SUBJECTIVE SLEEP AND PSYCHOSOCIAL OUTCOMES IN ADOLESCENTS AND YOUNG ADULTS WITH A CHRONIC MEDICAL CONDITION

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Bachelor of Science in Psychology
Bachelor of Art in History
University of Florida
Gainesville, FL
2017

Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
In partial fulfillment of
The requirements for
The Degree of
MASTER OF SCIENCE
JULY 2021

SUBJECTIVE SLEEP AND PSYCHOSOCIAL OUTCOMES IN ADOLESCENTS AND YOUNG ADULTS WITH A CHRONIC MEDICAL CONDITION

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Date of Degree: JULY, 2021

Title of Study: SUBJECTIVE SLEEP AND PSYCHOSOCIAL OUTCOMES IN ADOLESCENTS AND YOUNG ADULTS WITH A CHRONIC MEDICAL CONDITION

Major Field: CLINICAL PSYCHOLOGY

Abstract: Adolescents and young adults (AYA) with chronic medical conditions (CMCs) appear to be at risk for poorer sleep behavior, such as sleep hygiene and quality. Further research is needed to identify psychosocial mechanisms for the development of sleep difficulties in this population. We aimed to investigate whether sleep quality and hygiene are worse in AYA in the college setting with a CMC as compared to a matched sample physical healthy youth. We also proposed path models for how illness uncertainty, internalizing symptoms, and pre-sleep cognitive-emotional arousal (i.e., worry and rumination at bedtime) predict sleep quality in this population. College students (n = 274) with and without a self-reported CMC (n = 137 in each group) at a Midwestern university reported on anxious and depressive symptoms, sleep quality, and sleep hygiene. Partcipants with a CMC also reported on illness uncertainty. Path analysis was used to compare the *internalizing symptoms → cognitive-emotional arousal → sleep quality* relationship in participants with and without a CMC. Then, path analysis evaluated the direct and indirect effects of *illness uncertainty → internalizing symptoms → cognitive-emotional arousal → sleep quality*. AYA with a CMC generally reported poorer sleep behavior than the non-CMC group, including poorer sleep quality and greater cognitive-emotional arousal. The indirect effect of internalizing symptoms on sleep quality via cognitive-emotional arousal was significant in the CMC group, β = -.27, SE = .08, 95% CI [−.410, −.116]; this indirect effect was not significant in the non-CMC group, β = -.12, SE = .07, 95% CI [-.275, .018]. Illness uncertainty demonstrated a significant indirect effect on sleep quality though the consecutive influence of internalizing symptoms and cognitive-emotional arousal, β = -.20, SE = .06, 95% CI [−.341, −.094]. Results suggest that AYA with a CMC in the college setting are at risk for worse subjective sleep behavior than their peers. Findings from this cross-sectional assessment suggest that sleep quality in this population may be predicted by the relationship between internalizing symptoms and cognitive-emotional arousal. Finally, the association between illness uncertainty and sleep quality in AYA with a CMC may be explained by the consecutive influence of internalizing symptoms and cognitive-emotional arousal.

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CHAPTER I

SUBJECTIVE SLEEP AND PSYCHOSOCIAL OUTCOMES IN ADOLESCENTS AND YOUNG ADULTS WITH A CHRONIC MEDICAL CONDITION

Overview

Sleep is a critical behavior for biopsychosocial health, with insufficient sleep consistently linked to negative emotional, neurocognitive, and physiological functioning across the lifespan (Banks & Dinges, 2007; Chorney et al., 2008; Irwin, 2015; Kahn et al., 2013). During adolescence, biological preferences for delayed sleep onset, coupled with influential environmental factors (e.g., social events, technology use), often lead to increasingly delayed bedtimes and restricted sleep duration in youth (Colrain & Baker, 2011; Owens et al., 2017). These sleep problems often continue as adolsecents enter college (American College Health Association, 2019; Taylor et al., 2013), and such trends may be magnified for emerging adults with a chronic medical condition (CMC) transitioning to independence in the college setting.

Existing research demonstrates that youth with CMCs are at elevated risk for chronic subjective sleep disturbances (Koinis-Mitchell et al., 2012; Lewandowski, Ward, et al., 2011; Molzon, Bonner, et al., 2013; Valrie et al., 2013), including poor sleep hygiene and sleep quality. Sleep hygiene refers to the pre-sleep behaviors and environmental context which promote longer sleep duration and better sleep quality, such as regular sleep timing, limited napping, and avoidance of activating behaviors before sleep (Bartel et al., 2015; Lebourgeois et al., 2005; Stepanski & Wyatt, 2003). Such behaviors are normatively worse in adolescents and young adults (AYA) in the college setting (e.g., late-night caffeine, alcohol consumption, technology use; inconsistent sleep patterns; American College Health Association, 2019; Brown et al., 2002; Demartini & Fucito, 2014; Forquer et al., 2008; Hershner & Chervin, 2014; Scarapicchia et al., 2015). Subjective sleep quality refers to self-perceived sleep experiences such as feelings of wakefulness upon awakening, restfulness throughout the day, and undisturbed sleep throughout the night (Harvey et al., 2008). Poor sleep quality is generally quite prevelant in AYA in the college setting (Buboltz et al., 2009; Lund et al., 2010; Peach et al., 2016). However, limited research has specifically evaluated sleep hygiene and quality in AYA college students with a CMC (Molzon, Bonner, et al., 2013; Taylor et al., 2013).

Enhanced understanding of why AYA with a CMC are at risk for sleep disturbances is critical, as these problems represent a threat to their biopsychosocial health. Lewandowski and colleagues (2011) suggest that sleep difficulties in youth with a CMC may develop due to uncomfortable nocturnal symptoms (e.g., pain, discomfort, sleep-disordered breathing), medications that inhibit sleep through their pharmacological properties (e.g., corticosteroids), or the nighttime administration of medications. However, the potential psychosocial explanations for these sleep difficulties are largely unclear.

It is known that sleep behavior is consistently linked with psychosocial functioning across the lifespan, with insomnia and other sleep disturbances frequently comorbid with internalizing symptoms (i.e., general depressive and anxious symptoms; American Psychiatric Association, 2013; Chorney et al., 2008; Kahn et al., 2013). Broadly, the relationship between sleep behavior and psychosocial functioning is presumed to be bidirectional across development (Kahn et al., 2013; Semplonius & Willoughby, 2018). However, the role of psychosocial functioning in preceding sleep behavior may explained by heightened cognitive-emotional arousal (i.e., worrying or ruminating prior to sleep), which is often considered an aspect of sleep hygiene. Cognitive-emotional arousal may be caused or intensified by psychological distress and interfere with sleep onset and maintenance across the lifespan and among AYA specifically (Alfano et al., 2010; Fernández-Mendoza et al., 2010; Gellis et al., 2014; Lemyre et al., 2020; Peltz & Rogge, 2016). Prior research with adolescents with chronic pain demonstrated that negative psychosocial functioning and pre-sleep arousal are associated with poorer subjective sleep behavior (Palermo et al., 2007). Thus, poorer psychosocial functioning (e.g., greater internalizing symptoms) may predict poorer sleep in AYA with a CMC due to increased cognitive-emotional arousal. The comparison of such a mechanism (Internalizing Symptoms → Cognitive-Emotional Arousal → Sleep Quality) in AYA with and without medical illnesses would clarify the unique psychosocial mechanisms explaining poor sleep in youth with a CMC.

Illness Uncertainty and Sleep

To date, limited research has investigated specific psychosocial variables unique to pediatric populations that may predict common subjective sleep disturbances. One prominent and robust predictor of psychosocial functioning in youth with a CMC is that of illness uncertainty. Illness uncertainty refers to one's ability to understand or predict one's illness and its course

(Mishel, 1990; Mullins et al., 1997). When an individual with a CMC perceives their illness as ambiguous, complex, and unpredictable, they experience uncertainty that in turn leads to elevated psychosocial distress (Mishel, 1990; Mullins et al., 1997). Indeed, illness uncertainty is a consistent predictor of negative psychosocial outcomes, including internalizing symptoms and quality of life, among AYA with a range of CMCs (Carpentier et al., 2006; Mullins et al., 2017; Sharkey et al., 2018). Thus, although illness uncertainty has proven to be strongly related to the psychosocial outcomes of AYA with a CMC, to our knowledge, it has yet to be assessed as a predictor of subjective sleep disturbances.

Examining the relationship between illness uncertainty and subjective sleep sets the stage for developing a framework for the development of sleep disturbances in AYA with a CMC. As noted previously, cognitive-emotional arousal is highly relevant in the temporal relationship between psychosocial functioning and subjective sleep (Alfano et al., 2010; Fernández-Mendoza et al., 2010; Kahn et al., 2013; Lemyre et al., 2020). Thus, illness uncertainty may lead to increased stress and psychological distress, cascading into elevated cognitive-emotional arousal, and consequently diminished sleep quality (Illness Uncertainty → Internalizing Symptoms → Cognitive-Emotional Arousal → Sleep Quality). Investigation of this model would fill a gap in our understanding of the potentially modifiable, psychosocial mechanisms for poor sleep among AYA with a CMC, with the potential for generalizability to other pediatric populations.

The Current Study

In sum, it is suspected that AYA are at heightened risk for poor subjective sleep outcomes, but limited research has compared the sleep of college students with and without a CMC. Furthermore, potential differences in subjective sleep between these groups may be partly explained by negative psychosocial functioning contributing to sleep difficulties. Namely,

college students with a CMC may exhibit stronger relationships between internalizing symptoms (e.g., depressive and anxious symptoms) and subjective sleep than physically healthy peers. Increased illness uncertainty may also be a strong predictor of worse subjective sleep outcomes that is unique to youth with a CMC, but this relationship has yet to be evaluated. The following aims are the primary focus of the current study.

