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Title

The experience of sleep for women with borderline personality disorder: an occupational perspective

Authors

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Abstract

Introduction: Sleep difficulties are prevalent in borderline personality disorder (BPD), however the experience of sleep for individuals with a diagnosis of BPD has not been considered from an occupational therapy perspective.

Method: This study adopted a qualitative methodology. Semi-structured interviews were utilised to explore how sleep is experienced by four women with a diagnosis of BPD, in an inpatient setting. Interviews were recorded and transcribed verbatim.

Findings: Through thematic analysis four themes were identified: “there isn’t a proper pattern or structure to my sleeps,” “sleep is getting away for me,” “before I came in [to the unit] my life-work balance was all chaotic” and “I know the routine, but it doesn’t really seem to affect me”. These findings described the variety of problems experienced by participants in regards to sleep and the implications of sleep difficulties on occupational performance and participation.

Conclusion: Woman with BPD on an inpatient unit experienced a variety of sleep difficulties which impact on their ability to engage in occupations. Sleep and sleep difficulties should be explicitly addressed by occupational therapists and sleep interventions should be individually tailored; further research is required to examine occupational therapy interventions for sleep.

Introduction

Sleep takes up a third of our lives and underlies vital aspects of physical, cognitive and emotional health. Sleep can be defined as “a natural, periodic state of immobility where the individual is relatively unaware of the environment and unresponsive to external sensory stimuli” (Paterson, 2012, p18). On average humans sleep for 7 to 8 hours a day although this varies throughout the lifespan. Studies into adult sleep have suggested that women sleep better than men but that they are more susceptible to sleep difficulties and sleep disorders (Krishnan and Callop 2006). Sleep is regulated by circadian rhythm and the homeostatic recovery process and can be divided into two types, rapid eye movement (REM) and non-REM (NREM). Sleep progresses from NREM to REM in a series of 3 to 6 cycles a night (Patterson 2012). Disruption to sleep can occur for a number of reasons

including age and hormones and can also be an associated symptom of disorders such as dementia or anxiety. Primary sleep disorders such as insomnia, hypersomnia and parasomnia are associated with increased risk of obesity, cardiovascular disease and may be an independent risk factor for mental health problems such as depression (Riemann 2007; Neckelmann et al 2007; Hicks and Green 2012). Additionally, Banks and Dinges (2007) emphasised the importance of adequate sleep highlighting the numerous neurological deficits associated with restricted sleep, including slowed working memory, reduced cognitive throughput and depressed mood. Similarly a link between sleep deprivation and reduced interpersonal functioning and stress management has been documented by Killgore et al (2008), who also noted the importance of obtaining adequate sleep to support the development of effective coping skills.

Borderline Personality Disorder (BPD) and Sleep

An estimated 300,000 people aged 17 and above meet the diagnostic criteria for BPD in England (National Institute for Health and Care Excellence (NICE), 2009). BPD is believed to be more prevalent in women than men. Individuals with a diagnosis of BPD characteristically experience impairments in personality functioning (how they view themselves and others) and common difficulties include impulsiveness, unstable relationships, identity disturbance, emotional dysregulation and cognitive symptoms such as dissociation or paranoid ideation. The full diagnostic criteria for BPD can be found in the Diagnostic and Statistical Manual of Mental Health Disorders, 5th Edition (DSM-V) (American Psychiatric Association 2013).

There is substantial psychiatric literature that has highlighted the prevalence of sleep problems among people with a diagnosis of BPD. Selby (2013) suggested sleep disturbances are consistently associated with symptoms of BPD, while Schredl et al (2012) cited evidence that people with a diagnosis of BPD experience increased sleep fragmentation, poor sleep quality and tiredness during the day. Despite considerable literature evidencing the objective relationship between BPD and poor sleep quality, few studies have considered subjective sleep quality in individuals with this disorder; among those that do, self-report measures such as questionnaires are often utilised. Sansone et al (2010) investigated the relationship between sleep quality and BPD using the Pittsburgh Sleep Quality Index. They concluded that there is a statistically significant correlation between increasing borderline personality symptomatology and increased likelihood of sleep disturbances. These included participants experiencing extreme sleep difficulty with shortened sleep duration (32.9%), poorer subjective sleep quality (26.3%) and greater daytime dysfunction (11.8%). However, the inherent limitations of questionnaires prevent the exploration and gathering of rich information about the experience of a phenomenon (Bryman 2012), for example in the Pittsburgh Sleep Quality

