A USER-CENTERED APPROACH IN THE DEVELOPMENT OF AN EHEALTH
SLEEP INTERVENTION FOR ADOLESCENTS WITH AND WITHOUT
RECURRENT PAIN

By

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Dedication

This dissertation is dedicated to my grandmother, Grammie, Mrs. Dorothy Alan Bailey. There are so many aspects of my life that I can thank my grandmother for, and my education is but one of them. I can say with certainty that I would not be who I am today and doing what I am doing (on the brink of completing my PhD and starting a new life adventure), without her influence, example, motivation, support, generosity, and love. Thank you, Grammie, for being such a pivotal component of my life and my journey. I am dedicating this dissertation, and the work that I have put into it, to you. Thank you today, tomorrow, and for the rest of my life. I love you.

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Abstract

Healthy sleep is critical for adolescents' functioning. However, 25% of adolescents report sleeping less than the recommended 8-10 hours a night. Sleep and recurrent pain often occur together in adolescents, both negatively influencing functioning. While in-person adolescent sleep interventions are effective, several barriers impact access to treatment (e.g., clinician availability). The delivery of eHealth interventions has potential to improve access to evidence-based sleep treatment.

The primary objective of this dissertation was to follow a user-centered approach in developing an eHealth sleep intervention for adolescents with and without recurrent pain. This dissertation consists of three studies: 1) focus group testing, 2) usability testing, and 3) pilot testing of an eHealth sleep intervention.

Through online focus groups, opinions were gathered from adolescents (with and without recurrent pain) and stakeholders (parents, educators, health care professionals) about adolescents' use of healthy sleep practices and eHealth sleep intervention. Most healthy sleep practices were considered reasonable for adolescents to implement. However, many barriers to sleep practices were identified. Interactive features were desirable for an eHealth sleep intervention. Participants reported that a program appearing too educational was a barrier, while accessibility was a common facilitator. Most discussions were consistent across groups. Feedback from the focus groups was incorporated into development of *Better Nights, Better Days – Youth (BNBD-Youth)*.

Usability testing of *BNBD-Youth* revealed that the program was positively received for meeting adolescents' needs, with high overall ratings for usability. Minor modifications to the program based on suggestions from user feedback are recommended. Pilot testing of *BNBD-Youth* achieved high rates of participant retention, pre-post data collection, and diary completion. Further, *BNBD-Youth* led to significant improvement across several post-intervention sleep, daytime functioning, and pain outcomes. Finally, these results identified that a small-moderate effect size was needed to demonstrate significant change in sleep efficacy for future RCT testing.

Results of these studies support following a user-centered approach in developing and testing an eHealth sleep intervention for adolescents with and without recurrent pain. These findings are encouraging for larger-scale testing and implementation of *BNBD-Youth* with the goal of increasing adolescents' accessibility to evidence-based treatment and improving sleep and daytime functioning.

List of Abbreviations and Symbols Used

ADHD = Attention deficit hyperactive disorder

BNBD-Youth = Better Nights, Better Days - Youth

CBT = Cognitive behavioural therapy

CBT-D = Cognitive behavioural therapy for depression

CBT-I = Cognitive behavioural therapy for insomnia

CES-D = Center for Epidemiologic Studies Depression Scale

eHealth = Electronic health intervention

DOZE = Delivering Online Zzz's with Empirical support

FDI = Functional Disability Inventory

ISI = Insomnia Severity Index

M = mean

mins = minutes

$N; n$ = sample size / sub-sample size

NA = Not available

RCT = Randomized controlled trial

RM-ANOVA = Repeated measures analysis of variance

SD = standard deviation

SE = Sleep efficiency

SHI = Sleep Hygiene Index

SOL = Sleep onset latency

TST = Total sleep time

WASO = Wake after sleep onset

Chapter 1: Introduction

Prevalence of Adolescent Sleep Problems

It is estimated that of adolescents 12-18 years old, 10% meet clinical criteria for insomnia, defined as having difficulty initiating sleep, maintaining sleep, or early morning waking, and up to 30% of adolescents report experiencing some insomnia symptoms (Dohnt et al., 2012; Lewien et al., 2021; Liang et al., 2021; Owens, 2008). Adolescents commonly report trouble falling asleep (15-37%), waking up in the night with difficulty falling back asleep (16%), waking too early in the morning (14%), feeling unrested during the day (30%), and experiencing poor sleep quality (53%) (Ram et al., 2010; Varghese et al., 2021; Galan-Lopez et al., 2021; Tekcan et al., 2020). Up to 65% of adolescents report taking more than the optimal 30 minutes or less to fall asleep, with an average sleep onset latency of 47 minutes (Hysing et al., 2013). The median reported age of insomnia onset is 11 years, with the most common symptom being delayed sleep onset (Johnson et al., 2006). During adolescence, sleep duration continuously decreases with age from an average of 8.5 hours of sleep per night at age 13, to 7.3 hours per night at age 18 (Maslowsky & Ozer, 2014; Ram et al., 2010). Up to 85% of adolescents report sleeping less than the National Sleep Foundation's recommended 8-10 hours each night (Foundation, 2006; Galan-Lopez et al., 2021; Gariepy et al., 2020; Saxvig et al., 2020; Sousa-Sá et al., 2021). Adolescent sleep problems are reported to persist into adulthood for up to 50% of individuals, with significant negative impacts on daily functioning in both adolescents and adults (Hysing et al., 2020).