First, we aimed to compare the sleep hygiene and sleep quality of AYA with a CMC in the college setting to a matched sample of healthy peers, expanding on the limited prior research with this population. It was hypothesized that sleep hygiene and sleep quality would be significantly poorer for AYA with a CMC as compared to healthy college students. Next, we examined the mediating effect of cognitive-emotional arousal on the relationship between internalizing symptoms and sleep quality among AYA with and without a CMC. It was hypothesized that the indirect effect of cognitive-emotional arousal would be of stronger magnitude in AYA with a CMC compared to college students without a CMC. Our final aim was to examine the mediating effects of internalizing symptoms and cognitive-emotional arousal on the relationship between illness uncertainty and sleep quality among AYA with a CMC. It was hypothesized that illness uncertainty would have an indirect effect on sleep quality through internalizing symptoms and cognitive-emotional arousal.

CHAPTER II

METHOD

Participants and Procedures

College students with and without a self-reported CMC were recruited from a Midwestern, public university and complete online surveys on their demographic characteristics, sleep hygiene, sleep quality, anxious and depressive symptoms, and illness uncertainty as part of a larger study. Participants were compensated with course credit in fulfillment of undergraduate Psychology course requirements. The larger study was approved by the Oklahoma State University Institutional Review Board and all procedures adhered to the guidelines of the American Psychological Association.

Measures

Sociodemographic Characteristics

All participants self-reported their personal demographic information, including their age, sex, gender, race, ethnicity, education level, English as a second language status, first-generation student status, and chronic medical condition diagnosis and illness controllability/severity (if applicable) were collected. Study participants also reported on their caregivers' annual family income level and education level. Finally, time of survey completion in relation to the onset of the COVID-19 pandemic in the community was evaluated based on survey completion date (i.e., in relation to March 2020, when the university campus and surrounding area began to implement stay-at-home orders).

Mishel Uncertainty in Illness Scale, Community Form (MUIS-C)

Participants who self-reported having a CMC completed the MUIS-C, a measure of perceptions of illness-related uncertainty (Mishel, 1981). Composed of 23 items, respondents indicate their responses on a 5-point Likert scale ("Strongly Agree" to "Strongly Disagree"). Items are summed to create a total score, with higher scores indicating greater uncertainty. Previous studies suggest strong validity, as well as good to excellent reliability ($\alpha = .90$ in the present study; Mishel, 1981; Mullins et al., 2017; Sharkey et al., 2018).

Center for Epidemiological Studies Depression Scale (CES-D)

The CES-D is a 20-item measure of depressive symptoms (Radloff, 1977). Participants respond to items on a 4-point Likert scale ("Not at all or less than one a day" to "Nearly every day for 2 weeks"). The total score represents the sum of all items, with higher scores indicating higher levels of depressive symptomology. Past studies suggest good reliability and validity for the measure (Mullins et al., 2017; Radloff, 1977; Sharkey et al., 2018), and reliability was excellent in the total sample of the present study ($\alpha = .95$).

Self-rating Anxiety Scale (SAS)

The SAS is a 20-item measure of anxious symptomology (Zung, 1971). Participants respond to items on a 4-point Likert rating ("A little of the time" to "Most of the time") for anxious symptoms. Item-level responses are summed to create the total score, and higher scores indicate a greater level of anxious symptomatology. Similar to previous studies with college students, reliability was excellent in the combined sample of the current study ($\alpha = .90$; Mullins et al., 2017; Sharkey et al., 2018).

Adolescent Sleep Hygiene Scale-Revised (rASHS)

The rASHS is 24-item instrument assessing adolescent sleep hygiene, such as environmental factors, pre-sleep behavior, and pre-sleep cognitions (Storfer-Isser et al., 2013). Revisions to the original measure (Lebourgeois et al., 2005) were determined based on Confirmatory Factor Analysis (Storfer-Isser et al., 2013) among a community sample of adolescents ages 16-19 years. Participants respond on a 6-point Likert scale ("Never" to "Always"). The rASHS includes 6 revised subscales of sleep hygiene: Physiological (e.g., "I go to bed feeling hungry"), Behavioral Arousal (e.g., "I go to bed and do things that keep me awake"), Cognitive-Emotional (e.g., "I go to bed feeling upset"), Sleep Environment (e.g., "I fall asleep while watching TV"), Sleep Stability (e.g., "On weekends, I stay up more than 1 hour past my usual bedtime"), and Daytime Sleep (e.g., "I take a nap after 6 pm"). Each subscale score is derived from calculating the average for items within that subscale, and the average of all subscale scores serves as the total score. Higher scores indicate better sleep hygiene (e.g., higher scores on the Cognitive-Emotional subscale indicate lower cognitive-emotional arousal). In the rASHS validation study (Storfer-Isser et al., 2013), authors reported satisfactory concurrent and convergent validity. Similar to the validation study, in the present study, internal consistency for the subscales ranged from $\alpha = .44$ (Physiological) to $\alpha = .84$ (Cognitive-Emotional), with good total internal consistency for the measure ($\alpha = .86$). The Cognitive-Emotional subscale served as the measure of cognitive-emotional arousal.

Adolescent Sleep Wake Scale-Revised (rASWS)

All participants completed the rASWS, a 10-item instrument that measures self-percieved quality of sleep patterns, such as sleep onset and awakening from sleep (Essner et al., 2015). This measure and its original form have been validated among adolescents and young adults (ages 12-

25 years) with and without pediatric health conditions (Essner et al., 2015; Huber et al., 2020; Lebourgeois et al., 2005). The rASWS was revised from the original form using Exploratory Factor Analysis (Essner et al., 2015). Participants respond on a 6-point Likert scale ("Never" to "Always"). The rASWS includes 3 revised subscales of sleep quality: Falling Asleep and Reinitiating Sleep (e.g., "After waking up during the night, I have trouble going back to sleep"), Returning to Wakefulness (e.g., "In the morning, I wake up and feel ready to get up for the day"), and Going to Bed (e.g., "In general, I am ready for bed at bedtime"). Each subscale score is derived from calculating the average for items within that subscale, and the average of all subscale scores serves as the total score. Higher scores indicate better sleep quality. Internal consistency for the subscales of the rASWS in the validation study showed evidence for construct validity (Essner et al., 2015). Internal reliability on the subscales in the present study were good to excellent (α = .80 to .94), and we observed good total internal consistency in the present study (α = .89).

Data Analytic Plan

Prior to primary analyses, preliminary analyses were conducted in SPSS version 26 to evaluate the relationships between variables of interest and sociodemographic characteristics. Independent samples t-tests, analyses of variance (ANOVA), and bivariate correlations were used to identity significant relationships to inform the selection of covariates in subsequent analyses.

Aim 1: Differences in Sleep Hygiene and Quality Based on CMC Status

To address Aim 1, two independent samples t-tests were conducted with SPSS version 26 to compare the subjective 1) sleep hygiene (rASHS) and 2) sleep quality (rASWS) of college students with a CMC to a matched sample of physically healthy college students. Stata version

16.1 (Stata Press, 2019) was used to match CMC participants with physically healthy controls based on age, sex, race, and COVID-19 timing (i.e., data collected pre- vs. Post-COVID-19 pandemic).

Aims 2 and 3: Path Models

To evaluate Aims 2 and 3, path analysis, a type of Structural Equation Modeling, was used to simultaneously estimate multiple hypothesized pathways and indirect effects between variables of interest (please see Figures 1 and 2 for visual depictions). The models were tested using Mplus version 8.4 (Muthén & Muthén, 2017) with full information maximum likelihood and 5,000 bootstrapped resamples. Due to the strong correlation between CES-D (depressive symptoms) and SAS (anxious symptoms) scores, a latent variable was created representing "internalizing symptoms" to reduce redundancy in all path analysis models and improve interpretability. Demographic characteristics that were significantly related to variables of interest in preliminary analyses were regressed on all endogenous variables.

CHAPTER III

RESULTS

Our final sample included 274 participants, including 137 participants with a CMC (hereafter "CMC group") and 137 without a CMC (hereafter "non-CMC group"). Five participants with a CMC from the larger sample were unable to be matched and excluded from analyses. Sample size varied for some analyses as cases with incomplete data (i.e., missing data for some items) were included (n = 4). The sample was primarily female, White, non-Hispanic/Latinx, and of higher socioeconomic status (please see Table 1). Of note, we collected information on participant sex and gender, and two participants (one per group) identified as a gender other than cis-gendered male or female. Further descriptive information on the variables of interest can be found in Table 1.

Preliminary Analyses

Analyses reflected that select socio-demographic variables were related to our variables of interest in the general sample based on independent samples t-tests, ANOVA, and bivariate correlations. Participant sex was related to depressive and anxious symptoms such that females reported greater depressive and anxious symptoms than males in the overall sample, $t(75.67) = -2.34$, $p = .022$; $t(75.13) = -3.03$, $p = .003$, respectively. Older participant age was related to greater depressive symptoms in the combined sample, $r(268) = .12$, $p = .041$. Lower participant-reported annual family income was related to worse sleep quality and greater anxious and depressive symptoms (p-values = .014 - .034). Thus, participant sex, age, and annual family income were included in subsequent path analysis models as covariates. COVID-19 pandemic timing was not significantly related to variables of interest but was included in primary analysis given its potential theoretical relevance as a highly unique stressor. Participant race, ethnicity, first-generation college student status, education levels, and parental education levels were not significantly associated with variables of interest in t-tests and ANOVA analyses and thus not included in subsequent models. Please see Tables 2 and 3 for further information on relationships between demographic variables and variables of interest in the CMC and non-CMC groups.

Primary Analyses

Aim 1: Differences in Sleep Hygiene and Quality Based on CMC Status

Results of the independent samples t-test comparing sleep quality based on CMC status reflected worse overall sleep quality for participants with a CMC ($M = 3.20$, $SD = 1.02$) than without a CMC ($M = 3.79$, $SD = 0.96$), $t(272) = 4.89$, $p < .001$, Cohen's $d = .60$. Specifically, participants with a CMC reported poorer quality of falling asleep and maintaining sleep,

t(268.52) = 5.48, p < .001, going to bed, t(272) = 2.21, p = .028, and returning to wakefulness, t(272) = 4.01 p < .001.

