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Title

Addressing sleep problems and fatigue within child and adolescent mental health services: A qualitative study

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Ethical Permissions

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Conflicts of Interest

None identified.

Abstract

Background: Both fatigue and sleep difficulties are common symptoms of mental health presentations such as depression and anxiety. Despite this, little is known about how psychologists in Child and Adolescent Mental Health Services (CAMHS) assess and treat these common symptoms.

Method: Qualitative interviews with 9 psychologists working in CAMHS, analysed using thematic analysis.

Results: Fatigue and sleep problems do not tend to be the focus of assessment, because they are seen to be part of other presentations and not accorded priority. Psychologists struggled to differentiate fatigue from sleep problems, with greater clarity about sleep problems, which appear to be more routinely assessed. A number of barriers to addressing fatigue and sleep problems were identified, including lack of motivation from young people to make behavioural changes to address fatigue and/or sleep difficulties. Psychologists wished for more training, access to information for young people and families, and more service integration with paediatric physical health settings.

Conclusion: Sleep problems and fatigue may not be thoroughly assessed and addressed in CAMHS and are often conflated, with the focus on enquiring about sleep, not fatigue. Further research is required to elucidate whether the themes identified are more pervasive. Potential interventions include training and information provision.

Keywords: sleep, fatigue, qualitative methods, symptomatology, assessment

Introduction

Sleep-related problems and resultant sleepiness, and fatigue, are often assumed to be interchangeable, although they are in fact related but distinct constructs with different implications for assessment and treatment (Shahid, Shen, & Shapiro, 2010). Sleep problems encompass

difficulties with falling asleep, problems staying asleep, and problems with early morning waking, as well as oversleeping (Walker, 2017). Fatigue can be described as a decreased capacity for activities, physical and or mental, due to a lack of energy to perform the activities (Aaronson et al., 1999), which may or may not arise from sleep-related problems. Fatigue is normal, but if chronic and protracted, can be highly disabling.

Sleep problems and fatigue can exist as their own problem (e.g., Delayed Sleep Phase Disorder, Insomnia) but are also transdiagnostic symptoms of a number of other mental health disorders. For example, both are symptoms of Major Depressive Disorder (MDD) and sleep problems are symptoms of Generalised Anxiety Disorder (A.P.A., 2013). Child fatigue and sleep problems are also prominent in Child and Adolescent Mental Health Service (CAMHS) patients who meet service eligibility criteria but not full diagnostic criteria for a mental health disorder (Orchard, Pass, Marshall, & Reynolds, 2016). Therefore, sleep problems and fatigue are likely to be very commonly encountered in a CAMHS setting.

Fatigue is particularly common in those with low mood, and impacts significantly on functioning and if not addressed, may affect prognosis. Unsurprisingly, given the diagnostic criteria, rates of substantial fatigue in adolescents with MDD range from 43% to 73.3% (Goodyer et al., 2016; Orchard et al., 2016). Studies in adult populations with MDD have shown that residual symptoms can persist after successful treatment (Ghanean, Ceniti, & Kennedy, 2018; Kennedy, 2008; Kurian, Greer, & Trivedi, 2009), and predict subsequent relapse (Judd & Akiskal, 2000; Rapaport & Judd, 1998; Zajecka, 2013) as well as ongoing impairments in functioning (Judd & Akiskal, 2000; Nierenberg et al., 2010; Romera et al., 2013). In adult patients with depression, 20-38% of remitted patients still had substantial fatigue (Nierenberg et al., 2010; Nierenberg et al., 1999), suggesting that evidence-based treatments including pharmacological and psychological treatments may not fully address this symptom, which could pose a risk of relapse in recovered patients.