Impact of Poor Sleep in Adolescents

Poor sleep quality and quantity is known to influence several areas of daily life, including academic performance, cognitive processing, physical functioning, mental health, and risk-taking behaviours (Chaput et al., 2016; Hedin et al., 2020; Shochat et al., 2014). Later bedtimes and shorter sleep duration are commonly associated with poorer grades in adolescents (Hysing et al., 2016; Sharman & Illingworth, 2020; Short et al., 2013). These findings are unsurprising given that studies have shown sleep restriction to impair a variety of adolescent cognitive functions including attention, working memory, executive functioning, and alertness (Lo et al., 2016). In addition to academic and cognitive functioning, poor sleep in adolescents has been found to be associated with impaired physical health including being overweight, cardiovascular risk, acute illness, and recurrent pain (Hedin et al., 2020; Orzech et al., 2014; Short et al., 2011).

Other common comorbidities with sleep problems are mental health concerns such as anxiety and depression, such that 50% of adolescents with insomnia fulfill criteria for at least one psychiatric disorder (Ohayon & Roth, 2003). Adolescents with a reported sleep disorder diagnosis are considered to be at an increased risk of depressive symptoms (Inkelis et al., 2021). Conversely, longer sleep duration in adolescents is associated with fewer reported depressive symptoms and improvement in insomnia symptoms is reported to directly mediate long-term improvement in psychopathology symptoms (de Bruin et al., 2018; Pasch et al., 2010). Further, adolescent sleep problems have been found to be significantly associated with the onset of a depression, bipolar, or psychotic disorder by the age of 30 (Morishima et al., 2020; Scott et al., 2021). Sleep problems have also been found to be associated with risky behaviours in adolescents. Of high school students with

drivers' licenses, 40% report being sleepy while driving, and of those who had been in accidents, 11% reported having a car crash in which sleepiness was the main cause (Pizza et al., 2010). Other risky behaviours found to be associated with sleep problems in adolescents include impaired driving, cigarette smoking, and substance use problems (de Zambotti et al., 2018; Groenewald et al., 2021; Short et al., 2013).

Epidemiology of Recurrent Pain and Sleep Problems in Adolescents

Sleep problems and their associated impacts are even more common in adolescent populations with recurrent pain (pain that occurs at least once per week for a period of at least three months). Recurrent pain, most commonly headache, musculoskeletal pain, and abdominal pain, often onsetss during adolescence and influences up to 30% of adolescents (Gobina et al., 2015; King et al., 2011; Stanford et al., 2008). Similar to sleep problems, the onset of recurrent pain is due to a range of biopsychosocial factors and can also have broad impacts on school, psychological, and physical functioning (Palermo, 2000). Up to 50% of adolescents with recurrent pain report not meeting sleep needs, compared to 30% of pain-free adolescents (Owens, 2008; Palermo et al., 2011), with adolescents reporting weekly pain more likely to experience insufficient sleep duration (Klavina-Makrecka et al., 2020). Moreover, while daytime tiredness and waking during the night have been linked with the onset and aggravation of recurrent pain (El-Metwally et al., 2007; Lewandowski et al., 2010), poor sleep quality has been linked with limitations in daily activities in adolescents with recurrent pain (Palermo et al., 2008). A bidirectional relationship between sleep and pain in adolescents has been suggested, such that pain may impact sleep and conversely sleep disturbances may aggravate pain sensitivity and severity (Chambers et al., 2008; Dick, 2013; Lewin & Dahl, 1999; Valrie

et al., 2013). Adolescence is a challenging time to achieve appropriate sleep duration and quality, when these are not met, a number of deleterious effects may occur, even further affecting adolescents with recurrent pain.

Why is Adolescence Important for Sleep?

Worldwide, significant changes in sleep timing and duration occur in adolescence due to a range of biopsychosocial factors (Crowley et al., 2018; Gradisar et al., 2011; Olds et al., 2010). Biological changes during this developmental stage cause adolescents to experience a phase shift in circadian rhythms, resulting in less drive to fall asleep while transitioning their natural bedtimes and waketimes to be later in the day (Carskadon, 2011; Chung & Cheung, 2008; Crowley et al., 2018; Feinberg et al., 2006; Gradisar et al., 2011; Loessl et al., 2008).

While the biological phase shift leads adolescents to stay awake later at night and sleep in later in the morning, psychosocial barriers concurrently interfere with healthy sleep practices (referred to in previous literature as sleep hygiene) and contribute to increasing sleep difficulty. This is a time when parental control over bedtime decreases and autonomy for activities that interfere with healthy sleep practices increases (e.g., caffeine intake, social media use at night, variability in bed and wake times) (Mindell & Meltzer, 2008; Randler & Bilger, 2009; Short et al., 2011; Woods & Scott, 2016). Factors causing variability in adolescent sleep schedules and contributing to sleep problems include early school start times, academic commitments, participation in extracurricular activities, after-school employment, and socializing with friends (Gaarde et al., 2020; Owens, 2014). Further, adolescent use of electronic devices before bed have been linked

with poor sleep quality, delayed sleep onset, sleep interruptions, reduced sleep duration, and efficiency, as well as increased daytime sleepiness (Charmaraman et al., 2020; Fobian et al., 2016; Hale & Guan, 2015; Johansson et al., 2016; Kokka et al., 2021; Woods & Scott, 2016).

