Final report

March 2019

Innovating for Improvement

The development of an evidence-based treatment pathway for insomnia in prison

Imperial College London, Care UK and User Voice

The Health Foundation

About the project

Project title:

The development and evaluation of an evidence-based treatment pathway for insomnia in prison: a feasibility study

Lead organisation:

Care UK

Partner organisation(s):

Imperial College London, User Voice

Project lead(s):

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Part 1: Abstract

Background

- Two-thirds have sleep problems in prison which is strongly linked with low mood, anxiety, suicidality and other health-related outcomes
- Current sleep management in prison is insufficient, not equivalent standard to community and needs tailoring to specific needs of the prison population
- Imperial College London worked in partnership with Care UK and User Voice to develop a treatment pathway for insomnia in prison. The pathway centred on self-management, peer support and psychological therapy as opposed to sleep medication only.
- Our aim was to see if the pathway helped improved sleep and various health-related outcomes in one high secure prison in England.

Method

- We co-produced a sleep self-management booklet and adapted cognitive behavioural therapy for insomnia (CBTi) sessions to suit the prison environment
- Prisoners were trained as sleep peer workers to provide basic sleep care to participants and an Improving Access for Psychological Therapies (IAPT) worker was trained in CBTi
- Sleep masks and ear plugs were offered
- Participants completed assessments that covered health-related outcomes before and after the pathway

Results

- 36 participants started the pathway and 26 finished it (72%)
- People dropped out because they transferred out, disengaged or were referred to primary care for other medical conditions
- 9 in 10 significantly improved their sleep
- Mood, psychological wellbeing and cognitive functioning improved
- Suicidality, anxiety, sleepiness and fatigue reduced
- Acceptable intervention to help sleep problems in prison
- Peer support was vital to engagement in CBTi intervention

Key challenges

- Timing of treatment
- No referrals from new prisoners
- Length of time it took to start data collection because of unexpected lengthy security clearances and changes in staff
- Operational challenges in giving protected time to the CBTi therapist to deliver CBTi

Lessons learnt

- Security clearance takes time and should be anticipated when planning for future studies
- Protected time or a full-time member of staff is needed to deliver CBTi

Part 2: Progress and outcomes

Dewa and colleagues' earlier research was triangulated to produce a preliminary treatment pathway for insomnia in prison. In contrast to existing care for insomnia in prison, it utilises NICE guidance and uses a structured stepped-care approach that provides ongoing support for sleep problems. It centres on self-management, peer support and cognitive behavioural therapy for insomnia (CBTi) rather than medication alone.

Innovation is three-fold. First, Dewa and colleagues conducted a systematic review on insomnia in prison and found only 33 papers (Dewa et al., 2015). Results showed no robust overview of insomnia management strategies and no mention of self-management, peer support or CBTi. Second, their national survey of 84 prisons showed no prisons utilised self-management or peer support, few had a stepped-approach to insomnia management and only one prison reported they offered CBTi, however it is likely this was in the context of standard CBT, and not specifically for insomnia. Lastly, the study to design the pathway was made with key experts. In summary, the pathway was produced based on evidence, expert opinion, a peer-support framework and adapted from existing practice and NICE guidelines, making it an innovative approach to sleep management for prison settings.

In our project we:

- co-created a self-management sleep booklet with people with prison and insomnia experience and trained 12 prisoners (2 on each wing) in basic sleep management techniques. They were called *sleep peer workers*. They offered peer-support on wings to encourage engagement in a new sleep routine where clinicians are unavailable.
- offered environmental aids included sleep masks and ear plugs.
- adapted CBTi to suit the prison environment. Adaptations included: environmental aids to combat night-time observations from staff and excessive noise and stimulus control to be completed in cells, whereby the association between bed and sleep is encouraged by change of cell set-up reflecting time of day (e.g. arrange cell to be "living room" in day and "bedroom" at night).

Our primary outcome measure was:

- Improvement in insomnia symptoms using sleep condition indicator (Figure 1).