Total sleep hygiene was also worse for participants with a CMC (M = 3.99, SD = 0.63) compared to participants without a CMC (M = 4.23, SD = 0.64), t(270), p = .002, Cohen's d = .38. Significant group differences for subscales emerged with respect to physiological arousal, t(270) = 2.11, p = .036, cognitive-emotional arousal, t(270) = 4.34, p < .001, and daytime sleep t(270) = 2.14, p = .033. Means and standard deviations for the rASWS and rASHS total and subscale scores are displayed in Table 1.

Aim 2: Path Models for CMC and Non-CMC Groups

The direct and indirect effects of the internalizing symptoms → cognitive-emotional arousal → sleep quality relationship were evaluated for the CMC and non-CMC groups. Socio-demographic characteristics (i.e., age, sex, annual family income, COVID-19 status; not pictured in figure) were also included in the model and estimated on all endogenous variables. Model fit was good, $\chi 2(22) = 30.54$, p = .106, CFI = .99; TLI = .98; SRMR = 0.07; RMSEA = 0.05. Figure 1 displays the result of each model. In the CMC group (see Figure 1a), the internalizing symptoms latent variable had a significant direct effect on sleep quality, β = -.32, SE = .11, 95% CI [-.545, -.089]. Internalizing symptoms also demonstrated a significant indirect effect on sleep quality though cognitive-emotional arousal, β = -.27, SE = .08, 95% CI [−.410, −.116]. In the non-CMC group (see Figure 1b), internalizing symptoms also had a statistically significant direct effect on sleep quality, β = -.51, SE = .12, 95% CI [-.742, -.279]; however, the indirect path through cognitive-emotional arousal was not statistically significant, β = -.12, SE = .07, 95% CI [-.275, .018].

Aim 3: Illness Uncertainty Path Model

The direct and indirect effects of the illness uncertainty → internalizing symptoms → cognitive-emotional arousal → sleep quality relationship were evaluated for the CMC group. Socio-demographic covariates (i.e., age, sex, annual family income, COVID-19 status; not pictured) were estimated on all endogenous variables (i.e., internalizing symptoms, cognitive-emotional arousal, and sleep quality). Model fit was good, $\chi 2(6) = 5.48$, $p = .484$, CFI = 1.00; TLI = 1.00; SRMR = 0.01; RMSEA = 0.00. Model results are displayed in Figure 2. Illness uncertainty did not have a significant direct effect on sleep quality, $\beta = .03$, SE = .10, 95% CI [-.180, .230]. Illness uncertainty demonstrated a significant indirect effect on sleep quality though the consecutive influence of internalizing symptoms and cognitive-emotional arousal, $\beta = -.20$, SE = .06, 95% CI [−.341, −.094]. There was also a significant indirect effect through internalizing symptoms, $\beta = -.21$, SE = .09, 95% CI [−.396, −.038]. However, the indirect effect through cognitive-emotional arousal alone was not statistically significant, $\beta = .04$, SE = .04, 95% CI [−.023, .140]. Thus, upon accounting for internalizing symptoms, as well as the the consecutive influence of internalizing symptoms → cognitive-emotional arousal specifically, illness uncertainty was no longer significantly related to sleep quality.

CHAPTER IV

DISCUSSION

Despite a growing body of literature evidencing poor sleep outcomes in children and young adolescents with medical conditions (Koinis-Mitchell et al., 2012; Lewandowski, Toliver-Sokol, et al., 2011; Valrie et al., 2013), limited literature has investigated the subjective sleep behavior of emerging adults with a CMC (Molzon, Bonner, et al., 2013). Although there are numerous proposed physiological explanations for poorer sleep in youth with a CMC (e.g., symptoms-related sleep disruptions, medication-related disturbances; Lewandowski, Ward, et al., 2011), we have a limited understanding of the potential psychosocial mechanisms of sleep in this population. Thus, the current study aimed to investigate differences in the subjective sleep behavior in samples of AYA college students with and without a CMC. We proposed two models for understanding self-reported sleep quality in this population, including psychosocial variables relevant to youth both with and without a CMC (i.e., internalizing symptoms, cognitive-emotional arousal) and a variable unique to the CMC population (i.e., illness uncertainty).

Our first hypothesis was supported, and both sleep hygiene and quality were indeed significantly worse among AYA with a CMC compared to their physically healthy peers. This replicates the limited research demonstrating that AYA with a broad range of medical conditions report worse sleep outcomes than healthy youth (Molzon et al., 2013; Taylor et al., 2013). Thus, there is growing research support for the notion that AYA (and college students, specifically) with a CMC report poorer subjective sleep behavior. Of note, differences in sleep hygiene in the present study were primarily driven by college students with a CMC reporting greater napping/daytime sleep, heightened physiological arousal (i.e., going to bed after being physically active or having caffeine), and greater cognitive-emotional arousal (i.e., bedtime worrying or rumination). Overall, our results illustrate that youth with a CMC transitioning to independent living are more likely than their physically healthy peers to report poorer sleep behavior.

Although there are a number of potential physiological reasons for these differences in sleep between youth with and without a CMC (e.g., uncomfortable nocturnal symptoms), we focused on the potentially modifiable psychosocial processes that might explain these differences. We hypothesized that the indirect role of cognitive-emotional arousal (Internalizing Symptoms → Cognitive-emotional Arousal → Sleep Quality) would be stronger for participants with a CMC. Howevever, our findings indicate that this mechanism was supported for AYA with a CMC but not for their healthy peers. Specifically, the path from cognitive-emotional arousal to sleep quality was not statistically significant in the physically healthy sub-sample. Thus, the results of this cross-sectional investigation suggest that not only do AYA with a CMC report greater levels of cognitive-emotional arousal than their healthy peers, but also that cognitive-emotional arousal (i.e., bedtime worry or rumination) may play an important and unique role in the sleep quality of this population. Although speculative, it is possible that our finding reflects

that youth with a CMC who experience anxious and depressive symptoms have greater difficulties self-regulating in general as compared to their peers. Indeed, prior findings reflect that youth with medical illness report greater difficulties with emotion regulation than those without a CMC (Espeleta et al., 2020).

Finally, we proposed and tested a model for how illness uncertainty influences subjective sleep quality via consecutive psychological processes (Illness Uncertainty → Internalizing Symptoms → Cognitive-Emotional Arousal → Sleep Quality). Illness uncertainty was indeed associated with sleep quality, and our hypothesis was supported: illness uncertainty was related to sleep quality via internalizing symptoms and cognitive-emotional arousal. This means that, in emerging adults with medical conditions, increased illness uncertainty and corresponding greater depressive or anxious symptoms appear to lead to increases in maladaptive pre-sleep cognitions and emotions, which then interefere with sleep quality (e.g., increased difficulty initiating or maintaining sleep). These results suggest that the uncertainty of living with a chronic illness may have downstream effects on sleep through psychological processes such as difficulties regulating cognitive-emotional arousal.

Limitations

These findings are qualified by several methodological limitations. First, although the sample sige was relatively large, this study was cross-sectional in nature and lacked robust gender, racial, ethnic, and socioeconomic diversity. Thus, we cannot be assured of the temporal order of the constructs evaluated in the present study, and our results have limited generalizability to other groups. Importantly, this limited sample diversity may have resulted in an underestimate of effects, as the systems-based inequities of systemic oppression appear to cause poorer sleep outcomes among youth of marginalized identities (Billings et al., 2020). Of

note, we observed that lower family income was associated with worse sleep quality in our sample, suggesting that economic inequities may indeed impact college students' sleep (e.g., lower quality living conditions, busier schedules due to the need for employment). Moreover, the stress associated with ower socioeconomic status may itself contribute to worse psychosocial adjustment and pre-sleep arousal, and thereby reduce sleep quality (Bagley et al., 2015). Additionally, despite accounting for COVID-19 pandemic related timing in our analyses in matched sample selection and as a covariate in data analyses, it is possible that the stress of the pandemic affected our results by increasing psychosocial and sleep-related difficulties. Furthermore, the additional evaluation of objectively-measured sleep behavior would provide a richer understanding of the relationships among these constructs, as our use of subjective sleep measurement comes with limitations such as shared method variance. Thus, increased methodological rigor and sample diversity is important for future research in this area.

Future Directions

Future research should also consider how high-acuity conditions like cystic fibrosis or cancer might differentially impact the sleep of AYAs through these psychological mechanisms, particularly for youth in community (i.e., non-college) settings. Although medications and hospitalizations that interfere directly with sleep are likely influential upon sleep in these populations (Lewandowski et al., 2011), the heightened stress and uncertainty inherent to these conditions may be an understudied contributor to sleep difficulties in pediatric populations. Thus, the replication of these findings in such samples of youth with high acuity conditions, particularly with the use of longitudinal investigation, might clarify the present study's findings.

Clinical Implications

These findings have a number of clinical implications. First, although sleep hygiene management alone is likely inferior to cognitive-behavioral therapy (CBT) for treating clinically significant sleep problems (Friedrich & Schlarb, 2018), it is possible that targeted education about sleep hygiene would lead to improvements in other sleep behavior or aspects of adjustment in AYA in the college setting with and without CMCs. For example, Kloss and colleagues (2016) developed a "Sleep 101" series of educational workshops for undergraduate students which included elements of CBT and proved efficacious for increasing sleep hygiene knowledge and reducing sleep onset latency. Beyond such public health-centered approaches, psychosocial providers working with AYA with a CMC might consider specifically evaluating how their patients ruminate or worry before sleep as a potential target of intervention. For example, mindfulness-based stress reduction techniques (Perry-Parrish et al., 2016) may help youth self-regulate at bedtime to effectively reduce cognitive-emotional arousal. Finally, illness uncertainty is a psychosocial construct unique to people with medical illness and their family members that is potentially modifiable through education and problem-solving skills training (Mullins et al., 2012). With further research, illness uncertainity may be clinically targeted in AYA to improve not just general psychosocial functioning (Mullins et al., 2017), but also disrupt the cascading influence of psychosocial functioning on sleep behavior.