Index 'daytime dysfunction' is assessed through the question 'During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?'. Semiz et al (2008) also attempted to address this through the use of the Pittsburg Sleep Quality Index. Their consideration of subjective sleep quality highlighted a strong association between BPD and nightmares. However the participants were sampled from a unique ethnic group and were predominately male; consequently generalisability to other populations is reduced. Moreover, very little published literature was found regarding the experience of sleep for women with a diagnosis of BPD in the United Kingdom.

Sleep and Occupational Therapy

Sleep has been of interest to occupational therapists since the seminal work of Adolph Meyer who defined the importance of sleep and included it alongside work, play and rest when considering the main factors of performance in maintaining health (Meyer 1922, cited in Nurit and Michal 2003). Despite sleep being a domain of concern for the occupational therapist there is a paucity of research in occupational therapy literature into sleep and its impact on occupational functioning (Thew 2008). A comprehensive review by Green (2008) noted that the discussion of sleep within occupational therapy literature is inconsistent and superficial. Green suggested "the neglect of this interesting area is unjustified" (p339) and the lack of research could be due to the debate surrounding whether sleep is an occupation. Occupational therapists have placed greater value on other performance areas such as self-care, productivity and leisure, resulting in sleep and rest being comparatively overlooked (Nurit and Michal 2003).

Occupational therapy research related to sleep has considered chronic insomnia (Green et al 2005, 2008) and sleep apnoea (O'Donoghue and McKay 2012). Green et al (2005) used focus groups to explore the experiences of living with chronic insomnia and the consequences of poor sleep on people's day time activities. Participants reported major disruption to their occupational performance and felt their long-term health was affected. Furthermore, participants did not feel their sleep disorders were understood by health care professionals and wanted better information about the management of sleep disorders. However, the results of this study must be treated with caution as the researcher and the participants were clinically involved, which could result in a conflict of interests. Research by O'Donoghue and McKay (2012) explored the effects of obstructive sleep apnoea on health, well-being and occupational engagement. The authors found that problems with sleep led to restricted participation in meaningful occupation and affected executive functioning, psychological well-being and relationships. The authors advocated for more occupational therapy research on the experience of living with sleep disorders however no further

research from an occupational perspective has been conducted to date. Similarly, in an opinion piece, Fung et al (2013) have acknowledged this gap and have encouraged occupational therapists to facilitate the inclusion of sleep within practice, education and research.

This study has built on research into sleep and sleep difficulties in BPD and begun to address the lack of occupational therapy research into sleep as an occupation. The aim of the study was to explore the subjective experience of sleep for women with a diagnosis of BPD from an occupational perspective on an inpatient unit.

Method

Research design

A qualitative methodology was selected to gain a greater understanding of the subjective experiences, feelings and opinions of those being researched (Creswell 2013). The subjective nature of qualitative research has been criticised for its lack of scientific rigour and generalisability however, the purpose of this research was not to generalise the findings to a wider population, but to gather and appreciate each individual experience as described by the participants from a small sample size (Bryman 2012).

Ethical Considerations & Procedure

This study had United Kingdom National Health Service (NHS) ethical approval. Although the risk of distress to participants was low, as a potentially vulnerable client group the emotional wellbeing of the participants was carefully considered and strategies to minimise risk were put in place. Health profession staff were available should the participants have required any support during or after the interviews. In addition, the researcher has relevant experience of working with this client group and would have been able to offer immediate support if required.