Secondary outcomes included improvement on:

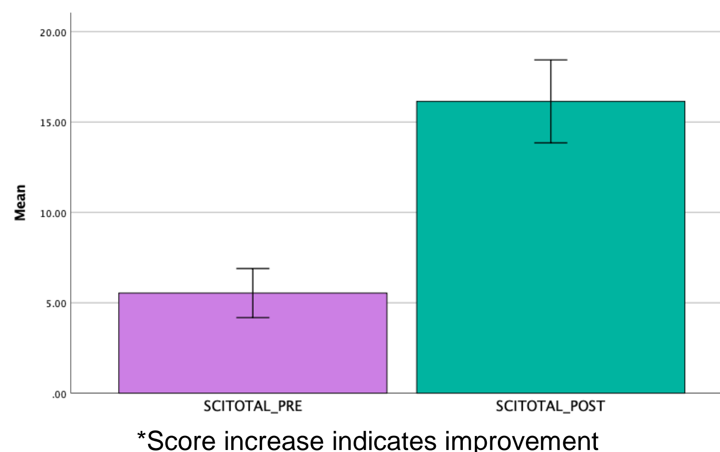
- Insomnia symptoms using Pittsburgh Sleep Quality Index (PSQI) and using actigraphy (e.g. wrist device that measures sleep-wake cycle over time).
- general health and wellbeing
- mood
- suicidality
- anxiety
- fatigue
- cognitive functioning
- sleepiness.

Participants were recruited for the project over 6 months. Forty-four potential participants were referred to the project via various routes (general prison staff, Improving Access Psychological Therapies (IAPT) worker or sleep peer worker) and 42 were deemed eligible (95.5%). Of these, 36 participants agreed to take part in the study (85.7%) and completed baseline outcome assessments. Twenty-eight participants (77.8%) completed these assessments after the intervention and scores were compared at the two-time points to assessment health improvement. Assessments were completed face-to-face with a trained researcher from Imperial College London. Analysis was completed by researchers at Imperial.

Sleep improvement

Almost everyone (96.4%) participants who completed both pre and post assessments improved their sleep after having the intervention.

Figure 1: Mean sleep score (SCI) improvement after having intervention across pre and post assessments



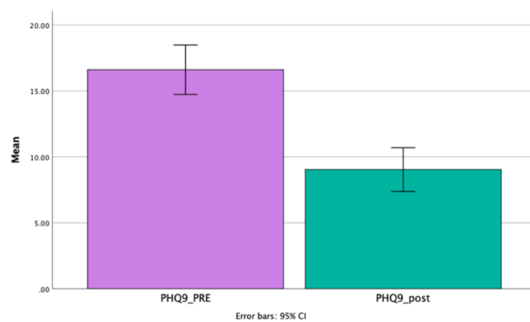
*Score increase indicates improvement

Improvement on psychological wellbeing, mood and other health-related factors

A paired-samples t-test was conducted to compare psychological wellbeing, mood and anxiety before and after the intervention. There was a significance difference in psychological wellbeing (t(27)= -5.373, p<.001), mood (t(27)= 7.046, p<0.001) and anxiety (t(27)= 4.868, p<0.001) scores before and after the intervention. Suicidality, fatigue and sleepiness also all reduced and cognitive functioning improved (see Figures 2-9). These results suggest that the sleep intervention has a positive effect on these health-related outcomes. Specifically, our results suggest that when prisoner-patients' sleep is treated using our intervention, their mental health and wellbeing improves (see Figures 2-9).

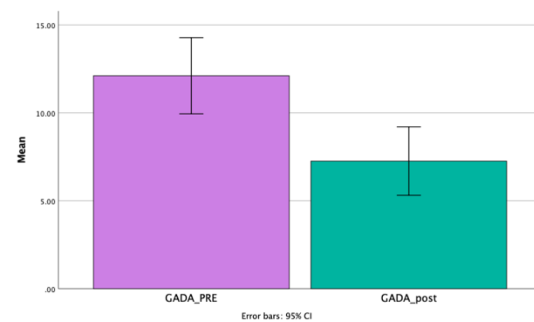
Figures 2-9: Mean score sleep, mental health and wellbeing and cognitive improvement after having intervention across pre and post assessments