The developmental changes that occur in adolescence culminate in what has been coined "the perfect storm" of biopsychosocial factors (Carskadon, 2011; Crowley et al., 2018). At a time when biological sleep patterns are naturally shifting to later in the day, psychosocial barriers to healthy sleep practices also increase. In addition to the biopsychosocial factors that interfere with sleep in adolescents, youth with recurrent pain experience pain-related barriers to sleep. Pain episodes may directly interrupt sleep as whereas pain-related thoughts and emotions may interfere with sleep. Insufficient sleep in youth with recurrent pain has potential to impair daytime functioning, which can in turn interfere with pain management, leading to a continuation of pain and sleep interference (Puzino & Mindell., 2015).

The interaction of these numerous biopsychosocial influences occurring in adolescents contributes to adolescent sleep changes and behavior, and negatively impacts several areas of adolescent daytime functioning. Multiple studies, however, have reported that when adolescents follow healthy sleep practices, such as turning phones off the hour before bed, they experience earlier bedtimes and sleep for longer (Bartel et al., 2019; Bartel et al., 2015). Increasing awareness of the importance of sleep and teaching healthy sleep practices during this vulnerable time is critical to combat the various factors influencing sleep difficulties in adolescence.

Treatment of Adolescent Sleep Problems

Despite its high prevalence and significant impact on daily living, adolescents'
problematic sleeping can effectively be treated, most often through targeted behavioural
strategies to manage healthy sleep practices (Lunsford-Avery et al., 2021).
Recommendations include advice about sleep behaviours and lifestyle factors such as
consistent bedtimes and waketimes, bedtime routine, active lifestyle, and no use of
electronics before bed, see Table 1.1 (Allen et al., 2016). Focus groups have identified
that while adolescents understand and are aware of healthy sleep practices, they have
limited success implementing them on their own (Godsell & White, 2019; Paterson et al.,
2019). Several factors have been reported that prevent adolescents from being successful
in changing their sleep behaviour, including time demands, varying habits, use of
technology, difficulty switching off their minds to fall asleep, and distracting bedroom
environments (Godsell & White, 2019; Paterson et al., 2019).

Based on an extensive review of the literature as well as an examination of several
existing systematic reviews (Åslund et al., 2018; Blake et al., 2017; Griggs et al., 2020;
McLay et al., 2020), ten interventions providing behavioural strategies to manage
adolescent sleep have been identified; see Table 1.2. Most adolescent behavioural sleep
interventions have used face-to-face individual or group-based approaches, with
consistent improvement in sleep outcomes, including sleep efficiency (proportion of time
in bed spent asleep), total sleep time, sleep onset latency (time it takes to fall asleep),
sleep quality, daytime sleepiness, anxiety, and depression (Bei et al., 2013; Blake et al.,
2016; Clarke et al., 2015; de Bruin et al., 2015; de Bruin et al., 2018; Gradisar et al.,
2011; Roeser et al., 2016; Schlarb et al., 2011; Tan et al., 2012).

Limited sleep intervention research has also targeted adolescents with recurrent pain. Two in-person studies (one parent-only, one adolescent-only participants) tested the role of sleep management for adolescents with recurrent pain and reported significant changes in the duration and frequency of pain, as well as improved sleep habits and insomnia symptoms (Bruni et al., 1999; Law et al., 2018). Studies that have provided pain management treatment to adolescents with recurrent pain have also reported positive changes in both pain and sleep outcomes (Degotardi et al., 2006; Fales et al., 2015; Law et al., 2015; Palermo et al., 2016; Palermo et al., 2009). However, there is currently a gap in research for development and testing of an eHealth sleep intervention with adolescents experiencing recurrent pain.

Across the studies testing in-person adolescent sleep interventions, administration of treatment was generally time intensive. While two interventions were only one session long to provide education about healthy sleep practices (Bruni et al., 1999; Tan et al., 2012), the remaining Cognitive Behavioural Therapy (CBT) based interventions ranged from six to ten, 45- to 90-minute, in-person or group therapy sessions, with all interventions requiring one or more trained professionals to administer treatment (Blake et al., 2016; Clarke et al., 2015; de Bruin et al., 2015; de Bruin et al., 2018; Gradisar et al., 2011; Law et al., 2018; Roeser et al., 2016; Schlarb et al., 2011; Tan et al., 2012). Although in-person interventions are generally effective for improving sleep outcomes, protocol compliance is one of the most common barriers to success of adolescent behavioural sleep interventions (Ruiter Petrov et al., 2014). Further, many of the interventions are resource intensive regarding time investment and utilization of health care providers (Gradisar & Richardson, 2015; Reardon et al., 2017).

