two half days. In addition, several areas were identified where participants felt that further training was required to develop, practice or embed expertise in areas such as communication skills and techniques for enabling lifestyle behaviour change.

Identifying training programme structure, content, method and approaches

In September 2011, I organised a meeting with key stakeholders and commissioners to review these programmes and discuss training needs of frontline staff in relation to health promotion and behaviour change skills. Based on the learning from the two programmes, the stakeholder group discussed ideas on how to take this training forward with a reduced budget and staffing, whilst still providing training that would meet the learning needs of staff. The group agreed that provision of health promotion messages for the local Public Health target behavioural risk factors of smoking,

alcohol, unhealthy eating and lack of physical activity, should go alongside the skills to raise issues and implement change.

It was decided that Motivational Interviewing should be incorporated and expanded as a key element underpinning the training, with consideration given to relating the training to practice and how participants would embed the learning. The group were of the opinion that the training would be more sustainable if held over one full day rather than three half days. The aim, objectives, and outcomes were decided (see Appendix C1), and the name of the training was to be Supporting Lifestyle Behaviour Change. I accordingly proposed that I research, plan and design a new training outline.

Producing training materials

I began work on the training outline by referring to the latest policy and guidance relating to health promotion and behaviour change, such as NICE guidance on Behaviour Change (2007) and the White Paper Healthy Lives, Healthy People (Department of Health, 2010). This guidance highlighted the need to equip practitioners with the necessary competencies and skills to support behaviour change using evidence-based tools and innovative approaches to support practice.

I researched the evidence-base on how best to train wide-ranging groups of health and social care professionals in behaviour change skills, incorporating the views of the professionals I had spoken to, feedback from previous programme evaluations, and the agreed aims and objectives. I wanted to ensure that the training met the diversity of experience of participants, so I familiarised myself with Kolb's (1984) learning styles. This helped me to understand different individual learning preferences, as well as highlighted the importance of experiential learning.

Motivational Interviewing has been defined as "a collaborative, person-centred form of guiding to elicit and strengthen motivation for change" (Miller & Rollnick, 2009: 137). It allows patients to elicit their own motivations for making behaviour changes in the interest of their health. Much of health care involves helping patients to manage long-term conditions where outcomes can be greatly influenced by lifestyle behaviour change (Rollnick, Miller & Butler, 2008). Evidence that Motivational Interviewing has been effective for the management of many types of long-term conditions and behaviour change related to self-management of disease, means that it is a key current behaviour change technique and communication method.

So, the challenge for developing a training intervention based on Motivational Interviewing is to convey enough detail about the strategies and principles of Motivational Interviewing to enable health and social care professionals to successfully apply the skills and practice effectively, whilst not over-burdening them with theory.

I reviewed the literature by the founders of Motivational Interviewing, Miller and Rollnick, as well as research that had utilised Motivational Interviewing as the basis for training health professionals in behaviour change skills (Madson, Loignon & Lane, 2009; Miller, Yahne, Moyers, Martinez & Pirritano, 2004). I also investigated Motivational Interviewing as a behaviour change technique (Abraham & Michie, 2008), and consulted The Health Foundation's publication on training professionals in Motivational Interviewing (2011).

Research shows that it is possible to train professionals and lay people in Motivational Interviewing. The key components emerging are inclusion of communication strategies, focusing on the principles of Motivational Interviewing, having opportunities to practice skills, and opportunities for ongoing feedback and review (The Health Foundation, 2011). These were, therefore, the core areas that I planned to include in this training, alongside updates on key health promotion messages.

Using appropriate media to deliver the training

I decided to start (see Appendix C2) with an introduction that welcomed participants and asked them what they hoped to get from the training, as this would be useful for reviewing their objectives at the end. I also planned to emphasise the applicability of health promotion and behaviour change/ Motivational Interviewing training to their practice and how the communication skills could also be used in other aspects of their life too. By starting off with this introduction I wanted to get their engagement right from the beginning.

Through my experience of delivering health promotion training, I knew the key healthy lifestyle messages for healthy eating, physical activity, alcohol and smoking. For this training outline, I updated my knowledge using our Public Health department's recommended literature, which I adapted, into the health promotion section, including quizzes, activities, worksheets and a case study (see Appendix C3).

The next part of the training focused on a group discussion around participant's experiences of encouraging health behaviour change with clients, why clients find it difficult to change behaviours, and the difficulties associated with giving advice. This

led on to a brief introduction to Motivational Interviewing, followed by communication skills and strategies – Open questions, Affirmations, Reflective listening, and Summarising (OARS) (Rollnick, Miller & Butler, 2008). These skills are key to building rapport with a client; they enable exploration and understanding of the client's perspective, and can be drawn upon at any stage. I took each of these in turn, giving the participants the opportunity to practice each skill in pairs or small groups to generate discussion and understanding.

Raising sensitive health issues was identified as an area in which staff lacked confidence. For this intervention, I introduced the idea of PAPA – an acronym for Permission, Ask, Provide, Ask. This is another Motivational Interviewing communication tool that guides a practitioner to gently raise a difficult topic without incurring resistance (Rollnick et al., 2008). Having outlined what PAPA was, I included a case study (see Appendix C3) to enable the participants to practice using the technique.

To further develop the skills of participants, I then introduced the four principles of Motivational Interviewing – express empathy, develop discrepancy, roll with resistance, and support self-efficacy. These principles can enable a client to start moving towards behaviour change successfully and with confidence. For each principle, I provided an introduction, followed by group work, a worksheet or case study (see Appendix C3).

In order to give participants an outcome to have in mind when putting these skills into practice, I included a section on SMART (Specific, Measurable, Achievable, Relevant, and Timely) goals. This technique would allow participants to help their clients set appropriate goals (see Appendix C3), and discussion would highlight what could be done if a client was not following or reaching their goal, and how to encourage achievement.

By the end of October 2011 I had completed the training outline and had sent it to the key stakeholders for feedback. Feedback was positive, but several people mentioned the need to provide role play opportunities in order to enable participants to practice skills in a simulated environment. To address this I observed another local behaviour change skills programme that specialises in training health professionals working in the field of long-term conditions. This training used actors for role-plays, which worked very well and I could see how this method would help facilitate learning. Adding a section for role-play, with trained actors and using participants' case studies, would allow for the skills learnt during the day to be applied to practice. I planned for the role-plays to be

facilitated in two groups, each with an actor, giving the opportunity for self-reflection, actor, group and facilitator feedback.

By November 2011 I had created a final training outline (see Appendix C4), dates were circulated, participants were booked on the training and I was ready to start delivering.

Delivering the training programme

I have now delivered this training over five individual training days from November 2011 to March 2012, implementing the methods, and facilitating the learning of seventy-one participants from a wide range of frontline services.

Reflection on delivery the training

Having delivered this course five times now, I feel much more confident in my knowledge and skills for facilitating training in Motivational Interviewing. I am able to talk around the topics, adding examples and discussion points based on my experience. I am pleased I have achieved this, and have had many people come up to me at the end of the day saying how much they have enjoyed the training and the varied teaching methods, which is really positive.

One of the key learning points through the process has been that it is beneficial to have two facilitators for this training. I started off delivering the training on my own, but found the practicality of running the two group role plays with actors difficult, and it is also a long day for the participants to listen to one facilitator. After the first two training days, I was able to arrange for an external facilitator to work with me. We discussed the training day together before co-facilitating the next three days. This has brought improvements to the training as I feel that working with someone else that is knowledgeable in the area has made the teaching style more varied, enhanced my understanding of the skills, as well as increased my confidence in training others in these skills.

I have also amended the role-plays with actors slightly. To start with I asked participants to use their own case studies to make the experience as relevant to their role as possible. This was partially helpful, but a great deal of time was spent on the background to the situation, so valuable time was lost actually practicing the skills. In addition, despite specifically asking participants not to choose their most difficult client, many wanted to practice skills on very challenging scenarios. I therefore decided to

change the case studies to be the same four cases that are used throughout the training day, so the participants are familiar with them, and I provided the actors with the detail beforehand so they were fully prepared. This worked much better and enabled a great deal more practice and skills development to occur.

Planning and implementing assessment procedures for the training programme

In order to monitor and support the training, I set up assessment and evaluation processes for reviewing the objectives at three time points – before the training, directly after the training, and at three months post-training (see Appendix C5 for evaluation forms). The three-month follow-up was designed to establish if participant intentions, confidence, skills and knowledge were retained once they had the opportunity to practice what they have learned. Other data that was gathered included the participants' roles and services they worked for.

I also worked collaboratively with the key stakeholders and commissioners to devise a series of indicators that supported the training outcomes. This then formed the Performance Review and Evaluation (see Appendix C6), which would enable decisions to be made about future delivery.

Evaluating the training programme

The assessment and evaluation has given a useful indicator of the participants' experience of this new training, as well as provided feedback that will shape the future development of the programme (see Appendix C6). The key messages were all on target for the objectives, which is encouraging, and I plan to discuss the results at the next review meeting with the stakeholders.

One consideration is whether to incorporate the embedding of skills through refresher sessions as a core component following training. The Health Foundation (2011) emphasised the importance of participants having opportunities for ongoing feedback and supervision, and the feedback that many would like a follow-up session or refresher suggests that in some cases this support may not be available. Thought needs to be given to how to increase the three-month follow-up response rate, in order

to fully understand the long-term impact of this training and participants' ongoing needs.

Conclusion

This case study looked at the planning, design, delivery, assessment and evaluation of this programme of training over six months. The challenge was to deal with the issues of cost, capacity and low attendance, whilst providing a training programme that participants valued and that equipped them with the skills to successfully enable lifestyle behaviour change.

Overall the Supporting Lifestyle Behaviour Change training programme has achieved this through successfully drawing together health promotion knowledge, with the skills and good practice of Motivational Interviewing.

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Appendix C1 – Teaching and Training professionals case study

Health Promotion and Behaviour Change training review meeting 23/09/11

BH introduced the current training programmes - Universal Health Promotion (delivered by the Health Promotion Strategist) and Tackling Health Promotion in Practice (behaviour change training delivered by a local university).

These programmes were well evaluated; however we are faced with issues of cost, capacity and low attendance.

Ideas discussed:

How best to take this training forward with a reduced budget and staffing, whilst still providing a training intervention that would meet the learning needs of staff.

- Training would be more sustainable if held over one full day rather than three half days.
- The group agreed that provision of health promotion messages for smoking, alcohol, unhealthy eating and lack of physical activity, should go alongside the skills to raise issues and implement change.
- Motivational Interviewing should be incorporated and expanded as a key element, relating the training to clinical practice and how staff would embed the learning.
- Name of the training intervention - Supporting Lifestyle Behaviour Change.

The objectives were:

1. To encourage practitioners to deliver lifestyle behaviour change interventions as part of their everyday work, opportunistically and as part of an episode of planned care, thus making every contact count towards prevention of ill health and reducing health inequalities.
2. To increase skills and confidence amongst practitioners to deliver evidence based health promoting interventions to promote the health of Islington's residents, and support patient's effective self management of long term conditions.
3. To strategically embed in all services, widening frontline delivery of behaviour change interventions.

The following aim and training outcomes were devised:

Aim: to provide frontline staff with training that will help them to support the promotion of health, lifestyle behaviour change, and self-management of chronic illness for adult populations.

Training outcomes:

- 80% of participants will show intentions to opportunistically raise health promotion messages with their clients.
- 80% of participants will show increased confidence in raising health promotion messages with their clients.
- 80% will rate an increase in their perceived skills in delivering behaviour change interventions.
- 80% of participants will show increased confidence in supporting behaviour change in their clients.
- 95% will know all the key health promotion messages on smoking, healthy eating, physical activity and alcohol at completion of the training.

Action: BH to research, plan and design a new training outline and send out to group for comments.

Appendix C2 – Teaching and Training professionals case study



Supporting Lifestyle Behaviour Change

Facilitator: Belinda Hemmings

1



What we are covering today

- Health promotion messages
- Why don't patients/clients change?
- To know the skills and principles of Motivational Interviewing
- To practice goal setting and action planning

2



Health Promotion

3



Relevance to your work roles

Health promotion, even evidence based and tailored to needs, can result in:

- Improved physical and mental wellbeing
- Better health and social care outcomes
- Reduction of health inequalities impact
- Increased life expectancy
- Extending quality of life and confidence in self-management

You can play an active role in promoting health and achieving positive outcomes to clients, carers, families and communities.

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4



Health Promotion Messages

- Keep it simple
- Stick to the Government guidelines
- Don't provide your personal opinion

5



Healthy Eating



6



8 Guidelines for a Healthy Diet

- Base your meals on starchy foods
- Eat lots of fruit and vegetables
- Eat more fish – including portions of oily fish
- Cut down on saturated fat and sugar
- Try to eat less salt – 6g max for adults
- Get active and try to be a healthy weight
- Drink plenty of water
- Don't skip breakfast!

7



The Eatwell Plate



8



Healthy Eating Quiz



9



Question 1

Ice cream and butter are considered dairy foods?

a) TRUE
b) FALSE

10



Question 2

The Eatwell plate is not applicable for vegetarians?

a) TRUE
b) FALSE

11



Question 3

How much of our daily diet should be carbohydrates?

a) 1/2
b) 1/3
c) 1/5

12



Base meals on starchy foods

- Try to choose wholegrain varieties where possible
- Be careful what we add to them – avoid fat & sugar
- 10% of energy should come from carbohydrates
- Try to encourage starchy food at every meal
- Breakfast – Breakfast cereal toast
- Lunch – Sandwiches/jacket potato
- Dinner – potatoes, rice, pasta



13



Question 4

How many portions of fruit & vegetables should we be eating each day?

a) 5
b) 8
c) 10

14



Question 5

Potatoes count as a portion of 5 a day?

a) TRUE
b) FALSE

15



Eat lots of fruit & vegetables

- 5 a day / 5 different ways
- Dried fruit – try to only eat at mealtimes
- Juice – pure juice/ 100% from concentrate
- **POTATOES DO NOT COUNT**



16



Question 6

If you drink one glass of orange juice, one glass of apple juice and one glass of pineapple juice in a day, you will have consumed the equivalent of 3 portions of fruit.

a) TRUE
b) FALSE

17



Question 7

A juice drink counts towards your 5 a day?

a) TRUE
b) FALSE

18



Question 8

We should be eating 2 portions of oily fish per week.

a) TRUE
b) FALSE

19



Eat more fish

- Aim for 2 portions of fish per week
- 1 should be a portion of oily fish
- Choose from fresh, frozen or canned

Oily fish
Salmon, trout, sardines, mackerel, herring, fresh tuna, pilchard, eel



20



Question 9

Saturated fat is a healthy fat?

a) TRUE
b) FALSE

21



Cut down on saturated fat & sugar

- Reduce the amount of saturated fat eaten
- Can raise blood cholesterol and risk of developing CVD
- Meat pies, sausages, hard cheese, pastry, cakes, biscuits, cream, soured cream, crème fraiche, coconut oil, coconut cream and palm oil



22



Question 10

We should replace sugar with honey?

a) TRUE
b) FALSE

23



Cut down on saturated fat & sugar

- Many foods contain added sugar, also high in calories
- Look for added sugars on ingredients list
- Sugar comes in many different guises:
 - Honey, sucrose, maltose, dextrose, glucose, hydrolysed starch, invert sugar, corn syrup



24



Cut down on saturated fat & sugar

Look at the labels to see how much fat/sugar foods contain (per 100g)

	Fat	Saturated	Sugar	Salt
HIGH	> 20g	> 5g	> 15g	> 1.5g
MEDIUM	5g – 20g	1.5g – 5g	5g – 15g	0.3g – 1.5g
LOW	< 5g	< 1.5g	< 5g	< 0.3g

25



Question 11

75% of the salt we eat on a daily basis is already in our food?

a) TRUE
b) FALSE

26



Try to eat less salt – MAX 6g

- 75% of the salt we eat already in the food we eat
- Breakfast cereals, bread, cold meats, soups, sauces, ready meals all high in salt



27



Get active & try to be healthy weight

- Portion size – only eat as much as you need
- Choose low-fat, low sugar options, eating plenty of fruit & veg and also wholegrains
- Being more active
- Not following crash diets
- Remember the energy balance



28

Decisional Balance - Helps clients to better prepare to make changes and face barriers - It can help you to explore any pre-determined benefits to not making a change At this stage it is useful to reflect the clients feelings as they have expressed them to you. Worksheet	Rolling with Resistance Resistance is a predictor of a patient's clients lack of involvement in your discussion about change. Adjusting to resistance is similar to avoiding argument. It offers another chance for you to express empathy by remaining nonjudgmental and respectful, encouraging the client to talk and to stay involved.	Types of Resistance - Arguing (challenging, discounting, hostility) - Interrupting (talking over, cutting off) - Negativity/denial (blaming, disagreeing, excusing, claiming impunity, minimizing, pessimism, reluctance, unwillingness to change, non-answer) - Withdrawal/ignoring (inattention, non-answer)	Rolling with Resistance techniques Reflective listening! - Affirmations and emphasizing personal choice - Accepting and Acknowledging personal feelings - Consider options - Offer support and encouragement
93	94	95	96
Rolling with Resistance Worksheet	Supporting Self Efficacy Self-efficacy is a person's belief or confidence in their ability to carry out a target behaviour successfully. We want to enhance the person's confidence in their ability to succeed in change.	Supporting Self Efficacy Exploring confidence and importance - How confident are you that you can change? - How important is it for you to change? - What makes you say X? - Why not a lower number?	Exploring Confidence What will hinder change? - Do you see any obstacles and how might you get over them? What will help change? - What personal strengths do you have that will help you succeed? - Who could offer you helpful support in making this change? - After what do you know has made a change like this? How did they do it?
97	98	99	100
Exploring Importance Costs to: - Staying the same - changing Benefits: - Staying the same - changing Revisit worksheet – in pairs	Reinforcing confidence - Reviewing past successes - Personal strengths and supports - Brainstorming - Hypothetical change	Tea Break! 	SMART GOALS WORK SHEET Activity In Pairs: Discuss with your partner something you would like to achieve and set a SMART goal. How do we reinforce successes? What to do if a patient/client is not reaching their goal?
101	102	103	104
Putting the skills together	 Evaluation and Finish!		

AUDIT – C

Questions	Scoring system					Your score
	0	1	2	3	4	
How often do you have a drink containing alcohol?	Never	Monthly or less	2 - 4 times per month	2 - 3 times per week	4+ times per week	
How many units of alcohol do you drink on a typical day when you are drinking?	1 - 2	3 - 4	5 - 6	7 - 9	10+	
How often have you had 6 or more units if female, or 8 or more if male, on a single occasion in the last year?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	

Scoring:

A total of 5+ indicates increasing or higher risk drinking.

An overall total score of 5 or above is AUDIT-C positive.



Case Study 1

Anne-Marie is a 35 year old female who works in an office job in the city. She has been referred to you by her GP as she is at high risk of developing diabetes. She has a Body Mass Index of 38 (obese) and used to be a smoker.

From your initial assessment you have found that Anne-Marie is aware that she is overweight and knows the risks of being overweight. She feels that some comments at work have been directed at her about her weight though her husband reassures her that, "I don't know what you are on about. You look great."

Her lunches at work consist of a sandwich, crisps and a juice drink and she admits to snacking on tea with biscuits or cake at breaks. She enjoys going out with her husband and two children for restaurant meals about 2 or 3 times a week before going to the movies or bowling.

She is a member of gym but she says she doesn't really attend it and she feels as if 'everyone is staring' at her when exercising.

Questions:

- **What health promotion advice would you give?**
- **Where would you refer to?**

Open and Closed Questions

In Pairs: Are these open or closed questions? Turn the closed questions into open questions.

1. Don't you think you should stop smoking?

Open/Closed? _____

2. Tell me about your blood pressure

Open/Closed? _____

3. Have you ever thought about walking as a form of exercise?

Open/Closed? _____

4. Smoking is bad for your health, can't you see that?

Open/Closed? _____

5. How have you been feeling lately?

Open/Closed? _____

6. What have you found difficult about your new diet?

Open/Closed? _____

7. Isn't it important for you to get fit?

Open/Closed? _____

8. Have you been going to the gym regularly?

Open/Closed? _____

9. What brings you to this appointment?

Open/Closed? _____

10. Have you been following the healthy eating guidelines I gave you from our last meeting?

Open/Closed? _____

Give examples of how you would ask a patient/client about what they want to cover in your meeting.

1. _____

2. _____

3. _____

Reflective Listening

'seeking to understand a speaker's idea, then offering the idea back to the speaker, to confirm the idea has been understood correctly'

Sample phrases for when you think your perceptions are accurate.

I understand the problem as...	I see the situation as...
I'm sensing...	Could it be that...
I wonder if...	Correct me if I'm wrong. ...
I get the impression that...	Let me see if I understand. You ...
As I hear it. You...	You feel
From your point of view	It seems to you
In your experience	From where you stand
As you see it	You think
You believe	What I hear you saying
I'm picking up that you	I really hear you saying that
Where you're coming from	You figure
You mean	

Phrases to use when you have difficulty understanding.

Could it be	I wonder if
I'm not sure if I'm with you, but	Would you buy this idea
What I guess I'm hearing is	Correct me if I'm wrong but
Is it possible that	Does it sound reasonable that you
Could this be what's going on, you	From where I stand you
This is what I think I hear you saying	You appear to be feeling
It appears you	Perhaps you're feeling
I somehow sense that maybe you feel	Is there any chance that you
Maybe you feel	Is it conceivable that
Maybe this is a long shot, but	Maybe I'm out to lunch, but
Do you feel a little	I'm not sure if I'm with you; do you mean
I'm not certain I understand; you're feeling	It seems that you
As I hear it, you	...is that the way it is?
...is that what you mean?	...is that the way you feel?
Let me see if I understand you; you	Let me see if I'm with you; you
I get the impression that	I guess that you're

How to raise health promotion

Permission –ask permission to share information. “*Would it be all right if we talk about...? Or, Would it be OK for me to give you some information on eating healthy foods?*”

Ask the patient what the individual already knows.

Provide tailored information

Ask what the patient thinks about the information you provided or how the person might use the information. Ask the person if more information is needed.

CASE STUDY 1

Suneela is a 54 year old South Asian woman who has a large family (5 children aged 12-25 years). She lives with her family including her mother-in-law who is aged 77 years.

She is overweight (Body Mass Index 28) and like some of her children is a smoker. She suffers from both Chronic Obstructive Pulmonary Disease and osteoarthritis.

Suneela has a supportive family who look after her. Due to her health needs she is very inactive and her family are taking on lots of the household chores. This has been on-going for the past 5 years. As a family unit the overall diet is one which is high in saturated fats, and lower in vegetables. Her children do a lot of the cooking or convenience foods are bought.

She is interested in changing her lifestyle as she feels she is unable to carry out her duties. Her family would like her to get better but feel unequipped to help her.

How would you raise health promotion / behaviour change with this client?

How to raise health promotion

Permission –ask permission to share information. *“Would it be all right if we talk about...? Or, Would it be OK for me to give you some information on eating healthy foods?”*

Ask the patient what the individual already knows.

Provide tailored information

Ask what the patient thinks about the information you provided or how the person might use the information. Ask the person if more information is needed.

CASE STUDY 2

Brian Brown is a 77 year old White British male who has been referred to you by his GP. He lives alone in housing association accommodation which is not really suitable to his needs. He has lived in Islington all of his life and does not have a lot of money. He suffers from high blood pressure, Type 2 diabetes and is obese (Body Mass Index 34).

Brian was referred because he has had difficulty walking and carrying out activities such as washing, dressing, shopping and cleaning. He appeared low in mood and is inactive. He lacks a social network and spends the majority of this time alone at home. He has a poor diet and a sedentary lifestyle which is says is due to lack of money.

How would you raise health promotion / behaviour change with this client?

ROLLING WITH RESISTANCE

John Smith is a 42 year old with a chronic lower back problem. You are seeing him as part of your normal clinic. His back pain has been limiting his activities and as a result he is unfit and has gained weight, creating a vicious circle of increased back pain and even less activity. He has already been told he should be taking some gentle exercise and losing weight as well as doing some specific exercises for his bad back. John is divorced and lives alone, he sees his children regularly but they are young and he feels unable to play with them as much as he would like because of the fear of further damaging his back.

When you try to discuss with John about increasing his physical activity he becomes irritable and argumentative. He tells you:

'I have tried to do these exercises but I just feel worse afterwards' and

'I don't really see the point in doing exercises when my back is sore'

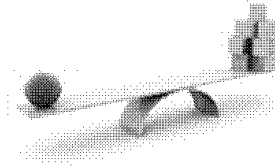
'I have tried dieting before; I just put the weight back on'.

What could you say to this client? (Write down 3 examples).

Reflecting Resistance:

Give 2 examples of affirmations you can give:

Give 1 example of how you could introduce PAPA (Permission, Ask, Provide, Ask):



Balance Sheet 1

The area in which I am thinking about changing is (e.g. my smoking behaviour, my eating behaviour)

.....

.....

If I DO change my behaviour											
     						     					

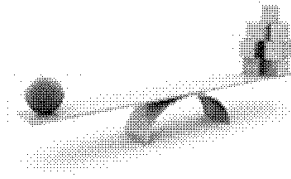
How certain are you that you want to change this behaviour?

On a scale of 1 to 10, how *certain (sure)* are you that you want to change this behaviour?

1 = Not certain at all 10 = Very certain

Circle a number on the line below

Not certain at all 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very certain



Balance Sheet 2

If you can think of more disadvantages than advantages of changing your behaviour, look at the disadvantages and discuss ways of reducing them.

Disadvantages of changing behaviour	Ways of reducing disadvantages
•	•
•	•
•	•

What are the advantages and disadvantages of NOT changing your behaviour?

If I DON'T change my behaviour	

How certain are you that you want to stay the same?

On a scale of 1 to 10, how <i>certain (sure)</i> are you that you want to stay the same? 1 = Not certain at all 10 = Very certain Circle a number on the line below Not certain at all 1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very certain

Supporting Self Efficacy – Useful Directive Questions

IMPORTANCE

On a scale of 1-10 where 1 is not at all important and 10 is very important how important is it for you to succeed?

Why not a lower number?

What are the benefits to changing?

What are the costs to staying the same?

CONFIDENCE

On a scale of 1-10 where 1 is not at all confident and 10 is very confident how confident are you that you can succeed?

Why not a lower number?

Do you see any obstacles and how might you get over them?

What personal strengths do you have that will help you succeed?

Who could offer you helpful support in making this change?

Who else do you know has made a change like this? How did they do it?

What successful changes have you made in the past? What helped you to change in this case?

If that obstacle was magically removed how would you go about making a change then?

Suppose you've succeeded and are looking back, what worked?