In summary, the results of the current cross-sectional study of self-reported sleep in college students with chronic medical illness suggests that sleep outcomes are significantly worse for this population than their physically healthy peers. We identified heightened illness uncertainty and cognitive-emotional arousal as potential constructs that, with further research, may prove to be modifiable predictors of sleep outcomes in AYA with a CMC.

APPENDIX

EXTENDED LITERATURE REVIEW

The following review will begin by discussing the interrelationship between objective and subjective sleep, including definitions of these two overlapping constructs. Next, a description of theoretical models of sleep difficulties will follow, including Harvey's Cognitive Model of Insomnia (2002), Espie's Psychobiological Model of Insomnia (2002), and Perlis and colleagues' Behavioral Model of Psychophysiological Insomnia (1997). The extant research investigating psychosocial functioning and sleep behavior in adolescents and young adults (AYA) with a chronic medical condition (CMC) will then be reviewed. Finally, a summary of the current study aims and hypotheses will be provided.

Objective and Subjective Sleep Quality

Sleep behavior can be measured both objectively and subjectively. Objective sleep broadly refers to sleep characteristics (e.g., sleep onset, sleep quantity, sleep stages) measured via the study of sleep-related physiology, including body movement and respiration. Such tools that measure objective sleep characteristics include polysomnography (PSG) and actigraphy. Subjective sleep refers to self-reported or proxy-reported sleep characteristics (e.g., sleep duration, sleep quality, sleep hygiene). With regard to sleep quality specifically, the measurement of objective and subjective sleep quality is multifaceted and difficult to clearly define, as it can encompass measured or self-reported total sleep time (TST), sleep onset latency (SOL), wake after sleep onset, sleep efficiency (i.e., the proportion of time in bed spent in sleep time), or Likert-scale ratings of the quality of sleep (Krystal & Edinger, 2008).

Interestingly, measures of subjective sleep quality are inconsistently related to facets of objective sleep (e.g., sleep quantity, sleep efficiency; Doane et al., 2014; Pilcher et al., 1997; Taylor et al., 2013). According to a review by Perlis et al. (1997), several paradoxes in sleep phenomena illustrate the complex relationship between subjective and objective sleep. Notably, the majority of individuals with diagnosed insomnia: (1) state that they were awake upon awakening from PSG-defined sleep, (2) overestimate their SOL, (3) underestimate their TST, and (4) appear to derive more benefit from sleep medications than explained objectively (Perlis et al., 1997). Such findings may be partly explained by cognitive processes - the moment of falling asleep is difficult to perceive and remember, perhaps distorting personal sleep perceptions (e.g., SOL seems longer than objectively estimated because it is challenging to recall; Harvey, 2002). Thus, the subjective experience of sleep can be quite different from objectively measured sleep characteristics.

Objective sleep variables consistently and strongly associated with subjective sleep quality are elusive. Akerstedt (1997) identified only two objective sleep variables predictive of subjective sleep quality: TST and slow-wave sleep (stages 3 and 4). A recent review found that subjective ratings of sleep quality are most strongly associated with the length of wake after sleep onset (WASO), with SOL and TST slightly less strongly correlated, whereas numerous other objective sleep measurements are not significantly associated (Krystal & Edinger, 2008). In a study among older adults, subjective sleep quality was predicted by enhanced sleep efficiency, increased TST, and greater sleep stage transition (Kaplan et al., 2017). However, the authors note that these variables collectively explained a relatively small proportion of the variation (11-17%) in subjective sleep quality (Kaplan et al., 2017). Certain qualities of non-Rapid Eye Movement (REM) sleep might be associated with subjective sleep quality, but further research is needed (Krystal & Edinger, 2008). Among youth transitioning to college, Doane et al. (2014) identified no objective sleep variables (e.g., sleep duration, sleep efficiency) associated with subjective sleep quality. Thus, sleep duration, sleep onset, sleep efficiency, and certain aspects of non-REM sleep architecture may be predictive of subjective sleep quality, but these to do not appear to be consistent, strong relationships.

Not only are there often inconsistencies between objective and subjective sleep, these two variables also appear to be differentially associated with important psychosocial outcomes. Among youth, research suggests that subjective sleep quality is more strongly linked with psychosocial functioning and psychological disorders than objective sleep measures. Alfano et al. (2015) found that children with anxiety had significantly poorer sleep quality as compared to children without anxiety, but detected no differences in objective sleep parameters. Studies evaluating sleep disturbances among children with depression have found similar discrepancies,

and objective, PSG-measured sleep is largely similar among youth with and without depression (Ivanenko et al., 2005). In the college student population, Pilcher and colleagues (1997) reported that sleep quality was more strongly related to a battery of psychosocial outcomes (e.g., depression, tension, fatigue) than sleep diary-derived sleep quantity. Doane et al. (2014) identified depressive and/or anxious symptoms as longitudinal predictors of SOL and sleep onset variability among youth transitioning to college. In sum, the existing literature suggests that subjective sleep quality is indeed primarily dependent on personal perception rather than objective characteristics of sleep. Nevertheless, subjective sleep quality should be an important focus of study among youth and in the college student population given what appear to be strong and consistent associations with subjective reports of clinical insomnia and psychosocial functioning (Doane et al., 2014; Pilcher et al., 1997; Shen et al., 2018; Taylor et al., 2013).

Sleep Hygiene and the College Setting

Sleep hygiene is another salient dimension or construct relevant to college students' sleep. Sleep hygiene describes a range of personal and environmental features that set the stage for healthy sleep, based on their associations with sleep duration, sleep quality, and influence on circadian timing (Bartel et al., 2015; Lebourgeois et al., 2005). Specifically, appropriate sleep hygiene includes a comfortable sleep environment, regular sleep timing, limited napping, as well as the avoidance of activating behaviors at bedtime like substance use, technology use, eating, physical activity, and cognitive-emotional arousal (i.e., worrying or ruminating at bedtime; Lebourgeois et al., 2005; Lebrun-Harris et al., 2018; Stepanski & Wyatt, 2003). Sleep hygiene education is typically provided as part of clinical intervention for sleep problems such as insomnia – but notably, poor sleep hygiene is not likely to be the primary cause of such problems

(Morin et al., 1999). Thus, good sleep hygiene practices are part of the foundation of healthy sleep.

College students may be at elevated risk for poor sleep hygiene, as their transition to independent living is associated with an increase in behaviors inconsistent with sleep hygiene recommendations. Namely, adverse health behaviors, including caffeine and alcohol consumption, are common and associated with maladaptive sleep patterns, including oversleeping and excessive sleepiness (American College Health Association, 2020; Demartini & Fucito, 2014; Scarapicchia et al., 2015). The technology use common in this population (e.g., cell phones, computers) can directly interfere with sleep patterns, as well. For example, the light emitted from cell phones and computers can affect circadian function via melatonin release, causing alertness at bedtime (Hershner & Chervin, 2014). Uncomfortable or uncontrollable sleep environments are also of concern, with many college students sleeping in residential halls with roommates and experiencing excessive light and noise (Lund et al., 2010; Sexton-Radek & Hartley, 2013). Further, college students' sleep patterns are often delayed (75 minutes later than high school students, on average; Lund et al., 2010) and inconsistent, with later bed and wake times on the weekends than during the week (Forquer et al., 2008; Gellis et al., 2014).

Finally, the social environment of college can specifically interfere with sleep. First-year college students interviewed about their sleep reported that their sleep patterns and practices are impacted by socializing (both in-person and online), a fear of missing out on late-night social activities, and distractions from community living (e.g., noise) and technology (e.g., receiving text messages; Adams et al., 2017). Thus, the college environment presents a host of barriers to attaining healthy sleep, and suboptimal sleep hygiene practices are common (Brown et al., 2002; Gellis et al., 2014). However, in a study of college students, Lund (2010) found that alcohol and

caffeine use, physical activity, and sleep schedule variability were not predictive of subjective sleep quality in a multiple regression - notably, self-reported tension and stress were significant predictors in this same regression equation. Thus, the subjective sleep quality of college students may be more strongly related to psychosocial functioning than environmental factors.

Cognitive-Emotional Arousal and Sleep

Cognitive-emotional arousal is conceptualized as a critical aspect of sleep hygiene, based on its relationship with sleep quality and quantity (Lebourgeois et al., 2005; Stepanski & Wyatt, 2003). Cognitive-emotional arousal (also termed cognitive-emotional hyperarousal, pre-sleep cognitive arousal and other variations in the literature) refers to a state in which thoughts and feelings are activated at bedtime (e.g., thinking about things one needs to do the next day, worrying about home or school). Cognitive-emotional arousal is similar to daytime cognitive activities like rumination and worry but distinguished for its occurrence during a period typically characterized by relaxation. According to a systematic review examining cognitive-emotional arousal, adults with chronic insomnia report that this cognitive activity primarily consists of problem-solving or planning for the future (Lemyre et al., 2020).