Another approach to addressing sleep challenges in adolescents has been through providing sleep education in schools. Sleep education is increasingly being delivered in schools, which is relatively easy to implement and allows for direct and quick access to large numbers of adolescents with content delivered during school hours in classroom-style formats (Chung et al., 2017). Recent reviews and large-scale randomized controlled trials (RCTs), however, have found that while these school-based programs are effective in improving knowledge about sleep, they are less effective in improving sleep behaviour (Blunden & Rigney, 2015; Blunden et al., 2012; Gruber, 2017; Kira et al., 2014; Rigney, Watson, et al., 2021; Wing et al., 2015). Moreover, school-based sleep education programs are often broad-based and regularly do not include options for individualized treatment. A potential solution for addressing barriers of adolescent accessibility and adherence to behavioural sleep treatment is in translating effective treatment to online delivery methods.

eHealth Interventions

Electronic health interventions (eHealth interventions) are treatments provided using electronic methods of delivery, such as websites accessed over the internet or applications for mobile phones. eHealth interventions offer accessible, cost-effective, and timely resources that address many barriers restricting adolescents from receiving in-person treatment and can include personalized and engaging features that are often lacking in school-based education programs (Cushing & Steele, 2010; Docebo, 2014). There are only three studies, however, that report development of online sleep interventions for adolescents, with all studies reporting sleep improvement, including

sleep hygiene, insomnia symptoms, and sleep quality (Carmona et al., 2020; de Bruin et al., 2015; Werner-Seidler et al., 2019).

An RCT that compared CBT for insomnia (CBT-I) delivered either online or in-person found that both delivery methods were equally effective for improvement in adolescent sleep outcomes (de Bruin et al., 2015). Although the online intervention required some therapist involvement via chat sessions and written feedback, it was found to be more cost-effective than in-person delivery and was also adolescents' preferred delivery method when given the choice (de Bruin, et al., 2015; de Bruin et al., 2016). The other two eHealth sleep intervention studies described development of app-based programs, *Sleep Ninja* (Werner-Seidler et al., 2017) and *Delivering Online Zzz's with Empirical support (DOZE)* (Carmona et al., 2020), with both studies reporting that adolescents were involved in early intervention development. Pilot testing of *Sleep Ninja*, however, revealed poor retention rates with only one-third of participants completing the program and users reporting too much text and repetitive information as main reasons for discontinuing (Werner-Seidler et al., 2019). Although pilot testing of *DOZE* demonstrated improvement in sleep outcomes, was appraised by participants as an acceptable app, and demonstrated feasibility of its use, only 24% of the sample were adolescents ranging from 15-18 years old with the remaining being 19-24 years old (76%), and demographics were not reported for the adolescents who provided input to the app's early user-centered development phase (Carmona et al., 2020).

The three existing eHealth sleep interventions are a promising start to the delivery of evidence-based behavioural sleep treatment to adolescents. However, each of these interventions had barriers that may interfere with administration or access to treatment.

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The involvement of a health care provider's written support prevents a web-based treatment from being a self-guided program entirely driven by adolescents, and also relies on the provider's availability as well as the need for resources to support their engagement (de Bruin et al., 2015). Program adherence and completion rates (Werner-Seidler et al., 2017), and minimal involvement of adolescents in pilot testing and development (Carmona et al., 2020) also demonstrate potential barriers to appropriately meeting adolescents' needs with existing eHealth sleep interventions. Although these app-based programs have involved end-users throughout intervention development, existing research leaves continuing gaps in meeting adolescents' needs.

User-Centered Design

User-centered designs include engagement of end-users throughout treatment development, with the purpose of creating a program that is useful and of value to the target population (De Vito Dabbs et al., 2009). The success of healthcare applications depends not only on the information provided, but also on how the application is interacted with and used. Involving end-users in design and testing increases the likelihood of promoting intended health outcomes (De Vito Dabbs et al., 2009). While in-person interventions can be tailored in the moment, web-based applications need to consider user engagement and personalization in advance. Despite a plethora of eHealth applications, only a small number report including end-users in empirical testing and development (Higgins et al., 2018; Majid et al., 2010). Early involvement of end-users in the design and testing of eHealth treatment can identify factors that encourage or deter use of an intervention. This user participation enhances the likelihood of intervention uptake through engagement and participation thus increasing the likelihood of improving

intended health outcomes (De Vito Dabbs et al., 2009). Adolescents' involvement in eHealth sleep intervention development is critical to understanding the barriers and facilitators to intervention use for development of an engaging and desirable end-product.

Dissertation Objectives

There is need for research developing and testing the efficacy of accessible adolescent eHealth sleep interventions for treating adolescent sleep problems. Focused integration of user-input at every stage is necessary to create an intervention that will be used and helpful for adolescents. As such, this research followed a user-centered approach in the development of an eHealth sleep intervention for adolescents with sleep problems, with and without recurrent pain. A series of studies was conducted in the development and testing of an adolescent eHealth sleep intervention, *Better Nights, Better Days – Youth* (*BNBD-Youth*) for adolescents with and without recurrent pain. Presented in Chapter 2 are the results of focus groups that were held with adolescents (with and without recurrent pain) and stakeholders associated with adolescents with and without recurrent pain (e.g., parents, educators, health care providers) to inform the barriers, facilitators, content, design, and presentation of *BNBD-Youth*. The intervention incorporated focus group feedback as discussed in Chapter 3. Described in Chapter 4 is usability testing by adolescents with and without recurrent pain of each session and the overall program to evaluate readiness of the intervention for future larger-scale RCT testing. Pilot testing by adolescents with and without recurrent pain, reported in Chapter 5, was conducted to evaluate readiness of future testing regarding the process of delivering an eHealth sleep intervention, as well as to evaluate preliminary efficacy and

identify an effect size estimate for sample size determination of future testing. An overall discussion of this series of studies is provided in Chapter 6.