Sleep problems are common amongst children and adolescents with a range of mental health problems, and may result in additional impairment and persist after successful mental health treatment, as well as posing a vulnerability to developing (further) problems. Rates of sleep disturbance in adolescents with MDD range from 71% to 91% (Goodyer et al., 2016; Orchard et al., 2016). Sleep disturbance has been associated with significantly poorer outcomes across the course of a depression treatment trial, which compared interpersonal psychotherapy to treatment as usual in a school based setting (McGlinchey, Reyes-Portillo, Turner, & Mufson, 2017). Sleep disturbance can be a precursor to depression onset, and a residual symptom after acute treatment (McGlinchey et al., 2017). In children and adolescents with anxiety disorders, as many as 88% experience sleep-related problems, which are associated with anxiety severity and impaired family functioning (Alfano, Ginsburg, & Kingery, 2007). Sleep problems may resolve with treatment focused on anxiety, although findings have been mixed, and there is some evidence that optimal (longer) sleep predicts more favourable outcomes (Alfano, 2018).

Although fatigue and sleep problems are commonly experienced by young people seen in CAMHS, these issues are often not routinely addressed. This is problematic as both can impact on functioning, the success of treatment, and be a residual vulnerability factor. Further, NICE guidance for children and young people recommends that sleep problems and fatigue should be addressed as part of treatment (NICE, 2005, 2015). This study aimed to explore factors that might be contributing to the lack of attention given to sleep disturbance and fatigue in adolescents with mental health problems by interviewing psychologists working in Child and Adolescent Mental Health Services (CAMHS). The objectives were to understand more about their views of and use of fatigue management and sleep hygiene strategies, and to develop ideas about how psychologists might be encouraged to pay greater attention to these common symptoms in routine clinical practice.

Method

Participants

Qualified psychologists working full-time or part-time in National Health Service (NHS) Child and Adolescent Mental Health Services (CAMHS) were considered eligible for the study. Assistant and trainee psychologists were not eligible. Participants were recruited until data saturation had been reached (Vasileiou, Barnett, Thorpe, & Young, 2018).

Materials

A brief demographic information sheet was completed at the beginning of the interview. The interview was semi-structured and consisted of open-ended questions aimed at eliciting the participant's knowledge, experience and confidence regarding fatigue and sleep problems (see supplementary materials for topic guide).

Procedure & Ethical Considerations

Ethical approval was granted by the Psychology Research Ethics Committee, University of Bath (PREC # 17-143) Psychologists working in 12 CAMHS in the South West of England were invited to take part in the study via an email invitation. A participant information sheet for the study was attached to the invitation email. Interested potential participants contacted the research team to find out more information about the study. Once given this information, those who agreed to participate were sent consent forms via email to complete before the interview. Written informed consent was obtained from all participants before they took part in the interview.

Interviews took place between February 2018 and April 2018. Interviews were conducted over the phone, via Skype, or at a location of the participant's preference. All interviews were audio-recorded and transcribed verbatim. Interviews lasted on average 23 mins 58s (range= 15 mins 14s - 36 mins 12s). Interviews were anonymised at the point of transcription.

Data analysis

The data was analysed using thematic analysis, which is a method used for identifying, analysing and reporting patterns within a set of data (Braun & Clarke, 2006). The analysis was conducted from an inductive or 'data-driven' approach, meaning that the codes and themes came directly from the data and were not designed to fit into a pre-existing theoretical framework (Braun & Clarke, 2006). An essentialist/realist epistemological framework underpinned the analysis, and themes were identified at a semantic level in order to focus on the explicit meanings of the data and report the reality of the participants. Data collection and analysis ran concurrently to explore initial themes. Transcripts were read and re-read several times in order for the research team to familiarise themselves with the data. NH-S and ML independently generated initial codes and ideas about developing themes from the first 3 transcripts, and then met to discuss these. Subsequently, this was repeated for the following 2 transcripts, with additional codes and the initial set of themes being revised and further developed. This process continued for the remaining transcripts, and was iterative.

ML is a Clinical Psychologist with extensive prior experience of working in CAMHS settings and in specialist fatigue services. Both NH-S and RR were psychology students at the time of working on this project, and were naïve to the CAMHS context and to sleep/fatigue as specific topics. RH is a Clinical Psychologist who has worked in paediatric sleep contexts, but has not worked in CAMHS in the UK. All authors sought to maintain a reflexive position about what prior assumptions they might bring to the analysis.