The body of literature investigating cognitive-emotional arousal and sleep is based on findings that individuals prone to sleep difficulties, particularly insomnia, tend to experience excessive pre-sleep biopsychosocial arousal (Lemyre et al., 2020; Riemann et al., 2010). Research in the area can be divided into two major categories: top-down processes (cognitively-based) and bottom-up processes (i.e., physiologically-based; Riemann et al., 2010). Physiological models of this hyperarousal propose that genetically determined neurological arousal causes cognitive-emotional arousal and thus sleep difficulties (Bonnet & Arand, 2010; Riemann et al., 2010). For example, individuals with primary insomnia demonstrate numerous

characteristics of sleep-related physiological hyperarousal, including abnormal hormone secretion, increased metabolic activation, and elevated sympathetic nervous system activation during sleep (Bonnet & Arand, 2010). This has led some to propose that a disorder of physiological hyperarousal underlies idiopathic or primary insomnia, such that such a disorder would explain the co-occurrence of poor sleep and related symptoms of arousal (Bonnet & Arand, 2010).

However, evidence for top-down processes focusing on cognitive-emotional arousal as a primary cause of insomnia or other clinical sleep problems is also strong. Harvey's Cognitive Model of Insomnia (2002) is a widely cited framework focusing on cognitive-emotional arousal as a precipitating and maintaining factor of insomnia. Harvey proposes that individuals with insomnia extensively worry about their sleep and the consequences of inadequate sleep, causing physiological arousal, selective attention to their sleep-related behavior, and a distorted perception of their sleep problems (see Figure 4). This chain of events cyclically supports the maintenance of insomnia, which is a particularly valuable aspect of this model (Hiller et al., 2015). A recent review confirmed the accrual of evidence supporting this model of insomnia, and its potential applicability to individuals with generally poor sleep (Hiller et al., 2015).

Additional models of insomnia integrate these top-down and bottom-up processes of arousal and sleep. Perlis and colleagues (1997) suggest an integrated conception of arousal and insomnia in his Behavioral Model of Psychophysiological Insomnia (see Figure 5). This framework proposes that activating events (e.g., life stress events) cause sleep-related problems that cascade into conditioned psychophysiological arousal (conceptualized as trait factors) before sleep. Further, Perlis et al. (1997) proposes that subjective sleep problems in individuals with insomnia may be credited to neurocognitive functioning, namely cortical arousal. That is, high

frequency electroencephalogram activity interferes with sleep onset such that individuals have enhanced memory of this period, and a distorted perception of the distinction between wakefulness and sleep (Perlis et al., 1997). Thus, the aforementioned discrepancies between objective and subjective sleep parameters may be credited to such neurological activity. Espie's proposed Psychobiological Model of Insomnia (2002) also elegantly assimilates components of sleep and arousal, with a focus on the role of affect regulation (see Figure 6). In this model, individuals without significant sleep problems ("good sleepers") accurately interpret their simultaneous physiological and psychosocial signals of sleepiness and have a bedroom sleep environment that further supports de-arousal and sleep (Espie, 2002). Whereas this process is involuntary and automatic among individuals with good sleep, individuals with insomnia experience a failure in these processes, in which the interacting model components are disrupted (Espie, 2002).

These models primarily focused on relationships between biopsychosocial arousal and insomnia can be extended to better understand poor sleep quality. Although physiological arousal plays a role in sleep disruption, cognitive-emotional arousal may be more strongly associated with subjective sleep disturbances as it better reflects the individual experience of sleep – thoughts and emotions are more likely to be subjectively attributed as the cause of sleep problems as opposed to physiological arousal, as suggested by Espie (2002). Indeed, elevated cognitive-emotional arousal might cause distorted perceptions of sleep, including TST and SOL among normative sleepers (Tang & Harvey, 2004). Further, increased cognitive-emotional arousal is associated with poorer sleep quality and greater sleep problems (e.g., sleep onset delay in individuals (including children and young adults) with and without clinical insomnia (Alfano et al., 2010; Cellini et al., 2017; Yeh et al., 2015).

Thus, across numerous models of insomnia/poor sleep, cognitive-emotional arousal is conceptualized as a critical predictor of sleep duration, sleep quality, and other sleep components – as well as a conditioned response to consistently poor sleep. Although somatic or physiological arousal is another important aspect of these models, the temporality of its relationship with cognitive-emotional arousal is difficult to disentangle (Kahn et al., 2013). However, cognitive-emotional arousal may best represent the self-perceived interpretation of arousal that interferes with sleep behavior and be more strongly linked with individuals' perceptions of their sleep than physiological arousal (Alfano et al., 2010; Cellini et al., 2017; Yeh et al., 2015).

Sleep in Youth with a CMC

There are numerous biopsychosocial explanations for the poor sleep generally observed in youth with a CMC, including mechanisms related to the illness and its treatment, immune functioning, and negative psychosocial functioning (Koinis-Mitchell et al., 2012; Lewandowski et al., 2011; Molzon et al., 2013; Valrie et al., 2013). Additionally, subjective sleep appears to be particularly relevant to the sleep of youth with a CMC, and cognitive-emotional arousal may be an important predictor of subjective sleep as among the general population.

As it concerns physiological mechanisms, there are numerous proposed contributing and maintaining factors for sleep disturbances specific to several CMC groups commonly represented among college students. For youth with asthma and/or allergies (approximately 9.4% and 19.3% of college students, respectively; American College Health Association, 2019), sleep disordered breathing or nocturnal aggravation of symptoms (e.g., nasal congestion) can lead to difficulties falling asleep or staying asleep (Fagnano et al., 2011; Koinis-Mitchell et al., 2012; Léger et al., 2006; Stores et al., 1998). Similarly, youth with pediatric pain conditions experience disrupted sleep due to uncomfortable symptoms that interfere with their sleep (Valrie et al.,

2013). Further, there is some evidence that analgesic or sedative medications prescribed for pain interfere influence the stages of sleep (Onen et al., 2005). Pediatric headache has specifically been associated with increased sleep disturbances (e.g., insufficient sleep duration, daytime sleepiness), and chronic migraine headaches (reported by 9.5% of college students; American College Health Association, 2019) may be related to sleep anxiety, parasomnias, and bedtime resistance (Gilman et al., 2007; Miller et al., 2003). Studies of adults with chronic migraine headaches suggest increased likelihood to experience insomnia and poor sleep quality – such findings may be due to individuals with chronic headaches and/or migraine headaches engaging in more daytime napping and excessive caffeine use (aspects of sleep hygiene; Yang & Wang, 2017). Finally, although there is limited research on sleep in individuals with pediatric gastrointestinal problems, a growing literature evidences sleep problems in youth with Crohn's disease, which could be credited to pain or inflammation (Benhayon et al., 2013; Kinnucan et al., 2013).

Further, evidence suggests that immune functioning may play a role in the sleep disturbances of those with a CMC. Elevated levels of inflammatory markers called cytokines (e.g., tumor necrosis factor, interleukin-6, C-reactive protein) have been found to be related to both poorer sleep functioning (i.e., sleep disturbances, sleep duration) and increased medical problems (Cohen et al., 2009; Irwin, 2015; Irwin et al., 2016; Shochat et al., 2014). Thus, immune functioning may be another mechanism connecting chronic illness with common sleep disturbances.

Thus, sleep disturbances among youth with a CMC appear to follow similar cycles: elevated symptoms or medication use disrupt sleep, which might decrease healing and immune function (Irwin et al., 2016; Motivala & Irwin, 2007) and aggravate daytime symptoms to further

disturb the next night of sleep. These trends may be aggravated for youth with a CMC in the college setting due to the aforementioned maladaptive sleep environment and sleep hygiene practices of this environment (Hershner & Chervin, 2014).

However, the sleep disturbances of youth with a CMC likely originate from not just physiological mechanisms, and psychosocial predictors of sleep merit further research. Notably, college students with a CMC typically report higher levels of psychosocial problems as compared to their healthy peers (Carpentier et al., 2007; Ferro et al., 2015; Herts et al., 2014). Research with adolescents with a CMC further suggests that this negative psychosocial functioning is associated with poorer subjective sleep quality and hygiene – perhaps is more strongly tied to subjectively than objectively measured sleep (Fidler et al., 2019; Palermo et al., 2007; Palermo & Kiska, 2005). Further, some research suggests that poor psychosocial functioning precedes subjective sleep disturbances in youth with a CMC. Hysing and colleagues (2009) found that children with a CMC were at elevated risk for subjective sleep disturbances as compared to healthy children, which was nonsignificant upon controlling for psychological disorders, suggesting potential causality. Palermo et al. (2007) identified depressive symptoms and pre-sleep worry (i.e., cognitive-emotional arousal) as significant predictors of subjective sleep in a sample of adolescents with chronic pain. Thus, negative psychosocial functioning may predict the subjective sleep of college students with a CMC, perhaps to a greater extent than among college students without a CMC.

Notably, a growing body of literature suggests that subjective sleep characteristics, rather than objective, may differ for those with and without a CMC. For example, differences in PSG-measured sleep were not observed in comparing adults with and without a medical condition (Budhiraja et al., 2011). Similar results have been found among adolescents with pain, with few

differences in sleep measured via actigraphy between children and adolescents with and without chronic pain, despite subjective discrepancies, which was predictive of psychosocial functioning (Haim et al., 2004; Palermo et al., 2007). Thus, although more research is needed, subjective sleep may be an important focus of research among youth with a CMC, particularly for youth with chronic pain conditions.

In the context of youth with a CMC, cognitive-emotional arousal has received little attention, but may be an important factor predicting subjective sleep disturbances. Among adults with chronic pain conditions, those with moderate to severe sleep problems report greater pre-sleep cognitive and somatic arousal than those with mild sleep problems (Dillon et al., 2012). In another study, pre-sleep cognitive arousal, not pain severity, was the primary predictor of sleep quality among adults with chronic pain (Smith et al., 2000). Relatedly, adolescents with chronic pain report higher pre-sleep cognitive-emotional and somatic arousal than healthy adolescents (Palermo et al., 2007). Additionally, in the same study, only chronic pain and cognitive-emotional arousal emerged as a significant predictor of insomnia in the total sample (Palermo et al., 2007). Thus, there is promising evidence that cognitive-emotional arousal is indeed an important predictor of sleep problems among individuals with a CMC as in the general population. However, more research is needed, particularly studies with youth with diagnosed with other chronic illnesses. Further, exploring additional psychosocial factors that predict the subjective sleep disturbances of youth with a CMC clarifies this population's specific risk for sleep disturbances and informs the development of targeted intervention.