SMART GOALS

Specific

Your goal should have its expected outcome stated as simply, concisely and explicitly as possible. This answers questions such as; how much, for whom, for what? If goals are too general they are more difficult to reach.

Measurable

It is important to assess how close you are getting to your goals each week/month etc so it is vital to have appropriate ways of measuring these, e.g. sliding scale (1-10), or as a hit or miss, success or failure.

Achievable

An achievable goal has an outcome that is realistic given your current situation, resources and time available. Goal achievement may be more of a “stretch” if the outcome is tough or you have a weak starting position.

Relevant

If your goal is not important to you, you will not be motivated to achieve it. It is important that goals are yours and not other people's. It should also help you on your mission or your “bigger” objectives.

Timed

A time-bound goal includes realistic timeframes. Short term goals are more successful than long term.

SMART or not?

- *If not SMART, how do we make it SMART?*

I am going to go swimming 3 times a week for the next 2 months

I am going to eat better

I am going to eat more fruit and vegetables this week

I am going to lose 2 pounds a week for 3 months

I am going to eat less chocolate this week

I am going to join the gym

I am going to limit my drinks to 3 a night, twice a week until Christmas

Appendix C4 – Teaching and Training professionals case study

Time	Section length	Learning outcomes	Activity	Notes	Additional resources
9:30	15 mins		Introductions Participant objectives Trainer objectives	Icebreaker question: First name, role, name one thing you would like to get from today	Flip Chart
9:45	75 mins	Participants will learn key health promotion messages on local priorities	PowerPoint slides Quiz and case studies		Services directory Leaflets Audit C tool Case study
11:00	10 mins		BREAK		
11:10	20 mins	Participants will explore the barriers to raising healthy lifestyle choices with clients	Question to Group – What experiences have you got when encouraging health behaviour changes with patients Question to group - Why do you think a patient often has difficulty changing an unhealthy behaviour?	Note on flipchart to compare successes and failures Discussion on difficulties of giving advice	Flipchart
11:30	15 mins	Participants will explore client-centred communication	Question to group: What is client-centred Introduction to Motivational Interviewing		
11:45	60 mins	Participants will learn and practice communication skills and strategies	Motivational Interviewing skills and strategies Open Questions Affirmations Reflective Listening Summaries	Run through each technique with activities / opportunities to practice	Yes / No game Open questions worksheet Reflective listening handout
12:45	45 mins		LUNCH		

13:30	30 mins	Participants will learn skills and practice how to raise a difficult topic.	How to raise a difficult topic Permission Ask Provide Ask Case study on raising a topic.	Teaching how to raise a difficult topic using the PAPA technique	PAPA case study
14:00	50 mins	Participants will learn the principles of Motivational Interviewing	Principles of Motivational Interviewing: Express empathy Develop discrepancy Roll with resistance Support self-efficacy	Discussion around each principle, using facilitator role-play and worksheets	Balance sheet worksheet Rolling with resistance worksheet Self-efficacy worksheet
14:50			BREAK		
15:00	15 mins	Participants will learn and explore goal setting techniques	SMART Goals Practice setting a SMART goal	Introduction to topic, SMART or NOT activity, practice setting own SMART goal	SMART or NOT worksheet
15:15	90 mins	Participants will practice the skills developed from the training	Role play with actors Two groups - use examples of the case study patients mentioned before to practice the skills learned in this workshop.	Own reflection, group / facilitator / actor feedback	
16:45	15 mins	Group evaluation	Review objectives of the training and summarise what has been learned. Complete evaluation form	Discussion topics: How do you see yourself using these skills? What would help you to utilise these skills?	
17:00			CLOSE		

Appendix C5 – Teaching and Training professionals case study

Supporting Lifestyle Behaviour Change Pre course Questionnaire

As part of the Supporting Lifestyle Behaviour Change programme, we will be carrying out an ongoing evaluation, whereby we ask you a set of questions before, after and 3 months following the training. This questionnaire looks at your confidence and intentions of delivering behaviour change. The other questionnaires will also incorporate what you know regarding the health promotion messages.

Please answer the questions as **honestly and instinctively** as possible. All answers will be treated confidentially and will be anonymous in the final evaluation report. ***Please choose your answer by ticking one box per question.***

A juice drink counts towards your 5 fruit and vegetables a day?

- True ☐
False ☐

Saturated fat is a healthy fat?

- True ☐
False ☐

75% of the salt we eat on a daily basis is already in our food?

- True ☐
False ☐

The recommended amount of physical activity for a healthy adult is:

- At least 150 minutes of at least moderate intensity physical activity a week ☐
At least 20 minutes of intense physical activity 3 or more times a week ☐
At least 60 minutes of at least moderate intensity physical activity on 5 or more days a week ☐

How many smokers will die as a result of a smoking-related disease?

- 1 in 2 ☐
1 in 50 ☐
1 in 100 ☐

Nicotine replacement products are recommended for adults who are trying to stop smoking

- True ☐
False ☐

3-4 units of alcohol is the recommended maximum daily guidelines of a maximum for:

- Men ☐
Women ☐

Thank you very much for completing this questionnaire.

Supporting Lifestyle Behaviour Change

End course Questionnaire

As part of the Supporting Lifestyle Behaviour Change programme, we will be carrying out an ongoing evaluation, whereby we ask you a set of questions before, after and 3 months following the training. This questionnaire looks at your confidence and intentions of delivering behaviour change and what you remember regarding the health promotion messages. We have also added a few questions asking for feedback on the training.

Please answer the questions as **honestly and instinctively** as possible. All answers will be treated confidentially and will be anonymous in the final evaluation report.

For this first set of questions, please tick the box that best describes how you feel about each statement:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
As a result of this training I will more likely raise healthy eating, smoking, alcohol and physical activity messages with my patients/clients when the opportunity presents itself					
As a result of this training I am more confident that when I raise health promotion messages that I do it effectively					
As a result of this training I feel I have better skills in facilitating behaviour change with my patients/clients					
As a result of this training I am more confident that when I discuss health or lifestyle behaviour change with my patients/clients that I am doing it effectively					

Please choose your answer by ticking one box per question

A juice drink counts towards your 5 fruit and vegetables a day?

True ☐

False ☐

More
questions
overleaf
→

Saturated fat is a healthy fat?

True ☐

False ☐

75% of the salt we eat on a daily basis is already in our food?

True ☐

False ☐

The recommended amount of physical activity for a healthy adult is:

At least 150 minutes of at least moderate intensity physical activity a week ☐

At least 20 minutes of intense physical activity 3 or more times a week ☐

At least 60 minutes of at least moderate intensity physical activity on 5 or more days a week ☐

How many smokers will die as a result of a smoking-related disease?

1 in 2 ☐

1 in 50 ☐

1 in 100 ☐

Nicotine replacement products are recommended for adults who are trying to stop smoking

True ☐

False ☐

3-4 units of alcohol is the recommended maximum daily guidelines of a maximum for:

Men ☐

Women ☐

What did you find most useful about today's training?

Are there any changes we could make to improve today's training?

What is the key message you take away from today's training?

What would help you develop the skills you have learned today so you can use them in your daily practice?

Supporting Lifestyle Behaviour Change 3 month questionnaire

As part of the Supporting Lifestyle Behaviour Change programme we are carrying out an ongoing evaluation whereby we ask you a set of questions before, after and 3 months following the training.

This questionnaire looks at your confidence and intentions of delivering behaviour change and what you remember regarding the health promotion messages.

Please answer the questions as **honestly and instinctively** as possible. All answers will be treated confidentially and will be anonymous in the final evaluation report.

For this first set of questions, please tick the box that best describes how you feel about each statement:

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
As a result of this training I will more likely raise healthy eating, smoking, alcohol and physical activity messages with my patients/clients when the opportunity presents itself					
As a result of this training I am more confident that when I raise health promotion messages that I do it effectively					
As a result of this training I feel I have better skills in facilitating behaviour change with my patients/clients					
As a result of this training I am more confident that when I discuss health or lifestyle behaviour change with my patients/clients that I am doing it effectively					

Please choose your answer by ticking one box per question

More questions
overleaf
→

A juice drink counts towards your 5 fruit and vegetables a day?

True ☐

False ☐

75% of the salt we eat on a daily basis is already in our food?

True ☐

False ☐

The recommended amount of physical activity for a healthy adult is:

At least 150 minutes of at least moderate intensity physical activity a week ☐

At least 20 minutes of intense physical activity 3 or more times a week ☐

At least 60 minutes of at least moderate intensity physical activity on 5 or more days a week ☐

How many smokers will die as a result of a smoking-related disease?

1 in 2 ☐

1 in 50 ☐

1 in 100 ☐

Nicotine replacement products are recommended for adults who are trying to stop smoking

True ☐

False ☐

Please tell us when you attended Supporting Lifestyle Behaviour Change Training

.....

Thank you very much for completing this questionnaire

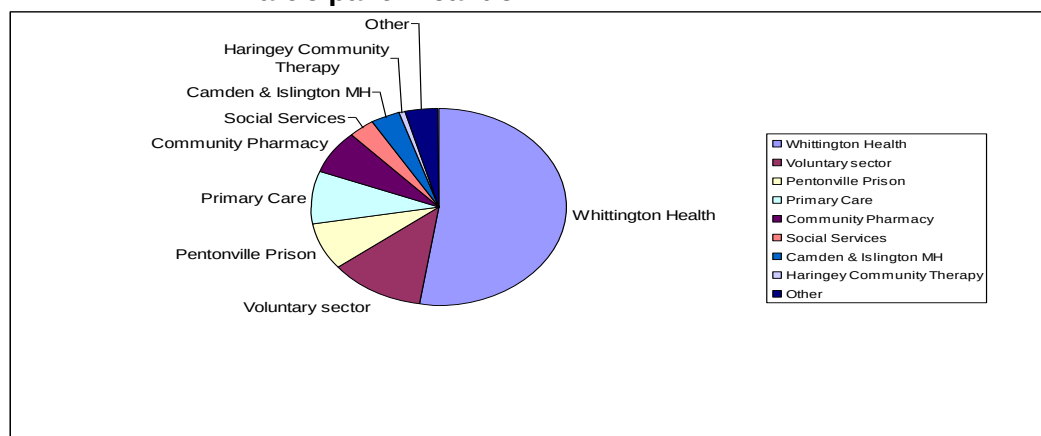
Appendix C6 – Teaching and Training professionals case study

Supporting Lifestyle Behaviour Change – Performance Review and Evaluation

The Supporting Lifestyle Behaviour Change training programme has been developed for health and social care staff who work with adults living in Islington. This training aims to support staff in developing health promotion and behaviour change skills.

From November 2011 to March 2012, five Supporting Lifestyle Behaviour Change training trainings were delivered, with 71 participants attending in total. Table 1 shows a breakdown of what services the participants were from.

TABLE 1. Participant Breakdown

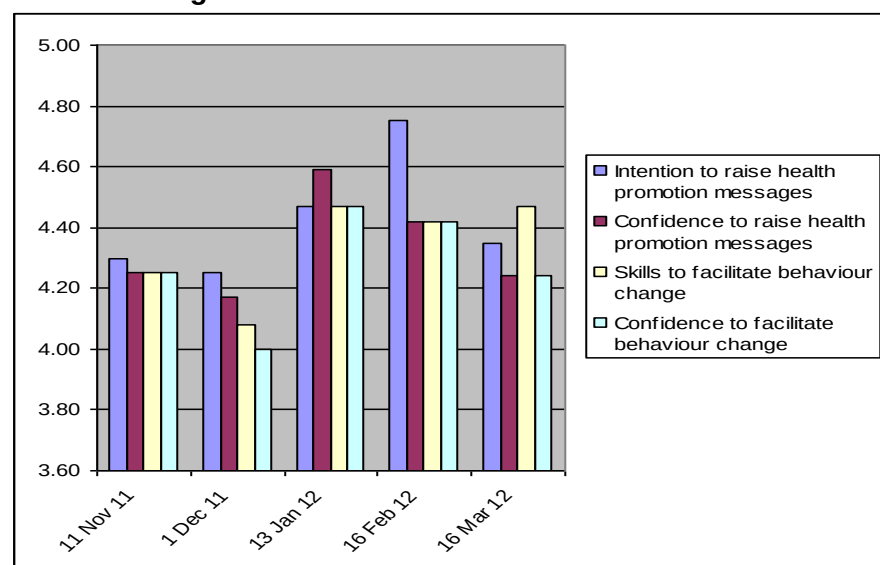


Outcome Evaluation

The evaluation focuses on knowledge in health promotion messages before training, and then asks questions on establishing intention, confidence and knowledge in delivering health promotion messages after the training and at three month follow-up.

Table 2 displays participant's ratings in intentions, confidence and skills for behaviour change after attending the training.

TABLE 2: Participant's Intentions, Confidence and Skills ratings (out of 5) after the training



The outcome evaluation has given a useful indicator of the participants' experience of this new training intervention. The targets have been exceeded for all outcomes, showing a minimum score of 92% over the target of 80%.

Follow up questionnaires have been sent out to participants three months after they have attended the training to establish if participant intentions, confidence, skills and knowledge have been retained once participants have had the opportunity to practice what they have learned in their workplace. Results so far are shown in Table 3.

TABLE 3: Participant's Intentions, Confidence and Skills (out of 5) after the training compared with three month follow-up

Indicator	Target	Frequency of monitoring	Comments
Participants intend to opportunistically raise health promotion messages with their clients	80% of participants intend to raise these messages with clients following the training	Before & after each training 3 months post-training	96.9% participants intend to raise health promotion messages with their clients following the training. 19% response rate: 83.3% participants intend to raise health promotion messages with their clients at 3 month follow-up
Participants feel more confident to raise health promotion messages with clients following the training	80% of participants feel confident or more confident to raise health promotion messages with their clients	Before & after each training 3 months post-training	92.6% participants feel more confident to raise health promotion messages with their clients following the training. 19% response rate: 94.4% participants feel more confident to raise health promotion messages with their clients at 3 month follow-up
Participants feel their skills have improved and they are able to deliver behaviour change interventions, including raising the issue and SMART goal setting	80% rate highly in or an increase in their perceived skills in delivering behaviour change interventions	Before & after each training 3 months post-training	93.7% participants feel their skills have improved and they are able to deliver behaviour change interventions. 19% response rate: 77.7% participants feel their skills have improved and they are able to deliver behaviour change interventions at 3 month follow-up
Participants feel more confident to support behaviour change in their clients e.g. referring to services, checking client progress, SMART goal setting	80% of participants rate their confidence as high or have increased confidence to support behaviour change in their clients following the training	Before & after each training 3 months post-training	96.6% feel more confident to support behaviour change in their clients. 19% response rate: 82.4% feel more confident to support behaviour change in their clients at 3 month follow-up
Participants will learn the key Health Promotion	95% of participants are aware of key	Before & after each training	98.6% received a pass mark (5 or more out of 7 correct answers) in a health promotion questionnaire

messages on 4 topic areas: Smoking, Alcohol, Physical Activity and Healthy Eating	messages following the training	3 months post-training	designed to ascertain their health promotion knowledge following the training. 19% response rate: 77.8% received a pass mark in a health promotion questionnaire designed to ascertain their health promotion knowledge at 3 month follow-up.
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Initial analysis shows a decrease in numbers of participants intending to raise health promotion messages, feeling that they have the skills to deliver behaviour change interventions, and feeling more confident to support behaviour change in their clients at three month follow-up. There has, however, been an increase in participants' confidence to raise health promotion messages with clients.

Without further investigation it is hard to interpret why these effects are seen at three month follow-up, but it could link to feedback from many participants that a refresher session or further support following the training would be beneficial. Thought needs to be given to how to increase the three month follow-up response rate of nineteen percent, in order to fully understand the long-term benefits to this training.

It also appears that participants are not retaining some of the key health promotion messages at three-month follow-up, despite achieving a 98.6% pass rate immediately after the training. This data needs to be considered in the light of the low response rate and therefore cannot be generalisable.

Programme feedback

Participants were each asked about what they found most useful about the training, any changes they would like to make to improve the training, what key message they would take away from the training and what would help them to develop the skills learned so that they could be used in daily practice. Here is a sample of some comments.

What did you find most useful about today's training?

- Role play with actors was fun and useful. Group discussions
- The session with the actors gave an opportunity to practice skills
- Health promotion refresher
- The actors brought it very much to life form. Very realistic!
- Understanding motivational interviewing
- Knowing how to address certain problems & use different tactics to use with challenging patients
- Everything very useful in my role
- PAPA – how to raise a difficult topic
- Role play and practice – putting a name to techniques use as a matter of training and understanding why use them
- Techniques to facilitate discussion around health promotion
- Strategies to approach patient to start making a change and allow them to make the decision
- Rolling with resistance
- Interactive, well-presented with varied teaching styles
- Gained confidence in giving information and using communication skills to deliver health promotion

Are there any changes we could make to improve today's training?

- How to deal with resistance – needs more exercise and role play
- More role play within group
- No – all very good
- The session was well structured and all the topics covered were relevant to my working life in Islington
- Slightly shorter or 2 days as too much information
- Perhaps a video/dvd?
- Less time spent on role play – feel uncomfortable doing this / rarely learn from role play
- Very slow pace – could be covered in half a day. Very brief overview of most topics. Was hoping for more detail re motivational interviewing
- Video, showing techniques in use
- Separate room for role-play as other group loud

What is the key message you take away from today's training?

- To promote health promotion as much as possible when applicable
- Learn how to make changes in patients by supporting and encouraging the need for change
- Need to ask open questions, getting the patient to think about their lifestyle, and what their priorities are
- That involving clients in health promotion is an effective way of promoting health
- Word choice is very important when questioning
- Everything discussed
- Listen and reflect
- Support service users to understand information, make their own decisions and maintain health behaviour change
- Government standards for health
- The value of taking time to explore motivation with the client instead of the practitioner agenda
- Try with each patient. Small steps are worth it even if someone is not responsive
- Be proactive in the way I use skills
- To continue what I do with the knowledge and confidence I can make a difference

What would help you to develop the skills you have learned today so you can use them in your daily practice?

- Follow up session
- Trying in practice, more training
- Further training on health promotion for different cultural/ethnic groups
- Prepare for my one-to-one meetings / use in supervision
- More practice and ongoing experience
- Training gave me foundation to build on
- More role play!
- Making time to reflect on consultations
- Refresher training
- Practice with colleagues and in personal life

Teaching and Training of the General Population

- A Case Study

In May 2012 I was approached to deliver a sleeping well workshop for Epsom Mental Health Week. This case study looks at the First Steps to Better Sleep teaching and training session I delivered in October that year.

Planning and designing the training programme to enable the general population to learn about psychological knowledge, skills and practice

Assessing training needs

Sleep is a key issue in maintaining good mental and physical health. Research has shown that 20-25% of the adult population has insomnia, and up to 10% on a chronic basis (Obayon, 2002; Lichstein, Durrence, Taylor & Bush, 2004). People with insomnia experience higher rates of relationship difficulties, poorer quality of life, depressed mood, reduced daytime alertness and productivity, and inability to concentrate (Espie et al., 2007; Mental Health Foundation, 2011).

Epsom Mental Health Week aims to promote education and understanding around mental health, and is coordinated by a local charity – Love Me Love My Mind. Based on interest in sleep (see Appendix C7) and learning from an MSc Behavioural Sleep Medicine module I recently completed, the organisers and I agreed that the provision of a session on techniques to improve sleep and well-being would be a great opportunity to provide support to the general population, as currently there are no other organisations providing sleep information or education in Surrey.

Identifying training programme structure, content, method and approaches

I needed to select a teaching technique that would be appropriate for the general population attending a one-hour drop-in session in the community. I therefore chose to use a workshop format of providing information, whole group discussion and problem solving, to enable participants to apply their learning.

The provision of health psychology theory and information needed to take into account potential knowledge of the group, individual learning styles, and be presented in meaningful language to facilitate learning. I therefore based my content on the

recommended UK reading age of nine years (Alderson, 1994) and the IAPT (Improving Access to Psychological Therapies) good practice guidance on the use of self-help materials (Baguley et al., 2010), in order to ensure accessibility for the general population.

Due to the potentially diverse experience of participants, I also familiarised myself with Kolb's (1984) experiential learning theory. This theory proposes four learning styles that people naturally prefer. My challenge for this session therefore was to find a way of maximising learning opportunities for the group, who may have a wide range of needs and preferences, within the time available. I did this by utilising a range of training methods informed by this learning theory.

Producing training materials

The session outline I produced had four sections (see Appendix C8). The first section provided an introduction to my role, anticipated learning outcomes, and ground rules for the session to focus on creating a safe environment to discuss potentially emotional issues.

The next section focused on well-being and sleep. The learning outcome for this section was to understand what sleep is and how sleep problems can affect well-being. This would be delivered through tailored group discussion, as well as correction of any mis-conceptions.

I followed this with how we can improve our sleep, by learning new strategies and being able to identify the interaction between our thoughts, emotions, body and behaviour. The module I completed focused on using Cognitive Behavioural Therapy (CBT) for addressing factors such as worry, negative emotions and thoughts associated with poor sleep. Techniques based on CBT can help people to establish a healthy sleep pattern (Espie, 2009) as well as cope with the stresses of daily living by feeling more in control.

In order to illustrate this in a lay-friendly way I decided to use a flipchart example to show a Five Areas CBT model of a common issue relating to sleep, then brainstorm with the group how changes could be made. The model (Williams & Garland, 2002) addresses five areas: the situation; thoughts; emotions; physical symptoms; and behaviour. This provides a structure easily understood by clients, thus enabling them to see the impact of specific elements, and how making changes in any one of these areas can lead to change in other areas.

Using appropriate media to deliver the training

I felt that the session needed to be delivered informally and interactively to suit the environment and group, thus encouraging participants to share their understanding and talk through issues relating to sleep. I designed facilitator notes (see Appendix C9) and planned to use flipchart as a visual aid. Prior to delivering the session, I confirmed the proposed training structure, content, timings and anticipated outcomes with the organisers.

Delivering the training programme

Reflection on delivery of the training

Twenty people attended and I was pleased with how the session went. People seemed engaged, asking questions relating to what they had previously heard about sleep, and having any worries they had about their own sleep problems alleviated by being given the opportunity to discuss issues in the group. Several people also came up to me at the end of the session to discuss whether what they were currently doing in relation to their sleep was helpful, and several described how they now realise that their thoughts might be impacting on their ability to sleep.

On reflection, I realised that in many cases when people asked questions in the group, I provided what I thought to be the answer. I think it may have been more helpful to ask them their thoughts, so that they could be guided to their own conclusion.

I felt that my delivery style was good. I varied my tone of speech and added humour where appropriate. I adapted my delivery style to respond to the group, to keep people engaged and to maximise their learning, linking in people's questions and comments in order to show I had taken their points on board, and I feel this worked well as a means of feedback too.

Planning and implementing assessment procedures for the training programme

I designed an evaluation form to assess people's learning needs and level of knowledge, as well as learning against the outcomes (see Appendix C10). This, in addition to the organiser's feedback form, could be completed within the workshop, and the information from both forms was to be utilised in the assessment and evaluation of

the session. Both forms were placed on chairs before the workshop started so that participants were aware of the assessment criteria. I then made time for questions at the end, and explained the evaluation forms and their meaning.

Evaluating the training programme

Having both forms enabled me to draw on useful information regarding the session as a whole, as well as the learning outcomes. The session was reviewed positively, with participants reporting gaining reassurance, learning new strategies, and expanding their knowledge (see Appendix C11).

As well as informing the evaluation and assessment of this session, these results will be useful for informing the development of future sessions on sleep. Many of the techniques can seem like common sense to people, but it is whether they are willing to take this on board and reflect on their own behaviour, which is key. If I did this session again I would like to have more time, in order to fully explore people's individual issues and support potential behaviour change.

Conclusion

This session enabled members of the general population to learn knowledge, skills and practices in health psychology, specifically around sleep. The assessment procedures show that the majority of participants met the learning outcomes.

Sleep is a key issue in maintaining good mental and physical health, and this experience has also given me an opportunity to utilise my learning from an MSc Behavioural Sleep Medicine module. I plan to keep up to date on developments in sleep and CBT for insomnia, as this is a current and well-defined area of need for physical and emotional well-being.

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Appendix C8 – Teaching and Training general population case study

First Steps to Better Sleep Session Outline

Time	Section length	Learning outcomes	Activity	Notes	Additional resources
16:00	10 mins		Introduction	Who I am Description of First Steps Learning outcomes Boundaries	Flipchart
16:10	15 mins	Understand what sleep is and how insomnia can effect well-being	Emotional well-being and sleep	Explain what sleep is Ask: why do we need it? Contemplate own sleep Ask: what is insomnia Explain above and what causes insomnia	Flipchart
16:25	25 mins	To learn new strategies to improve sleep Be able to identify the interaction between our thoughts, emotions, body and behaviour	How can we improve our sleep	Sleep education – lifestyle and bedroom factors Challenge your thinking How you can interrupt the cycle: Thoughts Behaviours incl relaxation Feelings Body / physical symptoms Any questions?	Five Areas model
16:50	10 mins		Evaluation		

Appendix C9 – Teaching and Training general population case study

Facilitators Notes

Introduction

- Me – First Steps Team Leader and Trainee Health Psychologist
- First Steps is an NHS mental health promotion service working across Surrey. Our aim is to provide advice and information on mental health and emotional well-being through self-help resources, educational groups and training.
- There are service booklets on the side/on your chairs
- Today's talk is about sleep. We know that sleep affects our mental health and our mental health affects our sleep. In fact, our sleep is often a measure of what's going on in our life
- This talk will cover:
 - What sleep is, why we need it, and how sleep problems can affect our well-being
 - The link between our thoughts, emotions, body and behaviours
 - New ways to improve sleep
- Do ask questions where you would like to, I just ask that you respect each other's comments and treat them confidentially

Emotional well-being and sleep

Sleep

- Is an important time when a lot goes on in both your mind and your body.
- Sleep stages - we have different types of sleep throughout the night
 - Light sleep, deep sleep, dream sleep - we cycle through these stages several times during the night.
 - Dreams are a normal part of sleep, whether we remember them or not

Why do we need sleep?

- Physical rest
 - Muscles need to rest
 - Helps the body to grow - the body works to rebuild itself for the next day. The harder our bodies work, the more rest they will need
- Mental rest
 - Sorting out things that have happened in the day and storing them in our memory
- Amount of sleep varies across lifetime - most adults do sleep for 8 hours, but people do differ a lot
- Not necessarily a link between amount of sleep and quality of sleep

What is insomnia?

- Definition - sleep problems that are disruptive and persist for six months or more
- Sleep disturbances are very common
- 20% (1 in 5) adults experience persistent sleep problems

What causes insomnia?