Mood



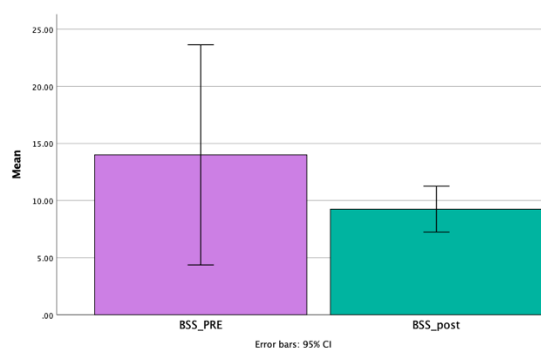
*Score decrease indicates improvement

Anxiety



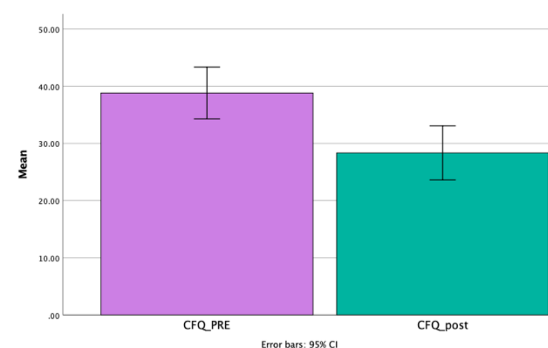
*Score decrease indicates improvement

Suicidality



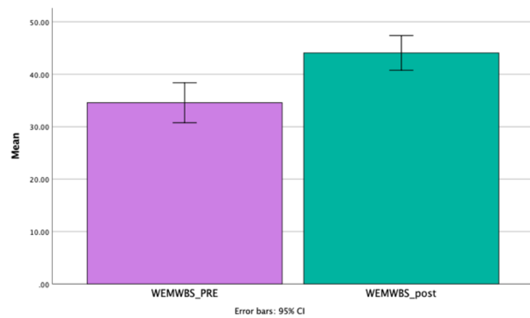
*Score decrease indicates reduction

Cognitive functioning



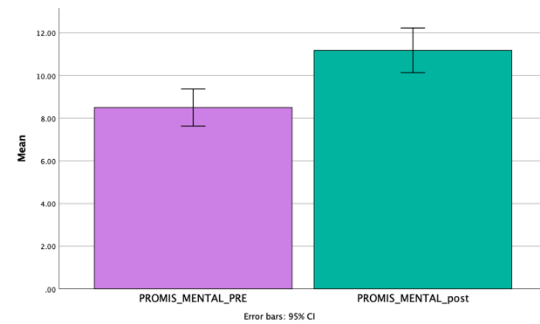
*Score decrease indicates improvement

Wellbeing



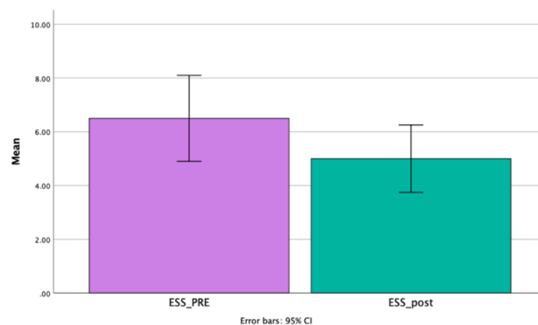
*Score increase indicates improvement

Self-reported mental health



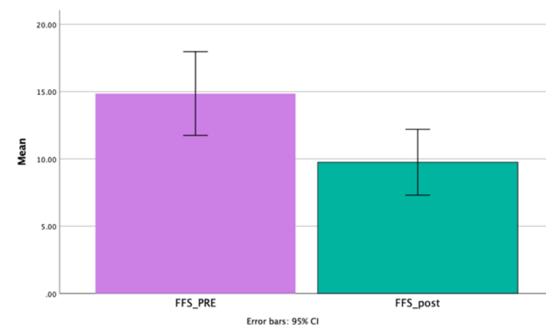
*Score increase indicates improvement

Sleepiness



*Score decrease indicates reduction

Fatigue



*Score decrease indicates reduction

Most interviewees mentioned the importance of good sleep in prison and how the intervention improved their sleep but had improved their wellbeing, increased their concentration and reduced anxiety. But most explained how if prisoners' sleep is improved it will improve their moods, reduce tempers and irritability and subsequently make prison a calmer experience for all.