Illness Uncertainty

The subjective sleep quality of youth with a CMC might be better understood by investigating other psychosocial factors, particularly cognitive appraisal mechanisms specific to

this population. Illness uncertainty is one such prominent construct. Illness uncertainty refers to the extent that an individual negatively appraises their illness and its course as ambiguous, complex, or unpredictable (Mishel, 1990; Mullins et al., 1997). Illness uncertainty has been shown to be consistently predictive of psychosocial functioning in youth with a CMC, and may indeed be particularly applicable to college students as they transition to independently managing their health care needs (Carpentier et al., 2006; Hommel et al., 2003; Mullins et al., 2017; Sharkey et al., 2018). Illness uncertainty has yet to be tested in relation to sleep difficulties or cognitive-emotional arousal. Theoretically, greater illness uncertainty, by increasing psychological distress, may cause elevated cognitive-emotional arousal before sleep (following Harvey's Cognitive Model of Insomnia; Harvey, 2002). The actual content of pre-sleep cognitive-emotional arousal is understood to be primarily related to problem-solving or planning for the future, and these thoughts may or may not be directly related to sleep (Lemyre et al., 2020; Wicklow & Espie, 2000). Thus, among youth with a CMC, the content of cognitive-emotional arousal is yet to be investigated but could entail problem-solving health-related concerns or worries about the physiological problems that disrupt their sleep (e.g., pain, sleep-disordered breathing).

If illness uncertainty is associated with increased psychosocial distress and increased cognitive-emotional arousal, then illness uncertainty may be indirectly related to subjective sleep quality (Illness Uncertainty → Anxious and Depressive Symptoms → Cognitive-Emotional Arousal → Sleep Quality). Investigation of this model may fill a gap in our understanding of the psychosocial mechanisms for poor sleep among college students with a CMC, with the potential for generalizability to other pediatric populations with further replication. Considering prior research testing illness uncertainty management interventions for families of youth with a CMC

appear to be effective in reducing distress (Hoff et al., 2005; Mullins et al., 2012), such a mechanism would have valuable clinical implications to inform our understanding of the development and maintenance of sleep disturbances in this population.

Summary

Although youth with a chronic medical condition (CMC) appear to be more likely to experience subjective sleep disturbances, including poorer sleep hygiene and sleep quality, few studies have examined the sleep of young adults or college students with a CMC. Additionally, there is relatively limited research on the psychosocial outcomes that theoretically precede these sleep disturbances. The current study aims to expand on the limited existing research examining sleep in college students with a CMC by investigating the extent of subjective sleep disturbances and their relationships with relevant psychosocial outcomes. The following aims are the primary focus of the current study.

First, we aimed to compare the sleep hygiene and sleep quality of AYA with a chronic medical condition (CMC) in the college setting to a matched sample of healthy peers, expanding on the limited prior research with this population. It was hypothesized that sleep hygiene and sleep quality would be significantly poorer for AYA with a CMC as compared to healthy college students. Next, we examined the mediating effect of cognitive-emotional arousal on the relationship between internalizing symptoms and sleep quality among AYA with and without a CMC. It was hypothesized that the indirect effect of cognitive-emotional arousal would be of stronger magnitude in AYA with a CMC compared to college students without a CMC. Our final aim was to examine the mediating effects of internalizing symptoms and cognitive-emotional arousal on the relationship between illness uncertainty and sleep quality among AYA with a

CMC. It was hypothesized that illness uncertainty would have an indirect effect on sleep quality through internalizing symptoms and cognitive-emotional arousal.

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Oklahoma State University Institutional Review Board

Date:	08/02/2019
Application Number:	AS-19-89
Proposal Title:	An Examination of the Psychosocial Impact of Chronic Illness on College Students
Principal Investigator:	Larry Mullins, Ph.D
Co-Investigator(s):	
Faculty Adviser:	
Project Coordinator:	Katie Traino
Research Assistant(s):	
Processed as:	Exempt
Exempt Category:	

Status Recommended by Reviewer(s): Approved

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in 45CFR46.

This study meets criteria in the Revised Common Rule, as well as, one or more of the circumstances for which continuing review is not required. As Principal Investigator of this research, you will be required to submit a status report to the IRB triennially.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be approved by the IRB. Protocol modifications requiring approval may include changes to the title, PI, adviser, other research personnel, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period. This continuation must receive IRB review and approval before the research can continue.
3. Report any unanticipated and/or adverse events to the IRB Office promptly.
4. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact the IRB Office at 405-744-3377 or irb@okstate.edu.

Sincerely,
Oklahoma State University IRB

LIST OF TABLES

Table 1
Sample Characteristics (N = 274)

	CMC Group (N = 137)	Non-CMC Group (N = 137)
Demographics	N (%) or M ± SD	N (%) or M ± SD
Age	19.70 ± 1.39	19.70 ± 1.39
Sex		
Female	115 (83.9)	115 (83.9)
Race/Ethnicity		
White/Caucasian	111 (81.0)	111 (81.0)
Black/African American	3 (2.9)	4 (2.9)
Asian/Asian American	1 (0.7)	1 (0.7)
Native American	13 (9.5)	13 (9.5)
Multiracial	6 (4.4)	6 (4.4)
Other	2 (1.5)	2 (1.5)
Ethnicity		
Hispanic/Latinx	13 (9.5)	16 (11.7)
Education		
Underclassmen	75 (54.7)	62 (45.3)
Upperclassmen	62 (45.3)	75 (54.7)
English-speaking as First Language		
English	136 (98.0)	135 (98.5)
First Generation College Student	34 (24.8)	26 (19)
Maternal Education		
Less than a college degree	44 (32.1)	37 (27.0)
College degree (Associate's or Bachelor's degree) and above	93 (67.9)	97 (73.0)
Annual Family Income*		
$0-49,999	20 (23.0)	24 (22.6)
$50,000-99,999	72 (43.3)	54 (34.3)
$100,000+	43 (31.9)	59 (43.1)
COVID-19 Pandemic Timing		
Prior to US COVID-19	45 (32.8)	45 (32.8)
After US COVID-19	92 (67.2)	92 (67.2)
Disease**		
Asthma	60 (43.8)	

Allergies	44 (32.1)	
Irritable Bowel Syndrome	12 (8.8)	
Inflammatory Bowel Disease	9 (6.6)	
Type I Diabetes	10 (7.3)	
Other (e.g., chronic migraines, fibromyalgia)	24 (17.5)	
Variables of Interest		
Illness Uncertainty (MUIS-C)	63.10 ± 16.04	
Depressive Symptoms (CES-D)	24.35 ± 14.38	16.63 ±12.62
Anxious Symptoms (SAS)	46.64 ± 11.96	37.47 ± 9.88
Sleep Hygiene (rASHS)		
Total Score	4.23 ± 0.64	3.99 ± 0.63
Physiological Arousal	4.80 ± 0.67	4.63 ± 0.70
Behavioral Arousal	2.90 ± 1.21	2.72 ± 1.21
Cognitive-Emotional Arousal	3.52 ± 0.96	4.06 ± 1.08
Daytime Sleep	4.90 ± 1.04	4.61 ± 1.20
Sleep Environment	5.13 ± 0.73	4.99 ± 0.77
Sleep Stability	2.59 ± 1.05	3.47 ± 0.95
Sleep Quality (rASWS)		
Total Score	3.20 ± 1.02	3.79 ± 1.15
Sleep Onset	4.40 ± 1.17	3.58 ± 1.31
Going to Bed	3.76 ± 1.15	3.44 ± 1.26
Returning to Wakefulness	3.21 ±1.32	2.60 ± 1.20

Note. MUIS-C = Mishel Uncertainty in Illness Scale, Community Form, CES-D = Center for Epidemiological Studies Depression Scale; SAS = Self-rating Anxiety Scale; rASHS = Adolescent Sleep Hygiene Scale, revised; rASWS = Adolescent Sleep Wake Scale, revised.
*Missing n = 2.
**Participants can list multiple medical conditions. Percentages indicate % of total participants that report the respective diagnosis.

Table 2
Bivariate Correlations in Chronic Medical Condition Sample

	1	2	3	4	5	6	7	8	9	10
1. Age	-	.74***	.03	.13	-.02	-.01	.11	.09	-.04	-.09
2. Education Level		-	.16	.15	-.06	-.06	.18*	.11	.14	-.07
3. Maternal Education			-	.30**	.05	-.04	.04	.03	.06	-.03
4. Annual Family Income				-	-.19*	-.15	.16	.18*	.17*	-.19*
5. CES-D Total Score					-	.81**	-.70**	-.48***	-.54**	.60***
6. SAS Total Score						-	-.63**	-.50**	-.52**	.61***
7. rASHS Cognitive-Emotional Arousal Score							-	.69***	.60**	-.45***
8. rASHS Total Score								-	.59**	-.29**
9. rASWS Total Score									-	-.36***
10. MUIS-C Total Score										-

Note. *p <.05, ** p <.01, *** p <.001
CES-D = Center for Epidemiological Studies Depression Scale; SAS = Self-rating Anxiety Scale; rASHS = Adolescent Sleep Hygiene Scale, revised; rASWS = Adolescent Sleep Wake Scale, revised; MUIS-C = Mishel Uncertainty in Illness Scale, Community Form.

