Integrating online communities and social networks with computerised treatment for insomnia: a qualitative study

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Aim
To explore patient and health professional perspectives and the role of social networking to develop a novel CCBT-IP programme to increase access to this form of intervention.

Design and setting
Semi-structured interviews and focus groups were conducted with a purposive sample of health professionals, and adults with insomnia.

Background
Insomnia is a common psychological complaint. Cognitive-behavioural therapy for insomnia (CBT-I) is effective, although, it is little used because of lack of trained providers.19,20 Computerised CBT-I (CCBT-I) may be a solution to this shortfall in access.

Aim of the study
The aim of this study was to investigate patient and professional perspectives, including attitudes, expectations, and beliefs towards online healthcare programmes that they had used to inform development of a novel CCBT-I platform. More specifically, the researchers aimed to explore participants’ preferences for content, style, and how they would negotiate information disclosure to health professionals or fellow insomniacs; identification of factors that would encourage referral, take-up, and adherence; and the effectiveness of a uniquely integrated CCBT-I and social networking application.

METHOD
A qualitative design was used to collect information from a wide range of purposively sampled professionals and patients. Both semi-structured interview and focus group methods were used to maximise the breadth and depth of perspectives. Participants were recruited from Lincolnshire and Nottinghamshire, UK. They included patients treated by their GP for insomnia, and potential service users with sleep problems; but for ease of terminology both are referred to as patients in this article.

A range of health professionals working with patients affected by sleep problems and insomnia were included. Patients were recruited through posters in public places and family practice waiting rooms, while health professionals were recruited from direct mailing to practitioners or via clinical leaders. A description of the health professionals and patients interviewed is available from the authors.

The patient sample was recruited on the basis of their having sleep problems and differing levels of computer literacy. Additionally, patients who had and had not used CBT and/or CCBT were recruited, to understand more broadly views about the potential of CCBT-I and reduce bias about the focus on a particular CCBT programme. Both patients currently seeking treatment and those not currently seeking treatment were included and therefore, because these groups may have been different, the study sought to maximise patient variation and the responses generated. Health professional participants were purposefully recruited on the basis of their profession and the length of time they had practiced. In addition, those who had and had not facilitated access to CBT and CCBT for patients were recruited to obtain a wide range of responses. The recruitment process was stopped when participants were not providing any new avenues of enquiry, that is data saturation was achieved.

Conclusion
Improving take-up and adherence to online programmes for insomnia requires design that is sensitive to user functionality. Enabling greater patient control and interaction with other users and professionals may stimulate positive experiences of online therapy. CCBT-I and CCBT with social networking has the potential to address the limitations of lack of online access or poor computer literacy.

How this fits in
Cognitive behavioural therapy for insomnia (CBT-I) has been demonstrated to be an effective treatment for insomnia but is not commonly used. This study shows that adults would be willing to be referred and practitioners would be prepared to refer to an online computerised CBT-I (CCBT-I) programme that includes social networking, provided contact was moderated and it had design features that increased trust and functionality. Results of the study are being used to develop a novel platform for CCBT for insomnia and other health conditions.
any mediating factors that may help design an application suited to the contemporary ways that people access online health care. The process involved three of the authors developing initial codes, two of the authors continuing to code data to generate new codes and potential themes, and three authors reviewing the codes and themes together in an iterative fashion, to generate the final themes and quotes that best illustrated these. Divergent views were actively sought and the different perspectives of the multidisciplinary research team were incorporated and developed during analysis.

RESULTS

Twenty-eight patients and 23 health professionals were interviewed between January and July 2011 at health premises, the university, or patients’ homes. These included: 17 individual and three focus group interviews with patients and eight interviews and three focus groups with professionals. Two meta-themes emerged from the data: trust and functionality (Box 1). Trust incorporated notions of integrity, assurance, and confidence in the programme. Functionality referred to the range and quality of functions that improved the usability and usefulness of the programme for patients. Trust for both health professionals and patients lay in accreditation of programmes; for professionals, trust also derived from the evidence of effectiveness, whereas for patients, trust depended on the doctor–patient relationship, ongoing professional support and feedback, and the quality of peer support, including perceptions of security and risk.

Trust

Trust in the programme: Most professionals were aware that CBT was recommended, was promoted, and used for common mental health conditions but GPs wanted firm evidence of effectiveness of CCBT-to have confidence to refer their patients:

**GP22:** I think it’s useful to have evidence that it does actually make a difference. Also that there is no evidence of harm or risk.