Results

Participant characteristics and self-rated knowledge or fatigue and sleep

A total of 9 clinical psychologists aged 28 to 46 years (8 female, 1 male, mean age= 33.6 years) participated in the study, with experience of working in CAMHS ranging from 6 months to 16 years (mean years= 4.1). Participants were asked to self-rate their knowledge of fatigue and sleep problems, and their experience of these problems on 1-10 Likert scales with 1 being none and 10 being extensive. Mean self-rated knowledge of fatigue problems was 6.3 (range= 4-7), and mean experience with fatigue problems was 5.7 (range= 3-7). Mean knowledge of sleep problems was 6.4 (range= 4-8), and mean score on experience with sleep problems was 5.8 (range=3-7). Two participants indicated that they had had further training in fatigue and sleep problems.

Themes

Table 1: Themes and sub-themes identified in thematic analysis

Themes	Sleep and fatigue are common but not prioritised	Differentiating between sleep and fatigue	What gets in the way of addressing sleep and/or fatigue problems	What can be improved
Subthemes	Sleep/fatigue is a common issue	General understanding of fatigue and sleep	Entangled problems makes it difficult to know where to start	What's already in place
	Sleep/fatigue issues are part of other conditions	Confusion between the specifics of sleep problems and fatigue	Difficulties with making changes	Ideal practice in the real world
	Not a priority	Attending to sleep but not fatigue		Lack of a shared understanding about medical versus psychological approach
Unrealistic expectations about sleep				
Assumption that sleep is basic knowledge that everyone knows				

Theme 1: Sleep and fatigue are common but not prioritised

Fatigue and sleep problems do not tend to be the focus of an assessment session in CAMHS, even if they are present.

Sleep/fatigue is a common issue

All participants stated that the majority of adolescents seen in CAMHS, across a range of presenting problems, also had problems with sleep and/or fatigue.

“Most young people I see I think probably most, at least half anyway, have some kind of sleep problem” (7)

By way of explanation, it was implied by some that the regular occurrence of these issues may in part be related to the age range the participants work with.

“I guess in working with adolescents there’s a lot of fatigue that goes ‘round, so I’d be kind of looking out for differentiations between normal tiredness from day-to-day activity and when it may be above and beyond the activity levels that the young person’s engaging with” (9)

This highlights an underlying assumption that experiencing some fatigue during adolescence is normal.

Sleep/fatigue issues are part of other conditions

Almost all participants continued to explain that although fatigue and sleep problems are regular occurrences, they are almost never independent from other presenting conditions, and thus tend to be seen as a by-product of those other conditions, rather than to be considered as a problem in themselves.

“I’ve worked with people where they-they have sleep problems but they wouldn’t have been referred and coming to see me for sleep problems...but it would-it would be a-among presenting difficulties” (9)

It seemed to be a common understanding that adolescents are not referred to CAMHS if they are only experiencing fatigue or a sleep problem. The participants reported that patients are referred to the service for mental health problems, and that any issues with fatigue or sleep would present as

part of their mental illness. Many participants also suggested that specialist services would be better placed to address fatigue and sleep problems if these were the primary presenting problems.

"I think with a specialist clinic so close by we don't tend to-when they do get referred to us we're asked to do not that bit of work we're asked to do more around mental health" (4)

Not a priority

As a result of fatigue and sleep problems often co-occurring with mental health problems, the focus of treatment for many participants was on treating the mental health problem.

"It seems part of the work but maybe not a central focus" (2)

Although the regular occurrence of these issues was acknowledged, fatigue and sleep problems were not a priority for most participants. Many would still intend to discuss sleep as part of the initial assessment, but it was admitted that the lack of priority means it does not always get on the agenda. It was also suggested that if a fatigue or sleep problem was not disclosed during the initial assessment, it might not be discussed again, which could cause problems later on in therapy.

"Yeah if it wasn't from the initial assessment or something that was a big problem, it probably would get missed until it kind of crept out somewhere" (9)

Theme 2: Differentiating between sleep and fatigue

All participants understood the importance of sleep and fatigue and the impact that it can have on day-to-day life. However, the distinction between the two concepts was often blurred, and the terms were used interchangeably.