Table 3
Bivariate Correlations in Physically Healthy Sample

	1	2	3	4	5	6	7	8	9
1. Age	-	.79***	.02	.03	.31**	.22*	-.07	.11	-.09
2. Education Level		-	-.01	-.01	.18*	.07	-.07	.03	-.04
3. Maternal Education Level			-	.31***	.03	-.02	-.06	.01	-.01
4. Annual Family Income				-	-.03	.02	-.05	-.07	-.02
5. CES-D Total Score					-	.81***	-.62***	-.47**	-.57***
6. SAS Total Score						-	-.60***	-.48**	-.55***
7. rASHS Cognitive-Emotional Arousal Score							-	.81**	.53***
8. rASHS Total Score								-	.51**
9. rASWS Total Score									-

Note. *p <.05, ** p <.01, *** p <.001
CES-D = Center for Epidemiological Studies Depression Scale; SAS = Self-rating Anxiety Scale; rASHS = Adolescent Sleep Hygiene Scale, revised; rASWS= Adolescent Sleep Wake Scale, revised.

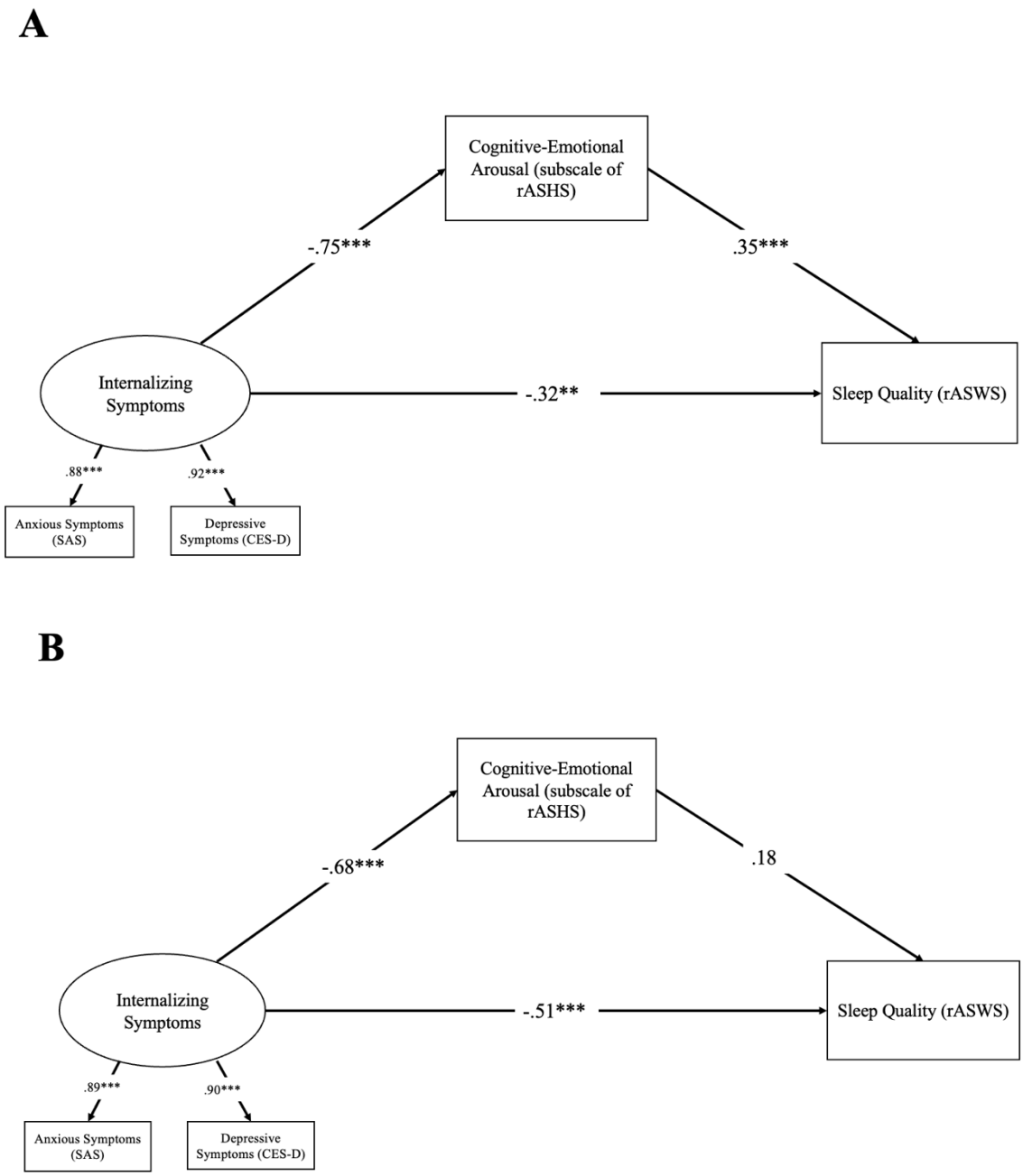

Figure 1. Path analysis diagram of Aim 2 (internalizing symptoms → cognitive-emotional arousal → sleep quality) in the CMC group (Figure 1a) and non-CMC group (Figure 1b).

Note. *p <.05, ** p <.01, *** p <.001. Covariates were included in the model (i.e., participant age, sex, COVID-19 status, annual family income) but not depicted. Higher Cognitive-Emotional Arousal scores indicate lower arousal; higher sleep quality scores indicate better sleep quality
CES-D = Center for Epidemiological Studies Depression Scale; SAS = Self-rating Anxiety Scale; rASHS = Adolescent Sleep Hygiene Scale, revised; rASWS = Adolescent Sleep Wake Scale, revised.

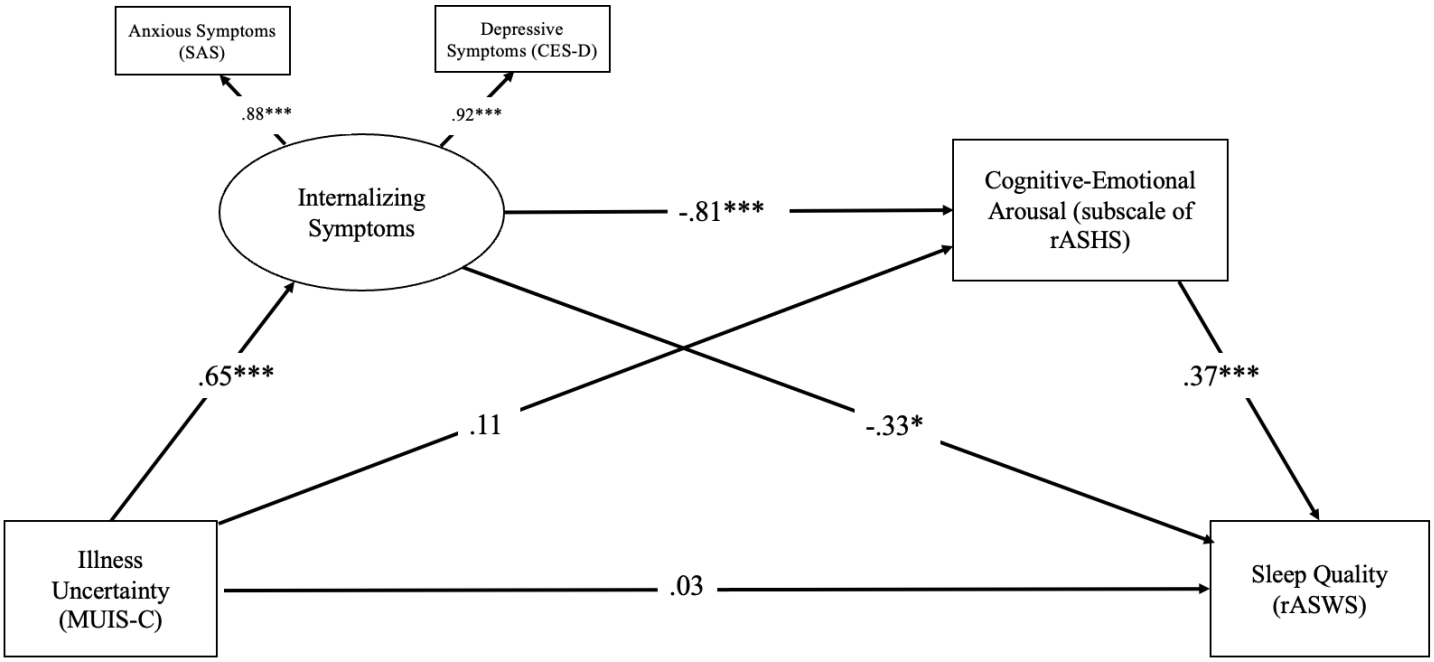

Figure 2. Path analysis diagram of Aim 3.
Note. *p <.05, ** p <.01, *** p <.001. Covariates were included in the model (i.e., participant age, sex, COVID-19 status, annual family income) but not depicted. Higher Cognitive-Emotional Arousal scores indicate lower arousal; higher sleep quality scores indicate better sleep quality
CES-D = Center for Epidemiological Studies Depression Scale; SAS = Self-rating Anxiety Scale; rASHS = Adolescent Sleep Hygiene Scale, revised; rASWS = Adolescent Sleep Wake Scale, revised; MUIS-C = Mishel Uncertainty in Illness Scale, Community Form.