- Stress and strain - can produce short-term sleep problems which can develop into longer-term problems because bad sleeping habits develop, or worries about sleeping start to take over

- Depression and anxiety - can bring on sleeplessness
- Life changes - moving house, changing jobs
- Shiftwork - always trying to adapt to different patterns
- Diet - either gaining or losing a lot of weight, eating at the wrong times
- Bedroom - mattresses, pillows, light, noise
- Sleeping pills - can make sleep worse by being addictive and changing the type of sleep that we actually get
- Pain, discomfort

Can insomnia cause harm?

- No - although it is distressing and can be depressing.
- The body is designed to handle some sleeplessness, but someone may experience problems with:
 - Poor concentration
 - Daytime tiredness
 - Irritability
- Can affect others in household - because you can be irritable and have problems concentrating
- Many people with sleep problems worry about them - even before they go to bed
- This can make it even more difficult to sleep
- Thinking 'I'm never going to get to sleep' or 'I'll be hopeless tomorrow' can make sleep harder to come
- Remember that you will sleep eventually, and you will cope the next day - think back to times when you have slept badly, but still managed to cope with the next day.

How can we improve our sleep?

Sleep education – lifestyle and bedroom factors

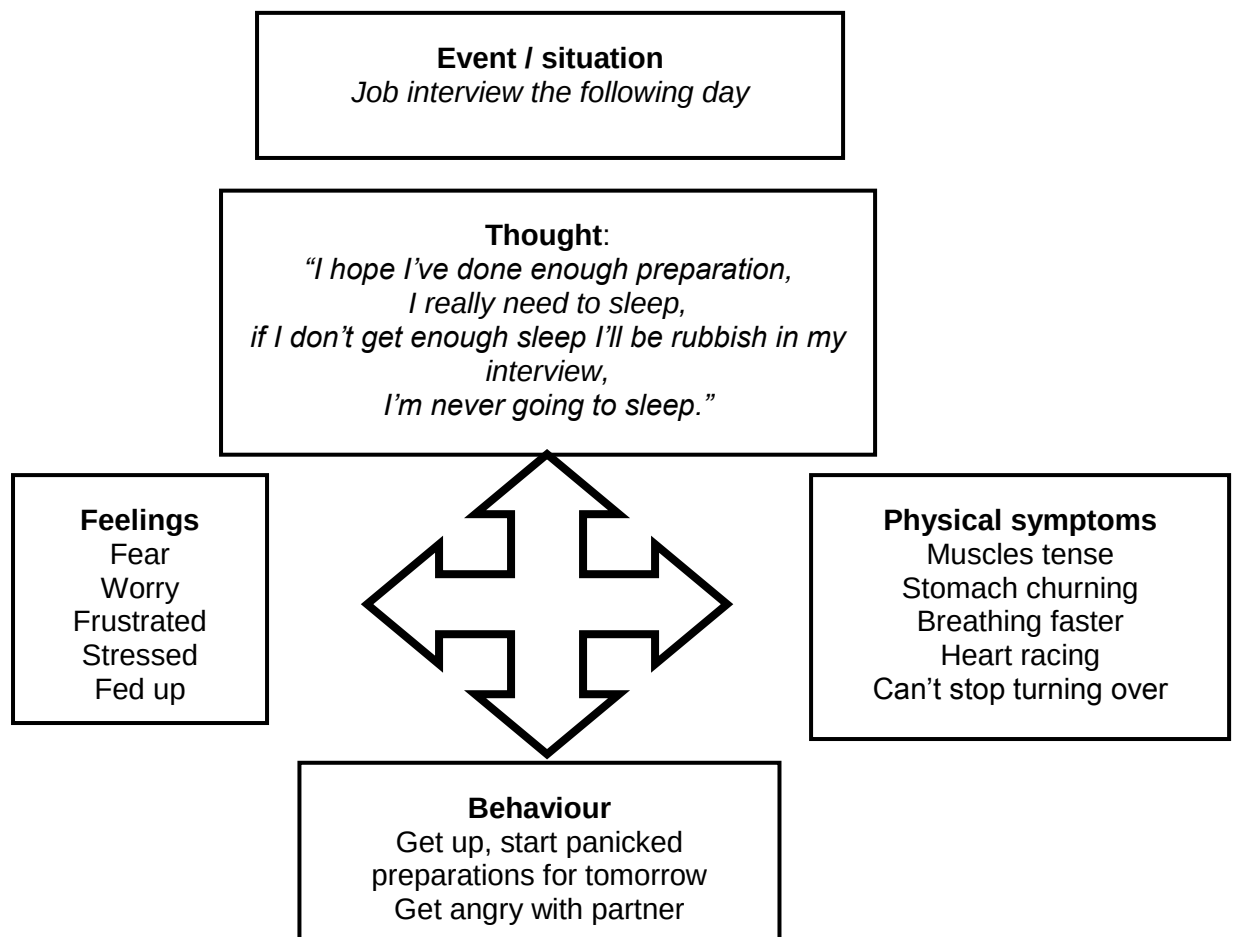
- There are aspects to our lifestyle that can affect the way you sleep, and sometimes small changes can make a big difference:
 - Caffeine - stimulant, 'picks you up', effects can last for several hours, in many different products, switch to de-caff or drink herbal teas in the evening
 - Nicotine - found in cigarettes, also a stimulant. Nicotine makes it harder to fall asleep and stay asleep. Try and cut down in the evening, and don't smoke if you wake up in the night
 - Alcohol - a depressant drug, but can disrupt sleep. May help you to fall asleep at beginning of night, but will make your sleep lighter later on. May also become addictive. Night-cap not recommended!
 - Diet - light snack before bedtime can help, but not too much food. Don't snack in the middle of night. Too much weight-loss can lead to short, broken-up sleep, but heavier people more likely to snore which can cause problems for yourself and partner.
 - Exercise - fit people are likely to be better sleepers, try taking regular exercise during the week, but avoid strenuous exercise before bedtime - it wakes up our bodies. Take exercise in the late afternoon or early evening.
- Your bedroom can influence your sleep as well
 - Noise - difficult to get to sleep and stay asleep

- Room temperature - too hot and we wake up more often and have less dream sleep; too cold and we cannot get to sleep and can have unpleasant dreams. Best room temperature is around 18°C. Put a thermometer in your bedroom
- Body temperature - take a bath two hours before bed, not immediately before bed
- Air quality - stuffy room can cause uncomfortable sleep
- Lighting - too much light causes wakefulness. Try thick curtains or even a blind
- Mattress and pillows - a good mattress is very important. Pillows are more personal taste.
- Distractions - TV, books etc. Don't watch TV or read books in bed.

Challenge your thinking

Five areas model

Your thoughts, your feelings, your body and your behaviours



Where can we interrupt this cycle?

Thoughts – want a sieve to shake up our thoughts to let some positive thoughts through. What alternative thought could we have?

"I've done plenty of preparation so I'm sure everything will go fine tomorrow, it's not surprising I'm a little nervous, I will sleep eventually and even if I don't get lots of sleep there have been times in the past when I have managed to cope after sleeping badly"

Remember:

- Keep your expectations realistic – everyone needs a different amount of sleep
- Put the day to rest – write down the main points of what has happened in your day and how it's gone – reflect and plan for tomorrow. Add any thoughts that come up while you're trying to sleep to your notebook
- Never try to sleep – it won't come about through effort
- Don't think the worst after a poor night's sleep or place too much emphasis on sleep

Behaviours

Establish a regular sleeping pattern:

- get up at the same time every day and no later than one hour even across the weekend
- avoid naps during the day

Sleep will come more quickly and it will be easier to stay asleep if your mind and body can respond to your bed as a signal to sleep.

- Only use your bed to sleep in
- *If you cannot sleep within 15 minutes, get up and go to another room - go back to bed when you are sleepy again, but not before.*

Make a pre-bed routine for winding down and relaxing

- *Winding down: slowing down activity, brushing teeth, setting alarm, putting on pyjamas*
- *Relaxing: listening to music, watching TV, reading, having a hot decaffeinated drink*

Relaxation can help you get to sleep and stay asleep

- You might find physical or mental activities relaxing
- You can also use relaxation techniques – practice in the daytime so you can find one that works for you that you can use at bed-time, e.g. deep breathing, muscle relaxation

What impact will these changes in our thoughts and behaviour have on:

How we feel – relieved, confident, happy

Our body – relaxes and moves less, slower breathing and heart rate

Evaluation

Really appreciate you taking the time to fill out the evaluation form, alongside the Epsom Mental Health Week form – enables us to develop and improve our talks.

I have spare pens & you can leave your forms on the chair.

Thank-you for your time today, it was lovely to meet you all – wishing you all happy sleeping!

Appendix C10 – Teaching and Training general population case study

Session title: First Steps to Better Sleep Date...../...../.....

We would greatly appreciate your comments to help improve future sessions.

1. What did you want to learn by attending this talk?

2. Please score your knowledge before and after attending this talk on a scale of 0 (no knowledge) to 10 (expert).

Before.....

After.....

3. Has this talk helped you learn what you wanted to?

Yes.....

A little.....

No.....

Please explain:

4. Please list the 3 most important things you have learnt from this talk:

1)

2)

3)

5. Would you recommend this session to a friend?

Not at all

Possibly not

Not sure

Yes

Yes definitely

1 ☐

2 ☐

3 ☐

4 ☐

5 ☐

Please Turn Over

Gender

Male _____

Female _____

Age Group

Under 20 _____

20-29 _____

30-39 _____

40-49 _____

50-59 _____

60-69 _____

70+ _____

Employment Status

Self-Employed _____

Full-Time Work _____

Part-Time Work _____

Unemployed _____

Retired _____

Student _____

Ethnicity**White**

British _____

Irish _____

Other _____

Asian or Asian British

Indian _____

Pakistani _____

Bangladeshi _____

Chinese _____

Other _____

Black or Black British

Caribbean _____

African _____

Other _____

Mixed

White and Black Caribbean _____

White and Asian _____

White and Black African _____

Other _____

Other Ethnic Group

Appendix C11 – Teaching and Training general population case study

Epsom Mental Health Week, St Barnabas Church - 10th October 2012 - BH evaluation forms											
1	Would you recommend this session to a friend	1 Least	2	3	4	5 Most					
			1	4	9	3					
2	What did you want to learn by attending this talk?										
	How to get out of a pattern which is disruptive and not conducive to a good nights sleep consistently										
	Strategies for better sleep										
	A few hints on how to actually have better and more refreshing sleep, how it can be improved										
	Techniques to achieve better sleep										
	Getting the best of sleeping techniques										
	Nothing new										
	Tips for better sleeping										
	Practical ways to improve my sleep pattern										
	Reasons behind poor sleep and possible strategies										
	Nothing new really										
	Expand my information on this topic										
	How to achieve better sleep pattern										
	Keep calm when trying to sleep										
	What disturbs sleep										
	Ideas to improve on sleep										
	Understanding difficulties related to sleep as sleep is very important to life in keeping human well-being and sanity										
	Nothing that I haven't read or listened to before										
3	Score knowledge before and after attending this talk on scale of 0 (no knowledge) to 10 (expert)										
	Before	1	2	3	4	5	6	7	8	9	10
	After			3	2	4	1	3	3	4	1
						1		5	5		126
4	Has this talk helped you learn what you wanted to	Yes	A Little	No							
	Explain:	4	10	3							
	Maybe need to readdress some elements of lifestyle										
	I've not heard about a sleep diary before. I don't have a computer so I'm afraid it pointless and impossible trying to urge and direct me towards such things as websites or emails										
	Right temperature of room; how our thoughts are interconnected										
	Affirmation and increased awareness										
	I did already know quite a lot of the information										
	Helpful CBT ideas										
	Nothing I didn't know already and a lot of input from audience was very much common sense and personal to themselves which has to be expected										
	I already had some knowledge										
	Explain more about sleep patterns, how to achieve sleep										
	To be positive rather than negative										
	Time was limited but learnt something										
	I've had a long term sleep problem and read articles, some of it is common sense and I'm hoping for a solution										
5	3 most important things you have learnt from this talk:										
	That it is not harmful to get so little sleep; that the situation can be improved with a little thought; may need to stop napping and dozing off so often										
	Booklet, course										
	Keeping our expectations realistic; time out for reflection; a sleep diary might be interesting										
	Try and have more positive thoughts; shouldn't have more than an hours sleep in morning at weekends; temperature of room										
	Regular pattern; get up out of bed same time everyday; confirmation of what I'm doing is ok										
	The First Steps course - will recommend it to someone										
	Subject is so vast that one hour talk is too little; idea that lack of sleep does not harm health - difficult to believe; that sleep is even more individual than I supposed										
	Thoughts cycle - feeling/body/behaviour etc										
	Positive thoughts; not to worry if you don't sleep - no physical harm; preparation for sleep (we do it with babies)										
	Importance of thought in the sleep process; getting the right environment										
	Things to avoid at bedtime; how to interpret why we don't sleep; to learn to not punish yourself for not sleeping										
	Get ready to sleep; keep your room for sleeping; keep calm and don't worry about trying to sleep										
	CBT; other people's view										
	Thoughts, feelings, behaviours - all impact on sleep										
	Wrong things we do; right thing we should do; to give importance to sleep										

Gender		Age Range		Employment Status		Ethnicity	
Male	3	Under 20		Self-Employed	2	White British	14
Female	14	20-29		Full-Time	3	White Irish	1
		30-39	1	Part-Time	3	White Other	1
		40-49	4	Unemployed	2	Asian Other	1
		50-59	7	Retired	4		
		60-69	5	Student			
		70+		Carer	1		
				Other			
				Not stated	2		

Epsom Mental Health Week, St Barnabas Church - 10th October 2012 - Love me Love My Mind evaluations

1	What attracted you to come to this talk?					
	Experience sleep difficulties myself					
	Have a sleep problem					
	The highlight of my day because the sleep workshop last year didn't really take place					
	EMHW brochure					
	Sleep strategies					
	Saw in mental health booklet at library and interested					
	The topic - have bouts of insomnia					
	Coming to next talk sharing coping strategies and also interested in sleep problems					
	Past inability to sleep					
	Sleep therapy					
	The leaflet which gave details of EMHW					
	Get a better nights sleep					
2	On a personal level, how important was the topic to you?					
	Very important	Somewhat important	Neither important nor unimportant	Somewhat unimportant	Very unimportant	
	5	7		1		
3	The content of the talk was:					
		5	4	3	2	1
	Extremely valuable	3	3	5	2	Of little value
	Detailed enough	5	2	2	4	Too general
	Current and relevant	6	3	3		1 Outdated
	Cohesive and logical	7	3	3		Fragmented
4	Was the content of the talk relevant and useful to you?					
	Yes	No				
	12	1				
	a. If yes, what was the most relevant and useful part of the talk?					
	Giving different perspective					
	To keep expectations realistic - a sleep diary might be interesting					
	Tips on how to facilitate sleep					
	Strategies					
	Positive thinking					
	Thinking element - negative and positive thoughts					
	How to break the link between thoughts and behaviour					
	Everything					
	Thoughts and feelings impact on sleep					
	Confirming best techniques of sleeping well					
	b. If no, please explain why. What would you change or do differently?					
	I had hoped for new information					
	I had hoped to learn something new					
	I wouldn't change anything because I am sure it was relevant to others and they seemed to be interested					
5	What part of the talk did you find most interesting?					
	Structure of talk and audience participation useful					
	One can become too reliant on sleeping tablets - I didn't know that					
	All					
	Thought patterns					
	People's contributions and bit connected with diagram					
	Thinking element - thoughts, feelings etc					
	How to break the link between thoughts and behaviour					
	Everything					
	Thoughts, feelings, body model					
	Information and discussion					
6	Overall the talk:					
		5	4	3	2	1
	Was easy to follow and understand	10	2	1		Was difficult to follow and understand
	Was long enough	7	4	2		Was too short
	Was excellent	4	3	6		Was poor
7	What is your overall assessment of this talk? Are there any other comments you would like to make?					
	It was very useful					
	Information was nicely put over by lovely lady, just I'd hoped to hear something new					
	A good reminder to those who need it					
	For me it was fairly basic					
	Good					
	Belinda's talk was inspirational					
	More specific sleep disorders to discuss					

Consultancy – A Case Study

In my Team Leader role with First Steps (Surrey Community Health), I am often approached in the capacity of a consultant for input and guidance on facilitating and enhancing mental health and emotional well-being. For this competency, I will describe a recent piece of consultancy work; how I planned this consultancy work; how I established and developed the relationship with the client; conducted the consultancy; and monitored the implementation and evaluation of this consultancy.

Assessment of requests for consultancy

The Surrey Suicide Prevention Strategy Group aims to reduce deaths by suicide and undetermined injury and to ensure that the prevention of suicides remains a priority across all agencies / partners. NHS Surrey Public Health manages the Group, and I am a member representing First Steps on behalf of Surrey Community Health. Other members include the NHS Surrey Associate Director of Public Health, Surrey and Borders Partnership Director of Quality, Surrey and Borders Partnership Head of Risk and Safety, Samaritans Directors, Citizens Advice Bureau District Manager, Royal Surrey Hospital Accident and Emergency Liaison, Richmond Fellowship Service Manager, Prison Service and Surrey Police, alongside a group of mental health service users.

In September 2011 I was invited to be part of a communications sub-group. The sub group's co-ordinator (Public Health Development Worker) had made an agreement to supply twelve monthly five-minute podcasts to a local radio station – Eagle - and needed consultancy input to produce these podcasts. In this sense and according to Schein (1999), the Public Health Development Worker was both a Contact and Primary client on behalf of NHS Surrey Public Health as the Sponsor; and Eagle was a Stakeholder.

I was approached in a consultative capacity to support these objectives, and commissioned to produce three of the twelve five minute podcasts. This initial request took the form of the Purchase of Expertise Model of consultancy (Schein, 1999). This model is one in which the client purchases the knowledge and expertise from the consultant, bringing a separate and autonomous perspective. This model is often of

short duration, and in this case it applied initially before moving into the Process Consultation model of consultancy. The Process Consultation model is characterised by the collaborative “helping relationship” between consultant and client, where the client provides input throughout the process (Schein, 1999). In this sense, as the consultancy was conducted, I brought my theoretical health psychology knowledge to the consultancy, to inform evidence-based practice, alongside skills for delivery of effective health promotion to a wide audience. This would be combined with client input throughout the process in the form of coordination of the podcast series.

In this way, the client and I were able to meet Earll and Bath’s (2004: 231) description of consultancy as *“a formal relationship where one part seeks help from another, the consultant’s role being to facilitate the process whereby both the consultant and client arrive at a mutually acceptable solution.”*

The first step was to identify the specific requirements, needs and expectations of the Public Health Development Worker in order to determine the appropriate level of intervention. I attended the sub-group meeting in October 2011 to enable me to ask questions of the client, begin discussions about taking forward this consultancy, and negotiate my involvement. At the meeting I met with other members of the Suicide Prevention Strategy Group that support people experiencing issues impacting on their mental health, and we discussed the schedule for the publication of the podcasts and the key topics that would raise awareness of issues that listeners may be struggling with, as well as local services that are available to support them.

This meeting gave me the opportunity of using my experience and knowledge of local health need to input into the plan for topics to be covered by the podcasts. In 2005, the National Institute for Mental Health in England launched new national guidance for mental health promotion, which identified key action areas and evidence for effective mental health promotion interventions. In view of this guidance NHS Surrey developed the Improving Mental Well-being in Surrey Strategy for 2008-2011 (2008). Key action areas identified were: marketing mental well-being and tackling stigma and discrimination; improving access to a wide range of sources of support for emotional and psychological difficulties; addressing health inequalities in mental health; employment and workplace; communities; later life; tackling violence and abuse.

The podcast topics therefore agreed were: an introduction to the podcasts and why mental health is important; alcohol misuse; debt; chronic pain; workplace stress;

healthy eating and physical activity for emotional well-being; social inclusion; men's health; bereavement; hearing voices; unemployment; and relationships.

The First Steps service is commissioned to raise awareness of and promote mental health and well-being, by providing evidence based self-help interventions, prevention advice and support within the community. Therefore the three podcasts that I would produce were to be:

- Introduction to the podcasts (renamed your mental health and emotional well-being)
- Preventing workplace stress
- Healthy eating and physical activity for emotional well-being

The Public Health Development Worker would liaise with the radio station each month and arrange a recording date. The podcasts would be available for download on their website (<http://www.964eagle.co.uk/podcastdirectory/nhs-mental-health.php>), and played on their sister station Eagle Extra. Eagle Radio would provide the Public Health Development Worker with the number of website hits for each podcast, which would form part of the evaluation of the series and my consultancy. These podcasts would then remain on the website for a number of years to form part of their podcast archive. I proposed that I also link the webpage to the First Steps website, and promote it in our monthly newsletter.

Following this meeting, I went back to my team to discuss the feasibility of the proposed consultancy, as it would require individual input in terms of resource development under my supervision. I emphasised the importance of communication across the team in order to identify possible constraints and deal with these. We discussed how I planned to go about implementing and producing the intervention and how I would coordinate it's monitoring. The team agreed this consultancy presented a great opportunity for raising awareness of mental health issues, as well as a chance to deliver some innovative work in mental health promotion.

Plan for consultancy

The client's objectives were to deliver twelve podcasts that:

- Consisted of advice and support for people who may be struggling with issues relating to their mental health and/or emotional well-being

- Raised awareness of the support services available to people experiencing emotional distress and thoughts of suicide

The client produced an implementation plan and I agreed that the three podcasts would be delivered in November 2011, March 2012 and May 2012 (see Appendix C12).

I formulated a consultancy contract for presentation to the client, including their objectives, my role as consultant, methodology, timescales, costs, monitoring and evaluation (see Appendix C13). Attending the meeting of the sub-group and negotiating how I would contribute to the client's objectives, greatly assisted the creation of this contract. It had been helpful to discuss needs, expectations and methodology at the meeting, alongside providing my input into potential topics, content, format and evaluation. In addition, I found having been to the consultancy workshop at university enabled me to understand the models of consultancy and the fundamental elements that I needed to consider. Producing the contract allowed me to reflect on the process of developing such a document, of which the key issue was the importance of ensuring that both parties are in agreement on how the consultancy will proceed.

Establish, develop and maintain working relationships with clients

The Public Health Development Worker approved my contract in the first instance, and we both signed our agreement. Initially as a Purchase of Expertise model, the client had been able to utilise my healthy psychology knowledge and mental health promotion expertise to implement a solution. Then as an ongoing Process Consultation, the development of this contract enabled the client to apply their problem solving skills, utilising the consultant to deliver the most effective intervention.

We agreed that we would jointly monitor my consultancy input, and that I would coordinate the production of the three podcasts, maintaining monthly communication via telephone calls, email and also at quarterly meetings of the Suicide Prevention Strategy Group in order to provide opportunities to discuss positive outcomes and raise any concerns. As we had already formed a working relationship through my attendance at the Group and the subsequent sub-group meeting, we both agreed that we could work together for mutually beneficial results.

Our rapport and good working relationship also facilitated an additional request for support when the agency due to deliver the December podcast was no longer able to produce it. I felt that this would strengthen the working relationship I already had with the client, and provide another opportunity to promote our service. The team did not have the knowledge to cover the pre-planned topic of alcohol misuse as part of alcohol awareness around Christmas time, but agreed to write some top tips for preventing stress over the festive period. I accordingly negotiated our commitment to writing and recording the podcast, on the agreement that we could write the content on keeping happy and healthy at Christmas time. The client was happy with this arrangement.

I wrote a script outline, using the format of top ten tips, then asked two members of the team to draft the content using self-help messages that we use across our resources (see Appendix C14). Having approved the content, I liaised with the Public Health Development Worker to find a convenient time (22nd December 2011) for one of my team members to attend the radio station. The recording was a success and both the radio station and the client were happy that the team and myself had been able to assist at the last minute.

Conduct consultancy

In order to establish a process for production of the podcasts, I agreed an implementation plan with the First Steps team for rotating responsibility across the team for drafting content based on my script outlines approximately two weeks before the recording date, followed by that individual attending the radio station for recording of the podcast. This plan would be regularly appraised, making adjustments with the team members if required. This also enabled the team to support the additional podcast in December as we had capacity at that time.

I began the process by researching effective podcast formats, such as those used on popular radio stations and news websites. I needed to ensure that the information given would inspire interest in the topic, be engaging and effective in promoting the need to maintain mental health and emotional well-being, and generally be something that people would choose to listen to.

Podcast One – Your Mental Health and Emotional Well-being

For the first podcast I decided to go for a case study format, including where to go for more support. Using my knowledge of the calls that First Steps receive on our phone

line and the real-life stories the team has heard from our psycho-educational groups, I wrote a script outline that utilised this knowledge so that the content would be relevant and accessible to the general population and the issues discussed would be applicable to anyone. I asked the agreed member of my team to draft the content, which I then reviewed and amended (see Appendix C15). I contacted the Public Health Development Worker to provide the content and arrange for the team member who had written the case study to attend the radio station on 16th November 2011. The recording went well and the podcast was uploaded onto Eagle's dedicated webpage.

Podcast Two – Preventing Workplace Stress

For the next podcast on workplace stress, I worked in collaboration with a local employment organisation and my co-Team Leader, as this is her area of expertise. I wrote a script outline, we agreed on the content and format of the podcast, and I arranged the recording of this podcast with the Public Health Development Worker as part of my contract with her (see Appendix C16). This went ahead as agreed on 16th March 2012.

Podcast Three – Healthy Eating and Physical Activity for Emotional Well-being

This podcast was an area where I was able to bring my health psychology expertise on the relationship between physical and mental health, through ensuring the content was based on current government guidelines and psychological principles. I therefore wrote the script outline and content for this podcast myself. I began by researching and identifying research-based persuasive messages to ensure the content of this podcast would be effective. Abraham, Southby, Quandt, Krahe and Van Der Sluijs's (2007) paper on how recommendations for the content of alcohol-education leaflets are rarely applied to publicly available health education leaflets was useful in this respect, and I wanted to ensure that the health promotion messages of my podcast were based on psychological theory for behaviour change.

I started the podcast with questions based on the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1982) in order to appeal to a wide audience:

- Are you starting to think that perhaps you should consider eating more healthily or starting to do more activity? (Stage 2: Contemplation) Or maybe you've never really thought about it? (Stage 1: Pre-contemplation)
- Have you ever made plans to change your lifestyle, but then struggled to keep it going? (Stage 3: Preparation)
- You might even be thinking about what activities are going on locally and/or asking your GP about healthy eating? (Stage 3: Preparation)

- Maybe you already eat a balanced diet and exercise regularly, (Stage 4: Action) or are a keen sportsperson who keeps an eye on what you're eating? (Stage 5: Maintenance)

I then followed this with an introduction to the podcast, followed by the provision of current guidelines for health promotion messages relating to healthy eating and physical activity. I included a description and examples of goal setting using the SMART principles, in order to enhance self-efficacy of the individual to feel able to carry out the desired behaviour. The podcast ended with further information on sources of support, specifically First Steps and the Crisis Service (see Appendix C17).