General understanding of fatigue and sleep

When asked to explain what fatigue and sleep problems were, participants varied in the level of understanding they conveyed.

"I haven't got a great understanding of fatigue, I've got a general understanding of fatigue" (7)

Overall, it appeared that the participants were more confident in describing sleep problems in comparison to fatigue. When asked about sleep, answers were much longer, and participants were often able to describe numerous sleep problems, their presentations and appropriate treatment. When asked about fatigue, answers were short and vague, often mentioning lack of energy, tiredness and its association with mood.

"I think I often tie together tiredness and fatigue and I ask about um I think most generally when people have low mood" (6)

Confusion between the specifics of sleep problems and fatigue

Furthermore, most participants conflated sleep problems and fatigue.

"Yeah it kind of feels like it's an issue with so many young people that we see um (pause) yeah I wouldn't differentiate" (4)

Some of the participants did not differentiate between fatigue and sleep problems at all, viewing them as the same issue which could be managed in the same way. The tendency to conflate the terms was also recognised by some participants.

"I would say fatigue is a lack of energy, drive um that is...often confused with but not particularly related to sleep problems" (7)

The confusion in differentiation appeared to stem from a lack of understanding of fatigue.

"Fatigue would just be linked to the fact that they're not sleeping very well and we can do sleep hygiene work" (5)

There appeared to be an assumption by some that fatigue is a by-product of interrupted or poor sleep, and that by working on sleep problems, fatigue will be solved as a result.

Additionally, not all of the participants use the term 'fatigue' when attempting to assess it during an appointment.

"I'll often ask about energy, so I suppose then I'm kind of asking about fatigue" (7)

When trying to assess fatigue, the participants often use terms such as lack of energy, drive or tiredness.

"I guess I'm just not sure if I'd use the word fatigue. I don't know." (6)

Attending to sleep but not fatigue

Overall, all participants seemed to be more confident in assessing sleep problems than fatigue.

"I'm not sure I would ask directly about fatigue actually. I ask about sleep lots" (7)

Again, fatigue is not always referred to explicitly. However, sleep is consistently asked about during initial assessments and follow-up appointments.

"I know it's something I would ask about just because it-so many people that I work with have difficulties with their sleep...so yeah it's just kind of part of the routine" (8)

Theme 3: What gets in the way of addressing sleep and/or fatigue problems

The third theme explores some of the difficulties that the participants struggled with when trying to address fatigue and sleep problems.

Entangled problems makes it difficult to know where to start

Participants recognised that sleep and fatigue are part of a complex presenting picture, in which it is difficult to identify where best to begin addressing these.

"...so it's kinda like what comes first chicken or the egg..." (5)

There was a sense that addressing one aspect of a problem might lead to improvements in other aspects, but an uncertainty pervaded about the best sequence of treatment targets.

"...I definitely found that a little harder to kind of work out which one to focus on as a priority and therefore ...where to base the intervention first...do we go for the fatigue first, do we try and um go for the mood first, if one helps the other is-is there a helpful order for that or not?" (9)

Difficulties with making changes

Even when participants had identified strategies that could be helpful, patients were seen to struggle with motivation to tackle the behavioural changes required for addressing problems with sleep and fatigue.

"I guess it's something to do with engagement and motivation for change otherwise they will struggle to even get off the starting block" (4)

A perceived solution to this was ensuring that the young person and their family were *"signed up"* (1) to the psychologist's rationale for taking a particular approach.

Lack of a shared understanding about a medical versus a psychological approach

Relatedly, a particular issue raised by some participants was a difference of opinion between families and the psychologist themselves about the cause of the problem and therefore what the solution could be.

"So they come and maybe they are expecting me to prescribe a tablet to help their child sleep and that's not what I'm gonna do" (1)

Families were reported to commonly frame sleep and fatigue problems as organic and requiring a medical solution, rather than considering psychological factors which might contribute to the problems or see a value in addressing the problems with psychological strategies.