**GP17:** Yes if I thought something was useful and I thought that there’s reasonable evidence to back it up, then I would feel happier to recommend it and perhaps more comfortable in suggesting it to people.

In general, trust derived from accreditation of programmes; for professionals, trust also derived from the evidence of effectiveness, whereas for patients, trust depended on the doctor–patient relationship, ongoing professional support and feedback, and the quality of peer support, including perceptions of security and risk.

**Trust in online peer support:**

- **Sharing information anonymously**
- **Information security and stranger danger**
- **User anonymity**
- **Asynchronous preferable to synchronous communication**
- **Being honest without telling others**
- **Moderation of posts**

**Functionality**

- **Useful features**
- **Information formats**
- **Interactive, individualised, and easily navigable**
- **Timing**

GPs acknowledged that CCBT-I could be a useful treatment option but felt that patients needed to be screened and trusted for mental health problems before referral. Some had referred for CBT or CCBT, with variable experiences. Very few patients with insomnia had an in-depth understanding of what CBT-I was, although some had accessed CBT for other mental health conditions and benefited from it.

**My sister who suffers a little bit from anxiety as well...** I said “Oh you want to ask your doctor about CBT” and I was trying to explain it to her, and the one thing I found that I couldn’t be tangible, I couldn’t say “Oh well it gives you this and it gives you that” and I sounded like I was talking about some I don’t know, listfod (alternative) therapy which CBT isn’t at all...it sounded like I was asking her to sort of burn the oals, you know (patient 26: male aged 35 years)

Additionally, participants felt that CBT-I should be delivered through accredited, non-commercial organisations:

**I would want to know a bit more about it. I would want to know about its provenance. I would want to know... who’s created this, is it a commercial organisation, is it a professional health organisation, is it an educational institution, where’s it come from?...I’m not sure I would have faith that I would have actually checked talking to them, they might just be passing it on... How thoroughly do people who recommend it, know it?” (patient focus group – patient 22: female aged 43 years)

If it was accredited by a university or medical college or something like that it would be a good start.” (GP focus group – GP22: GP principal, male)

If there was a direct link from a GP practice, so that means that we’ve already vetted it and we agreed to it, or if it was something that NICE (National Institute for Health and Clinical Excellence guidance) agreed to” (GP focus group – GP22: GP principal, male)

Practitioner enthusiasm, based on trust in the product, was felt to increase referral and uptake:

**I think if you were enthused about it and when you communicated this to the person...and you would have a bit more more likely to do it...I think that’s the main difference between referring to CBT-I and I think you have to have success and I didn’t have much success, but she said she really trusted it and she enthused about the thing... that seemed to be one of the big differences.” (CMHT 88: psychological wellbeing practitioner, male)

Professional support for specific practitioner groups was also enhanced or lessened by personal knowledge or feedback from patients:

**Most people haven’t (had) a website because it’s very intense. It just takes longer, it’s intellectually actually very challenging so I think a lot of people just give up. They get fed up of the intellectual effort they have to put into it... just a random survey people just hadn’t [sic]” (GP focus group – GP17, principal, male)

Trust in the patient–professional relationship: Patients were less likely to feel they were being treated dispassionately by being referred to CCBT if they trusted the referring GP and if CBT-I was part of a package of ongoing care:

**I think if it was a programme like on prescription, go away I’d do this...and come back and see me. That would be fine because you know that it’s continuing care. It’s not like off you go and don’t come back” (patient focus group – patient 22: female aged 43 years)

Patients generally supported the notion of their progress within CCBT-I being fed back to a health professional, particularly those with whom a good relationship already existed:

Some patients wanted to select which information was reported and concerns were raised in relation to continuity of care if patients did not regularly see the same healthcarers professionally.

**I think one of the problems with GPS those days is usually you don’t see the same GP. I mean I’m in a very modern practice and we’re on a carousel so you get whoever comes next and for me to see my GP to talk about my withdrawal plan, I’m going to have to book 2 weeks in advance. That’s the reality of modern health care.” (patient focus group – patient 18: male aged 50 years)

Health professionals were open to receiving information, with their patients’ consent, provided that it did not require too much additional work, because they felt that identifying and monitoring patterns of response to treatment might be clinically helpful. Access to CCBT-I was an important consideration for those who did not, or chose not to, consult with their GP for insomnia.