I arranged with the Public Health Development Worker to go to the radio station on 14th May 2012 to record the podcast. The recording went well, and doing the recording myself gave me a valuable appreciation of the experience of my team members previously.

Close of consultancy

The completion of this podcast has brought me to the end of my consultancy on this project, and I have therefore agreed to close the contract from June. The client and I have agreed that my consultancy input has met her overall objectives to deliver the series of podcasts with Eagle Radio, at the time points agreed. I will however remain in contact with the Public Health Development Worker and be available to assist again if needed during the remaining four months of the project.

Monitor the implementation of consultancy

The client and I jointly monitored this consultancy through ensuring that I provided health psychology expertise to the sub-group, contributing to the decision on which key topics would raise awareness of issues to support the general population, and producing three of the podcasts using health psychology theory and principles according to the schedule.

Our monitoring took the form of monthly email and telephone updates, and preparation of agenda items to present at the quarterly Suicide Prevention Strategy Group. This worked well as we had regular and open communication, measuring progress against the objectives, reviewing needs and negotiating any unexpected issues, such as agreeing and implementing the additional podcast.

One less successful element of this process has been how the radio station has promoted the podcasts on their website and the client's involvement with this. It was agreed that Eagle would provide additional information relating to the content of the podcasts, as well as use the titles that they were given by the authors of the podcasts. They have however used their own abbreviations for the titles, which has been frustrating as they do not necessarily accurately portray the content of the podcast, and could therefore prevent someone from accessing it. I spoke to the Public Health Development Worker about this, but they have not been changed. Being aware that she felt that the sub-group was very fortunate to have these podcasts produced and promoted by the radio station at no cost, I wonder whether she has not wanted to cause any difficulties with Eagle by asking for the wording of the webpage to be changed. As a Stakeholder in this consultancy, it is unfortunate that this change could not be properly negotiated with Eagle, and discussing this when assessing the request for consultancy may have been helpful.

Another consideration for assessment and planning of future consultancies might be to have more control over gathering evaluation data, as in this instance I have been reliant on the client in order to get the final figures. I may have been able to go direct to Eagle, having had contact myself, but this would be inconsistent with my contract with the client. I have therefore had to wait some time to gain this information.

Evaluate the impact of consultancy

The four podcasts have provided advice and support for people who may be struggling with issues relating to their mental health and/or emotional well-being, as well as raised awareness of the support services available to people experiencing emotional distress and thoughts of suicide. I have liaised with and had regular contact with the Public Health Development Worker throughout, enabling the podcasts to be available for download on the radio station's website and broadcast on their sister station.

The sub-group had agreed that the number of hits for each podcast on the radio station's website would provide us with beneficial information to assess the impact of the podcasts. When I went to the radio station to record my podcast in May 2012, I asked for figures whilst I was there in order to gain an understanding of how popular the podcasts were and provide feedback to the team. I was really pleased to hear that the podcasts had received nearly 1500 hits, and in August 2012 this was up to 1800 hits, with Podcast One the most popular, receiving over 700 hits. Eagle have fed back

that this is a greater number than some of the podcasts that they have produced and broadcast, so it's a great way to get our health psychology and promotional messages out to a wide audience.

In addition, the Public Health Development Worker and I had agreed that we would review the consultancy process and discuss the dissemination of results once the agreed podcasts had been delivered. We have now done this and she is really pleased with how the podcasts have gone, and feels that it has been a great piece of work that everyone has contributed to (see Appendix C18). Schein (1999) discussed the collaborative "helping relationship" in process consultancy, where the client provides input throughout the process. The Public Health Development Worker and I have worked well together in this respect. She will also be disseminating the work with the local Health and Well-being Board and is happy for the evaluation data to be publicly available. I will be writing an article for the First Steps newsletter as well as an update on our website.

In response to the popularity of the podcasts, Eagle have suggested a monthly radio slot including guest speakers and an opportunity for the public to get involved. This would however have a cost attached and the services involved are not able to fund this at present, but it is testimony to the success of these podcasts that the station would be interested in exploring this idea.

I already had a good working relationship with the client, but I believe this has helped to encourage future joint working and the client now knows that she can request further consultancy from me and that it will be a success. The client has been able to apply her problem-solving skills, utilising my skills to implement an effective intervention. This supports Earll and Bath's (2004) portrayal of consultancy.

Conclusion

I was asked to carry out a consultancy project producing a series of mental health podcasts for a local radio station, that would consist of advice and support for people who may be struggling with issues relating to their mental health and/or emotional well-being.

I was able to bring my theoretical health psychology knowledge to the consultancy, informed by evidence-based practice and knowledge of delivering effective health

promotion to a wide audience. Additionally this has been embedded in existing organisational structures, which suggests a positive outlook for future consultancy requests.

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Appendix C12 – Consultancy case study

Podcasts Mental Health Promotion 2011/12

Theme	Lead agency	Name of lead	Key areas to cover	Month	Reason month chosen
Intro- recognising MH/ feeling low (Self Help- supporting others)	First Steps	Belinda Hemingway	Introduction to podcasts	November 2011	Opening
Alcohol Misuse	TBC	XXX	Recognising when alcohol is an issue Self-medicating for stress relief, peer pressure. What you can do instead Services/ people who can help	December 2011	Festive drinking pressures
Debt	CAB	XXX		January 2012	Post xmas
Chronic pain	SABP	XXX		February 2012	World cancer day/ dignity action day/ gold heart day
Workplace stress	First Steps supported by Richmond Fellowship	Belinda Hemingway	Stress Bullying/ harassment Risk of redundancy	March 2012	
Social inclusion	Richmond fellowship	XXX		April 2012	
Physical Health- eating well and physical activity	First Steps	Belinda Hemingway		May 2012	Making positive changes
Mens Health	Samaritans	XXX		June 2012	In line with men's health month
Bereavement	SOBs/ CRUSE	XXX		July 2012	
Hearing Voices	SABP	XXX		August 2012	
Unemployment	Richmond Fellowship	XXX		September 2012	Inline with education season; people job hunting and end of summer holidays
Relationships	Approach Relate,		• Positive relationships • Domestic abuse	October 2012	In line with domestic abuse week

Appendix C13 – Consultancy case study

First Steps Consultancy Proposal and Contract for Mental Health Podcasts October 2011 – June 2012

Client: XXX
Public Health Development Worker
NHS Surrey

Consultant: Belinda Hemingway
First Steps Team Leader
Surrey Community Health

The consultant is undertaking a DPsych in Health Psychology at City University London

Introduction and Aim

In order to support the delivery of the Suicide Prevention Strategy, the client has negotiated an arrangement with Eagle Radio for the production of twelve monthly podcasts. These podcasts will meet the communication sub-group's aim to use media to support people struggling with issues relating to their mental health and/or emotional well-being, as well as promote services available to support local people.

The client has requested consultancy input to support the production of these mental health podcasts.

Objectives

The client's objectives were to:

- Be provided with the podcast content consisting of advice and support for people who may be struggling with issues relating to their mental health and/or emotional well-being.
- Broadcast monthly podcasts on the radio station which would be made available for download on their website.

The consultant's role is to:

- Provide health psychology expertise to the sub-group in order to take this work forward
- Contribute to the decision on which key topics would raise awareness of issues to support the general population

- Commit to the production of three podcasts using health psychology theory and principles

Methodology

The client requires the consultant to use health psychology theory and principles to inform the development of these podcasts using evidence-based practice and skills for delivery of effective health promotion to a wide audience.

The consultant will produce three podcasts (introduction to the podcasts and why mental health is important, workplace stress, and healthy eating and physical activity for emotional well-being). The three podcasts will be delivered in month one (November 2011), month five (March 2012) and month seven (May 2012).

Costs

This consultancy will be undertaken as part of the role of First Steps Team Leader; as such no fees will be requested.

Monitoring

The contract will be jointly monitored between the client and consultant. The client will ensure that the consultancy input meets the objectives, and the consultant will monitor and review the provision of health psychology expertise to produce three of the podcasts at the time points agreed. Monitoring will be carried out through monthly email and telephone updates, and preparation of agenda items to present at the Suicide Prevention Strategy Group.

Evaluation

The consultancy will be evaluated via the provision of data on website hits from Eagle Radio. In addition, once the agreed podcasts have been delivered, the client and consultant will review the consultancy process and discuss the dissemination of results.

Client



Date 10th November 2011

XXX, Public Health Development Worker, NHS Surrey

Consultant



Date 10th November 2011

Belinda Hemingway, First Steps Team Leader, Surrey Community Health

Appendix C14 – Consultancy case study

Eagle FM podcast – First Steps **Keeping Happy and Healthy at Christmas Time**

Christmas is supposed to be the season of goodwill, joy and laughter but it can also be a time of stress, money worries and family arguments! If you're having a tough time this year or just want to keep yourself happy and healthy through the festive season then you might want to try some of these top tips.

- 1) Try and keep your expectations realistic. We all want to have the perfect Christmas but in reality we all burn the turkey or forget the batteries sometimes. If we set ourselves up to think that nothing short of perfection will do, we are bound to end up feeling a bit disappointed. Try and think about what you might say to a friend in the same situation, you will probably find that you would tell them not to worry so much and that they've done a great job!
- 2) Aim to set yourself a budget and stick to it. It can be easy to fall into the trap of spending more than you can afford and ending up in debt. Be clear with friends, family and children about what you can afford to spend – most people are in the same boat and may even be relieved that you brought the subject up! If you need some advice about managing your finances, it can be helpful to have a chat with your local Citizens Advice Bureau or the Debt Advice Foundation.
- 3) Christmas is typically a time for being a bit indulgent but try not to overdo it. Excessive sugar, salt and caffeine can mimic stress responses and make you feel more tense and anxious. Having a bit of balance in your diet and making sure that you are getting plenty of whole grains, fruit and vegetables along with a few treats will help you stay well and reduce those guilty feelings come the New Year
- 4) Similarly, many of us drink a bit more than usual at this time of year. Having the occasional drink is fine but be aware that alcohol can be a depressant and if you are feeling a bit down, it is likely to make you feel worse rather than better. Alcohol can also interfere with some types of medication and prevent it from working properly, so it is important to be aware of this. Having too much to drink can also make it harder to cope with frustrations and irritations and increase the risk of those family rows.
- 5) Christmas can be a busy time for many of us with lots of things that need to get done. Keeping lists can help you feel more organised and in control but try not to put too much pressure on yourself to get everything done at once. Make sure that you have allowed yourself some time to relax; this could be by going for a walk, having a soothing bath, listening to music or taking some time out with a festive film. Having some time for yourself can help you recharge your batteries and can actually mean that you get more done.
- 6) Are you lonely this Christmas? Not all of us have people close to us that we can spend time with over the festive season. If possible try and stay in contact with people by phone, email or text message. Look out for community events like carol singing or craft workshops where you can be around other people, many of whom might be in a similar situation to yourself. Many areas also run community lunches at Christmas; your local community centre or village hall may have more information on this. You might be interested in doing some

voluntary work like helping at a hostel, visiting a lonely older person or manning a phone line.

- 7) Try to reflect on the positive things that have happened over the year. It can be easy to dwell on all the negatives especially if you are feeling low or stressed. Write a list of all the things that have gone well, no matter how small and give yourself credit for what you have achieved. If you like to make New Years resolutions, keep them realistic and achievable by breaking longer term goals down into smaller chunks. For example if you want to lose weight, start by thinking about how you can gradually build up your activity levels and cut back on the less healthy things rather than starting a strict diet regime that goes out of the window by the end of January.
- 8) We all have a limited capacity for stress. If you think of this as being like a jug that holds all of your stress, you can gradually learn to recognise when your jug is getting full. It might be that something that usually wouldn't bother you suddenly seems much harder to cope with and you can feel overwhelmed. You can take a bit back out of the jug by making sure you have enough time to rest and relax, and also through practising techniques such as breathing exercises for getting through those stressful situations.
- 9) Be aware that your usual routine is likely to be significantly altered over Christmas and this can be quite stressful for a lot of people. You may also be spending a lot more time with people that you don't usually see that often which can lead to tensions. If this is something that affects you try and keep some structure to your day, for example by keeping up with an exercise routine or setting an alarm to get up in the mornings.
- 10) Most importantly of all, if you are finding things difficult, you don't need to bottle it up or struggle on alone. If it is difficult for you to talk to friends or family then there is a huge variety of support available and being able to talk about your problems is the first step to feeling better. If you would like more information on where to look for emotional support, please call First Steps on 0808 801 0325. We can offer free, confidential advice and further information on how to look after your emotional well-being.

If you are struggling with your emotional well-being over the Christmas period then there are a number of places to get support. You can speak to your GP or call NHS Direct or First Steps. If you are looking for support outside of office hours you can contact the Samaritans or in a crisis situation please call 0300 456 83 42. If you are looking for advice and support around drugs or alcohol then Surrey Drug and Alcohol care run a free, confidential 24 hour phonenumber on 0808 802 5000

Appendix C15 – Consultancy case study

Eagle FM podcast – First Steps **Your mental health and emotional well-being**

Rebecca's story

My name is Rebecca and I suffer from depression.

It all started about a year ago after I split up with my boyfriend and moved jobs. Initially I was managing ok but then I found that I just started to feel tired all the time. It seemed like such an effort to get out of bed in the morning and even to do things like wash my hair or cook dinner. I felt like I was going to burst into tears all the time and I had no idea why. My friends started commenting that I never seemed to want to go out with them anymore and if I did I was either really quiet or I found myself biting people's heads off for no good reason. I just didn't want to do anything but curl up under the duvet and block the whole world out. I couldn't understand what was wrong with me, I didn't feel like myself at all – I couldn't concentrate, I couldn't think straight and I lost all my confidence. I had gone from being an organised, bubbly, sociable person to feeling like I was moving through each day on autopilot. I didn't even feel sad really, I didn't feel anything at all most of the time, just sort of numb. I kept telling myself that things weren't really that bad and that I should just pull myself together and sort myself out but I didn't know where to start.

Eventually my mum persuaded me that it might be helpful to talk to my doctor. I didn't want to and thought he would just say that I was wasting his time, as I didn't have a 'real' illness. I thought he would tell me to just stop feeling sorry for myself. Or worse, what if he said that something was seriously wrong? What would people think if they found out? I could lose my job even. Eventually I realised that I couldn't go on feeling the way I did, it was affecting my work, my friendships and my family. Some days I had even wondered whether I really wanted to carry on at all.

When I went to the doctor I was really relieved by his reaction. He told me that the way I was feeling was pretty normal and that one in four people are affected by depression and anxiety at some point in their lives. I realised that I was unwell but that I wasn't 'mental' and that by talking about it, I could find ways to start feeling better. He gave me some information for an organisation called First Steps and said that they could help me get back on the path to emotional well-being.

I wasn't really sure what to expect when I called the First Steps advice line but the person I spoke to was really friendly and helpful. I didn't have to give any of my personal details so I wasn't worried about work finding out anything that I didn't want to tell them. They gave me lots of helpful advice on places to go for more information and taught me some techniques like how to relax through breathing exercises.

I realised that by avoiding all the things I used to enjoy, I was ending up feeling worse because all I was doing were the things that didn't really make me happy. Although it was quite difficult to start going out again, I learned to break things down into smaller steps like just meeting one friend for a coffee and chat then moving on to spending an evening out with a group. By setting myself small goals I felt like I was moving forward without putting too much pressure on myself or being unrealistic about what I could do.

I looked a lot at the way that I was thinking about my situation and kept a diary of all the negative thoughts I was having. I found that I was often being really hard on myself and only seeing the negative things that were happening, rather than any positive things. The self-help information asked me to think about what I would say to a friend

in the same situation and I found that it would always be much kinder than the things that I was saying to myself.

Gradually I learned to start taking control of how I was behaving and that improved the way that I was feeling. I also learned to let go of some of the things that were out of my control, although this took a lot of practice and I don't always get it right. Self-help was really useful for me although my GP and First Steps told me how I could get some one to one counselling or therapy if I needed it, and also who to call if I had an emotional crisis and needed help.

I would advise anyone feeling low or anxious or stressed to talk about it with friends, family or professionals. It surprised me just how many people felt the same way as I did and how much support is available. Even when I'm not feeling down or depressed I now keep up with the techniques I've learned just to help me manage all the day to day stresses and ups and downs and keep myself emotionally well.

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Does this sound familiar? Can you relate to Rebecca's story?

If you're worried about yourself or someone else contact First Steps on 0808 801 0325 or email first.steps@nhs.net

First Steps offers advice and information on common mental health and emotional issues via the website www.firststeps-surrey.nhs.uk, phone-line, leaflets and evidence-based self-help booklets and recommended reading. The service additionally holds a vast amount of information on how to access useful local and national organisations.

First Steps also run workshops called Emotion Gyms to help you understand common emotional issues and to teach you how to maintain and improve emotional well-being.

The service is free and confidential, so don't feel alone. Everybody experiences emotional difficulties at some point in their lives. This often has an effect on daily activities and quality of life. In fact, one in four people experience symptoms of anxiety and/or depression at some point in their life.

There is a wide range of useful information available and there is a lot that you can do to help yourself, as well as a number of people who can help you.

The First Steps service aims to provide you with the tools to help you help yourself.

If however you find yourself needing urgent support out-of-hours, please call the crisis helpline on 0300 456 8342.

Never underestimate the importance of your mental and emotional well-being – remember being mentally healthy is just as important as being physically healthy.

Appendix C16 – Consultancy case study

Eagle FM podcast – First Steps **Preventing workplace stress**

Introduction:

Stress and bullying in the work place is not uncommon but can have a significant impact on how somebody feels. Stress is what we feel when we perceive that the pressures and demands we have, exceed what we feel able to cope with and can affect a persons physical and emotional health.

Bullying is any offensive, intimidating, malicious or insulting behaviour, an abuse or misuse of power through means that undermine, humiliate, denigrate or injure the recipient.

Stress can have a significant impact on individuals, families, work places, communities and the economy. Each new case of stress, which requires sick leave, leads to an average of 29 days off work and stress is estimated to cost around £4 billion each year. Stress also causes less productivity of staff that do not take sick leave and can have a negative impact on team morale and well-being.

So if a person is experiencing stress in the work place, what would you suggest?

It is important to remember that you are not alone. There are a number of self-help strategies that can help to reduce your stress and a number of sources of support. Here are a few of our favourite tips:

- Take control
 - Quite often you cannot control or change an event or situation, but you can always control your actions/ reaction to it. Channel your energies into the element of the situation that you can control and try not to ruminate on the elements that you cannot change. It's not about agreeing with or condoning a situation, its just recognising that ruminating on it is not helpful
- Seek help
 - This could be asking for support from your line manager, occupational health, a colleague/friend or seeking advice from an external service like your Union, First Steps or Richmond Fellowship.
- Set boundaries
 - Be realistic about what you can achieve. Thinking about what you might say to a friend can be helpful with this. Unrealistic expectations will reduce productivity and increase your stress. Take regular breaks and do not regularly exceed your work hours. This significantly increases the likelihood of requiring time off work for a stress-related illness. If given a choice, most employers would rather you took a break on a regular basis, than having six weeks off work unwell
- Environment
 - De-clutter your environment by filing, using notebooks, diaries, etc. This can help you to feel calmer, in control and may save time in the long run
- Look after yourself
 - Getting active, healthy eating and having time to unwind will all increase your ability to manage stress. Make time for family, friends and hobbies

Bullying may be by an individual against an individual at work or by someone in a position of authority such as a line manager or supervisor or it may involve groups of colleagues. It may be obvious and observed by co-workers or it may be insidious and hidden. Whatever form it takes, it is unacceptable and unwelcome to the individual concerned. Bullying should not be tolerated in the workplace, but if you think you may be being bullied it can be difficult to know what to do about it.

So could you give us some examples of what bullying is?

Some examples of bullying may include:

- Spreading malicious rumours, or insulting someone by word or behaviour (particularly on the grounds of age, race, sex, disability, sexual orientation and religion or belief)
- Excluding people or victimising them
- Unfair treatment
- Ridiculing or demeaning someone, picking on them or setting them up to fail
- Inappropriate micro management- overbearing supervision and constant checking or misuse of power or position
- Unfairly blocking promotion or training opportunities thereby preventing individuals from progressing and reaching their full potential at work
- Deliberately undermining a competent worker by overloading or underloading and constant criticism of their work
- Unwelcome sexual advances and the display of offensive materials

Bullying may not necessarily be face to face. It may also occur in written communications, electronic e-mail, social media, telephone and voice mail etc. If you think you are being bullied, it is best to talk it over with someone.

Sometimes what seems like bullying might not be. For example, you might have more work to do because of a change in the way your organisation is run. If you find it difficult to cope, talk to your manager or supervisor, who might be as concerned as you are. Sometimes all it takes is a change in the way you work to give you time to adjust

If you are being bullied then speak to someone about how you might deal with the problem informally. This might be:

- an employee representative like a trade union official
- someone in the human resources (HR) department
- your manager, supervisor or friend at work

Some employers have specially trained staff to help with bullying problems or you could speak to your Union representative (if you have one) an organisational counsellor or welfare worker; or you may have an EAP programme. If the bullying is affecting your health, visit your doctor.

The bullying may not be deliberate. If you can, talk to the person in question, who may not realise how their behavior has been affecting you. Work out what to say beforehand. Describe what has been happening and why you object to it. Stay calm and be polite. If you don't want to talk to them yourself, ask someone else to do so for you.

Write down details of every incident and keep copies of any relevant documents. Making a formal complaint is the next step if you can't solve the problem informally. To

do this you must follow your employer's grievance procedure which should give you information about whom to complain to and how your complaint will be dealt with.

Sometimes the problem continues even after you have followed your employer's grievance procedure. If nothing is done to put things right, you can think about legal action, which may mean going to an Employment Tribunal. Get professional advice before taking this step.

If you feel you are being bullied at work there are a broad range of organisations providing in-work support, and the NHS in Surrey provides a free job retention service through Specialist Advisors at Richmond Fellowship and ESRA. They can be contacted through New Thoughts in Woking and Redhill on 03000 121048. They will be able to signpost you to relevant information or organisations, or may even take up your case on your behalf.

If you're worried about yourself or someone else's emotional health contact First Steps on 0808 801 0325 or email first.steps@nhs.net. First Steps offers advice and information on common mental health and emotional issues, please contact us for more details. We are also able to offer bespoke training around work stress for teams, individuals and line managers.

If however you find yourself needing urgent support out-of-hours, please call the crisis helpline on 0300 456 8342.

Appendix C17 – Consultancy case study

Eagle FM podcast – First Steps **Healthy Eating and Physical Activity for Emotional Well-being**

Introduction:

- Are you starting to think that perhaps you should consider eating more healthily or starting to do more activity? Or maybe you've never really thought about it?
- Have you ever made plans to change your lifestyle, but then struggled to keep it going?
- You might even be thinking about what activities are going on locally and/or asking your GP about healthy eating?
- Maybe you already eat a balanced diet and exercise regularly, or are a keen sportsperson who keeps an eye on what you're eating?

However you view your physical health and the lifestyle choices you make, you may not realise that healthy eating and physical activity are linked to how emotionally healthy we feel too.

As well as providing some tips for healthy eating and keeping active, this podcast will explain how you can start to make changes that could improve your health. Here's Belinda Hemingway, Team Leader at First Steps, to explain more.

There are small steps that everyone can take to keep happy and healthy, without having to go to a gym, or change everything you eat! Firstly, let's look at healthy eating...

A balanced diet can make you feel better about yourself as well as being of benefit to your body and immune system. We just need to ensure we have a range of different food types in varying portion sizes.

Consider these healthy eating tips:

- Base your meals on starchy (carbohydrate) foods for energy e.g. wholegrain bread/cereal/pasta, brown rice, jacket potatoes
- Eat lots of fruit and vegetables
- Eat more fish – including 1 portion of oily fish per week
- Cut down on saturated fat and sugar
- Try to eat less salt – 6g max for adults
- Drink plenty of water or other fluids
- Cut down on caffeine – try herbal teas instead
- and Don't skip breakfast!

So now let's talk about physical activity or exercise.

Regular exercise is good for us in many ways: it increases our confidence and how we feel about ourselves; it lifts our mood; it releases tension and frustration; it relieves stress and anxiety; boosts energy as well as helps us relax; helps us sleep better and helps to prevent physical illness, such as colds and viruses as well as heart disease, stroke and cancer.

Exercise is not just about improving your physique, losing weight, improving cardiovascular functioning and gaining muscle size. There are other benefits which are equally important as looking good and feeling physically healthy. It is important to try to focus on things that you are able to do rather than the things that you cannot.

The social interaction experienced at, for example, an aerobic class, or neighbourhood walk with others may also improve mood, as well as being a good physical activity. With this in mind, a combination of the two is a powerful tool to maintain our well-being. Furthermore, exercise has been reported to be more effective than antidepressant medication in treating mild to moderate depression.

Consider outdoor exercise. Exercise in natural surroundings such as the countryside or a park is especially recommended because contact with nature and green spaces has a positive effect upon mental health. Gardening is an ideal activity of this sort, providing mental, practical and social benefits

The type of activity that you do will vary according to your physical health, fitness, the amount of time you have and how much you enjoy it. It is recommended that you do 150 minutes of moderate intensity activity across a week. You might find that it is easier to break this into three ten minutes bursts, or thirty minute sessions, on five days of the week.

So you might be thinking that all sounds very good in principle, but where do I start?

How important is it to you that you make these changes? How confident do you feel about making steps to change your lifestyle? Belinda picks it up from here...

Goals give us a sense of purpose and allow us to achieve tasks that may feel overwhelming or unachievable. In fact, most people find that working towards realistic goals is motivating and satisfying, but it is important to start off by setting the right goals to ensure success.

There are 5 important aspects to consider when setting yourself a goal, and these can be remembered by the word SMART. SMART stands for Specific, Measurable, Achievable, Realistic and Timely:

S	Specific	By being specific about your target goal you will be able to take pride in achieving it
M	Measurable	Just wanting to "lose weight" is not measurable; being fit enough to run one mile is, or to build up to swimming 20 lengths
A	Achievable	Recognise your limits, if you set goals too high you are more likely to quit and feel that you failed. Go with what is right for you, big or small
R	Realistic	Be realistic, if you haven't been swimming for years, having a goal to swim 40 lengths maybe unrealistic, 10 would be better!
T	Timely	Think when the best time is for you to fit in some activity into your day and try not to tackle too many goals at once

Start off setting yourself a series of small goals that will help you to reach your ultimate goal. By working on and achieving small targets, your confidence will increase far more than if you are trying to achieve goals which are too difficult.