Research Question 1: What are adolescents' and stakeholders' perceptions of healthy sleep practices and eHealth sleep intervention use in adolescents with and without recurrent pain?

To inform program development, focus groups were held with adolescents (with and without recurrent pain) and corresponding stakeholders (i.e., parents, educators, health care professionals). The primary aim of this research was to gather input from adolescents and stakeholders on 1) healthy sleep practices, specifically practices that are perceived as reasonable and difficult to implement, as well as barriers and facilitators to following healthy sleep practices; and 2) eHealth interventions, including desired content, features, and visual presentation, as well as barriers and facilitators to using an eHealth intervention. The secondary aim of this research was to compare responses between adolescents and stakeholders and between stakeholder and adolescent groups related to pain- and pain-free discussions to identify potential differences that may need to be considered for implementation in an eHealth sleep intervention. The feedback from this focus group study was integrated into the development of an eHealth sleep intervention, *Better Nights, Better Days – Youth (BNBD-Youth)*.

Research Question 2: Does usability testing of BNBD-Youth support readiness of future RCT testing regarding user experiences?

Usability testing of *BNBD-Youth* was conducted to identify readiness for future larger-scale testing. User experience with the developed intervention was evaluated with

adolescents 14-18 years old who experienced symptoms of insomnia, with and without recurrent pain. Usability was assessed using Morville's user experience honeycomb to evaluate the intervention on seven usability dimensions: useful, usable, findable, desirable, accessible, credible, and valuable (Morville & Sullenger, 2010). Given the common comorbidity of recurrent pain and sleep, the secondary focus of this study was to identify whether recurrent pain frequency influenced user experience as determined through usability ratings.

Research Question 3: Does pilot testing of BNBD-Youth support readiness for future RCT testing regarding procedures, outcomes, and effect size estimate?

Pilot testing of *BNBD-Youth* was conducted to evaluate the process of delivering the eHealth sleep intervention to adolescents. This pilot study aimed to evaluate the procedures of testing *BNBD-Youth* for online participant recruitment, screening, engagement, intervention adherence, and data collection. This testing also aimed to examine preliminary pre-post efficacy of the intervention on sleep, daytime functioning, and pain outcomes, evaluate the influence of pain frequency on preliminary efficacy, and estimate the effect size needed to identify differences in sleep improvement for future efficacy testing.

Table 1.1 *Overview of Healthy Sleep Practices*

Label	Definition
Sleep duration	8-10 hours of sleep each night, without any naps during the day
Consistent times	Going to bed and waking at the same time (within 1 hour) every day, including weekends
Bedtime routine	Doing the same things in the same order around the same time, every night before bed
Caffeine	No caffeine in the few hours before bed
Exciting activities	No exciting activities in the hour before bed (e.g., video games)
Hunger	Not going to bed hungry, or consuming a large meal before bed
Relaxed	Being relaxed and calm before bed
Location	Sleep in the same location every night
Bedroom	Sleep in a dark and quiet bedroom
Electronics	No electronics (including phones) in the bedroom, and no use of electronics one hour before bedtime
Room for sleep	Using the bed and bedroom only for sleep
Eating healthy	Eating a healthy, well-balanced diet
Physical activity	Engaging in regular physical activity

Note. Healthy sleep practices were defined according to the ABC's of SLEEPING framework (Allen et al., 2016).

Table 1.2. *Overview of Adolescent Behavioural Sleep Interventions*

Study	Design	Population	Age, *n*, Sex	*N*, Sex	Delivery	Intervention vs. Control	Duration	Outcome(s)
Bei et al., 2013	Single-arm pilot	Sleep problems & anxiety (female-only)	13-15 years (*M* = NA)	*n* = 62; 100% female	Group (youth)	CBT/Mindfulness	6, 90-minute weekly sessions	Improved sleep quality, SE, SOL, TST, daytime functioning
Blake et al., 2016	RCT	Sleep problems & anxiety	12-17 years (*M* = 14.4)	*n* = 123; 60% female	Group (youth)	CBT/Mindfulness vs. study skills control	7, 90-minute weekly sessions	Improved sleep quality, SOL, daytime sleepiness, anxiety symptoms
Bruni et al., 1999	RCT	Poor sleep practices & migraine	5-14.5 years (*M* = 10.3)	*n* = 70; 46% female	In-person (parent-only)	Healthy sleep practices vs. no treatment	1 session	Migraine duration, frequency, sleep habits
Carmona et al., 2020	Single-arm pilot	Dissatisfact-ion with sleep	15-24 years (*M* = 20.17)	*n* = 83; 69% female	App-based	CBT-I	4 weeks	Improved SE, TST, time awake, morning time in bed, insomnia severity, anxiety, depression, fatigue