**If you don’t see it (insomnia) as a problem, and you haven’t gone searching for like medical help or anything... I tend not to go doing anything” (patient 10: female aged 56 years)

Trust in online peer support: Some patients were happy to share their experiences relating to insomnia and communicate with others online. They felt it would be reassuring and decrease their sense of isolation to know that there were other people with the same condition. Others wanted to communicate online but remain completely anonymous or use a pseudonym:

"Oh it would be nice to have a pseudonym!... It’s like being in the corridor with a bag on my head.” (patient 10: female aged 56 years)

Fears of not knowing who else was online was a concern for many. Additionally, giving out personal information, which might end up in the wrong hands, or leaving a digital footprint (personal identifiable evidence of having used the site), which might be accessed by others, were concerns:

**I think I’d be a bit reluctant if I didn’t know them. They’d have to be friends... but I don’t know about strangers, and I don’t think my doctor had actually checked talking to strangers in the night or whatever.” (patient focus group – patient 02: female aged 45 years)

I’m very wary of the internet, we leave digital footprints wherever we go and you never know what’s going to come back and haunt you and I think the more that you are in a professional working environment the more you need to be careful about what you put online. You’ve got to keep it within certain parameters.” (patient 21: female aged 56 years)

Among those who were happy to engage in online chat with others, there was a preference to discuss issues only with people similar to themselves in terms of age or particular condition, for example bereavement or a mental health problem:

**If your sleep was related to trauma, or your sleep was related to pain, or bipolar or whatever, it would not make sense to you to have been in a general sleep body where you could participate but also go down to the sub and another practitioner related to advice. Because I do think you listen to your own group.” (patient focus group – patient 18: male aged 50 years)
Patients considered asynchronous rather than synchronous communication to be safer, that is posting a note, commenting on a forum, or adding to a thread and rating others’ postings, rather than engaging in online communication in real time:

"But rather than have it almost real time because that might create more issues than it’s worth really. So it would be nice to be able to read somebody’s comments that they might have left several hours before." (patient 26: male aged 35 years)

Some participants preferred to be ‘lurkers’, looking at others’ online information rather than sharing their own ideas or questions. (A ‘lurker’ is a person who reads online discussions on a forum/thread or other interactive systems, but rarely or never actively participates or contributes.) Reasons given for this were lack of time, and redundancy or duplication of information:

‘Normally if you do a search you’ll find that someone’s had the same issue as you, you find out what they’ve done to rectify those issues and take that information away from it and that’s all I needed to do… in theory.” (patient 36: male aged 51 years)

Despite a perceived risk that lay ideas or lay notions might be inaccurate, most patients thought they would be able to evaluate online advice appropriately. Health professionals were less convinced:

“You’d just weigh it up and decide whether to do it… I don’t think there’s any advice that anybody is going to post that hasn’t been in the press or wherever. It’s certainly going to be something really unusual isn’t it?" (patient focus group – patient 09: male aged 57 years)

"I can read a page, and then by the time I’ve read the other page I’ve forgotten what the instructions of what they’ve got to do... And you get feedback that says maybe that’s an old bit of news that’s on your front page it’s got to be fresh all the time you need someone to keep it fresh all the time.’ (patient 36: male aged 51 years)

Patients wanted to know what the normal sleep pattern was, how theirs compared with the norm, and whether it merited medical attention:

‘I need to know that my sleep pattern was doing more harm than good... because I think it’s not normal, but whether it’s within the range of normality or whether it’s outside of it… I would like to know at what point the medical profession would consider a sleep pattern as something to do something about.” (patient 21: female aged 56 years)

Completing a sleep diary was seen by patients as a way of identifying a pattern to their sleep problem and recording possible lifestyle causes for which they welcomed personalised feedback. Professionals felt sleep hygiene was valuable and that their patients either did not know about or did not implement this advice, whereas patients felt that they already knew about and had tried sleep hygiene. (Sleep hygiene is a set of behaviours and environmental factors that patients are advised on to help them overcome their insomnia.)

‘Most of them already have a mindset, as soon as you start talking about sleep hygiene being the way to go, they switch off. That may be a prejudice of mine but that’s my observation.” (GP focus group – GP 22: male GP principal)

Participants varied in preferences for the level of information detail. Some participants preferred to read everything for me personally.’ (patient 40: male aged 51 years)

"I’ve seen a psychologist and gone through sleep hygiene and things but it doesn’t really work… I’ve tried all the sleep hygiene things, where you go to bed at the same time, get up at the same time and all that, have a daily sleep routine… I’ve done all that.” (patient focus group – patient 02: female aged 45 years)

A number of participants wanted information on the causes of insomnia and the drugs available to treat it (prescribed or over the counter). Online lectures and professional advice were also suggested.