"I've also worked with families where I think that they um perhaps are preoccupied with there being something wrong in inverted commas with the child like something organic" (1)

Unrealistic expectations about sleep

Some participants noted that families have, what they considered to be, unrealistic expectations about sleep.

"There can be a lot of um expectations of kind of perfect sleep which is really unrealistic ... most adults don't sleep all the way through the night, we often have disturbed sleep and then...just don't necessarily remember it or see it as problematic" (1)

It was seen as important to assess beliefs about sleep.

"I'd be interested about what ideas they've heard from a kind of cultural level about y'know how much sleep they should be getting...and what helps with sleep cos often you hear some interesting ideas from people" (2)

Assumption that sleep is basic knowledge that everyone knows

Participants recognised that a level of understanding about sleep is often assumed, and therefore, the value of basic sleep information may be undermined.

"I think sometimes as a clinician, especially to do with sleep problems, you can feel that you're just giving quite basic and generic advice" (9)

Theme 4: What can be improved

The final theme explores the resources that the participants currently have access to, and what the participants would want access to in an ideal world.

What's already in place

Participants mentioned giving information about sleep and fatigue, but there did not seem to be any consistently used standard resources.

"...I just kind of utilise um (pause) err kind of more arbitrary scales or ... a scale of nought to ten of how you're feeling" (6)

"I just sometimes say the Childline website, Young Minds, all those things just getting y'know general just resources for the young people really" (8)

As a result of the lack of consistent resources, participants seemed to lack clarity on what advice to give and how best to address sleep problems and fatigue.

Ideal practice in the real world

All participants seemed keen to improve on current practice, whilst also being realistic about what was possible within the constraints of the system in which they work. Many participants wanted more training and support.

"I guess it's just learning from others really so I would think training would be really helpful (8)

"I think as a clinician it's always nice, always always nice to be signposted to really accessible information which is, y'know, easy to print, easy to download, easy to read"(6)

Training, for instance, was seen to have the potential for improving clinical care.

"I think more training and addressing um fatigue and sleeping problems as well as other kind of transdiagnostic factors I think would be really helpful in making our um treatments more um effective as well as more efficient um for people" (11)

They also wanted more information for families.

"And things that you can give to families even, little hand-outs about fatigue and what they can do to help themselves manage it" (7)

More service integration to improve the pathways of care, within a biopsychosocial framework was seen as important.

"So you don't feel like you're being passed from service-between services but there's one service that can take care of their kind of holistic needs." (2)

Discussion

We sought to explore the views of child psychologists about sleep and fatigue problems within their clinical practice. Despite the regularity with which these symptoms were encountered, these problems tended not to be a priority, and were seen as part of a complex presenting picture in which it is difficult to separate one symptom from another and select it as a treatment target. There seemed to be a general lack of differentiation between fatigue and sleep, and psychologists tended to be more confident about and more systematic in their approach to assessing sleep than fatigue. Patient motivation to make changes, as well as the lack of a shared conceptual understanding of how psychological factors can contribute to sleep and fatigue problems, were experienced by child psychologists as barriers to tackling these common symptoms. Although child psychologists recognised that young people and their families may hold unrealistic expectations about sleep, they also assumed that information about sleep and sleep hygiene strategies is basic and therefore undermined the value of providing this information and advice, despite evidence that brief psychoeducational interventions can lead to improvements in self-reported sleep quality and well-being (Paavonen, Huurre, Tilli, Kiviruusu, & Partonen, 2016). There was a clear need for training and support about sleep and fatigue problems.

That both sleep and fatigue problems were common but often not seen as a priority, may be related to the importance that psychologists attribute to fatigue and sleep in the context of mental illness. To make a diagnosis of MDD (A.P.A., 2013), for example, two of the possible 9 symptoms are fatigue (lack of energy) and sleep disturbance. Yet, with regard to fatigue specifically, it does not appear that this is systematically assessed and therefore, may be missed or overlooked. Furthermore, whilst most treatment protocols for cognitive behaviour therapy (CBT) for depression in children and young

people include strategies to stabilise sleep and to increase activity (Verduyn, Rogers, & Wood, 2009), it appears that in practice, more attention and importance is accorded to doing more complex cognitive and behavioural work, particularly in the context of complex case presentations. Yet, it could be argued that in the face of complexity, taking a seemingly more simple approach which targets more fundamental elements and could allow for a relatively quick success for the client, may have greater value and appeal. Psychologists also appeared to view significant fatigue and sleep problems as requiring specialist assessment and treatment that was outside of their remit within CAMHS work, despite the evidence base showing simple cognitive and behavioural techniques can successfully address these issues (Moseley & Gradisar, 2009; Taveras, Rifas-Shiman, Oken, Gunderson, & Gillman, 2008).