Goal setting is an on-going process. Regularly look again at what has gone well or less well and why this might be the case. Set new goals or adapt the ones you have. Give yourself a reward for what you achieve, even if you did not complete the goal but gave it a good shot!

Remember, change is not always easy, and there maybe slips or lapses along the way. This is normal, so don't be put off or be hard on yourself if you find that you can't always stick to the plan.

For any extra information on the topics we've discussed or on generally keeping happy and healthy, do contact First Steps. Remember being mentally healthy is just as important as being physically healthy!

First Steps offers advice and information on common mental health and emotional issues via the phone-line (0808 801 0325), email (first.steps@nhs.net), website (www.firststeps-surrey.nhs.uk), evidence-based self-help booklets and recommended reading, including the Physical Activity and Healthy Eating for Emotional Well-being booklet.

The service additionally holds a vast amount of information on how to access useful local and national organisations. The service is free and confidential.

If however you find yourself needing urgent support out-of-hours, please call the crisis helpline on 0300 456 8342.

Behaviour Change Intervention - A Case Study

This case study will look at the assessment of need, formulation and setting up of a psychoeducational intervention for pulmonary rehabilitation patients, implementation of the intervention, and the evaluation of eighteen months delivery from November 2011 to April 2013.

Assessing the suitability of pulmonary rehabilitation patients for a health-related behaviour change intervention

In September 2011, in my capacity as Team Leader at First Steps, I was contacted by a respiratory physiotherapist requesting psychological input into their rolling pulmonary rehabilitation programmes, for patients with Chronic Obstructive Pulmonary Disease (COPD) and other lung conditions in East Surrey. She had identified a link between stress and anxiety and breathlessness, as well as patients suffering with low mood as they struggled to adapt to their lung disease and its associated complications. The physiotherapist did not feel that patients fully understood the link between their physical condition and their mental health, did not know that they could improve their well-being through self-help strategies, and therefore had no knowledge of how they might be able to do this. She recognised the need for psychological intervention and wanted to improve the service given to the respiratory patients (Appendix C19).

The programme ran for eight weeks involving two sessions per week of tailored physical exercise and education. The programme was run by the physiotherapist, who facilitated all the physical exercise sessions and eleven out of sixteen of the educational topics. In addition, a respiratory nurse delivered three of the educational topics, and a dietician delivered a session on healthy eating. The physiotherapist approached First Steps to provide the remaining education session for each of the two eight week rolling programmes that ran in separate locations. This equated to about once a month alternating locations. I agreed to consider this and carry out some brief research into the benefits of psychological interventions in pulmonary rehabilitation, as well as determine what recommendations existed for the level of intervention to be provided.

COPD is a disease of the lungs that is characterised by airflow obstruction or limitation,

and is a term widely used by clinicians to describe conditions such as emphysema, chronic bronchitis and chronic unremitting asthma (Department of Health, 2012). The airflow obstruction is usually progressive, not fully reversible, and does not change markedly over several months. It is therefore treatable, but not curable (Department of Health, 2012). The principal cause of COPD is smoking. Early diagnosis and treatment can slow decline in lung function and hence lengthen the period in which a patient can enjoy an active life, but COPD is still the fifth biggest cause of mortality in the UK, and an estimated 13% of the population of England over age 35 have undiagnosed COPD (Department of Health, 2011). In Surrey, approximately 1.2% of the population has a diagnosis of COPD, which is lower than the national average of 1.7% (JSNA 2012), but early identification, diagnosis and intervention are still key. In addition, COPD is also often associated with other conditions, for example, about 40% of people with COPD also have heart disease, and significant numbers have depression and/or anxiety disorder (Department of Health, 2011). There is therefore a pressing need to improve outcomes for people with COPD.

Pulmonary rehabilitation is a multi-disciplinary programme for patients with chronic lung disease, including COPD, and consists of exercise, education and psychosocial support. Pulmonary rehabilitation has been shown to improve health related quality of life, function, and breathlessness (General Practice Airways Group, 2008) and is recommended in guidelines by the Healthcare Commission (2006) and the National Institute for Health and Clinical Excellence (NICE, 2010).

Having reviewed the literature, I found that enhancing quality of life and self-management for people with COPD is essential, and therefore understanding of strategies to maintain physical and psychological health would be extremely beneficial. Improving and Integrating Respiratory Services (IMPRESS) guidance (2011) supported this position by stating the importance of having at least one session of pulmonary rehabilitation focused on addressing psychological issues. More recently, the Department of Health (2012) has suggested that psychological and behavioural interventions are recommended as part of the pulmonary rehabilitation process, and that staff with competencies appropriate for psychological input should be supporting specialists in chronic respiratory care in delivery of *“psychological impacts and minimising their effects”* (Department of Health, 2012: 17). The request for psychological input also fitted with one of the aims of the First Steps service, which is to develop, deliver and evaluate sessions on mental health and emotional well-being and the interaction with physical health. I accordingly contacted the respiratory physiotherapist and agreed our input.

Identifying and negotiating the behaviour change goals with stakeholders/clients

I arranged to have a telephone meeting with the physiotherapist to assess the specific needs of patients that attend pulmonary rehabilitation, and what she felt patients would most want to get from the intervention. The key issues identified were adjusting and adapting to chronic respiratory disease, and needing strategies to manage stress and anxiety.

The identified and agreed objectives of the behaviour change intervention were therefore:

- For patients to perceive the information provided as useful in improving their emotional well-being
- To facilitate a change in knowledge of a range of strategies to manage emotional well-being with a chronic respiratory disease
- For patients to show intention to use the strategies discussed

I agreed that the intervention would be delivered from November 2011 on an ongoing basis and that myself and another member of my team, also studying for the DPsych, were ideally placed to develop and deliver this intervention.

Assessing determinants of relevant current behaviour/ presenting challenges (i.e. cognitive, behavioural, social, motivational, cultural, contextual)

The challenge for this intervention was to provide patients with the opportunity to reflect on their attitudes and beliefs, and provide knowledge on, and encourage intention to use the strategies discussed in a one-hour timeframe. As the key issues were adjusting and adapting to a chronic illness, and needing strategies to manage stress and anxiety, it was decided that utilising the Transtheoretical Model (Prochaska & DiClemente, 1982), the Health Belief Model (Rosenstock, 1966; Becker and Rosenstock, 1987) and Social Cognition Theory (Bandura, 1986), specifically self-efficacy, would support exploration of behaviour change. In addition, the session would be delivered in a Cognitive Behavioural Therapy format to assist identification of thoughts, emotions, physical symptoms and behaviours that help or hinder the management of stress and anxiety.

Motivational Interviewing (Rollnick, Miller & Butler, 2008) techniques as a form of client-centred guiding throughout the session, such as open questions and reflective listening, were also used to enable exploration of patients' own personal motivations for change. These techniques helped build rapport, express empathy, support self-efficacy to facilitate coping, and develop discrepancy between where a patient is now and how they would like things to be different in the future. The overall goal in the formulation of this behaviour change intervention was to improve quality of life, promote self-management, and lessen the psychological impact of their chronic disease.

Developing a behaviour change plan grounded on available literature on effectiveness and psychological principles

As pulmonary rehabilitation is delivered in a group setting, and guidance suggests that education takes the form of topic-based talks and group discussions (IMPRESS, 2011), a psychoeducational intervention was developed based on the identified need for patients to develop self-help strategies to manage their emotional well-being, whilst adjusting and adapting to their lung disease.

In addition, I found Beattie's (1991) model of four paradigms (health persuasion, personal counselling, community development, and legislative action) useful in terms of developing an intervention that focuses on why behaviour happens (health persuasion), working with this specific patient group to identify changes they could make (personal counselling), and empowering individuals to make changes within the context of evidence-based research (community development).

The intervention was designed (see Appendix C20) to start with an introduction, followed by a group discussion around how long-term health conditions can impact on emotional health, and the common symptoms of emotional distress. The session then went on to encourage self-efficacy by emphasising that anxiety, stress and low mood is common with COPD, and the importance of adapting and developing strategies to manage their condition. As an initial exploration of stress, the analogy of a "stress jug" was given. This led to the identification of thoughts, emotions, physical symptoms and behaviours, using a CBT Five Areas model (Williams & Garland, 2002) to enable the group to see the impact of these and how changes could be made. A section on achieving emotional well-being followed, in order to explore where people might be in the Transtheoretical Model (Prochaska & DiClemente, 1982) in relation to initiating

behaviour change, and how the elements taken from the Health Belief Model (Rosenstock, 1966; Becker & Rosenstock, 1987) such as costs, benefits and motivation could impact a change in behaviour. Discussing the fact that change is possible also draws on self-efficacy, from Social Cognition Theory (Bandura, 1986), that the person is capable of carrying out new behaviours.

As adjustment and adaptation were key issues in the assessment of need for this intervention, role change as opposed to role loss was discussed next, using case studies and encouraging people to share their own brief experiences of difficulties they had faced and ways they had gone through the process of adjustment by making changes. The aim of this was to enable the exploration of barriers to change and any discrepancies between where people are now and what they want to achieve, using Motivational Interviewing techniques including rolling with resistance (Miller and Rollnick, 2009). Finally, to support self-efficacy and enable the patients to see how they might implement a sustained behaviour change, a section on SMART (Specific, Measurable, Achievable, Relevant, and Timely) goals ended the intervention.

Ensure monitoring and support for behaviour change plan

In order to maintain ongoing monitoring of the intervention, an evaluation form was designed to incorporate the agreed objectives of the behaviour change intervention and our service monitoring requirements (see Appendix C21). This was to be given out after the intervention had been delivered.

Myself and the other team member delivered an initial pilot session in November 2011. The physiotherapist fed back that people had found the different techniques to manage stress and anxiety, and the opportunity to discuss the impact of their disease, very helpful. She did say that a couple of patients mentioned to her that they had received a bit too much information, especially after having participated in an hour of exercise prior to the session. Upon reflection, and on discussion with the co-facilitator, it was agreed that some of the information could be reduced and the introduction was amended to be more engaging from the start. The question, “Why do you think it’s relevant to talk about emotional well-being in the context of pulmonary rehabilitation?” was asked. This question was intended to enable the group to see the link between physical and emotional health, specifically areas such as stress, anxiety and breathlessness in COPD, the challenges of managing the condition, feeling vulnerable and disempowered, and any loss of role, rather than us tell them. This stimulated

discussion and helped understanding of the interactions between mental and physical health with lung disease. The discussion on common symptoms of emotional distress was also removed, instead talking through the symptoms of stress and anxiety, asking the patients how they would recognise these symptoms physically, in their thinking and in their behaviour. In addition, the long-term conditions cycle was amended to be more specific to lung disease.

The IMPRESS (2011) guidance suggests that patients appreciate written material as well as self-help plans and home training diaries. As patients felt that they had received too much information in the session, and the physiotherapist did not provide any written information related to anxiety and stress, my co-facilitator and I developed a handout that covered the main points from the session for patients to take away with them (see Appendix C22). In our subsequent jointly facilitated session, it was felt that the changes had been successful as the intervention felt more collaborative between the facilitators and patients. Feedback from patients received via the physiotherapist was positive, especially with regard to talking about how their lung disease made them feel. Following the successful pilot, my co-facilitator and I agreed to alternate delivery from then onwards as it felt unnecessary to have two facilitators following a successful pilot and given the small group size. Throughout the process, I remained in regular contact with the physiotherapist, reviewing the ongoing sessions, discussing any concerns and negotiating the team's input, which she felt was beneficial.

In December 2012, I felt that asking whether or not patients had learnt anything new from the intervention was not truly capturing a change in knowledge, so the evaluation question was changed to assess changes in knowledge before and after attending the intervention (Appendix C23). After each session, the evaluation forms were reviewed and as a result feedback was often incorporated into the following session. I have also kept an ongoing reflective diary for my professional development and competence related to the intervention (see Appendix C24), and have found this particularly helpful in reflecting on the session following delivery, as well as reviewing how I have sometimes managed quite complex and unpredictable groups, without prior knowledge of the patients, their varying condition severity, or how they are currently managing in their day-to-day lives.

Evaluate outcome

To determine the efficacy of the intervention, the outcomes were evaluated through patient evaluation forms, feedback from the physiotherapist, and my own reflections. In the eighteen months that this intervention was delivered, one hundred and fifty-six patients have participated and one hundred and thirteen completed evaluations (see Appendix C25).

The majority of patients reported finding the information provided in improving emotional well-being as “quite useful”. The respiratory physiotherapist has said that the groups vary with regards to their needs, perception and acceptance of their condition, sometimes depending on whether they are newly diagnosed or have been living with the condition for some time, which may impact on their perception of the usefulness of the information.

For change in knowledge, assessed by the question “have you learnt anything new”, the majority of patients said “not sure”. Changing the question to a knowledge score before and after the intervention helped to assess knowledge change more effectively. In total the knowledge score before the session was 123, and after the intervention was 244, which almost doubled.

In terms of whether the patients were likely to use any of the strategies discussed and if so which, the majority of patients said that they intended to use the strategies discussed. Intended strategies reported included ways to manage stress and anxiety, setting goals, giving themselves more time to relax, and thinking more about dealing with problems and situations in the context of managing their condition.

The analysis of the data derived from the evaluation forms also provided useful feedback relating to the experience of patients in being part of a psychoeducational group, and how the session could be further developed to make the best use of time.

Negotiate completion, follow-up/ referral/ dissemination as appropriate

The intervention remains ongoing, but there are some small changes that I would like to make. The intervention needs to be impactful from the start but also quickly move onto strategies to improve well-being, so that if people are tired from the exercise session they are still involved in the key points early on. I plan to remove the cycle of

lung disease and emotional impact, as alongside the stress jug analogy and the CBT Five Areas model, there seem to be too many diagrams where the key points could be made clearer. Based on patient feedback, I believe the focus is better placed on ways to improve emotional well-being through developing new roles, adapting to their condition, or finding ways to still do the activities that they enjoy.

Identifying thoughts, emotions, physical symptoms and behaviours using a CBT Five Areas model has been helpful but I am considering whether changing the situation example from 'fatigue following a long day' to something more specific such as 'gardening all day' might make it clearer in relation to COPD. That way the physical symptom might be 'noticing becoming breathless', followed by the thought that 'I have done too much, I can't cope', the emotion 'anxious or panicky', leading to the behaviour 'stop doing any more gardening or any other activity that requires physical effort'. This would then aid discussion around the impact of this and how changes could be made.

Sources of further information are always provided to acknowledge the boundaries of the intervention and to minimise any possible risk. The services offered by First Steps are always reiterated at the end in case of the need for follow-up or referral. In the changing NHS landscape, I have had to evidence how this intervention contributes to the First Steps service specification in order for it to continue. So far our ongoing involvement has been agreed, which I am pleased about, as without this patients on the pulmonary rehabilitation programme would not receive any psychological or behavioural intervention.

Conclusion

Overall, utilising health psychology theory and models to inform structure and content has contributed to the implementation of an appropriate, effective behaviour change intervention. I believe the intervention has met the aims and as a result patients are gaining considerable awareness and support around managing their emotional well-being. It is giving them permission to talk about emotions, which can be very difficult, and to discover that they are not alone in their struggles to manage their condition and its impact. The formal evaluation of the programme, in addition to other patient feedback, has informed successful changes made to subsequent sessions.

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Appendix C20 – Behaviour Change Intervention case study

Pulmonary Rehabilitation Session Plan

Introduction – Introduction to First Steps.

Group discussion: Why do you think it's relevant to talk about emotional well-being in the context of pulmonary rehabilitation?

e.g. stress, anxiety and breathlessness, role loss, feeling vulnerable, feeling like life is not fair, feeling disempowered

(facilitator to provide information to the patients that we are aware of how long term health conditions can have an impact on physical health)

- Emotional well-being and mental health concerns are major health issues in their own right. But they can also greatly affect physical health. On the other hand, your physical health condition can also have a great impact on your emotional wellbeing and overall mental health (e.g. anxiety and depression).
- **Example:** breathlessness can be linked to frustration, panic and stress, which increases sensations of breathlessness – it can become a vicious circle

Symptoms of Stress and Anxiety

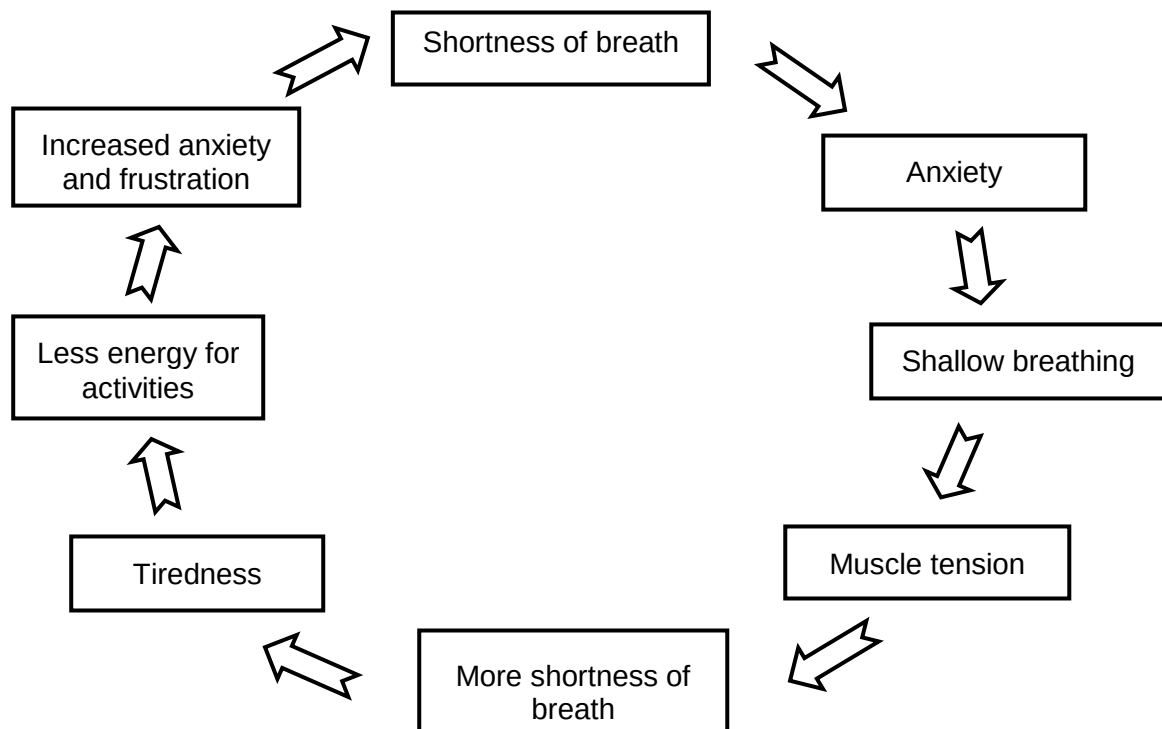
How would you recognise your symptoms of stress and anxiety?

- What physical symptoms do you experience?
- How does your thinking affect you?
- What sort of behaviours do you notice?

Stress and anxiety can impact on our lives, and can result in:

- difficulty concentrating / muddled thinking
- increased forgetfulness
- short temper
- feeling overwhelmed
- getting frustrated and picking fights with others
- seeing only the negative
- constant worry
- headaches
- breathlessness
- not being able to do the things that you used to do

People who have breathing problems often find themselves in a cycle where the symptoms of lung disease interact with the symptoms of anxiety and stress:

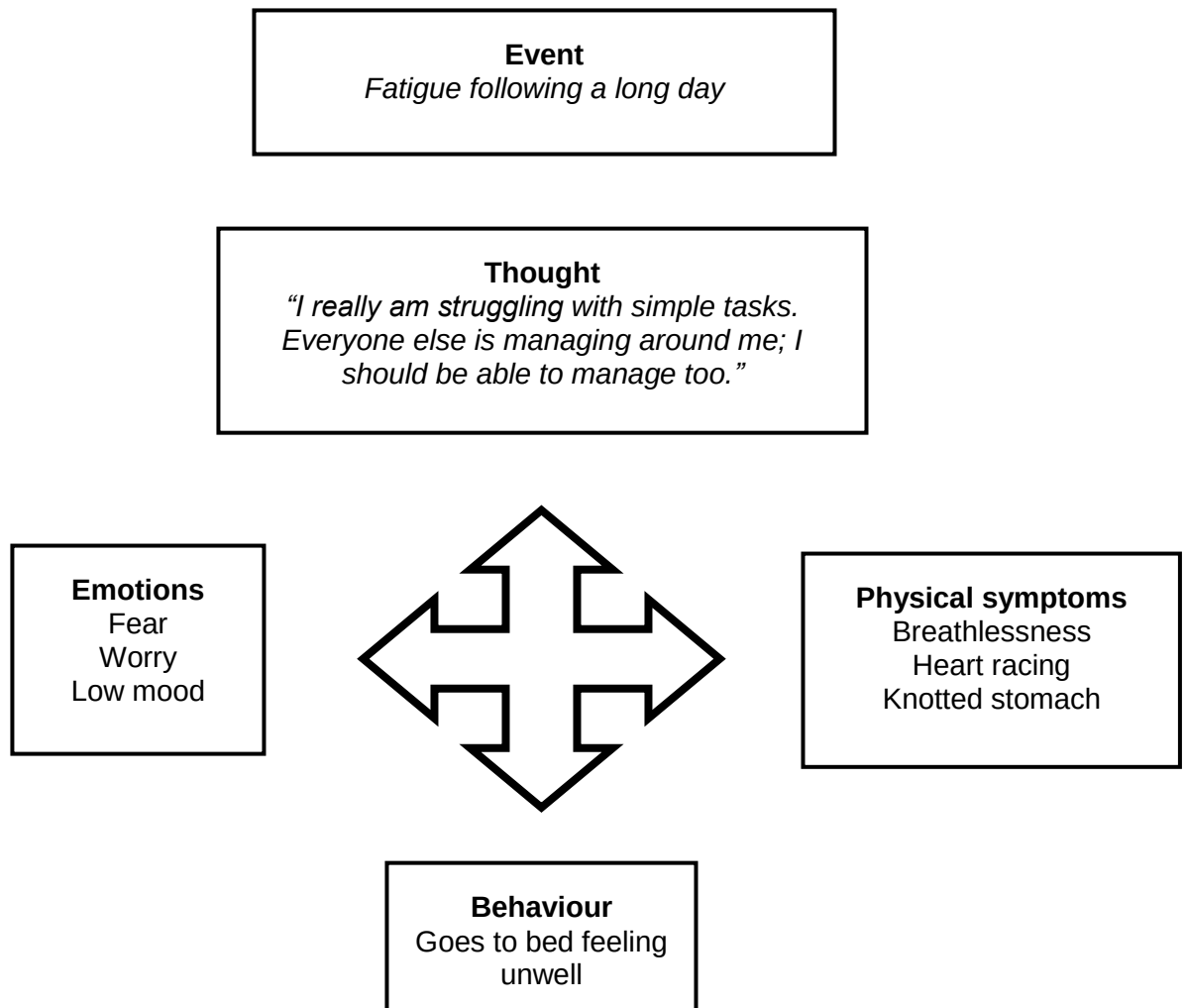


BUT there is something we can do about this. Finding/developing new roles, as well as adapting, is an important part of making the most of your life.

Stress Jug – draw the analogy of the stress jug and explain how we all have a capacity for a certain amount of stress in our lives, and that it is important to reduce the amount of stress so that we are able to keep emotionally well.

Your thoughts, your emotions, your body and your behaviours

How can we go about identifying where our stress, anxiety and low mood comes from?



How is this going to impact the person?

Where could we break this cycle and increase the chance of a more positive outcome?

Secrets of Everyday Emotional Well-being

Just as achieving physical fitness takes time, practice and commitment, so too does achieving mental fitness. There are 3 basic principles in obtaining emotional wellbeing: the first is to **maximise the things that make you feel good, and minimise the things that make you feel bad**; second is **valuing yourself**; and third is to **recognise that you can change**.

Some feel good factors include:

- making time for relaxation
- being able to express your feelings
- having achievable goals to aim for
- making time for the things you enjoy
- maintaining a healthy diet
- work you find rewarding (if you are still working)
- time to yourself, to do the things that interest you
- time for friends and family

Some things to minimise:

- unnecessary stress
- feelings of rage or frustration
- expecting too much of yourself and negative thoughts and feelings

Self Management Skills

- Take care of health problems
- Carry on doing normal activities
- Manage emotional changes

Roles

Throughout life, we are required to carry out many different roles. For example, you may be required to be a mother or a father, a brother or a sister, a specific role at work. Perhaps you have a role within your local community; perhaps you are a part of a sports team or another club. However, when you develop a chronic illness such as lung disease, you may find that you are unable to do the things that you once were able to do within your roles – *does anyone have any experience of this?*

Because of your condition, you may notice that the roles you once had have been changed. However, it might be about adapting these roles to suit your current situation.

Example: we know of a woman who was a keen gardener, but as a result of her COPD found it difficult to maintain her garden in the way that she wished. She was able to arrange for a neighbour to mow her lawn and instead of planting flowers in the garden, she designed many window boxes and plant pots. This added colour to her garden and allowed her to carry on enjoying her hobby.

Has anyone got an example of their own that they would be happy to share?

Action Plans

Some people find it useful to set themselves an action plan, e.g.

- Something you want to do
- Is it achievable?
- Make it action specific (how will you do what you do?)

Make sure any goal setting that you do is:

Specific
Meaningful
Achievable
Relevant
Timely

And make sure to:

Evaluate
Redo

Appendix C21 – Behaviour Change Intervention case study

Date/...../.....

We would greatly appreciate your comments to help improve future sessions. Please feel free to make comments in the spaces provided below.