Visual formats using photos or animations, games, puzzles, or humourous content were suggested to engage and encourage interactive learning:

‘I’d quite like e-learning to be interactive, so you’re doing things along the way rather than just reading so, you know, having simple puzzles or something, have a picture of a bedroom with various things in it and say what which of these is not conducive to you having a good night’s sleep, and so you take out the TV and you take out the radiator being turned up full blast and/or do you want extra curtains or whatever, so things you can’t find that you maybe have done for yourself… And you get feedback that says maybe you’ve found five things there and there were 10 there… or whatever.” (pharmacist focus group — GP 14: male community pharmacist)

Seeing videos of others with sleep problems sharing their stories was considered helpful:

‘Actually it would good to have a video because you could then see the person, because it would have more of an impact than just reading… because you feel it worked for so and so and so it could work for me as well.” (patient focus group — patient 29: female aged 23 years)

Text was the least popular format. Only one patient said they preferred text, whereas many others felt it would be a barrier to engagement. Some participants suggested that, if used, should be in short blocks and easy to read in both font size and language:

‘I can read a page, and then by the time I’ve read the other page I’ve forgotten what the first page said so have to go back again.” (patient 31: male aged 38 years)

Participants varied in preferences for the level of information detail. Some participants found text to be informative, to the point, and in ‘bite sized’, easy-to-read chunks with headlines, bullet points, or summaries. Others wanted the opportunity to access more detail if desired.

Interactive, individualised, and easily navigable. Patients wanted information input to be interactive, individualised, and easily navigable and gave some examples of how this might work. They wanted to document a sleep diary and lifestyle factors that generated a personalised plan advice and recommendations:

‘Possibly, maybe a custom-built plan for the individual… inputting individual circumstances it could give them individual feedback or advice, tips, and products you may find helpful… So I would like to be
asked a few things, like what have you had to eat or whatever, how much do you drink, caffeine or whatever, and how much do you smoke, and then maybe, a timetable, when you get up when you go to bed, how long you should leave before going to bed after you’ve eaten or had a drink, maybe alcohol or caffeine or smoke. (patient 15: male aged 20 years)

Patients wanted flexibility to select learning that they felt might be most relevant to them, using a search facility or frequently asked questions. Several patients wanted to access ideas and tips online, ideally via a mobile application, when they could not sleep.

‘If I had sleep app on it (mobile phone), when I can’t sleep I can just go on it and it might just help with sleep or something. I might be just scrolling and think, somebody has just said this helps so I’ll try it.’ (patient focus group – patient 29: female aged 23 years)

Links signposting patients to other sites were suggested to reduce overcrowding the site and enable users to access more detailed information.

Timing: Most users were prepared to access CCBT-I for short periods but not necessarily every day.

For others, time was not an issue, they would spend as long as was needed to get what they needed out of the package, with access being more likely in the evenings.

‘Most people would struggle to concentrate on anything for more than 20 minutes. I don’t do TV then. That’s what I do TV channel’ (patient GP22: male GP principal).

‘Again that’s difficult because the time that you spend will be in relation to the amount that you need to know and the amount of information that’s available. You would give it the time that you felt it needed, so if it got my interest and I felt I was getting something out of it, I would spend whatever time it took.’ (patient 21: female aged 56 years)

DISCUSSION

Summary

Two main themes were identified: trust and functionality. Features designed to increase trust in CCBT-I and improve programme functionality were perceived to increase the likelihood of successful uptake and adherence. Patients were more likely to accept a credible evidence-based programme for insomnia when referred by a trusted professional as part of ongoing care. Interaction with other users who perceived to provide mutual support, gave concerns, including fear of others online and information security. Patients welcomed multiple applications, access in short periods, self-assessment, and a personalised, interactive approach, they also wanted interaction with others to be moderated or overseen.

Strengths and limitations

The strengths of this study were the exploration of different perspectives, triangulation of data (confirmation of findings from different groups of participants), and divergent case analysis from a wide range of patients and health professionals. This was a multidisciplinary study involving academics from general practice, nursing, sleep science, psychology, social science, and human-computer interactions, affording a range of perspectives. The study recruited from one area of the UK, which may not reflect experiences elsewhere, but the authors are confident that their methods generated conceptual generalisability.