Participants

The participants in this study were recruited from an inpatient unit with a specialist intervention programme for women with a diagnosis of BPD and/or Complex Post Traumatic Stress Disorder; this will be referred to as 'the unit' throughout the article. Not all clients on the unit had a diagnosis of BPD therefore purposeful sampling was utilised to recruit participants. The inclusion criteria were women with a diagnosis of BPD, over 18 years old, who were not detained under the Mental Health Act. Those excluded from the study were clients who were unable to give informed consent to participate and those experiencing an episode of psychosis. The ability to consent was determined by an occupational therapist at the unit who acted as a gatekeeper. The diagnosis of BPD had been

made according to the Zannarini rating scale (Zannarini 2003). At the time of the study there were nine woman on the unit, eight woman met the inclusion/exclusion criteria and were provided with participant information; to ensure potential participants did not feel obliged to partake they were informed about the study and invited to take part by the gatekeeper.

Four people agreed to take part in the study. Of these four, one had been on the unit for 2 months and three had been admitted for 7-12 months. All participants were aged between 24 and 48 years old. The mean age of the group was 34 years. All four interviews were conducted at the unit in a quiet room to ensure privacy. Information regarding the purpose and nature of the study was provided to the participants in advance of the study and written consent was obtained by the researcher prior to the interviews. The participants were informed of their right to withdraw from the study at any point until the data had been analysed.

Data collection

Semi-structured interviews were conducted, which ranged from 20-45 minutes. Semi-structured interviews are a common method of data collection in qualitative research and were selected for this study as a way of eliciting rich and unique detail (Low 2013). In order to increase the validity of the study, the interview schedule was constructed using open ended questions to ensure the data collected was relevant to the topic whilst allowing the participants to discuss their experiences freely (Forrester 2010). Examples of interview questions are presented in table 1. The interviews were recorded with a digital tape recorder to enable the researcher to fully engage with the interviewee whilst a complete record was obtained (Low 2013). Data from the interviews were transcribed verbatim, using pseudonyms for participants to protect confidentiality and anonymity.

1. Is sleep important to you?
2. How many hours of sleep do you get per night? Would you like more/less?
3. Has your sleeping pattern changed since you have been on the unit?
4. Is your sleep undisturbed? If yes, how many times on average do you wake up during the night?
5. If you wake up during the night, what do you do to get back to sleep?
6. If you sleep too much/too little, does it affect what you do during the day?
7. Do you ever discuss your sleeping pattern with health professionals?
8. Do you take any medication that affects your sleep?

9. Do you feel tired throughout the day?
10. Do you rest throughout the day?
11. Would you consider resting an important part of your day?

Table 1. Example interview questions

Data analysis

Once the interviews were transcribed, data was analysed manually using thematic analysis: “a method for identifying, analysing and reporting patterns (themes) within data” (Braun and Clarke 2006, p79). As the researcher had previous experience of working with people with BPD bracketing was used during the analysis process to mitigate for any preconceptions about the subject under investigation and allowing for new interpretations to be revealed (Bryman 2012).

Braun and Clarke’s (2006) guidelines for thematic analysis were adhered to throughout the process of analysis (Table 2). Initially, transcribed interviews were repeatedly read and examined for meaning and patterns. Any thoughts or ideas were noted as they can influence the interpretation of the data (Creswell 2014). Subsequently, chunks of meaningful data were highlighted to form codes and were then grouped together with similar codes and reviewed to find themes.

Phase	Description of the process
Familiarisation	Transcribe, read and re-read data, note down initial ideas.
Generate initial codes	Systematically code data; collate data relevant to each code.
Search for themes	Collate codes into potential themes.
Review themes	Check if the themes work in relation to the coded extracts and entire data set.
Define and name	On-going analysis to refine the theme and the overall story of analysis, generate names.
Produce the report	Select vivid, compelling extract examples.

Table 2. Braun and Clarke’s (2006) phases of thematic analysis

Rigour

The rigor of the analysis was enhanced by the researcher moving back and forth between the phases of analysis, supporting the trustworthiness of developing themes (Creswell 2014). The data analysis process was also overseen by an academic supervisor to ensure credibility (Bryman 2012).

It was recognised that the expectations and background of the researcher could influence the theming process, (Creswell 2014) therefore to increase the transparency of the study a reflexive diary was kept throughout; this helped to monitor any personal views and raise awareness of any potential bias.

Findings

Four themes emerged from the data: problems with sleep, sleep as a coping mechanism, lack of routine negatively impacting the sleep wake cycle and the ineffectiveness of generic sleep hygiene advice. The content of each them will be explored here using quotations from the interviews.