There were marked differences in how the psychologists talked about fatigue as compared to how they talked about sleep. There is recognition that sleep problems are common within the CAMHS service, and as a result asking about sleep has become a natural, automatic part of the routine, even if the problem is not then directly addressed. However, fatigue problems are also common within the service, yet there is not this same focus. Psychologists appeared to be relatively confident about assessing sleep problems and providing advice about management, whilst they seemed much more hesitant about defining and assessing fatigue, and about managing it, suggesting participants are less confident in their understanding of fatigue. They also seemed to view fatigue as a by-product of sleep problems, despite it appearing as a separate symptom on, for example, the DSM-5 diagnostic criteria for depression. This may relate to wider societal views on sleep as problematic and a potential target for medical intervention, whilst fatigue may be seen in more controversial terms (Stuart, Smart, Dallos, & Williams, 2015).

Whilst psychologists identified what they saw as unrealistic expectations about sleep, and expressed a view that sleep information is essentially common-sense, their responses also conveyed to some

extent a lack of understanding of the value and importance of sleep, and the potential physical and mental health consequences of even relatively small amounts of sleep (Walker, 2017). This undervaluing of sleep could contribute to the tendency to minimise the potential benefits to well-being of addressing sleep problems. Addressing this issue may be particularly important given growing evidence that sleep interventions can lead to reductions in young peoples' depression symptoms, potentially precluding the need, at least for some young people, for more extensive psychological therapy (Gee et al., 2018; Orchard et al., submitted). Addressing sleep problems at an early stage of treatment holds promise for working more efficiently and therefore improving cost effectiveness and reducing illness burden.

Strengths and Limitations

This study recruited psychologists from across a number of CAMHS within a large geographical area. However, only psychologists were included, and therefore, the views of other multidisciplinary professionals working in the CAMHS context remains to be explored. By virtue of the recruitment method, it is possible that those with a vested interest in sleep and fatigue problems may have put themselves forward to participate. As this was an exploratory study, we did not seek to recruit a representative sample necessarily, nor do we assume that our findings are necessarily generalizable to the wider CAMHS psychologist population. A follow-up study, using quantitative methodology to further elucidate the potential patterns identified here, and recruiting participants systematically to be representative of psychologists working in CAMHS would enable these inferences to be made. Although our sample is relatively small in number, there was considerable consistency amongst the themes we identified across the interviews, and no new themes were generated after the first 5 interviews.

Clinical and Research Implications

Sleep and fatigue are common symptoms of mental health problems that can be central to the maintenance of these difficulties and could impact on treatment success. Yet, both issues are relatively neglected in both assessments and treatments by psychologists working in CAMHS. This initial exploration into the experience of psychologists working in CAMHS indicates that more extensive research is warranted, particularly around training needs and, relatedly, how to treat sleep amongst the complex presentations often facing CAMHS clinicians. Both sleep and fatigue provide relatively discrete treatment targets that can be addressed using cognitive and behavioural methods, and the resultant changes to patient well-being could be very powerful. In addition to training, psychologists could benefit from having access to freely accessible, high quality, evidence based information about sleep and fatigue to share with young people and families. There is also a need to consider the benefits of models of service integration and joined up working with paediatric services to enable the management of physical and mental health through a more holistic biopsychosocial approach. Beyond CAMHS, this project also highlights the need for psychoeducation about sleep at a broader level, possibly through school based programmes although these have mixed findings to date (Gruber, Somerville, Bergmame, Fontil, & Paquin, 2016; Rigney et al., 2015).

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