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Study	Design	Population	Age, n, Sex	N, Sex	Delivery	Intervention vs. Control	Duration	Outcome(s)
Clarke et al., 2015	Pilot-randomized trial	Insomnia & depression	12-20 years ($M = 16.5$)	$n = 41$; 63% female	In-person (youth)	CBT-I & CBT-D vs. CBT-D (only)	10 weekly sessions	Improved TST, insomnia severity, depression symptoms
de Bruin et al., 2015, 2018	RCT	Insomnia	12-19 years ($M = 15.6$)	$n = 116$; 75% female	Internet + Therapist feedback vs. Group (youth)	CBT-I (internet) vs. CBT-I (group) vs. waiting list	6 weekly sessions + 1 booster (Group: 90 minutes; Internet: set times)	(Internet & group) Improved SE, SOL, TST, WASO, psychopathology symptoms
Gradisar et al., 2011	RCT	Delayed sleep phase disorder	11-18 years ($M = 14.6$)	$n = 49$; 47% female	In-person (youth and parent)	CBT + Bright light therapy vs. waiting list	6 (4 weekly, 2 bi-weekly) 45-minute sessions	Improved SOL, TST, WASO, daytime sleepiness, fatigue, earlier sleep, and wake times

Study	Design	Population	Age, n, Sex	N, Sex	Delivery	Intervention vs. Control	Duration	Outcome(s)
Law et al., 2018	Single-arm pilot	Migraine & insomnia	11-17 years ($M = 15.5$)	$n = 21$; 81% female	In-person (youth)	Hybrid CBT for headache and insomnia	6 sessions + 1 booster (over 6-12 weeks, 60-90 minutes per session)	Improved headache frequency, insomnia symptoms, activity limitations, sleep quality, habits, and patterns
Schlarb et al., 2010; Roeser et al., 2016	Single-arm pilot	Insomnia	11-16 years ($M = 13.73$)	$n = 18$; 55% female	Group (youth and parent)	CBT-I	6, 100-minute weekly sessions	Improved SE, SOL, TST, and feeling rested
Tan et al., 2012	Single-arm pilot	Sleep problems	10-18 years ($M = 12.9$)	$n = 33$; 55% female	In-person (youth and parent)	Healthy sleep practices	1, 90-minute session	Improved sleep hygiene, quality, sleep disturbances
Werner Seidler et al., 2019	Single-arm pilot	Sleep problems	12-16 years ($M = 13.7$)	$n = 50$; 66% female	App-based	CBT-I	6-weeks	Improved insomnia, sleep quality, depression, and anxiety

Note. CBT-I = Cognitive Behavioural Therapy for Insomnia; CBT-D = Cognitive Behavioural Therapy for Depression; M = Mean; N

= sample size; NA = Not Available; RCT = Randomized Controlled Trial; SE = Sleep Efficiency; SOL = Sleep Onset Latency; TST =

Total Sleep Time; WASO = Wake After Sleep Onset.

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Chapter 2: Focus Groups to Inform User-Centered Development of an eHealth Sleep Intervention for Adolescents

The manuscript based on this study is presented below. Readers are advised that Michelle Tougas, under the supervision of Dr. Penny Corkum, participated in the initial conceptualization of the research study, helped to develop the study protocol, and prepared submissions for ethical review, was responsible for recruitment, completed and oversaw data collection, coding, data analysis/interpretation for all components included in this study. Michelle Tougas also applied for and was successful in obtaining funding to support this research. All aspects of this research were done in consultation with the dissertation committee (Dr. Christine Chambers, and Dr. Isabel Smith). Michelle Tougas was responsible for all aspects of the writing process and received editorial feedback from dissertation committee members. The following manuscript is being prepared for publication submission as:

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Abstract

Introduction: Adolescence is a developmental stage that often coincides with increasing sleep problems. Focus groups were conducted to inform development of an adolescent eHealth sleep intervention by exploring opinions about 1) healthy sleep practices; and 2) using an eHealth intervention. Methods: Adolescents 14-18 years old experiencing symptoms of insomnia, with and without recurrent pain, and associated stakeholders were recruited. Across 6 online focus groups, 24 adolescents participated (14 pain-free, 10 with pain; 10 male, 14 female). Across 7 online focus groups, 22 stakeholders participated, including 8 parents, 9 school professionals, and 5 health care providers (10 male, 8 female). Using content analysis, subthemes were induced from transcripts. Results: Most healthy sleep practices were perceived as reasonable for adolescents to implement, except avoiding technology before bed and using bedrooms only for sleep. Many barriers to sleep practices were identified, the most common being having a variable schedule. Content addressing adolescent-specific barriers was considered important to include in a sleep intervention. Desirable eHealth components included interactive features, videos, audio, and pictures to present information. A common barrier to using an eHealth sleep intervention was the program feeling too academic, with accessibility as a common facilitator. Conclusions: This research represents the first step in a user-centered approach to developing an adolescent eHealth sleep intervention. These results provide insights from a range of perspectives on guiding adolescents to follow healthy sleep practices. Next, these findings will be integrated in the development of an eHealth sleep intervention for adolescents with and without recurrent pain.