Theme 1: “There isn’t a proper pattern or structure to my sleeps”

Participants experienced a wide variety of sleep problems. Each reported difficulties or concerns regarding the quality and/or duration of their sleep, however their experience greatly varied. Some participants found it easy to get to sleep and would often sleep throughout the day, as outlined by Jane:

...I’ve been sleeping a lot more during the day and stuff, and just shutting down...I’ve not had much trouble getting to sleep but I have been sleeping way too much.

Similarly Amy also described oversleeping; yet rarely felt she had rested:

I think a really good night’s sleep is very rare for me...I just very rarely feel like I’ve rested.

Conversely, other participants regularly experienced broken sleep due to nightmares and flashbacks of traumatic experiences in childhood, causing them to feel apprehensive and fearful about going to sleep at night and waking up in the morning. Lisa explained:

...I’d love to have a night even just 6 hours unbroken, it’s the broken sleep that I get, and I was getting to the stage where I was getting scared to go back a sleep because I didn’t want another nightmare...that’s the bit that upsets me that I’m always fearful when I wake up.

Alongside the variation in sleep patterns between participants, it was found that most of the participants had experienced very different types of problems with sleep throughout their lives and whilst being on the unit. Whether it be sleeping too much, not sleeping enough or constantly waking

up throughout the night, each participant illustrated the consequences of their problems on the ability to fully engage in everyday occupations. Difficulties included reduced participation in work and leisure occupations. For Jane who worked as a delivery driver, this had major implications:

I love driving it's like an amazing thing, but what I do find is that when I'm driving long distances I get really tired really quickly, and I find it hard to stay safe so I generally don't drive very long distances because I get tired very, very quickly...I want to be able to drive long distances but not feel dangerous.

Sleepiness i.e. a desire to fall asleep can be experienced by anyone after a night of poor sleep; however problems with sleep and associated nightmares and /or flashbacks had been an issue throughout participants' lives and the consequences had accumulated over time. Lisa found it very difficult to concentrate after a typical night's sleep and suggested her long-term health had been affected:

...they [nightmares] leave me with bad feelings when I wake up and it takes ages to shake the feeling off. You know sometimes I can be all morning with the feelings left from the nightmares...my memory is terrible and I think that's due to sleep.

Theme 2: **"Sleep is getting away for me"**

Each of the participants placed great value on sleep and spoke about how they felt a good night's sleep helped to improve their daytime functioning, as outlined by Becky:

I feel less tired, my head feels clearer it's easier to think erm, I feel less disconnected I think I don't, I think I don't disconnect as much as I usually would.

Similar experiences were discussed by others, particularly in regards to feeling rested, calmer and more able to cope. However, for two of the participants sleep served additional purposes and provided a means of escape. This was exemplified by Amy, who used sleep as a coping mechanism to get away from reality and other clients on the unit:

They [health care professionals] suspected that I got stuck in REM and it was a subconscious choice to do that because it was better than being awake...it was coping strategy completely, erm, yeah, it was just rather than facing the day, or that you know the stuff I can create in my head is a lot more appealing than the stuff that goes on when I'm awake so I'll just stay here... sleep is getting away for me...I find people incredibly difficult to be around, they drain me.

A similar account was reported by Jane:

It's [sleep] a chance to shut off and not actually think about things and not have to worry about things, I know sometimes in your dreams it's your mind working overtime but it's just feeling rested, feeling relief and not thinking.

Theme 3: "Before I came in [to the unit] my life - work balance was all chaotic"

The third theme describes the ways in which the unit has helped to establish a day and night time routine, creating structure for most of the participants throughout the day, until they retire to bed. Prior to admission on the unit, two participants discussed the lack of routine they had, describing their lifestyles as chaotic and erratic. This influenced participant's work-life balance and affected their ability to form a healthy sleeping pattern. Jane explained:

...before I came in my life-work balance was all chaotic...I wouldn't be getting to bed 'til maybe 2 [am] not having to get up for work 'til like 8 or 9 [am], then going to my other job for 10 [am]...and then grabbing a couple of hours when I got back before going out again.