> *"Pathway great idea because when people can't sleep of a night more chance of tempers being flared up on the wings and we are in a violent environment and if people aren't sleeping, if they get help and sleep they'd feel more relaxed and more calm during the day…hopefully that might reduce some of the flare ups and people can concentrate more on their work and maybe courses so it might help the place to settle and stay calm" (Participant 2)*

> *"if they want people to have good behaviour [in the] day and have a positive mind and go to work, do a good job and work on their offending… then they need to have a good night's sleep. If they can get that through support then it's surely*

going to get them up for a better life in prison" (Sleep peer worker 1)

"It's not just your sleep… it's getting them engaged in activities during the day… it's getting them to think about their whole day and life as a whole. It's not just improving their sleep… it's improving other aspects of their life as well" (CBTi therapist)

Peer support worked and was vital

Peer workers (n=3), purposefully selected participants (n=5) and the CBTi therapist were interviewed by the research assistant or User Voice to explore their experience of the intervention. Peer support was described as vital to engage prisoners in the CBTi intervention and aid implementation. Sleep peer workers developed rapport with the prisoner-patients and they facilitated swift referral to CBTi.

"If they needed to talk to me I was there… I've learnt a lot myself…feeling responsible and make a difference to people and not be a drain on people [but] give something back" (Sleep peer worker 1)

"Peer workers have been a crucial, important part of it [pathway]" (CBTi therapist)

Self-management sleep booklets and environmental aids were valued

All interviewees mentioned that the sleep packs were good, valued and easy to understand. Specifically, the participant interviewees explained how the sleep booklet was professional in appearance, user friendly and was tailored to the prison environment.

"[the sleep] packs were really good. They are really accessible for the majority of people. Really clear to understand. They [were] done really nicely… I mean I think people are more likely to respect it as it looks really professional and they are so used to here getting things on bits of paper… and the colour and the design… I think that was really positive and engaged people a lot more than if they'd had a A4 print out of the information" (CBTi therapist)

One person explained how he had used the advice from the sleep pack:

"I don't sit on the mattress during the day. So I've got this chair and I'm on that [in the day]. So I always spend the day on my chair. I never use the bed until I'm going bed" (Participant 2)

The prison environmental aids of eye mask and ear plugs went down very well with patients. Nightly security checks meant some patients experienced the light going on or a torch being shined at them going every 2 hours which usually disturbed their sleep. However, patients indicated that the ear masks helped block out the light so much that they didn't notice or wake up during these checks. Patients described a similar experience with using the ear plugs to block out noisy neighbours and staff.

CBTi well received but some operational challenges in the prison environment

Most participants received CBTi due to the severity of their sleep problem. They indicated a positive experience, that weekly sessions were appropriate and that every module as useful. They described being happy to be supported throughout. The CBTi therapist also described how the patients were generally engaged in working through the modules.

> *"People have responded really well to the [CBTi] modules… really engaged well. [they] are on board with it"* (CBTi therapist)

However, some issues with implementing CBTi in the prison environment were described by interviewees. For example, the CBTi therapist mentioned changes in the prison regime had a negative effect on patients coming to the their CBTi appointments and that a long break between when she was trained and when CBTi was introduced impacted her confidence to deliver CBTi.

> *"Mid-way through the pathway they changed the whole way of managing appointments which impacted on the amount of missing appointments [with the patients]… that's just the nature of prisons"* (CBTi therapist)

> *"Too long a break between the staff training in CBTi and doing it… [and] you need a specific person dedicated [to it] with no shadow of a doubt"* (CBTi therapist)

Part 3: Cost impact

NHS England commission prison healthcare throughout England. Whilst there has not been a cost evaluation on the study, the quantitative results and qualitative feedback from patients demonstrates an improvement in their wellbeing, other health-related outcomes and awareness. An improvement in self-efficacy and wellbeing will evidence the reduced need for access to health services as preventative approach. Notably, no participants were prescribed medication for sleep problems during the study. We planned to monitor the number of self-harm incidents and resultant self-harm monitoring because of their relationship with sleep problems however we were not able to collect this data because of time and staff constraints on the project. However, whilst we have low numbers, our findings suggest, that improving sleep reduces suicidality, which in the future should reflect a reduced number of suicide observations (i.e. open ACCTs). This should save money and staff time.