Comparison with existing literature

For insomnia, a recent qualitative study wanted CCBT-I to be credible, non-commercial, regularly updated, and user-friendly. Previous studies have reported health information to be more credible if it is attributed and endorsed by government or a reputable body.44 Although users have also been shown to be wary of commercial interests and concerned about adware and pop-ups,45 they trusted CCBT-I.45

Individuals wanted CCBT-I to be personalised to their perceived needs, with control over what information was shared and when, and how. They preferred information in short blocks with visual and audio features rather than just text. Language, clarity, tone, and comprehensibility of information are key presentational considerations but breadth, depth, accuracy, and scientific quality have also been shown to be important for credibility of online health information.46 Good content presentation using a professional design and quality graphics also tend to enhance credibility.47 Professionals and patients welcomed the opportunity to offer or be offered treatment other than a sleep hygiene leaflet or hypnotic drugs.48 Referral for CCBT-I was considered to be more acceptable when existing professional–patient relationships were deemed good and part of a care pathway. Previous research has found that referral and monitoring by health professionals tends to increase trust, whereas lack of trust in health professionals leads to greater dissatisfaction with services.49 However, those who did not wish to visit their GP for their insomnia also wanted to be able to access CCBT-I directly. Interaction with other online CCBT-I users via a social networking interface was felt to provide mutual support, particularly if there were perceived similarities between users (so called ‘homophily’) and if interactions were moderated. In contrast, there were concerns about privacy or lateral ‘theths’ to personal safety. In one study, [poor] psychological health predicted levels of preference for online social interaction.50 This, in turn, predicted negative outcomes associated with problematic internet use,51 concerns that were not voiced by participants of the present study.

There are notable similarities and differences between online health communities (including those for chronic illness) and social networking sites. Sites such as Facebook tend to foster pre-existing relationships while in contrast, online communities tend to increase opportunities for mutual understanding and interaction with other users.52

Interaction with other online CCBT-I users via a social networking interface was felt to provide mutual support, particularly if there were perceived similarities between users (so called ‘homophily’) and if interactions were moderated. In contrast, there were concerns about privacy or lateral ‘theths’ to personal safety. In one study, [poor] psychological health predicted levels of preference for online social interaction.50 This, in turn, predicted negative outcomes associated with problematic internet use,51 concerns that were not voiced by participants of the present study.

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Ethical approval

Leicestershire, Northamptonshire and Rutland Research Ethics Committee Reference 10/H0408/78. Research governance approvals were gained from both Nottinghamshire and Lincolnshire Primary Care Trust and Mental Health Trusts.

Provenance

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Competing interests

Kate Cavanagh is a consultant to Ultrasis and is a member of the research team. She has received honoraria for speaking at conferences. The Mental Health Research Network for helping the research team. The authors have no other interests.

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Although patients in the present study felt they would be able to distinguish accurate from inaccurate information, health professionals were more doubtful about this.53

Users in the present study preferred greater control over interactions through asynchronous rather than real-time responses. Both asynchronous and real-time (synchronous) online communication have advantages and disadvantages. While some users dislike slower feedback, others prefer the convenience of asynchronous communication, as it can be difficult to talk to others because of different time schedules and zones. Multiple users have an opportunity to read and respond to a posting and it may be difficult to find a particular individual online at any one time.54

Implications for practice and research

The rapidly increasing familiarity and use of social networking provides an unprecedented opportunity for health interventions to be delivered via this platform. Internet-delivered interventions with peer-to-peer support are showing positive effects on health outcomes.55 The findings of this study provide detailed evidence on design features that users suggest may improve uptake and adherence to online health interventions for insomnia and other mental health complaints. Further research is needed to determine whether incorporation of these features into other online health communities may be weaker, they may be less affected by stigma about the condition and thereby increase opportunities for disclosure.56

Known disadvantages of online health interventions include the potential for mutual understanding and interaction with other users via asynchronous posting and it may be difficult to find a particular individual online at any one time.54

Improving uptake and adherence to online programmes for insomnia requires design features focusing on trust and functionality. Enabling greater patient control and interaction with other users and professionals may stimulate positive experiences of online therapy. CBT-I would enable greater access to treatment but is limited by lack of online access or peer computer literacy.
Appendix 1. Topic guide

- What are health professionals and patients experiences with cognitive behavioural therapy (CBT)/
  computerised CBT (CCBT) for insomnia (CCBT-I) and why it may, or may not have worked
  in the past
- What would encourage GPs (and other health professionals) to refer patients for CCBT-I and would
  patients be willing for that referral?
- What do GPs/other health professionals and patients think about communicating progress from the
  completed CCBT-I package to their GP or other nominated health professional?
- What would patients and health professionals like to see in the CCBT-I package and how would they
  like it presented?
- How long would patients be willing to spend on the CCBT-I package per day?
- What do patients think about communicating including through an online social network with others
  suffering from sleep problems as part of the CCBT-I package?
- What ethical processes and safeguards need to be considered and in place?