1. Would you recommend this session to a friend?

Not at all	Possibly not	Not sure	Yes	Yes definitely
1	2	3	4	5

2. Are you likely to use any of the strategies discussed today?

Yes _____ **If so, which?** _____
No _____

3. How useful has the information from this session been in improving your emotional well-being?

Not at all	Not very	Not sure	Quite useful	Very
1	2	3	4	5

4. Have you learnt anything new from this session?

Nothing		A Little		Lots
1	2	3	4	5

5. What was your favourite part of this session?

6. Are there any improvements you think we can make to this session?

Please Turn Over

Gender

Male _____

Female _____

Age Group

Under 20 _____

20-29 _____

30-39 _____

40-49 _____

50-59 _____

60-69 _____

70+ _____

Employment Status

Self-Employed _____

Full-Time Work _____

Part-Time Work _____

Unemployed _____

Retired _____

Student _____

Ethnicity

White

British _____

Irish _____

Other _____

Asian or Asian British

Indian _____

Pakistani _____

Bangladeshi _____

Chinese _____

Other _____

Black or Black British

Caribbean _____

African _____

Other _____

Mixed

White and Black Caribbean _____

White and Asian _____

White and Black African _____

Other _____

Other Ethnic Group

Appendix C22 – Behaviour Change Intervention case study

How your physical health can impact on your emotional well-being

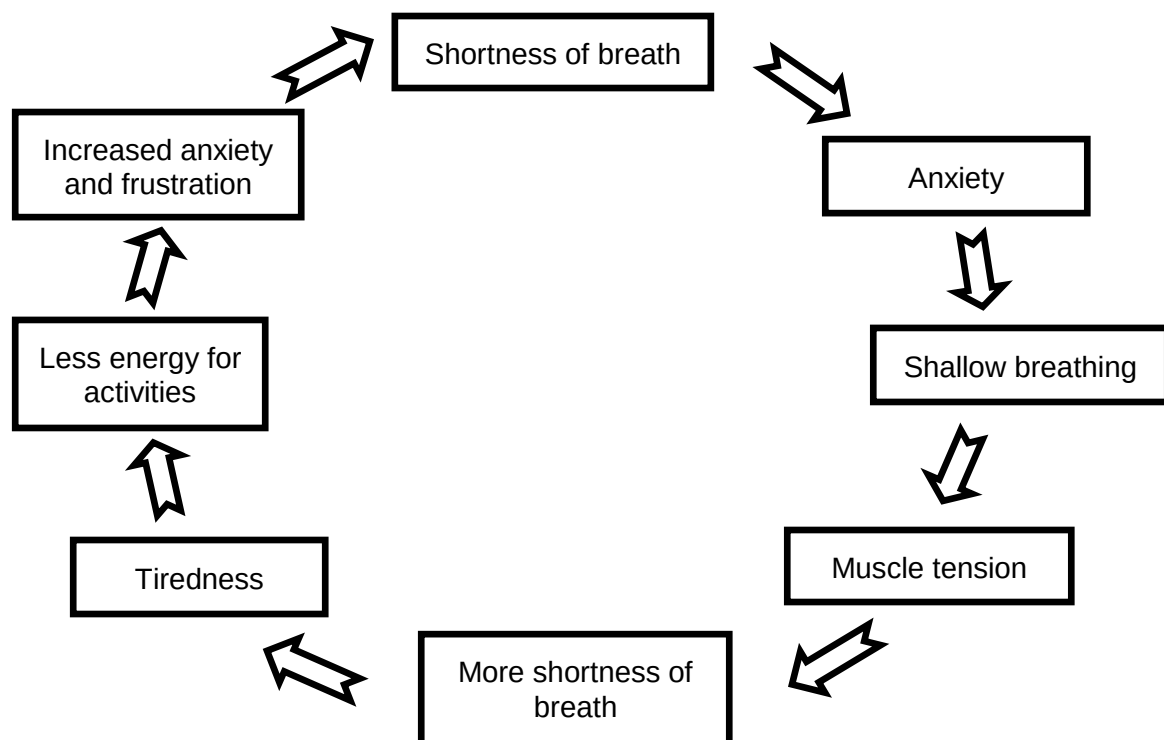
Emotional well-being and mental health concerns are major health issues in their own right. But they can also greatly affect physical health. On the other hand, your physical health condition can also have a great impact on your emotional well-being and overall mental health.

Symptoms of stress and anxiety

Stress and anxiety can impact on our lives, and can result in:

- difficulty concentrating/muddled thinking
- increased forgetfulness
- short temper
- feeling overwhelmed
- getting frustrated and picking fights with others
- seeing only the negative
- constant worry
- headaches
- breathlessness
- not being able to do the things that you used to do

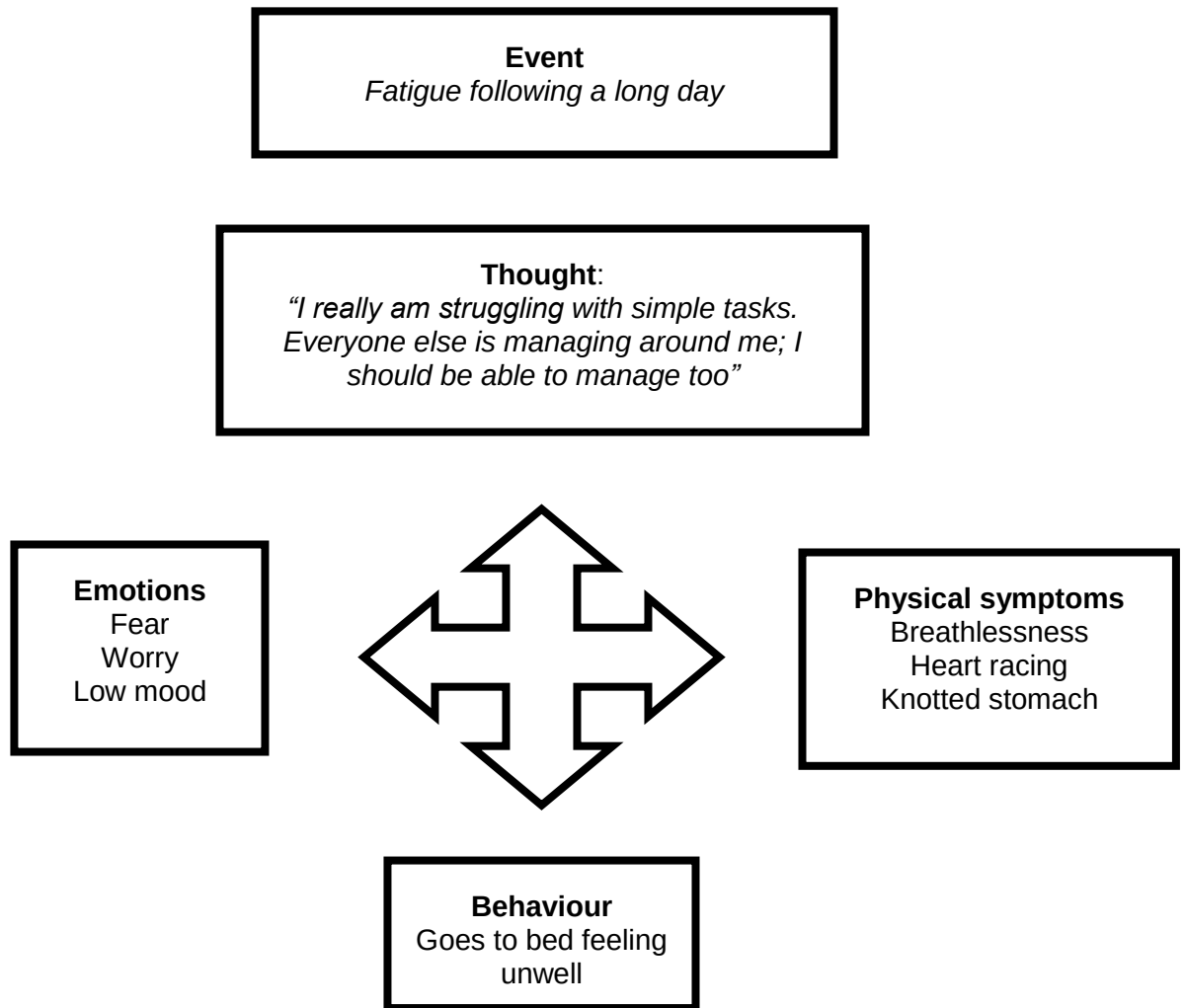
People who have breathing problems often find themselves in a cycle where the symptoms of lung disease interact with the symptoms of anxiety and stress:



BUT there is something we can do about this. Finding/developing new roles, as well as adapting, is an important part of making the most of your life.

Your thoughts, your emotions, your body and your behaviours

How can we go about identifying where our stress, anxiety and low mood comes from?



How is this going to impact the person?

Where could we break this cycle and increase the chance of a more positive outcome?

Secrets of everyday emotional well-being

Just as achieving physical fitness takes time, practice and commitment, so too does achieving mental fitness. There are three basic principles in obtaining emotional well-being: the first is to **maximise the things that make you feel good, and minimise the things that make you feel bad**; second is **valuing yourself**; and third is to **recognise that you can change**.

Some feel good factors include:

- making time for relaxation
- being able to express your feelings
- having achievable goals to aim for
- making time for the things you enjoy
- maintaining a healthy diet
- work you find rewarding (if you are still working)
- time to yourself, to do the things that interest you
- time for friends and family

Some things to minimise:

- unnecessary stress
- feelings of rage or frustration
- expecting too much of yourself and negative thoughts and feelings

Self-management skills

- Take care of health problems
- Carry on doing normal activities
- Manage emotional changes

Roles

Throughout life, we are required to carry out many different roles. For example, you may be required to be a mother or a father, a brother or a sister, a specific role at work. Perhaps you have a role within your local community; perhaps you are a part of a sports team or another club. However, when you develop a chronic illness such as lung disease, you may find that you are unable to do the things that you once were able to do within your roles – *does anyone have any experience of this?*

Because of your condition, you may notice that the roles you once had have been changed. However, it might be about adapting these roles to suit your current situation.

Example: we know of a woman who was a keen gardener, but as a result of her COPD found it difficult to maintain her garden in the way that she wished. She was able to arrange for a neighbour to mow her lawn and instead of planting flowers in the garden, she designed many window boxes and plant pots. This added colour to her garden and allowed her to carry on enjoying her hobby.

Action plans

Some people find it useful to set themselves an action plan, eg.

- Something you want to do
- Is it achievable?
- Make it action specific (how will you do what you do?)

Make sure any goal setting that you do is:

Specific

Meaningful

Achievable

Relevant

Timely

And make sure to:

Evaluate

Redo

This information has been provided by First Steps, Surrey. If you would like to contact us regarding additional support, please call 0808 801 0325 on Mondays and Wednesdays 10am to 4.30pm, and Thursdays 11am to 5.30pm. Alternatively, please email us on first.steps@nhs.net

Appendix C23 – Behaviour Change Intervention case study

Date/...../.....

We would greatly appreciate your comments to help improve future sessions. Please feel free to make comments in the spaces provided below.

1. Would you recommend this session to a friend?

Not at all	Possibly not	Not sure	Yes	Yes definitely
1	2	3	4	5

2. Are you likely to use any of the strategies discussed today?

Yes *If so, which?* _____
No _____

3. How useful has the information from this session been in improving your emotional well-being?

Not at all	Not very	Not sure	Quite useful	Very
1	2	3	4	5

4. Please score your knowledge before and after attending this session on a scale of 0 (no knowledge) to 10 (expert).

Before..... *After*.....

5. What was your favourite part of this session?

6. Are there any improvements you think we can make to this session?

Appendix C24 – Behaviour Change Intervention case study

Reflection on Behaviour Change Intervention

When I first began this intervention, I felt quite nervous as I had not worked with this patient group before, and was still learning about their conditions, prognosis and how they might be having a difficult time adjusting to their condition. However getting to know the respiratory team and the patient group better, understanding the consequences of the development of the conditions, ongoing monitoring and delivery of the intervention has enabled me to develop an area of expertise that I did not previously have.

The pulmonary rehabilitation programme is delivered quite informally, but there is an underlying feeling of importance to the learning skills of self-management and improving people's health. Some groups have been fairly newly-diagnosed patients, so have talked about modifying their lifestyle due to their condition, but other groups have been far more debilitated by their disease and the impact on their emotional well-being has correlated with this.

Some groups have been quite chatty and happy to engage with the discussions, but others have been quieter, just nodding their heads. Sometimes I have worried that the quietness is because people are not finding the intervention helpful, but I think it is probably that they are just absorbing the information and being quietly reflective. Also, talking about emotional well-being can be very difficult if it is not something that you normally talk about, especially in a one-off session.

There have been a couple of instances where patients have been a bit stuck on aspects of their lives which they feel are particularly difficult and they have been resistant to the intervention as a result, for example, being on their own as many of their friends have passed away, feeling like they can no longer do things with their grandchildren, or believing that the self-management strategies will not make any difference as their problem is how other people are with them. In these situations, I have found by using reflective empathic listening I have been able to talk through these difficulties and enable the patient to find small areas where positive changes could be made.

When patients have been happy to contribute their own experience it has really brought the intervention to life by enhancing the key points, adapting my facilitation and encouraging others that change is possible. For example, a man who was able to

speak about the positive changes he has made as a result of physiotherapy input, particularly in breathing control, which in turn was enabling him to do more activity such as walking his dog. This was a great example to discuss the effects of doing something to improve your emotional well-being despite having a long term condition, as the difference in how this man felt before and after being able to manage his breathing was immense. Another man contributed his example of hoovering the house, and how he now does a room a day so as not to exhaust himself, and that way he feels like he is getting somewhere, albeit slower than he used to.

I feel I have developed a much better understanding of the impact of lung disease and how important it is to be discussing emotional well-being. The intervention has enabled patients to find new ways of approaching their condition with the aim of this having a positive impact on their lives. One woman once asked if it is “weird or stupid” that she gets really breathless when she is about to leave the house. We talked about why she views it that way and she says she looks forward to going out and does not understand why she suddenly gets so breathless, but wonders if it might be anxiety. I reiterated that many people only recognise the physical feelings of stress and anxiety and that it is worth thinking about the Five Areas model to see if there are any underlying thoughts relating to going out. She did also mention that she has been out for dinner with her oxygen and there have been rows of empty tables around her when a restaurant is otherwise full, but she says she does not care about what other people think – I do wonder though if that is really the case.

She also mentioned about the fact that you cannot see lung disease and sometimes because of that people do not think you are ill and have the same expectations of you as always. She mentioned her son saying that she is not a very hands-on grandmother, which she found very hurtful because she is doing all the things that are helpful in terms of adapting to her illness and still doing things with her grandchildren but maybe doing drawing or cooking instead of going out. She compared herself to their other set of grandparents who are rich and healthy, so her son has high expectations of her. We talked a little about the overlaps with mental health and physical health conditions that you cannot see, and how there is still unfortunately a lot of stigma and discrimination around this, as people do not understand.

Many people attending the intervention have more easily identified with the physical symptoms of stress and anxiety, but some do mention aspects such as muddled thinking and getting frustrated. When I have asked the group whether some of the

emotional and behavioural elements have an impact, people have often nodded and there have been murmurs of agreement, which is encouraging.

It can sometimes be challenging to come in and do a single intervention in an hour to a new group of patients each time, as I never know their background, condition severity or how they are doing on the programme. I get the feeling that there can be quite wide-ranging experiences of lung disease in the groups, so some may be experiencing severe breathlessness at times, and the accompanying anxiety and fear, whereas others are not at that stage and so may not see the full relevance of what we are discussing and I do not want to worry them either.

However, the physiotherapist has also verbally fed back to me that the intervention is giving people the opportunity to reflect on the impact of their condition and allow discussion of any difficulties they are having, for instance in one session she mentioned afterwards that I had managed to get one of the patients to contribute much more than he normally does, so that was really encouraging.

As well as the evaluation forms, people have come up to me afterwards to thank me, and several have mentioned how the information will also be useful for their husbands, relatives and friends who have been stressed, anxious or low in mood recently.

Appendix C25 – Behaviour Change Intervention case study

Behaviour Change intervention Evaluation Report

This case study looked at the assessment of need, formulation and setting up of a psychoeducational intervention for pulmonary rehabilitation patients, implementation of the intervention, and the evaluation of eighteen months delivery from November 2011 to April 2013.

The identified and agreed objectives of the behaviour change intervention were:

- For patients to perceive the information provided as useful in improving their emotional well-being
- To facilitate a change in knowledge of a range of strategies to manage emotional well-being with a chronic respiratory disease
- For patients to show intention to use the strategies discussed

One hundred and fifty-six patients participated and one hundred and thirteen completed evaluations.

Objective 1 – Usefulness of information provided

22% of patients said “not sure”, 53% of patients said “quite useful”, and 25% of patients said “very useful”. The respiratory physiotherapist has said that the groups vary with regards to their needs, perception and acceptance of their condition, sometimes depending on whether they are newly diagnosed or have been living with the condition for some time, which may impact on their perception of the usefulness of the information.

Objective 2 – Knowledge of strategies to manage emotional well-being

Initially assessed by the question “have you learnt anything new”, 5% of patients said “not at all”, 8% said “possibly not”, 41% said “not sure”, 25% said “yes”, and 21% “yes definitely”. Changing the question to a knowledge score before and after the intervention helped to assess knowledge change more effectively. In total the knowledge score before the session was 123, and after the intervention was 244, which almost doubled.

Objective 3 – Intention to use strategies discussed

The majority of patients said that they would be likely to use the strategies discussed. Intended strategies reported included ways to manage stress and anxiety, try not to put too much pressure on themselves, set SMART goals, have goals to aim for, give

themselves more time to relax, think more about dealing with problems and situations, try not to get too stressed and worry about things, do what they can, stand back to think and reassess, and that the session helped them to understand their condition.

Feedback from the patients that answered that they were unlikely to use any of the strategies included - because it was something they learnt years ago, needing more time to think about it, or wanting to find out more about things.

General Feedback

The analysis of the data from the evaluation forms also provided useful feedback for us as facilitators of the intervention, and the patient experience of being part of a psychoeducational group. Comments included, talking to someone who understands, group participation, listening to people's comments, talking about emotions and what you can do to relieve stress, a chance to express yourself, giving our opinion and ideas, hearing other peoples problems and associating them with one's own, letting you know it was quite normal to be anxious with a lung disease, being able to ask questions face to face with someone, helping us to overcome anxieties and frustration, and identifying where and how difficulties arise and overcoming them.

As the principal cause of COPD is smoking, many of these patients may well have used smoking as a means of coping prior to their diagnosis, or may still smoke, so opportunities to learn new ways of managing their emotional well-being appear to be especially helpful.

In addition, useful feedback for the ongoing development of the session included needing more time and it being a long time to concentrate. There were several instances where the exercise session beforehand ran over so we only ended up with about three-quarters of an hour to run the session. This has been discussed with the respiratory team and they do try to finish on time, but this has been difficult with larger groups. In addition, the fact that the patients have been exercising for an hour beforehand has meant that a few times people have been so tired they have found it difficult to concentrate for the intervention.

SECTION D

SYSTEMATIC REVIEW

**Mindfulness-based interventions for enhancing
the physical rehabilitation of adults with or at risk
of coronary heart disease**

ABSTRACT

Objective

With supporting evidence that mindfulness enhances psychological well-being, and that positive psychological well-being is associated with a reduced risk of cardiovascular disease, evidence is needed to identify the specific physical health outcomes that are impacted by mindfulness.

Method

A comprehensive review was conducted to identify the effects of mindfulness-based interventions on physical health outcomes. The search strategy established a total of 770 studies, of which 9 met the inclusion criteria and were included in the review.

Results

Mindfulness-based interventions appear to be effective in enhancing the physical rehabilitation of adults with and at risk of coronary heart disease, but this is not an entirely consistent finding. The intervention may have beneficial effects by improving psychological distress, increasing awareness and helping people to feel more in control of and cope with the impact of coronary heart disease, rather than its effect on specific physical health outcomes.

Conclusion

Mindfulness-based interventions could be included as part of health education or treatment programmes in order to contribute to secondary prevention through encouraging lifestyle and health behaviour change. Future studies need to consider employing randomised controlled designs, large sample sizes with male and female participants from a range of socio-economic backgrounds, and long-term follow-up of at least one year.

INTRODUCTION

Mindfulness meditation has origins in Buddhism (Kabat-Zinn, 1990). Kabat-Zinn popularised the concept of mindfulness in the West, and described it as purposefully paying attention to the present moment in a curious, open way without judgement (1994). This can be achieved through meditative practices, such as breathing meditation. An example is given by Robins, Kiken, Holt and McCain (2014: 511), *“...mindfulness practice is being mindful of a particular object or phenomenon, such as one’s breathing...When thoughts and emotions arise, they are noticed kindly and simply as thoughts and emotions. This maintains or returns awareness to the present moment, where attention can again be anchored on the breath”*.

The principle of mindfulness has gained importance in promoting healthy functioning and self-regulation of emotion and behaviour; as people practicing mindfulness strive to stay in contact with the experience of the present moment in an attentive, conscious, and accepting manner (Burg, Wolf & Michalak, 2012). One goal of mindfulness practice therefore is to enable an individual to make conscious life choices, allowing for a greater appreciation of possible responses to life events (Malarkey, Jarjoura & Klatt, 2013).

Mindfulness-based interventions

There has been an increase in interest for specific interventions that utilise mindfulness across psychological and physical health. Mindfulness-based interventions include mindfulness-based stress reduction (MBSR) (Kabat-Zinn, 1990), mindfulness-based cognitive therapy (MBCT) (Segal, Williams & Teasdale, 2002), acceptance and commitment therapy (ACT) (Hayes, Luoma, Bond, Masuda & Lillis, 2006), and other modifications or variations of these that incorporate mindfulness training.

The Mindfulness-Based Stress Reduction (MBSR) programme was developed by Kabat-Zinn (1982) as a stress reduction programme to address chronic pain. The structured programme is the most commonly applied intervention (Carlson, 2012) and consists of eight 1.5-2.5 hour weekly sessions and an eight-hour intensive day-long mindfulness retreat. It includes instruction and practice in mindfulness meditation, yoga exercises, body scanning, and discussions related to stress perception and coping. Daily homework includes meditation, yoga and reflective tasks. Participants are

encouraged to be increasingly mindful in everyday activities, such as walking, eating, and talking (Kabat-Zinn, 1990, Baer, 2003).

Guthrie and Nayak (2012) suggest that people have to make a series of adjustments as they learn to cope with illness, including managing their emotions and mental health. Grossman, Niemann, Schmidt and Walach (2004) conducted a meta-analysis of MSBR and related health benefits, where they concluded that mindfulness training may have the potential to enable people to manage their chronic disease and associated stress. MBSR utilising mindfulness meditation has therefore been proposed as a means to help manage a variety of adverse health issues, having shown positive effects on mind, body and behaviour (Ludwig & Kabat-Zinn, 2008; Greeson, 2009). A change in perspective can occur, that allows reflection and the ability to manage difficult feelings and situations, and thus a reduction in disease symptoms and improvement in psychological outcomes (Carlson, 2012). Merkes (2010) agrees that participating in a MBSR programme may enable better coping with symptoms, overall well-being and quality of life, as well as better outcomes for people with chronic disease.

Mindfulness-based interventions for other psychological and physical conditions

MBSR and mindfulness meditation programmes have been evidenced to reduce psychological distress such as anxiety (Vollestad, Sivertson & Nielson, 2011), depression (Bohlmeijer, Prenger, Taal & Cuijpers, 2010; Fjorback, Arendt, Ornbol, Fink & Walach, 2011), stress (Dobkin & Zhao, 2011; Khoury et al., 2013), and psychological and physical symptoms in cancer (Smith, Richardson, Hoffman & Pilkington, 2005; Matchim, Armer & Stewart, 2011; Henderson et al., 2012; Lengacher et al., 2012). In addition, research has shown support for improving outcomes for type 2 diabetes (Rosenzweig, Reibel & Greeson, 2007; Hartmann et al., 2012), obesity (Tapper et al., 2009; Daubenmier et al., 2011), insomnia (Cincotta, Gehrman, Gooneratne & Baime, 2011; Gross et al., 2011), chronic pain (Wong, Chan & Wong, 2011; Brown & Jones, 2013; Reiner, Tini & Lipsitz, 2013), general medical symptoms (Dobkin & Zhao, 2011), asthma (Pbert et al., 2012), blood pressure and heart rate (Barnes, Davis, Murzynowski & Treiber, 2004; Hughes et al., 2013), cardiac arrhythmia (Ditto, Eclache & Goldman, 2006), and mixed medical patients (Reibel, Greeson, Brainard & Rosenzweig, 2001; Majumdar, Grossman, Dietz-Waschkowski, Kersig & Walach, 2002,

Samuelson, Foret & Baim, 2010; Simpson & Mapel, 2011), which encourages further exploration in other populations.

Mindfulness-based interventions for adults with or at risk of coronary heart disease

Coronary heart disease is the UK's single biggest killer, responsible for around 73,000 deaths each year, and with around 2.3 million people currently living with the disease (British Heart Foundation, 2015) that could be supported to modify known risk factors. Investigating the effectiveness of an intervention that may enhance the physical rehabilitation of adults with or at risk of this disease has therefore begun to be explored. Tacon, McComb, Caldera and Randolph (2003) reported that based on their findings, MBSR programmes hold promise as a complementary therapy to traditional health care for individuals with heart disease. In 2010, Allexandre, Fox, Golubic, Morledge and Fox published an abstract of their preliminary findings from a randomised controlled trial among individuals with moderate cardiovascular risk, comparing mindfulness, yoga, and conventional relaxation. The findings indicated that the practice of mindfulness significantly improved inflammatory markers, as well as anxiety, perceived stress and fatigue. However, the final results have not yet been published.

Many rehabilitation and psychoeducational programmes currently contain health education with management of stress-related symptoms (Dusseldorp, van Elderen, Maes, Meulman & Kraaji, 1999). De Waure et al. (2013) concluded that multifactorial lifestyle interventions aimed at improving modifiable risk factors in patients with established coronary heart disease reduces the risk of fatal cardiovascular events, and therefore may have added value in secondary prevention. Janssen, Gucht, Dusseldorp and Maes (2013) conducted a meta-analysis of randomised trials of primary and secondary care lifestyle modification programmes, and concluded that such programmes can improve risk factors and related lifestyle behaviours, as well as reduce mortality, cardiac readmissions, and non-fatal infarctions. However, there have been mixed findings as to whether there can be long-term benefits following such programmes (De Waure et al., 2013; Janssen et al., 2013).

In their review of positive psychological attributes and cardiac outcomes, DuBois et al. (2012) found significant evidence that positive attributes, especially optimism, may be associated with improved cardiac outcomes, associated with increased participation in

beneficial cardiac health behaviours, e.g. healthy eating, physical activity. Boehm, Vie and Kubzansky (2012) agree with the evidence suggesting positive psychological well-being is associated with reduced risk of cardiovascular disease. They suggest that this may be due to individuals with positive psychological well-being being more inclined to engage in health behaviours known to be helpful in the prevention of cardiovascular disease, such as physical activity, maintaining a healthy diet, and avoiding smoking.