The areas of direct service costs were the time and training of the CBTI member of staff. This had an impact in terms of time out of the service, on-going supervision and support for the participants; however, this is in line with community expectations of CBTi. Once the group was running it meant that the CBTi therapist was spending a large amount of time implementing the sleep work which had a financial impact on the rest of the service to maintain business as usual. Going forward, we feel one member of staff should be assigned to the role of CBTi therapist in each prison rather than trying to combine this work with other tasks. An assistant psychologist (NHS band 4) would be able to take on this role in the future. In the future, in a larger study, a full economic evaluation would be possible, and focus on potential savings from a reduced number of healthcare consultations for sleep complaints with primary care and prescriptions of sedative medications.

Part 4: Learning from your project

We achieved more than originally expected. We expected to see an improvement in some prisoner-patients' sleep, but we saw improvement in almost all prisoner-patients. Moreover, the impact on mental health and wellbeing was improved across the board. In addition, we got excellent feedback from the sleep peer workers and Care UK healthcare staff leads in taking this forward.

The contribution of the CBTi therapist, Natalie Pattinson undeniably made a substantial difference to the success of this project. She was instrumental in assessing sleep and eligibility in potential participants, delivering the therapy and organising the sleep peer workers. Without her, the project would have failed because we wouldn't have been able to train another member of staff in time to meet our objectives.

The trained sleep peer workers had lived experience of sleep problems in prison. This was important as they were able to easily gain rapport and inform the prisoner-patients about the study because they were knowledgeable and had experience in overcoming their sleep problem. They encouraged engagement of prisoner-patients in the CBTi intervention to help facilitate their referral. Their passion for the project was pivotal in the success of the study, from the development of the self-management sleep booklets to providing ad hoc sleep support on the wings.

Finally, our research assistant, Bethan Thibaut, helped to ensure all data was collected. Having this dedicated resource was essential because she was security cleared and had access to the site, prisoner-patients and prison staff.

Staff and organisational buy-in was achieved by engaging local and regional leadership early, ensuring good communication and support to solve practical issues, e.g. security clearance.

The Care UK safer prescribing strategy supports the reduction of the use of tradeable medications, including medication to aid sleep. The levels of prescribing are tracked regularly to ensure focus on prescribing and encourage the use of alternative treatments for sleep and pain management in particular thus providing a supportive culture in which to undertake this study.

Aspects that didn't work out quite as planned included:

1. Timing of the treatment
2. Timing of data collection

3. No new prisoners were recruited to the project

At the start of the project, we anticipated needing security clearance for the researcher, and had planned to undertake this whilst awaiting ethics approval. However, this took five months to come through which significantly delayed the project and starting data collection. Furthermore, a change in governor at the prison resulted in an initially less supportive approach to User Voice to visit the prison in order to undertake data collection. This was resolved following discussion with the new governor and agreeing a plan to grant access over a 1-week period to undertake interviews.

Operational challenges for the healthcare team in HMP Wakefield meant there the CBTi therapist was not able to be dedicated to the role and had to manage competing priorities. Whilst the intent was to provide protected time, this became difficult when another member of staff left. Senior management within Care UK worked with local management to support the delivery of CBTi until the end of the project. The original sponsor of the study within Care UK also left the organisation just as the study started and the subsequent senior resource who led on the project from a Care UK perspective also left halfway through the study, resulting in loss of continuity and focus within Care UK. This meant that there was a less proactive approach to problem solving that is the normal culture of Care UK.

Whilst the security challenges of working in a maximum security prison were anticipated it became obvious that a change of personnel, both from a prison and Care UK perspective impacted on the ability of other partners to visit the prison and undertake data collection. This was mitigated by limiting the number of members of the team who visited the prison and a change in the way the data was collected.

Whilst a stable prison population is very helpful in terms of ease of follow up of study participants, the lack of new receptions in the Category A prison did meant that there were limited opportunities to examine whether aspects of the intervention could be useful for prevention rather than treatment. The study focused therefore only on treatment outcomes.