Introduction

One in four adolescents reports sleeping less than the recommended 8-10 hours a night (Gradisar et al., 2011). Adolescence is a developmental period in which changes to sleep often occur due to a range of biopsychosocial factors (Crowley et al., 2018). Adolescents experience a phase shift in circadian processes resulting in a physiological change that drives staying up later at night and sleeping later in the morning (Carskadon, 2011). This is also a time of reduced parental involvement in regulating sleep schedules, as well as increased autonomy for activities that may contribute to adolescent sleep difficulties (Short et al., 2011). While adolescents continue to wake early for school start times, these increased social activities and variable schedules, along with the biological shift to later sleep times, interfere with healthy sleep (Paksarian et al., 2015).

During adolescence, recurrent pain (at least once per week for at least three months) often begins and influences between 13 and 32% of adolescents (King et al., 2011). Whereas 25% of pain-free adolescents report sleep problems, this is reported in up to 50% of adolescents with recurrent pain (Owens, 2008; Palermo et al., 2011). The onset of recurrent pain can also have broad negative impacts on academic, psychological, and physical functioning (Palermo, 2000). A model of sleep and pain in adolescents has suggested a bidirectional relationship, wherein pain may interfere with sleep and sleep disturbances may aggravate pain (Chambers et al., 2008; Dick, 2013). While appropriate sleep duration and quality is challenging to achieve in adolescence, youth with recurrent pain are even more affected.

Inadequate sleep quality and quantity in adolescents has been linked to negative effects on their psychological (e.g., increased rates of mental health disorders), academic (e.g., poorer grades) and physical (e.g., increased rates of metabolic disorders) functioning (Fakier & Wild, 2011; Shochat et al., 2014). Moreover, daytime tiredness and night waking have been linked with the onset and aggravation of recurrent pain (El-Metwally et al., 2007; Lewandowski et al., 2010). Considering the effects of poor sleep on adolescent functioning, increasing awareness of the importance of sleep, and teaching healthy sleep practices are critical during this vulnerable time.

Healthy sleep practices (previously referred to as sleep hygiene) include following recommendations about sleep behaviours and lifestyle factors such as using the bed only for sleeping, establishing a bedtime routine, and following an active lifestyle (Allen et al., 2016). Adolescents have reported understanding and being aware of healthy sleep practices, however, have difficulty successfully implementing them on their own (Godsell & White, 2019; Paterson et al., 2019). Adolescents have reported several factors that prevent successful healthy sleep practices, including available time, varying schedules, nighttime use of technology, active minds at night, and a distracting bedroom environment (Gaarde et al., 2020; Godsell & White, 2019; Paterson et al., 2019).

Most adolescent sleep interventions have used face-to-face delivery methods and research has found consistent improvements in sleep outcomes (Blake et al., 2018; Clarke et al., 2015; de Bruin et al., 2015; Tan et al., 2012). For pain-free adolescents, improvement in sleep hygiene, sleep quality, and sleep duration were reported for in-person interventions providing healthy sleep practices (Tan et al., 2012), and individual or group-based cognitive behavioral therapy for insomnia (Blake et al., 2018; Clarke et al., 2015; de Bruin

et al., 2015). Only two studies have reported focusing sleep intervention testing on recurrent pain adolescent populations, where managing sleep in pain populations has been reported to be associated with improved insomnia symptoms, sleep habits, pain frequency and duration (Bruni et al., 1999; Law et al., 2018). Across these studies, in-person interventions were generally time-intensive, ranging between six to ten, 90– to 100-minute weekly in-person or group therapy sessions. Further, adolescents' protocol compliance is one of the most common barriers to success of adolescent behavioural sleep interventions (Ruiter Petrov et al., 2014). While in-person interventions are generally effective for improving sleep outcomes, they are resource-intensive and difficult for adolescents to access and engage with (Gradisar & Richardson, 2015).

Sleep education delivered in schools allows for access to large numbers of adolescents (Chung et al., 2017). In an effort to overcome some of the barriers to treatment in a clinical setting, content is delivered during school hours in classroom-style formats. However, while these interventions have shown improvement in adolescents' sleep knowledge, their impact on changing sleep behaviours has been inconsistent (Blunden & Rigney, 2015). Further, sleep education programs typically focus on education, rather than behavioural strategies and do not include options for tailored treatment or specialized information such as the link between pain and sleep.

The implementation of eHealth interventions is on the rise and can help to address adolescent engagement and accessibility. Online interventions continue to evolve with advances in technology, allowing for tailored and personalized content delivery. User input is a key component in the development of desirable and engaging eHealth interventions (De Vito Dabbs et al., 2009). While in-person interventions can be tailored in the moment, web-

based applications need to consider user engagement and personalization in advance. Despite the potential for eHealth to overcome several barriers interfering with adolescents' access to effective health interventions, the majority of available health care applications do not follow a user-centered design and fail to involve users in the development process (Majid et al., 2010). End-users involved in the early design and testing of an intervention can allow for consideration of factors that encourage or deter use of an intervention. Understanding user needs from the beginning of conceptualization increases the likelihood of developing a product that will meet user needs and guide improvement in health outcomes (De Vito Dabbs et al., 2009).