However, whilst on the unit most participants had developed a structured routine that encouraged a more regular sleep/wake cycle. One participant suggested this had helped to improve her sleep quality and as a result, she felt more able to participate in group therapy sessions and leisure activities.

Theme 4: 'I know the routine, but it doesn't really seem to affect me'

In terms of a night time routine, personal strategies and principles of sleep hygiene were discussed by participants; reading, writing in diaries and listening to music were listed among the techniques that helped them to relax and prepare to go to sleep at night. Becky explained:

...I usually put my music on and I've got a disco ball that goes round, I usually fall asleep with that on...I usually have my teddy and a blanket as comfort...that's my routine.

However, for some of the participants rather than initiating sleep, maintaining sleep and waking up earlier than desired were major problems. As a result the sleep hygiene advice they received was met with scepticism as participants did not feel it addressed their specific needs, Lisa explained:

It's just standard [advice] like, hot milk, er banana, a night time routine of having a bath and you know, I know the routine, but it doesn't really seem to affect me, because I do get to sleep...it's the waking up

Despite finding sleep hygiene interesting, each participant expressed similar views in regards to its effectiveness, as outlined by Becky:

It kind of just felt like I was given information on something I knew already, if that makes sense?

Discussion

The findings of this study have suggested that BPD is associated with a variety of sleep problems by women on an inpatient unit. Consistent with Selby's (2013) examination of BPD and sleep disturbances, problems with sleep were reported by all of the participants; issues included difficulty initiating sleep, difficulty maintaining sleep, waking earlier than desired and oversleeping. Furthermore, although the subjective experience varied among the participants, each expressed dissatisfaction and concern with the quality and quantity of their sleep. The perceived implications of sleep problems were multifaceted; not only were meaningful occupations such as work restricted, the participant's health, well-being and cognitive functioning were also compromised.

The findings were similar to those of O'Donoghue and McKay (2012) in that participants felt disturbed sleep led to cognitive deficits, specifically relating to concentration and memory. The participants felt the sleepiness associated with poor quality sleep had a negative effect on their daytime functioning and consequently caused disruption in occupational participation. This was of particular relevance to Jane who due to safety concerns felt unable to fulfil her desired occupation of driving. Moreover, this impact on daytime functioning was of particular concern to those who experienced nightmares and flashbacks. Not only was sleep disturbed, but the effects of nightmares lasted for prolonged periods of time and made it difficult for participants to engage in daily occupations. These findings are consistent with those of Sansone et al (2010), particularly in regards to the association of BPD with poorer subjective sleep quality and greater daytime dysfunction.

While Sansone et al (2010) identified an association between BPD and shortened sleep duration, two participants in the present study identified problems with over sleeping and sleeping during the day. In a study conducted by Stalker et al (2005) going to bed was listed among the personal strategies employed by individuals with a diagnosis of BPD to help them cope with their difficulties. The present study supported these findings as two of the participant's utilised sleep to escape reality and the complex symptomology of BPD. The findings also support Green's (2008) suggestion that for individuals with a mental illness, sleep can serve purposes other than restoration.

Participants also discussed the nature of their night time occupations and how they are used to facilitate relaxation before going to sleep at night. General sleep hygiene advice is recommended by

NICE (2009) for the treatment of sleep problems in BPD and was found to help the participants establish a night time routine, which prior to admission on the unit had been difficult to achieve. However, the perspectives of the participants suggested that generic recommendations are not always useful in addressing their specific needs, particularly those who had problems with maintaining sleep and waking earlier than desired. The frustration with the management strategies advised for sleep difficulties is consistent with the findings of Green et al (2008), who suggested this could be due to a lack of training in this area.

Study limitations

This study was conducted on a small number of participants, all of which were female and recruited from an inpatient unit; the researchers acknowledge that participants on an inpatient unit could have a more severe form of BPD than those living in the community. It is also not possible to ascertain how the very nature of being on an inpatient unit could impact on sleep. As such, the small sample size, homogeneity of participants and specific context limits the transferability of the findings. However, the use of small sample sizes is advocated in qualitative research to allow for rich and meaningful data collection in ways too complex for quantitative research (Bryman 2012).