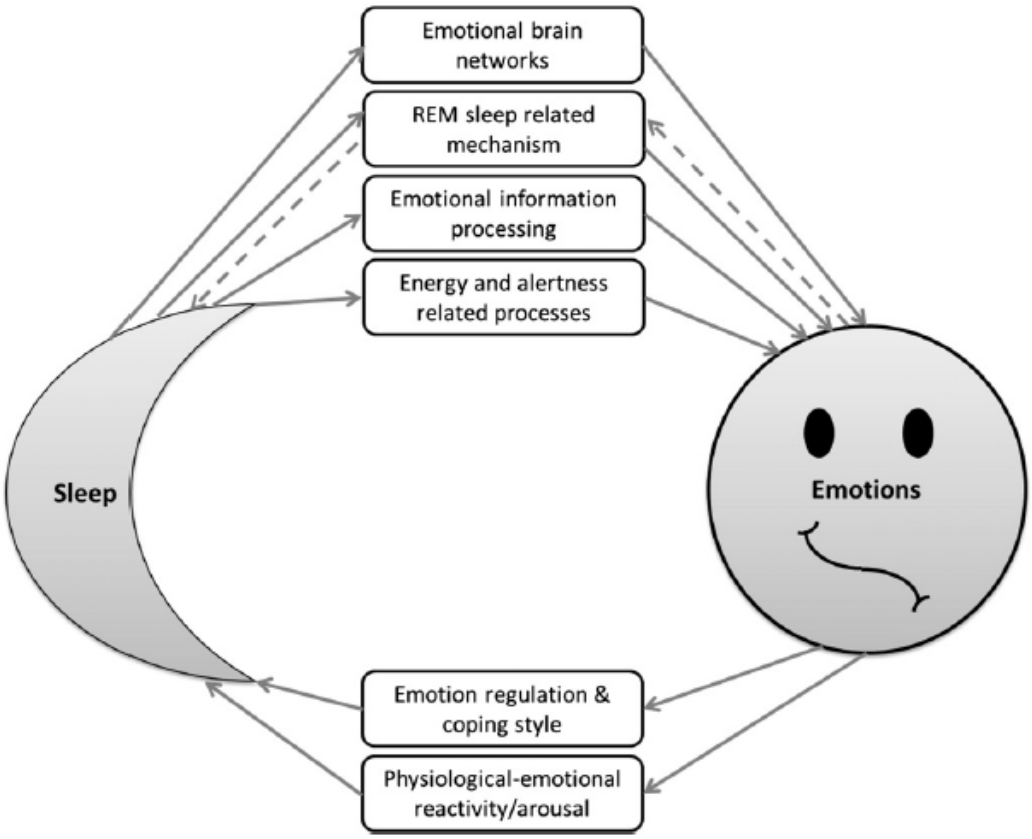

Figure 3. Summary of empirical bidirectional relationships between sleep and emotions (Kahn et al., 2013).

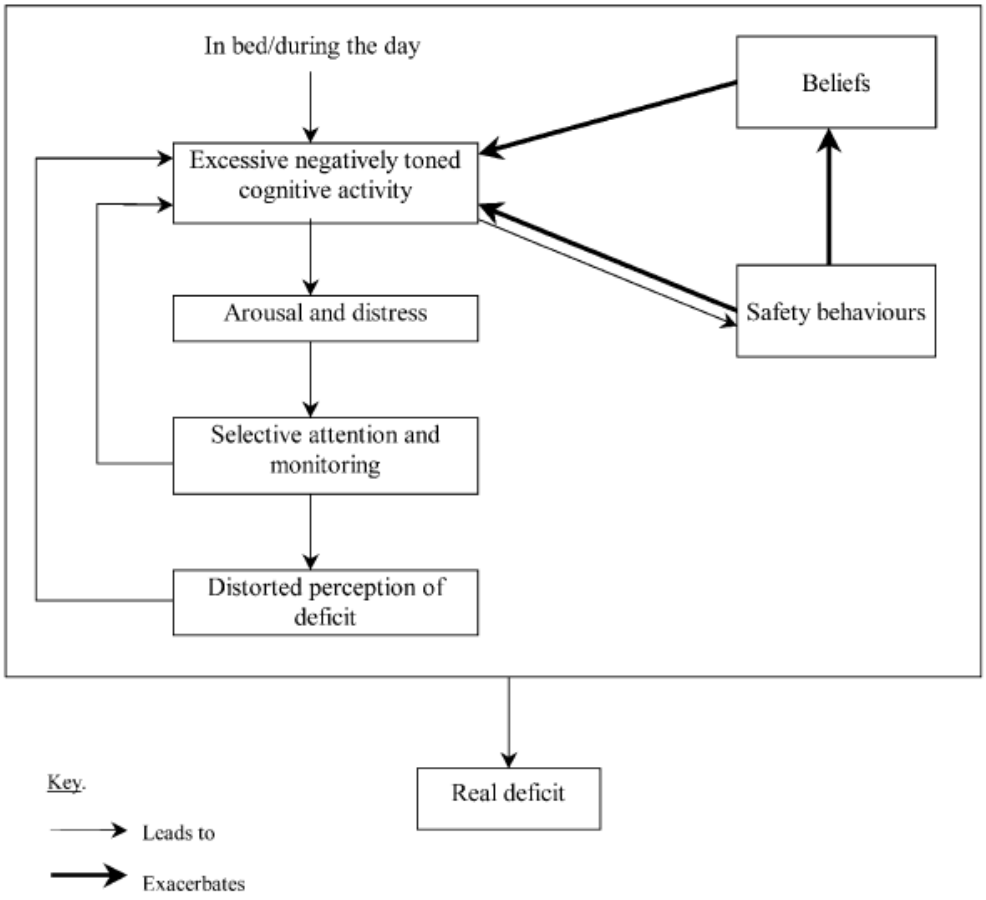

Figure 4. Cognitive Model of Insomnia (Harvey, 2002).

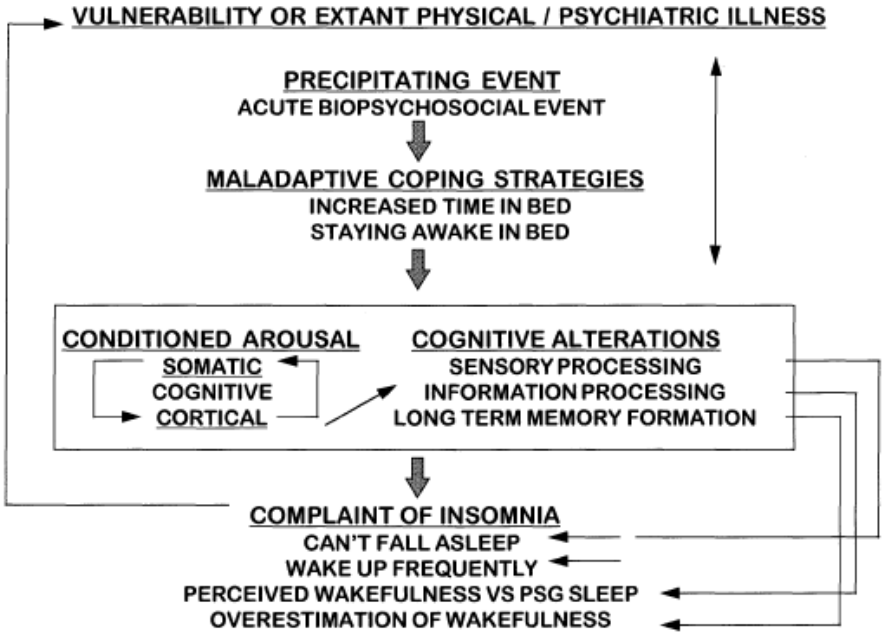

Figure 5. Behavioral Model of Psychophysiological Insomnia (Perlis et al., 1997).

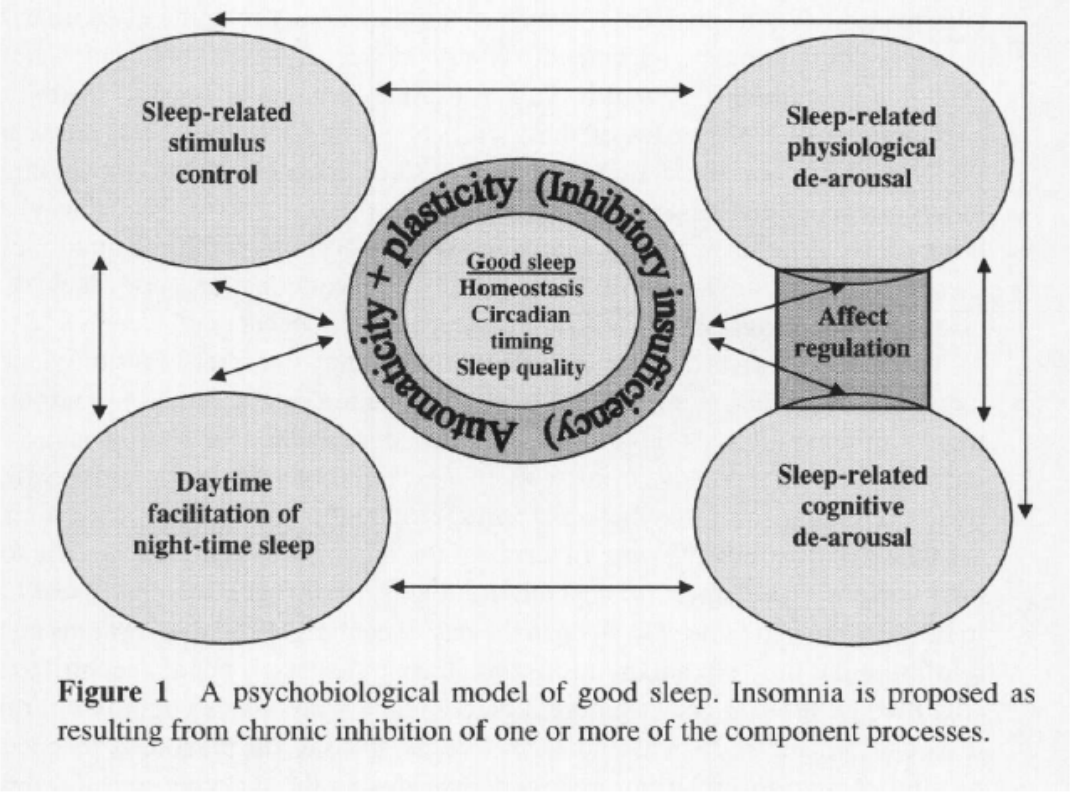

Figure 1 A psychobiological model of good sleep. Insomnia is proposed as resulting from chronic inhibition of one or more of the component processes.

Figure 6. Psychobiological Model of Insomnia (Espie, 2002).

VITA

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