In the UK, cardiac rehabilitation aims to promote health, and help people recover and get back to as full a life as possible after a cardiac event such as a heart attack, or after having treatment such as coronary bypass surgery (British Heart Foundation, 2013). Programmes typically require attendance at one or two-hour sessions, once or twice a week for eight to twelve weeks. Sessions are usually run in a hospital or a community or leisure centre, and may be done in group sessions or individually. Programmes vary widely across the country, but usually include one or more of the following: exercise, health education, relaxation and psychological support.

Griffiths, Camic and Hutton (2009) used Interpretive Phenomenological Analysis (IPA) to explore participant experiences of a mindfulness-based cognitive therapy group (MBCT) for cardiac rehabilitation, and to provide information on how the components of mindfulness as an intervention are understood, experienced, and put into practice. They identified themes of awareness, within group experience, commitment, relating to the material, and acceptance. The development of awareness was seen as a helpful experience, enabling the reduction of stress and worry, which alongside the normalising effect of being part of a group, led to an improved perception of cardiac problems, and therefore acceptance of their personal health and how they interacted with the world.

Making lifestyle behaviour changes is challenging for patients, and patients participating in healthy lifestyle programmes may understand why changes are needed but frequently do not achieve targeted outcomes. Psychosocial risk factors greatly influence patients' ability to make behaviour changes but are often not targeted in cardiovascular care programmes (Burns & Hardwick, 2011). Mindfulness could therefore play a part in cardiac rehabilitation, in order to enhance both psychological and physical health outcomes.

Rationale for conducting this systematic review

Previous systematic reviews looking at the effectiveness of mindfulness-based interventions have focussed mainly on psychological outcomes. Physically oriented measures, such as medical symptoms, sensory pain, physical impairment, and functional quality of life, have been less frequently assessed (Grossman et al., 2004). With supporting evidence that mindfulness enhances psychological well-being, and that positive psychological well-being is associated with a reduced risk of cardiovascular disease, evidence is needed to identify the specific physical health outcomes that are impacted by mindfulness in order to potentially enhance physical rehabilitation of adults with or at risk of coronary heart disease.

To ascertain whether or not a similar review was being conducted, or had been recently completed, the Cochrane Collection Centre for Reviews and Dissemination including Database of Abstracts of Reviews of Effects (DARE) was thoroughly searched. A scoping review was also conducted to assess the type and amount of literature on this topic, which helped to develop the review question and set the parameters of the review.

Aim - to assess the effectiveness of mindfulness based interventions for enhancing the physical rehabilitation of adults with or at risk of coronary heart disease.

Objective - to identify the effects of mindfulness-based interventions on physical health outcomes.

METHOD

The systematic review was conducted following the guidance produced by the Centre for Reviews and Dissemination (2009) and Dempster (2011).

Inclusion criteria

- Participants = adults over eighteen years old with or at risk of coronary heart disease (including clinically elevated blood pressure)
- Intervention = group and individual mindfulness-based interventions
- Comparison = usual care, alternative intervention, waiting list, general population control, no comparison

- Outcomes = physical health outcomes (e.g. exercise capacity, health and medical symptoms, blood pressure, body mass index, fatigue) assessed pre and post intervention (including studies with both psychological and physical outcomes)

Study design was not set as an inclusion criteria due to the emerging nature of research in this area.

Exclusion criteria

- Variables potentially important for the development of cardiovascular disease but in largely healthy samples, e.g. heart rate control and blood pressure
- Mixed populations, e.g. coronary heart disease and diabetes, where results were not reported by disease
- Qualitative studies
- Studies with only psychological outcomes
- Non-English language papers – only the abstract in English

Search strategy

The search strategy was based on the scoping search. Keywords, synonyms and variations in spelling and vocabulary were identified. Search tools, including using AND, OR, exact phrases (“...”) and truncation (*) were utilised. The search terms were: coronary OR chd OR angina OR heart OR “myocardial infarction” OR angioplasty OR cardi*

AND

Mindfulness

The following electronic databases were searched during August 2014: CINAHL, MEDLINE, PsycARTICLES, PsycINFO, EMBASE, AMED and Cochrane Database of Systematic Reviews. No date restrictions were used.

Further additional sources were also searched: reference lists from relevant studies and review papers, searching relevant internet resources, citation searching (using Web of Science) and contacting study authors. Handsearching of the Journal of Psychosomatic Medicine was conducted, as this was the most referenced journal during electronic searching, in addition to abstracts from conference proceedings. In

this way, the search aimed to avoid publication bias where the intervention effect could be overestimated (Song, Eastwood, Gilbody, Duley & Sutton, 2000).

Four authors were contacted to request full articles from abstracts. Two studies were subsequently excluded but provided useful background; one provided an additional paper found during citation searching, and one author did not respond.

Studies were selected through removal of duplications, initial screening of titles and abstracts, full text review of articles against inclusion criteria and citation searching – see Figure D1.

1(a): Studies identified from electronic searches = 681	
	Duplicates = 99 Citations excluded by initial screening of title and abstracts = 538
Potentially relevant articles reviewed = 44	
	Articles excluded after full text reviews with reasons: • Review article = 11 • Not a population with or at risk of heart disease = 16 • Mixed population = 3 • No physical outcomes = 7 • Qualitative study = 1 • Study protocol only = 1
Full text articles reviewed and meeting inclusion criteria = 5	
	Articles meeting inclusion criteria gained from citations = 0

1(b): Studies identified from reference lists of review articles = 19	
	Duplicates = 6 Citations excluded by initial screening of title and abstracts = 7
Potentially relevant articles reviewed = 6	
	Articles excluded after full text reviews with reasons: • Not a population with or at risk of heart disease = 3 • Intervention not focused on mindfulness = 2
Full text articles reviewed and meeting inclusion criteria = 1	
	Articles meeting inclusion criteria gained from citations = 0

1(c): Studies identified from internet resources = 6	
	Articles excluded after full text reviews with reasons: • Review article = 1

	• Mixed population = 1 • Intervention not focused on mindfulness = 1 • Only preliminary results in abstract and no response from authors = 1
Full text articles reviewed and meeting inclusion criteria = 2	
	Articles meeting inclusion criteria gained from citations = 0

1(d): Studies identified from reference lists of relevant studies = 64	
	Duplicates = 21
	Citations excluded by initial screening of title and abstracts = 27
Potentially relevant articles reviewed = 16	
	Articles excluded after full text reviews with reasons: • Review of psychoeducational cardiac programmes = 3 • Review of psychosocial outcomes = 2 • Intervention not focused on mindfulness = 8 • Qualitative study = 1 • Not an intervention = 2 (1 paper led to discovery of another relevant study)
Full text articles reviewed and meeting inclusion criteria = 1 (via other study)	
	Articles meeting inclusion criteria gained from citations = 0

Final articles for inclusion in systematic review = 9	
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Figure D1: Flowchart of search strategy (adapted from Abbott et al., 2014)

Data extraction

A data extraction form was developed to reflect the review question and the studies available (see Appendix D1). This enabled the gathering together of information about study characteristics and findings to aid quality assessment, interpretation of findings, and data synthesis.

Quality assessment

Appropriate criteria for assessing quality of studies with mixed designs were developed from guidance by Downs and Black (1998). Relevant elements of the author's checklist

for measuring quality for randomised and non-randomised studies were taken to assess overall study quality, validity (bias), and power, to allow comprehensive review of particular methodological strengths and weaknesses. Four additional criteria were added to reflect the nature of the articles included (see Appendix D2), alongside a total score and quality rating of high, medium or low.

Two reviewers assessed the nine studies. This assessment involved the author providing the second reviewer with the nine papers, alongside the data extraction form and an un-scored quality assessment checklist. Having read the papers and referring to the data extraction form, the second reviewer then scored the quality assessment checklist. The two reviewers met to discuss their independent scoring and the extent to which they agreed in their decision making. Formal assessment of the reviewers' level of agreement was conducted using the kappa statistic (Cohen, 1960), as suggested by Dempster (2011). There was substantial agreement between the reviewers' judgements, $k=0.813$, $p<0.0005$. The few remaining differences were resolved through further discussion. Of the nine studies, four were assessed as medium quality, and five as high quality.

Studies Identified

The search strategy established a total of 770 studies - electronic searches identified 681 studies, the reference lists of review articles found 19 studies, Internet resources identified 6 studies, and the reference lists of relevant studies found 64 studies. Citation and hand searching did not identify any further studies. A total of 72 potentially relevant studies were reviewed, of which 9 met the inclusion criteria and were included in the review. The reasons for exclusion of studies are provided in the flowchart of the search strategy (Figure D1).

Study characteristics

The nine studies included were published over a ten year period between 2004 and 2014. Five took place in the USA (Robert-McComb, Tacon, Randolph & Caldera, 2004; Chang et al., 2005; Sullivan et al., 2009; Olivo, Dodson-Lavelle, Wren, Fang & Oz, 2009; Falk, Smith & James, 2014), one in Canada (Blom et al., 2014), one in New Zealand and India (Parswani, Sharma & Iyengar, 2013), one in India (Nehra, Sharma, Kumar & Nehra, 2014), and one in the Netherlands (Nyklicek, Dijkman, Lenders,

Fonteijn & Koolen, 2014). Five studies were randomised controlled trials (RCTs) (Chang et al., 2005; Parswani et al., 2013; Blom et al., 2014; Nyklicek et al., 2014; Nehra et al., 2014), one a pilot RCT (Robert-McComb et al., 2004), one a prospective cohort study (Sullivan et al., 2009), one a feasibility pilot study (Olivo et al., 2009), and one a quasi-experimental study (Falk et al., 2014). A total of 648 participants were involved in the studies, but the number varied greatly from 7 in one study to 208 in another. Drop out rates were reported in all studies where applicable. One study only had female participants (Robert-McComb et al., 2004), one study only male (Parswani et al., 2013), and the remaining seven studies were mixed. Participants had a range of cardiac diagnoses – see Table D1 for more detail.

Intervention

Eight of the nine studies described their intervention as Mindfulness-Based Stress Reduction (MBSR) (Robert-McComb et al., 2004; Sullivan et al., 2009; Olivo et al., 2009; Parswani et al., 2013; Blom et al., 2014; Nyklicek et al., 2014; Nehra et al., 2014; Falk et al., 2014), although four of these were adapted from the original (Kabat-Zinn, 1982) programme (Sullivan et al., 2009; Olivo et al., 2009; Nyklicek et al., 2014; Nehra et al., 2014), and one was delivered on an individual rather than group basis (Parswani et al., 2013). The other study included mindfulness meditation as part of a group relaxation intervention (Chang et al., 2005). Aside from the study with individuals, seven of the group sessions ran for between three and fifteen weeks (Robert-McComb et al., 2004; Chang et al., 2005; Sullivan et al., 2009; Olivo et al., 2009; Blom et al., 2014; Nyklicek et al., 2014; Falk et al., 2014), with each session lasting between one-and-a-half and two-and-a-half hours. The other group session stated that ten to seventeen sessions were run, but did not describe the length of these sessions (Nehra et al., 2014). All studies involved home practice, one study had an evaluation session (Nyklicek et al., 2014), and one study included a day retreat as per the original programme (Blom et al., 2014).

Facilitation of the interventions varied. Five of the studies did not report who delivered the intervention (Robert-McComb et al., 2004; Parswani et al., 2013; Blom et al., 2014; Nehra et al., 2014; Falk et al., 2014), clinical psychologists delivered the intervention in two studies (Chang et al., 2005; Nyklicek et al., 2014), and specific mindfulness instructors delivered the intervention in the other two studies (Sullivan et al., 2009; Olivo et al., 2009).

Of the eight studies that used a control group or treatment as usual, three were waiting list controls (Robert-McComb et al., 2004; Blom et al., 2014; Falk et al., 2014), four were treatment as usual (Chang et al., 2005; Sullivan et al., 2009; Parswani et al., 2013; Nehra et al., 2014), and one designed a self-help booklet based on the mindfulness-based group content (Nyklicek et al., 2014). Treatment as usual was in the format of group cardiac/health education.

Outcomes

Physical outcomes varied widely, which reflects the fact that physical responses to mindfulness-based interventions are only beginning to be explored. Exercise capacity was explored in two studies using a bicycle (Robert-McComb et al., 2004; Chang et al., 2005), health and medical symptoms in three studies (Sullivan et al., 2009; Olivo et al., 2009; Nehra et al., 2014), blood pressure in two studies (Parswani et al., 2013; Blom et al., 2014), body mass index in one study (Parswani et al., 2013), stress hormones in one study (Robert-McComb et al., 2004), fatigue and chronic pain in one study (Falk et al., 2014).

Two studies assessed mindfulness skills (Nyklicek et al., 2014; Falk et al., 2014), and all studies included measures for either quality of life, psychological well-being, perceived stress, or anxiety and depression, in addition to the physical outcomes.

Quality

Quality criteria were set as follows: a score of 7 or below was classified as low quality; a score between 8 and 11 was classified as medium quality; and a score of 12 or 13 was classified as high quality. The lowest scoring study with a score of 8 (Nehra et al., 2014) was therefore defined as being of medium quality; two studies scored 10 (Olivo et al., 2009; Falk et al., 2014), and one study 11 (Robert-McComb et al., 2004) which were also of medium quality. Four studies scored 12 and were defined as being of high quality (Chang et al., 2005; Sullivan et al., 2009; Parswani et al., 2013; Nyklicek et al., 2014), and one study scored 13 (Blom et al., 2014), which was the highest possible score for quality.

All studies received top scores on five of the twelve criteria: clearly described aim/objective; main outcomes clearly described and appropriate; eligibility criteria

clearly described; intervention clearly described; and main findings clearly described. The quality criteria with the lowest overall scores were for lack of follow up beyond post-intervention and sample size. Only three studies carried out a follow up beyond immediate post-intervention (Sullivan et al., 2009; Parswani et al., 2013; Blom et al., 2014), and four of the studies had a sample size of thirty or less (Robert-McComb et al., 2004; Olivo et al., 2009; Parswani et al., 2013; Falk et al., 2014). Two of these studies (Robert-McComb et al., 2004; Olivo et al., 2009) were pilots, one was an RCT (Parswani et al., 2013) and the other a quasi-experimental study (Falk et al., 2014). Due to the sample sizes and nature of the intervention, all of the studies were at risk of bias as participants were aware of their intervention allocation, but most studies attempted to counteract this by incorporating a control group.

See Table D1 for a summary of the above, and Appendix D1 and D2 for full data extraction information and quality assessment checklist.

Study	Design	Intervention	Participants	All outcomes	Quality score
Robert-McComb (2004)	Pilot RCT	Group MBSR 8wk x 2hr with home practice	18 females CVD	Stress hormones Physical functioning Exercise response	Medium
Chang (2005)	RCT	Group relaxation response (incl. mindfulness meditation) 15wk x 1.5hr with home practice	95 armed forces veterans, 99% male, moderate severity CHF	Quality of life Exercise capacity	High
Sullivan (2009)	Prospective experimental cohort	Group skills-based MBSR plus education on coping and support, 8wk x 2.25hr with home practice	208, 70% male, left ventricular ejection fraction <40% and CHF	Depressive symptoms Psychosocial distress Health status (clinical, symptom and overall)	High
Olivo (2009)	Feasibility pilot study	Group meditation-based stress reduction (adapted MBSR) 4wk x 2.5hr with home practice	31, 71% female, 40% CHD, 60% high risk	Depression, Anxiety, Stress, Hostility, Medical symptoms Quality of life	Medium
Parswani (2013)	RCT	Individual MBSR, 8wk x 1-1.5hr with home practice and adapt behaviours	30 males CHD	Anxiety, Depression, Perceived stress, Blood pressure, Body Mass Index	High
Blom (2014)	RCT	Group MBSR 8wk x 2.5hr, 6hr retreat and home practice	101, 64% female, unmedicated hypertension	Blood pressure	High
Nyklicek (2014)	RCT	Group brief MBSR, 3x 1.5hr plus home	108, 81% male, had PCI for blockage of	Psychological wellbeing	High

		practice and evaluation session	coronary artery	Quality of life Mindfulness	
Nehra (2014)	RCT	Group adapted MBSR with MBCT, 10-17 sessions	50 gender matched, CHD	Perceived stress Health complaints	Medium
Falk (2014)	Quasi-experimental	Group MBSR, 8wk x 1.5hr with home practice	7, 57% female, cardiac diagnosis	Anxiety, Depression, Fatigue, Chronic Pain, Mindfulness skills	Medium
CHD – coronary heart disease; CHF – chronic heart failure; CVD – cardiovascular disease; MBCT – mindfulness-based cognitive therapy; MBSR – mindfulness-based stress reduction; PCI – percutaneous coronary intervention; RCT – randomised controlled trial:					

Table D1: Summary of studies included in systematic review

RESULTS

Studies have been grouped by physical health outcomes, in order to assess the effectiveness of mindfulness-based interventions for enhancing the physical rehabilitation of adults with or at risk of coronary heart disease. It was not possible to conduct a meta-analysis as outcomes varied widely. Results are presented as a narrative synthesis. Design, intervention, and quality considerations are also discussed.

Exercise capacity

Robert-McComb et al. (2004) carried out a pilot RCT that examined the effects of MBSR in women with cardiovascular disease on resting levels of stress hormones (using 12-hour fasting blood serum samples), physical functioning (using the Physical Component Summary Measure of the Medical Outcomes Study 36-item Short-Form Health Survey - SF-36), and submaximal exercise responses (recorded using a stationary bike in a laboratory and assessing oxygen consumption, heart rate and breathing patterns). Eighteen women were randomly assigned to either the intervention or control groups. The intervention group received the MBSR programme one night each week for two hours over a period of eight weeks. The waiting list control group were given the opportunity to participate in the programme once the pilot was complete. Pre-post test hormonal measurements and physical function were assessed, and the submaximal exercise test was completed following the intervention. There

were no significant differences between the groups for these key outcomes, but there were significant differences between groups for ventilation ($p<0.01$), and between group ($p<0.01$) and time ($p<0.01$) for breathing frequency during exercise. There was a decrease in resting levels of cortisol in the intervention group while the control group had no change, so this may be considered meaningful even though it did not reach significance. As a pilot, and one of the first to study these effects, this study could assist with power calculations for a larger trial, but in itself was limited in the conclusions that could be drawn, due to the small sample size and lack of long-term follow-up. In addition, the sample was all female and mostly of white ethnicity and high-socioeconomic status, which further limits the generalisability of the findings. However, the study still achieved a medium quality score, and lends support to the idea that breathing patterns could be changed through increased conscious awareness during exercise.

Chang et al. (2005) designed a RCT to evaluate the effect of a relaxation response intervention that included mindfulness meditation on quality of life (using the Minnesota Living with Heart Failure and Functional Assessment of Chronic Illness Therapy-Spiritual Well-being questionnaires), and exercise capacity (assessing peak oxygen consumption using a bicycle) of ninety-five veteran chronic heart failure patients. Thirty-one patients in the intervention group attended a weekly one-and-a-half hour relaxation response group for fifteen weeks with home practice. A fifteen-week cardiac education programme covering medical, pharmaceutical, lifestyle, nutrition and psychosocial issues (twenty-four patients) was used as an alternative intervention, and usual care was the control group (twenty-eight patients). Pre-post quality of life and exercise capacity was assessed at baseline and after the intervention, or between fifteen to nineteen weeks post-baseline. Eighty-seven percent of the enrolled participants completed both pre and post measures. Results showed that the relaxation response group had significantly better quality of life change scores in peace-spiritual ($p=0.01$) and emotional ($p=0.07$) scales, but no significant difference on physical quality of life or exercise capacity. This high quality scoring study concluded that a relaxation response intervention can improve some elements of quality of life in chronic heart failure patients, and thus may have beneficial effects if integrated with cardiac rehabilitation programmes, but was limited in its generalisability to the population due to ninety-nine percent being male and the majority being of white ethnicity, as well as the lack of long-term follow-up.

Therefore, there was no significant effect on exercise capacity from mindfulness-based interventions overall. However, some evidence was found in the medium quality study

(Robert-McComb et al., 2004) for improvements in ventilation and breathing frequency, and reductions in resting levels of cortisol. No evidence was found for increasing exercise capacity in the high quality study (Chang et al., 2005), although improvements were found for quality of life.

Health, medical symptoms and quality of life

Sullivan et al. (2009) assessed the impact of a mindfulness-based psychoeducational intervention on depression, psychosocial distress, clinical symptoms and health status in two-hundred-and-eight patients with chronic heart failure, using a prospective experimental cohort design with a geographical control (>90 miles from the centre) receiving usual care. The intervention comprised eight weekly sessions, each lasting two-and-a-quarter hours, with home practice. Depressive symptoms were assessed using the Center of Epidemiology Depression 10-item scale, psychosocial distress using the Profile of Mood States, and clinical symptoms and health status using the Kansas City Cardiomyopathy Questionnaire. The authors developed the intervention which taught skills based on MBSR plus education on improving coping skills including better social support, living with heart failure, spirituality, and an expressive support group. The facilitators were trained mindfulness meditation instructors from a range of professions. Results showed a significant improvement in depression at three and six months in the intervention group (three month change from baseline -1.74 vs 0.46 for control, $p=0.013$; six month change from baseline -1.37 vs 0.90 for control, $p=0.007$). However, both groups' scores had increased at twelve months. One mood state profile was significant at three and six months, that of tension-anxiety ($p=0.003$), but not at twelve months. In contrast, health status and clinical symptoms were not significant until the twelve month point, which showed a sustained improvement ($p<0.05$). The main limitation of this study was due to the intervention group being assigned based on nearest travel distance to the hospital, rather than as part of a randomised controlled trial. A strength of the study was the post-intervention twelve-month follow-up, showing improvements in health status and clinical symptoms, which implies such an intervention may play a role in comprehensive treatment programmes. The authors also suggest that reduced symptom reporting may be due to better coping skills and less distress.

Olivo et al. (2009) reported on their pilot study on the feasibility and effectiveness of a brief meditation-based stress management programme for thirty-one patients with (forty percent of sample) or at risk (sixty percent of sample) of coronary heart disease. The

authors assessed interest and availability, as well as psychological (Centre for Epidemiologic Studies-Depression Scale, State-Trait Anxiety Inventory, Perceived Stress Scale, Cook-Medley Hostility Scale), overall health (SF-36), and medical symptoms (Medical Symptoms Checklist) tested pre and post-intervention. The intervention was an abbreviated MBSR programme, covering the same material as the standard MBSR programme but in less detail, delivered over four weeks by a MBSR instructor and with home practice. The objective was to encourage commuter patients to attend. The participants were twenty-nine percent male and seventy-one percent female, mostly of high socio-economic status. The overall results indicated that the brief intervention was highly feasible with good adherence, but only significant differences pre and post intervention were found for depression ($p=0.04$) and stress ($p=0.03$). When participants were asked their opinion about the length of the programme, some initially stated that a longer course would have been a deterrent. However, on completing many stated that they would have been interested in continuing. The authors suggest that clinicians may attract more patients with shorter introductory courses that then lead onto more comprehensive programmes. Although the study was not an RCT, and had no long-term follow-up, the results indicate that meditation-based interventions could be used as part of secondary prevention programmes encouraging lifestyle and behaviour change, by improving some psychological distress.

Nehra et al.'s (2014) RCT assessed the efficacy of an adapted MBSR programme at reducing perceived stress and health complaints of fifty mixed-gender patients with coronary heart disease. The Perceived Stress Scale and Health Complaints Scale were used pre and post intervention. The authors based their programme on a combination of MBSR and mindfulness-based cognitive therapy (MBCT), which was completed in ten to seventeen sessions. The control was treatment as usual. Whilst scoring medium quality, further detail on the intervention in terms of specific content and length of sessions was not reported, and key limitations are not acknowledged in the article, hence the lowest score for included studies in this review. However, the authors report significantly decreased perceived stress ($p=0.01$), as well as a reduction in cognitive and somatic health complaints ($p=0.02$) post-intervention, which could potentially be an effective way of helping people to cope with heart disease.

Nyklicek et al. (2014) examined the effectiveness of a brief mindfulness-based intervention for increasing psychological well-being and quality of life in one-hundred-and-eight percutaneous coronary intervention (PCI) patients, compared to a self-help booklet, as an RCT. The intervention was a brief MBSR programme of three weekly

ninety-minute to two-hour sessions, with home practice and an evaluation session two weeks later. The sessions were delivered by a clinical psychologist with training in mindfulness, and the self-help booklet was written by the same psychologist, based on the equivalent programme content as the intervention group. The majority of participants were men (eighty-one percent) and outcome measures were completed pre and post for all. Psychological well-being was assessed using the Symptoms of Anxiety-Depression Index, Perceived Stress Scale and Dutch Global Mood Scale. Quality of life was assessed using the World Health Organisation Quality of Life-Brief questionnaire, with four domains, namely physical health, psychological health, social relationships, and environment. The Seattle Angina Questionnaire was used to obtain health-related quality of life, and mindfulness was assessed using the short-form of the Freiburg Mindfulness Inventory (FMI-s). Compared to the control group, the intervention group showed larger increases in psychological ($p<0.05$) and social ($p<0.05$) quality of life. For symptoms of anxiety ($p<0.01$) and depression ($p=0.10$), and perceived stress ($p=0.15$), this effect was only shown in participants under the age of sixty. These effects were mediated by an increase in mindfulness. However, there was no significant difference in physical or medical quality of life between or within groups. The only criteria missing from the quality check for this study was lack of long-term follow-up, in addition to not having a passive control group, which prevents further conclusions regarding effectiveness of the self-help booklet. However, it appears that increase in mindfulness may be resulting in beneficial psychological effects, although only for younger participants for some symptoms.

Therefore of the range of studies exploring health, medical symptoms and quality of life, there were improvements in health symptoms in the high quality study (Sullivan et al., 2009) but these were not seen until twelve-month follow-up. Nehra et al's (2014) study did find improvements in somatic health complaints, however this was the lowest scoring medium quality study. Neither Olivio et al's (2009) medium quality study or Nyklicek et al's (2014) high quality study found improvements for these outcomes, but psychological outcomes were improved.

Blood pressure and body mass index

Parswani et al.'s (2013) multinational study examined the effects of a MBSR programme on symptoms of anxiety and depression (assessed by the Hospital Anxiety and Depression Scale), stress (Perceived Stress Scale), blood pressure and body mass index in thirty patients with coronary heart disease. The RCT had pre, post and

three month follow up measures in place, with a treatment as usual control, namely one health education session. However, unlike the other studies included in this review, the intervention was delivered in one to one-and-a-half hour individual sessions. The programme was eight weeks in length, with home practice and encouragement to adapt health behaviours such as increased exercise and healthy eating. Men and women were invited to participate, but only males took part. This high-quality scoring study reported a significant reduction in symptoms of anxiety ($p = .001$) and depression ($p=0.01$), perceived stress ($p=0.001$), and blood pressure ($p<0.05$) for the individuals receiving the intervention compared to those in the control. There was no significant difference in body mass index between groups. Scores at three month follow-up were not significantly different from post-intervention, but the mean scores gained were maintained, except for blood pressure which showed further improvements. However the authors acknowledge that periodic changes were made to anti-hypertensive medication during the course of the study which may have assisted in blood pressure lowering. The relatively small sample size limits generalisability of the findings. This was the only study found as part of this review that assessed body mass index and whilst no significant differences were found between groups, reductions in body mass index within the intervention group could indicate a benefit for including mindfulness in addition to health education as a method of increasing awareness.