A clustered randomised controlled trial (RCT) across several prisons is needed to ensure the intervention is effective before full implementation, however, in the first instance it needs further development. Key learnings will be to integrate self-management and peer support with CBTi rather than standalone elements. This will lead to quicker treatment goals and limited replication. Moreover, staff feedback indicated the sleep booklets could better reflect the CBTi sessions, as CBTi was the main part of the pathway, and prisoner feedback indicated that environmental aids could be offered earlier. As such, in the future both will be

introduced in session one of CBTi. The CBTi will also be adapted to consider common treatment barriers (e.g. high levels of co-morbid physical health problems that impact on sleep) and prisoners with various clinical presentations.

Management of sleep problems in a prison environment is a common source of stress for clinicians, especially prescribers. Until now there have been very limited alternatives to prescribing. This project has demonstrated that there is an effective low cost intervention that can improve sleep, have a positive impact on other health outcomes and also provide increased skills and self confidence in peer workers. This is exciting and has the potential to make a massive difference to the lives of prisoners.

Senior support and continuity of leadership is important in sustaining focus on a longer term project and supporting the local team in delivery. It would have been helpful to have had a stable steering group so knowing that people were going to move on would have been really useful. However, this is the reality of working life so we would build in more succession planning and have less reliance on a small group to mitigate this. If we had realised the extent of the challenge of the security clearance for User Voice that occurred as a result of a change in prison governor we would have perhaps chosen to undertake the study in a lower security prison.

The key aspects of the project are fully transferable into other environments; be that prisons or other health or secure institutions. The operational implementation would require the same project planning. In terms of resource requirements, specifically the CBTi groups and dedicated staff. But also the sustainability of the project over a period of time. The initial planning would require in- depth risk analysis in order to provide consistency and success, allowing for changes in oversight and board members depending on the organisational culture and time allowed for implementation.

Part 5: Sustainability and spread

We are intending to continue with the use of the booklets and peer support workers in the original prison and widen the use across the Care UK prison network using a regional roll out approach. CBTi will not be included in this initial roll out due to the funding implications but we (Care UK) will be exploring funding options to support this given the impressive results of the initial study. This has senior support and sponsorship with the Care UK Health in Justice Service Line.

An application for further research funding to extend the scope of the study to 4 further Care UK prisons is in progress. We intend to set some more quantitative measures to be included in future research to compliment the qualitative data. This has not been possible in the initial study due to how the data is entered

into the clinical records at present. This can be addressed in future research by use of a template on the system to ensure consistent coding to support data collection.

We believe that the resources needed to roll out the booklet and sleep peer workers are available within Care UK and fits with the strategic direction of Care UK Health in Justice services. However, to role our CBTi will require more significant investment and will need discussion with regional NHSE commissioning teams. Care UK has a large network of prisons (43 establishments across the country) and therefore could spread this work quite extensively. We will be presenting the work at a senior leadership team meeting shortly to gain support for regional roll out of the project. We request further support from Health Foundation, as discussed at the final event, to take our project forward and to specifically:

- Further develop and print sleep booklets
- Train other prisoners in basic sleep management and staff in CBTi
- Have a psychology assistant co-ordinate the initial roll out and to help facilitate engagement activities with staff to help embed the materials and new sleep management within select Care UK prisons

The intervention has been shown to be effective in a small cohort of prisoner-patients. Given the nature of sleep issues are common to the prison environment we believe that the use of the intervention is replicable across all prisons. Further research to explore this in more depth will help us to understand what adaptations may be needed for different environments (e.g. remand prisons, female prisoner-patients).

Lindsay was invited to present initial findings at the new *Forensic Aspects of Sleep: research and service development* conference in Newcastle however unforeseen personal events meant she was unable to attend. She is also now part of a national cross-disciplinary forensic sleep research group who will meet regularly to develop project proposals centred on sleep in secure environments. We have presented our progress and initial findings at the Care UK Clinical Effectiveness meeting, Care UK Best Practice Day and at the Dr Foster Unit. Our poster came third in the National Care UK Conference 2018 and our final results will be presented at this year’s conference. We are currently preparing our main academic paper and will be putting in for an HSJ award.