Member checking could have been employed by sending the participants a summary of the themes to ensure they were congruent with the participant's experiences (Bryman 2012); however this was not possible within the scope of this study due to time limitations. It is hoped the transparency with which the study is described facilitates the credibility of the findings.

Furthermore, a challenge when considering the experiences of individuals with BPD is that only a minority of individuals present with no comorbidity (Department of Health 2009). On reflection, it is clear that it would have been useful to ask participants for details of any comorbid conditions such as depression, where a well-documented association with sleep problems has been identified (Luca et al 2012). However, Harty et al (2010) examined the association between sleep problems and BPD and found a significant relationship even when controlling for depression and substance misuse; it can therefore be assumed that the sleep problems would have been present in the participants regardless of any potential co-morbid conditions.

Implications for professional practice

The findings from this research add to both the psychiatric literature highlighting the sleep difficulties experienced by individuals with a diagnosis of BPD on inpatients units, and to the growing body of occupational therapy literature advocating for the inclusion of sleep within occupational therapy practice, education and research (Fung et al 2013).

The findings do suggest that occupational therapists should assess how sleep problems affect occupational performance and engagement and that intervention should be provided to enhance sleep quality. The use of sleep diaries to examine sleep routines (Thew 2008) together with the careful assessment of periods of wakefulness and night time occupations are necessary to assess the complex sleep needs of individuals with BPD. In addition any nightmares, flashbacks and the associated emotions should be evaluated and managed. Although no research has been undertaken relating to specific sleep interventions for those diagnosed with BPD, there is a growing body of literature highlighting the benefits of non-pharmacological approaches such as improving sleep routines and habits, participating in meaningful daily occupations and cognitive and behavioural interventions (Thew 2008). Improving the sleep in individuals with BPD could not only enhance occupational performance it could also improve their ability to manage the complexity of their disorder, employ coping strategies and enhance daytime functioning (Selby 2013; Fung et al 2013). Additionally supporting individuals to develop structured day and night time routines that are transferable beyond the artificial inpatient environment, where structure is provided by the expectations of an intensive specialist programme, is essential for any gains made to be sustainable.

This study has also highlighted the dissatisfaction of participants in the knowledge and training in sleep of health care professionals, particularly the provision of generic sleep hygiene advice. Stores (2007) reported that medical students receive an average of just 15 minutes training on sleep and its disorders. This limited training extends to nurses and psychologists, although it is not known how occupational therapy education compares (Green et al 2008). Clinicians need both greater awareness and training in sleep difficulties and how support can be provided.

Identification of future areas for development and research

The impact of sleep on occupational performance and participation is now considered within the scope of occupational therapy practice (Fung et al 2013). This study has highlighted how those with a diagnosis of BPD can experience sleep difficulties however further research is required into occupational therapy assessment and intervention to address these problems.

A lack of understanding of sleep and sleep disorders by occupational therapists and other health care professionals has been identified. The education of clinicians and students regarding sleep is a potential area for development in this field and is central to improving interventions with this population (Selby 2013).

Furthermore, from the literature review it became apparent that there is no research into the experience of BPD and sleep from more culturally diverse populations, including males and

participants who were not receiving treatment in an inpatient setting. Research with other populations and with differing research methodologies would contribute to knowledge in this area.

Conclusion

In adopting a qualitative research approach, this study has explored the experiences of sleep for women with a diagnosis of BPD in an inpatient setting. Individuals with a diagnosis of BPD were found to be particularly vulnerable to sleep difficulties, used sleep as a coping mechanism and found daytime routine helpful in enhancing sleep, although the subjective experience of sleep varied among the participants. Sleep quality was also found to have an impact on engagement in occupation. Despite the identified study limitations, these findings begin to offer occupational therapists an understanding of the impact of sleep difficulties for individuals diagnosed with BPD. The findings suggest that occupational therapists need greater knowledge of sleep difficulties and that they should explicitly address sleep in their assessment and intervention, although further research into interventions to address sleep is required.

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Key findings

- Woman with BPD on an inpatient unit experience sleep difficulties which impact on their participation in daily occupations.
- Generic sleep hygiene advice does not address individual sleep needs.

What the study has added

This study has highlighted the need for occupational therapists to provide individual assessment and interventions to address sleep difficulties.

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