Blom et al. (2014) examined whether an eight-week MBSR programme could lower blood pressure in one-hundred-and-one untreated participants with stage one hypertension. This well-designed RCT scored the maximum quality score in this review. The primary outcome assessed was change in awake and twenty-four hour ambulatory blood pressure from baseline to twelve weeks between participants. The secondary outcome was within-group change from pre to post intervention, as well as persistence of the effect of the MBSR on blood pressure twenty-four weeks from baseline. The intervention was delivered as per the original Kabat-Zinn (1982) programme, with sessions lasting two-and-a-half hours plus home practice, and a six-hour retreat. However, no significant differences were found in the primary outcome, though a small but significant reduction in blood pressure was found within groups for female participants from the whole cohort from pre to post intervention (awake systolic $p=0.01$ and twenty-four hour systolic $p=0.01$) ambulatory blood pressure.

As a result, improvements in blood pressure from mindfulness-based interventions are difficult to assess. Whilst Parswani et al's (2013) high quality study found a significant reduction in blood pressure, changes made to medication during the course of the study potentially confounded the results; particularly given that Blom et al's (2014) very

high quality study did not find a significant difference. No significant differences were found for reductions in body mass index between groups in Parswani et al's (2013) study, but there was some reduction within the intervention group.

Fatigue and chronic pain

Falk et al.'s (2014) research report was the only study included in the review that assessed fatigue and chronic pain amongst the outcomes. This quasi-experimental study evaluated the effects of an eight-week MBSR programme on psychological and physiological symptoms in cardiac patients, compared to a waiting list control group. This study was very limited in its sample size, even as a pilot, with only seven participants receiving the intervention and four in the control group. The intervention itself was similar to the original programme, delivered over eight weeks with home practice. However, the sessions were slightly shorter at one-and-a-half hours, and there was no day retreat. A range of pre and post outcome measures were used to assess anxiety (Clinically Useful Anxiety Outcome Scale), depression (Center for Epidemiologic Studies Depression Scale), fatigue (Brief Fatigue Inventory), chronic pain (Chronic Pain Grade Questionnaire) and mindfulness in relation to the other outcomes (Mindful Attention Awareness Scale). There was no statistically significant difference between pre and post scores in or between groups ($p > 0.05$), but eighty-six percent stated that they would continue to practice mindfulness. The study scored a medium quality rating, with the small sample size and lack of follow-up beyond post-intervention being the key issues. The authors suggest that the value of mindfulness to participants may not lie in reduction of disease symptoms, but in the perception that they have a degree of control over how they perceive their experience (Falk et al., 2014).

There was therefore no significant effect on fatigue or chronic pain from a mindfulness-based intervention as part of Falk et al's (2014) medium quality study.

Result summary

As all the included studies scored medium or high on the quality criteria, this helped to interpret results and review effectiveness across studies. Intervention length, format, and who facilitated the programme did not appear to have an influence on findings. Specific physical health outcomes that could be potentially enhanced by mindfulness were identified, but further studies are required to fully assess this impact. Rather, the

intervention appears to have beneficial effects by improving psychological distress, increasing awareness and helping people to feel more in control of and cope with the impact of coronary heart disease. Mindfulness-based interventions may also be beneficial as part of health education and treatment programmes for those at risk of developing the condition.

DISCUSSION

Considering the variability across studies, these results provide initial support for mindfulness-based interventions being effective in enhancing the physical rehabilitation of adults with and at risk of coronary heart disease, but this is not an entirely consistent finding.

Physical and psychological health outcome measures across the included studies varied widely, and only one study delivered the intervention exactly as the original programme, with the day retreat, and this found no significant effects between groups (Blom et al., 2014). Adapting the original programme does not appear to have any adverse impact, but there is a need to carry out further well-designed studies, utilising randomised controlled designs, and large sample sizes with male and female participants from a range of ethnicities and socio-economic backgrounds.

The importance of long-term follow-up of at least one year is highlighted in Sullivan et al. (2009). This was the only study in the review to have this length of follow-up and it was the only time-point in the study where health status and clinical symptoms were shown to have significantly improved. The lack of this length of follow-up in other studies means that important physical health outcomes may therefore have been missed.

Due to the emerging nature of this area of research, the inclusion criteria for this review were fairly wide. This enabled a thorough review of the current literature, but also meant that there was variability of design, interventions and quality across studies. Future systematic reviews should consider limiting included studies by specific cardiac diagnoses, in order to assess specific outcomes and underlying mechanisms of action. In addition, including clinically elevated blood pressure does not appear to have provided any supplementary findings.

This systematic review has found similar limitations as reviews based on psychological outcomes. These include small numbers of participants, lack of an active control group, the inclusion of only subjective endpoints that may not capture the impact of mindfulness on health behaviours, and infrequent use of biological measures, alongside lack of long-term follow-up (Mars & Abbey, 2010; Malarkey et al., 2013).

This review therefore cannot provide strong evidence for a definite conclusion as to the effectiveness of mindfulness-based interventions for enhancing the physical rehabilitation of adults with or at risk of coronary heart disease, but it does provide a useful direction as to how the intervention might work and why in this population group.

As with other physical health conditions, mindfulness-based interventions appear to improve physical and psychological outcomes for people with and at risk of coronary heart disease. This appears to work in the same way as concluded by Merkes (2010), that participation in a mindfulness-based programme is likely to result in coping better with symptoms, improved overall well-being and quality of life, and enhanced health outcomes for people with chronic disease. This in turn may facilitate support for lifestyle behaviour changes required as part of secondary prevention and forming the bulk of many UK cardiac rehabilitation programmes. The qualitative findings of Griffiths et al. (2009) reported earlier, also support the idea that the development of awareness is a helpful experience, enabling the reduction of stress and worry, an improved perception of cardiac problems, and therefore acceptance of personal health.

While mindfulness-based interventions have shown positive results in patients with coronary heart disease, some elements of the programme may be a barrier to patients with severe illness, due to the need to attend weekly sessions and home practice. The bulk of the research has been conducted on these programmes. However, basic mindfulness techniques can be integrated into clinical practice (Robins et al., 2014). The ability to direct the mind to create an internal state of receptive attention to and awareness of the present moment can be cultivated with routine practice of fairly basic, established techniques (Shapiro, Brown, Thoreson & Plante, 2011). Although many situations, such as chronic illness, are long-standing and seemingly unchangeable, practicing mindfulness can shift one's perception and relationship with these stressors (Robins et al., 2014).

Edelman et al. (2006) constructed personalised health plans including mindfulness meditation, relaxation training, stress management, motivational techniques, health education and coaching for patients with one or more known cardiovascular risk

factors. The primary outcome measure was ten-year risk of coronary heart disease, and the study found a statistically significant difference in the rate of risk improvement between the intervention and control groups, in addition to increased days of exercise and greater weight loss for those who took part in the intervention. Reibel et al. (2001) examined the effects of MBSR on health-related quality of life as well as physical and psychological symptoms in a heterogeneous patient population and found significant improvements in health-related quality of life, alleviation of physical symptoms, and decreased psychological distress, with some significance still maintained at one-year follow-up. Keyworth et al. (2014) used mixed methods to investigate whether a brief, manualised meditation and mindfulness intervention can reduce worry and thought suppression and improve subjective health and well-being for people with diabetes and coronary heart disease. They found a significant difference in worry and thought suppression pre and post intervention, and qualitative data showed that meditation gave an opportunity to engage in activity that bridged mind and body, citing relaxation, improved sleep and physical health, plus acquisition of mindful ways of thinking. The authors suggest therefore that mindfulness can be feasibly incorporated into self-care routines, which reduces reliance on medical management of illness. These three studies all included mixed populations, and were therefore excluded from this review. However, their results provide useful general considerations of how brief mindfulness techniques can be incorporated into practice, as well as how long-term the impact can be.

Some research has begun into phone and web-based methods of mindfulness training. Salmoirago-Blotcher et al. (2013) have reported that mindfulness training can be effectively phone-delivered and may improve mindfulness and anxiety in cardiac defibrillator outpatients. Gluck and Maercker (2011) found that a web-based mindfulness programme was a feasible and agreeable intervention for participants who experienced increased psychological well-being when practiced regularly.

Cavanagh, Strauss, Forder and Jones (2014) make the case for learning mindfulness and acceptance by self-help, as the well-established interventions typically involve large resource commitments for both the provider and participant. The authors present a systematic review and meta-analysis of studies that have evaluated the effectiveness and acceptability of low-intensity interventions including mindfulness and acceptance-based components. On average, two-thirds of participants completed post-intervention measures, which showed that these components produced significant benefits in comparison to controls on measures of mindfulness/acceptance, depression and anxiety.

Carlson (2012) suggests that adapting and tailoring mindfulness-based interventions to individual needs, home programmes, online versions, and shorter groups, could be beneficial to reach larger populations, particularly in rural or remote locations. Both Carlson (2012) and Dobkin, Hickman and Monshat (2014) agree that treatment fidelity is essential, including training professionals to deliver the interventions, as various adaptations continue to evolve and in order to ensure outcomes are achieved.

CONCLUSION

This systematic review has found that mindfulness-based interventions appear to be effective for enhancing the physical rehabilitation of adults with or at risk of coronary heart disease. Such interventions may have beneficial effects by improving psychological distress and resilience, increasing self-regulation, awareness, and helping people to feel more in control of and cope with the impact of coronary heart disease, rather than its effect on specific physical health outcomes.

The short-term effects found for measures of psychological well-being and quality of life, lend support to the suggestion that mindfulness-based interventions could assist with physical rehabilitation or simply reduced symptom reporting due to better coping skills and less distress. This in turn may encourage lifestyle and health behaviour change through conscious life choices, and improving modifiable risk factors such as smoking, physical activity and diet. Mindfulness-based interventions could be included as part of the relaxation and psychological support component of cardiac rehabilitation, or as part of health education or treatment programmes, in order to contribute to secondary prevention. This review is therefore helpful for informing health psychology and clinical practice.

This is still an emerging area of research, and future studies need to consider employing randomised controlled designs, large sample sizes with male and female participants from a range of socio-economic backgrounds, and long-term follow-up of at least one year.

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Appendix D1 – Data Extraction

Record	Author	Title	Type	Country of origin	Aim / objectives	Study design & blinding	Inclusion & exclusion criteria	Recruitment procedures
1	Robert-McComb, J	A pilot study to examine the effects of a mindfulness-based stress reduction and relaxation programme on levels of stress hormones, physical functioning, and submaximal exercise responses	Original article	USA 2004	Examine effects of MBSR on resting levels of stress hormones, physical functioning, & submaximal exercise responses	Pilot RCT	Documented CVD & approval by cardiologist	Medical settings
2	Chang, B-H	A relaxation response randomized trial on patients with chronic heart failure	Original article	USA 2005	To evaluate the effect of a relaxation response intervention on CHF patients	RCT, 3 groups – relaxation response, cardiac education, usual care. Patients not blinded	Ambulatory CHF patients – see p2 for exclusion	Primary care clinics
3	Sullivan, M	The Support, Education, and Research in Chronic Heart Failure Study (SEARCH): A mindfulness-based psychoeducational intervention improves depression and clinical symptoms in patients with CHF	Original article	USA 2009	Assess the impact of a mindfulness-based psychoeducational intervention on depression, anxiety, quality of life, symptoms, & medical outcomes in patients with CHF	Prospective experimental cohort study	CHF diagnosis with left ventricular ejection fraction <40%, NY Heart Assoc class 1 or greater, no immediate life-threatening comorbid disease, ability to participate in an adult education group & no current history of substance abuse	Heart failure progs at university medical centres, general cardiology practice, local community practice & regional newspaper adverts

4	Olivo, E	Feasibility and effectiveness of a brief meditation-based stress management intervention for patients diagnosed with or at risk of coronary heart disease	Original article	USA 2009	Pilot study to gather preliminary info regarding feasibility of abbreviated MBSR prog for patients with or at risk of CHD, with regard to interest & availability. Secondary aim to investigate whether reduced depression, perceived stress, anxiety & hostility	Not reported	Adults with CHD or at high risk. CHD incl CAD, CHF, MI, CABG, valve repair, transplant &/or aneurysm. High risk incl two or more established risk factors: male >45, female >55, family history, smoker, hypertension, cholesterol, diabetes. Need to speak English, give consent, no active psychosis or dementia	Patients at medical centre via adverts & cardiologist promotion
5	Parswani, M	Mindfulness-based stress reduction program in coronary heart disease: a randomized control trial	Original article	New Zealand & India 2013	Examine the effect of the MBSR prog on symptoms of anxiety & depression, perceived stress, BP & BMI in patients with CHD	RCT with pre, post & follow up assessments.	Hospitalised or symptoms of heart disease within last year, ejection fraction >35% with ability to read, write & speak English. Exclusions listed, mainly mental illness	Inpatient and outpatient services
6	Blom, K	Hypertension analysis of stress reduction using mindfulness meditation and yoga	Original article	Canada 2014	Whether 8-week mindfulness-based stress reduction therapy prog could lower BP in untreated participants with stage 1 hypertension	Randomised, prospective, 2-arm, wait list controlled trial Sealed envelope method using a permuted block design. Patients not blinded, but instructors were.	Screening and diagnosis of stage 1 hypertension No underlying risk factors	Referring physicians, local newspapers ads, posters local hospitals. Pts allocated in a 1:1 ratio to either immediate intervention or wait list control.

7	Nyklicek	A brief mindfulness based intervention for increase in emotional well-being and quality of life in percutaneous coronary intervention (PCI) patients: the MindfulHeart randomized controlled trial	Original article	Netherlands, 2014	Examine the effectiveness of a mindfulness based intervention compared to a minimal self-help format	RCT	Excluded age 70+, current psych treatment, serious physical (heart failure, cancer) or psychological (psychosis, suicidal ideation) comorbidity, brain damage, lack of Dutch language, recent change in meds,	Invitation letter following PCI procedure
8	Nehra, D	Efficacy of mindfulness-based stress reduction programme in reducing perceived stress and health complaints in patients with coronary heart disease	Original article	India 2014	Assess the efficacy of MBSR prog in the mgmt of perceived stress and health complaints in patients with coronary heart disease	RCT	Diagnosed with CHD, discharged from hospital to GP after MI or angina, under 55yrs, not participated in similar progs	Not reported
9	Falk, J	Effects of a mindfulness-based stress reduction program on cardiac outpatients – a pilot study	Research report	USA 2014	To evaluate the effect of an 8-week mindfulness-based stress reduction program on psychological and physiological symptoms in cardiac patients	Quasi-experimental pre-test post-test design with a non-equivalent control group	Adult patients 18+ currently under care of physician for cardiac diagnosis Excluded caregivers, not under care, previously taken MBSR or mindfulness training	Convenience sample of patients with cardiac diagnoses from cardiology dept and community health calendar of events

Record	Pt age, gender, ethnicity, SES	Disease characteristics	No. of pts (eligible, enrolled, randomised, included in analysis, withdrawals, exclusions, lost to follow up)	Intervention and how developed	Setting & delivered by	Co-interventions
1	All women, details p822	CVD	20 (10 in each group) with 1 drop out in each group = 18	8-week 2hr MBSR prog with tapes for home practice. No one day retreat	University campus & lab for cycle test	Waiting list control
2	Veterans - male 99% & women 1%, details p2	Moderate severity chronic heart failure	95 randomised from 482 eligible (see p2 for detail)	15 weekly 90-min group sessions to learn 8 techniques to elicit the relaxation response (incl mindfulness meditation).	Clinical psychologists with the aid of tapes. Practice at home twice a day using tapes and keep diary	Cardiac education – 15 weekly 90-min lectures Usual care
3	70% male, mean age 61, median NYHA class II – p86 more detail	Left ventricular ejection fraction <40% & CHF	208 - 108 intervention, 100 control 36% had family member, friend or carer attend	Teaching skills based on MBSR plus education on improving coping skills incl better social support, living with heart failure, spirituality & an expressive support group 1x week for 2.25hrs over 8wks Tapes for 30min/day practice	Mindfulness meditation instructors from 4 professions – cardiology physician, psychiatrist, cardiology nurse, rehab counsellor	Geographical control (>90 miles from centre) with usual care treatment
4	29% male, 71% female. Age 34-76, mean 55.89. Other details p519.	40% diagnosed CHD, 60% high risk	35 pts (4 dropped out)	4-week Meditation-Based Stress Management Prog (shortened & adapted MBSR)	MBSR instructor	None
5	Males, age range 30-65. Women were	CHD	30	8 weekly individual sessions of structured MBSR (no more than 10wks due to rescheduled appts)	Delivered at outpatient clinic	Treatment as usual (one health education session)

	invited but declined			Practice sessions at home using tape & encouraged to adapt health behaviours e.g. at least 30mins exercise & diet		
6	Men & women 20-75yrs, details p126	Known unmedicated stage 1 hypertension, with mean awake ambulatory systolic or diastolic BP $\geq$ 135/85mm Hg or mean 24hr ambulatory BP $\geq$ 130/80mm Hg. No medication for at least 6mths	Eligible 483 Excluded 382 Randomised 101 (see p124 for all details)	8-wk MBSR prog completed during initial 12-wk period. Multicomponent group intervention designed by Kabat-Zinn that provides training in mindfulness meditation as a self-regulation approach to stress reduction & emotion mgmt	Not reported	Wait list control
7	20 women, 88 men, mean age 55.8 – more detail p139	Had PCI procedure	114 – ended with 56 in intervention & 52 in control analysed	Brief MBSR prog of 3x weekly 90-120min training meetings & evaluation session 2wks later Daily home practice 30mins	Clinical psychologist with experience of mindfulness	Self-help booklet based on training written by same psychologist & containing same content/exercises to practice
8	Groups were matched by age (range 25-55), sex and place of living	CHD	50 pts	10 – 17 sessions combination of MBSR and MBCT	Not reported	Treatment as usual

9	Intervention -7 pts 57% female, 43% male Age 65-81 Control-4, 50% male, mean age 66	Cardiac diagnosis	11 with 6 non-study caregivers Control = 5 patients	8 x 1.5hr sessions Meditation techniques, mindful movement, discussion. Practice at home 30mins daily x 6 days/week for duration of course	Not reported	Cardiac patients on wait list for next course
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Record	Outcome definition used	Measurement tool used	Length of follow-up, number &/or times of measurements	Type of analysis	Results	Notes
1	Stress hormones Physical functioning Submaximal exercise response	Pre-post fasting blood serum State-Trait Included: Anxiety Inventory SF-36 Riding stationary bike for 20mins to see effect of relaxation response on physiologic variables	Pre & post intervention	2 (group) by 2 (time) ANOVA with repeated measures Sample size not adequate, even as pilot study	No signif for resting levels of stress hormones or physical functioning. No signif for submaximal exercise response, but signif between groups for ventilation & breathing frequency time (increased conscious awareness of breathing patterns learnt during MBSR?)	Reduced generalisability of findings & limitations described
2	Efficacy of a relaxation response intervention prog on QoL & exercise capacity	Minnesota Living with Heart Failure Questionnaire Peak oxygen consumption (exercise bicycle test)	Baseline (at recruitment) with follow up at last session of RR or EDU (or no later than 19wks if missed) / mailed out to UC group. Returned at bicycle test	Regression on each QoL scale and exercise capacity. Pairwise comparisons among 3 groups Adequate sample size	No sig diff among 3 griups in physical QOL subscales, but some on spiritual & emotional QOL. No sig diff in exercise capacity.	Good description of limitations relating to review. Useful background & own study
3	Depressive symptoms	Center of Epidemiology – Depression (CES-D) 10-	Follow up at 3, 6 & 12 months incl clinical	Repeated measures	Patients incl if >1 session attended, but >85% attended >5.	May play role in

	Psychosocial distress Health status Oclinical, symptom & overall summary)	item Profile of Mood States (4 of 6) Kansas City Cardiomyopathy Questionnaire	outcomes (death or hospitalisation), measured depression, psychosocial distress & CHF symptoms - or	Adequate sample size	Signif improvement in depression at 3 & 6 months, but both groups increased by 12mths 3 out of 4 POMS scales not signif, but 1 (tension-anxiety) was signif at 3 & 6mths but not 12. KCCQ signif at 12mths but not earlier = sustained improvement in physical symptoms No diff in 1-yr death/hospital	comprehensive treatment progs (p88). Likely that reduced symptom reporting due to better coping skills & less distress Limitations described
4	Feasibility & promise of using a brief MBSM prog within CHD population (descriptive) Measures of depression, anxiety, stress, hostility, medical symptoms, and quality of life	Centre for Epidemiologic Studies-Depression Scale; State-Trait Anxiety Inventory; Perceived Stress Scale; Cook-Medley Hostility Scale; Medical Symptoms Checklist; SF-36 Weekly diaries	4 weeks (completion of intervention)	Mixed model repeated measures Adequate sample size,	Considered highly feasible & 86% attended all 4 classes & reported practising at least 1 of the practices. Depression & stress signif reduced after intervention. No signifs for other measures.	Limitations described
5	Reduction in symptoms of anxiety & depression, perceived stress, BP & BMI	Hospital Anxiety and Depression Scale; Perceived Stress Scale; BP and BMI.	Baseline, 8-10wks then 3-mth follow up	Independent sample t-tests & chi square for baseline comparison. Paired sample t-test comparing outcomes for both groups. Sample size not adequate	Signif reduction in symptoms of anxiety & depression, perceived stress & BP in intervention group than TAU. No signif in BMI between groups, but was signif difference within intervention group, whereas not in TAU. 17 available at 3-mth follow up (12 MBSR & 5 TAU) – scores not signif diff from post-intervention but means gains maintained, except BP which showed further improvements. 9 of 12 reported maintaining mindfulness meditation 2-3 times/week.	Limitations described Periodic changes were made to anti-hypertensive meds during course of study which may have assisted in BP lowering. Reduction in BMI indicates

						benefit of incl mindfulness in addition to health education – increased awareness
6	Primary: Change in awake and 24-hr ambulatory BP from baseline to 12wks between subjects Secondary: Within-group change from pre to post intervention, as well as persistence of effect of the MBSR on BP 24wks from baseline & effects on night time BP Correlations between amounts of homework practiced, class attendance & BP change & existence of sex/gender effects	Change in awake & 24-hr ambulatory BP from baseline to 12wks	12wks with 24wk post baseline APBM assessment	Repeated measures ANOVA Baseline comparisons with t tests & McNemar tests of independence Adequate sample size	No significant differences in primary outcomes. Small effects in secondary outcome. No correlations in exploratory outcomes, some gender effects in secondary outcome	Limitations described
7	Psychological well-being	Symptoms of Anxiety-Depression index Perceived Stress Scale Dutch Global Mood Scale WHO Quality of Life-Bref Seattle Angina Quest Freiburg Mindfulness	Before and after	ANCOVAs on psych well-being & QoL. Repeated measures MANCOVA on mindfulness Adequate sample size	Increased psych well-being in intervention but only in patients <60yrs Improvement in general & social QoL in whole sample Physical & medical QoL no signif diff Increase in mindfulness mediated diffs between groups on and & dep, psych	Limitations described Clinical implications p143

	Quality of Life Mindfulness	Inventory Recording practice time			QoL & partly on perceived stress Amount of practice different, suggesting group format is motivating	
8	Whether MBSR reduces perceived stress and health complaints in CHD patients	Perceived Stress Scale Health Complaints Scale (somatic and cognitive complaints)	Post-assessment carried out 10-17wks after pre-assessment & education session for TAU & at completion of interventions for MBSR group	T-tests – but only listed on table, not reasoning why used Adequate sample size	Significant decreased perceived stress and reduction in physical and cognitive complaints	No limitations discussed
9	Changes in scores measuring symptoms of: anxiety depression fatigue chronic pain Relationship of mindfulness skills to scores	Clinically Useful Anxiety Outcome Scale Center for Epidemiologic Studies Depression Scale Brief Fatigue Inventory Chronic Pain Grade Quest. Mindful Attention Awareness Scale Journal tool	Before and after	Wilcoxon Signed Ranks test between pre and post scores. Mann Whitney U sig of score changes between groups Sample size not adequate even as a pilot study	No sig change in or between groups. No of pts not large enough to demonstrate stat significance.	Limitations described

Appendix D2 – Quality Assessment Checklist (based on Downs & Black with additional criteria to reflect nature of articles)

Article	Robert-McComb 2004	Chang 2005	Sullivan 2009	Olivo 2009	Parswani 2013	Blom 2014	Nyklicek 2014	Nehra 2014	Falk 2014
1. Is the aim/ objective of the study clearly described? Yes – 1 No – 0	1	1	1	1	1	1	1	1	1
2. Are the main outcomes to be measured clearly described and appropriate? Yes – 1 No – 0	1	1	1	1	1	1	1	1	1
3. Were the eligibility criteria specified? Yes – 1 No – 0	1	1	1	1	1	1	1	1	1
4. Are the characteristics of the patients included in the study clearly described? Yes – 1 No – 0	1	1	1	1	1	1	1	0	0

5. Is the intervention of interest clearly described? Yes – 1 No – 0	1	1	1	1	1	1	1	1	1
6. Was a comparison intervention used? Control/TAU–2 Population – 1 No – 0	2	2	1	0	2	2	2	2	2
7. Was follow up beyond post-intervention carried out? Yes – 1 No – 0	0	0	1	0	1	1	0	0	0
8. Are the main findings of the study clearly described? Yes – 1 No – 0	1	1	1	1	1	1	1	1	1
9. Were the statistical tests used to assess the main outcomes appropriate? Yes – 1 No – 0 Unable to determine – 0	1	1	1	1	1	1	1	0	1

10. Were losses of patient to follow up taken into account? Yes – 1 No – 0 Unable to determine – 0	1	1	1	1	1	1	1	0	1
11. Was the sample size adequate? Yes – 1 No – 0	0	1	1	1	0	1	1	1	0
12. Are the key limitations described? Yes – 1 No – 0	1	1	1	1	1	1	1	0	1
TOTAL SCORE	11	12	12	10	12	13	12	8	10
QUALITY	Medium	High	High	Medium	High	High	High	Medium	Medium