With adolescents' widespread use of the internet, interventions provided online offer potentially cost-effective and timely delivery methods (Cushing & Steele, 2010; Docebo, 2014). Despite these advantages, only three online sleep interventions for adolescents have been published to date, with each study reporting positive changes in sleep outcomes (de Bruin et al., 2015; Carmona et al., 2020; Werner-Seidler et al., 2019). The available research provides a promising start for online delivery of sleep interventions to adolescents. Two studies reported including adolescent end-users in the development process, however one had a sample that included only 24% of adolescent participants 15-18 years old (the remaining sample being 19-24 years old, Carmona et al., 2020), and the other reported that only one-third of participants completed the entire intervention during pilot testing (Werner-Seidler et al., 2019). More research is needed for further intervention development and testing to meet adolescent needs for eHealth sleep treatment delivery.

This current paper describes the first step of a user-centered process for the development of an eHealth sleep intervention for adolescents with sleep problems, with and without recurrent pain. The primary aim of this research was to gather input through focus groups from adolescents and stakeholders (i.e., parents, educators, health care professionals) on 1) healthy sleep practices that are perceived as either reasonable or difficult to implement, as well as barriers and facilitators to following healthy sleep practices; and 2) desired content, features, and visual presentation of an eHealth sleep intervention, as well as barriers and facilitators to using an eHealth intervention. The secondary aim of this research was to compare responses between adolescents and stakeholders, and between pain and pain-free participants, to identify potential differences that may need to be considered for implementation in an eHealth sleep intervention.

Methods

Participants

Adolescent participants were eligible if they were between the ages of 14 and 18 years, experienced at least mild insomnia problems of falling or staying asleep, lived in Canada for at least six months, were enrolled in a Canadian junior high or high school, were proficient in English, and had access to a computer with Internet. Adolescents with pain were required to experience recurrent pain that occurred at least once per week for at least three months, with sleep problems perceived as related to pain.

Stakeholders were recruited into pain-free and pain groups based on their interaction with adolescents experiencing recurrent pain. Parents were eligible if they had a child who met the adolescent eligibility criteria (their child did not need to participate in

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this study). School professionals (i.e., teachers or school counsellors) were eligible if they were working with adolescents aged 14-18 years. Health care professionals were eligible if they were working in a Canadian clinical practice and had experience treating adolescents with recurrent pain. Adolescent and stakeholder participants were excluded if they reported experiencing an intellectual disability, and/or visual or hearing impairment that would interfere with participation.

Procedure

Participants were recruited across Canada through online advertisements, websites, social media, mailing lists, posters, and word of mouth. Interested individuals completed an online eligibility questionnaire and consent form. All consenting participants were emailed a link for an online survey to gather demographic information.

A synchronous online focus group design was followed for four groups: 1) adolescents without pain, 2) adolescents with pain, 3) stakeholders corresponding to adolescents without pain, and 4) stakeholders corresponding to adolescents with pain. Focus groups were conducted using Blackboard Collaborate (Blackboard, 2021), a secure online web conferencing software. Each 1.5-hour focus group was led by two moderators (M.T., G.B., J.M., or L.K.) using a discussion guide that included semi-structured, open-ended questions (available upon request). The questions focused on which healthy sleep practices adolescents perceived as reasonable or difficult to implement, barriers to following healthy sleep practices, and suggestions for content, features, visual presentation of an eHealth intervention, as well as barriers and facilitators to using an eHealth intervention. Participants in the pain-related groups were additionally prompted about the

role that pain may have in each topic. Focus groups were audio-recorded and transcribed (by J.M., L.K., or M.T.). All participants were emailed an honorarium $20.00 gift card.

Measures

Screening Questionnaires

Screening questionnaires assessed eligibility regarding adolescent age, insomnia symptoms, pain frequency (to identify eligibility of adolescents reporting recurrent pain) and school attendance. Stakeholders defined their role (e.g., parent, school professional, health care provider, and related to pain- or pain-free discussions). All participants were screened for Canadian residency, English proficiency, access to a computer with Internet, and cognitive or visual/hearing impairment.

Using the 7-item Insomnia Severity Index rated on a 5-point Likert scale with scores ranging from 0-28, adolescents had to endorse at least mild insomnia symptoms (score of 8 or above) (Morin et al., 2011). Subthreshold insomnia is identified with scores of 8-14, and clinical insomnia identified with scores of 15-28. The ISI shows high internal consistency in adolescents ($\alpha = 0.90$) (Chahoud et al., 2017).

Demographic Questionnaire

The demographic questionnaire asked participants to report age, sex, and ethnicity. Adolescents were also asked to report pain type(s), average intensity over the past two weeks (10-point numerical rating scale), and how long they had been experiencing pain. Stakeholders were not asked to report on insomnia or pain.

Sleep Hygiene Index

The Sleep Hygiene Index (SHI) is a 13-item scale developed from the International

Classification of Sleep Disorders diagnostic criteria that assesses sleep hygiene, also

referred to as healthy sleep practices (American Academy of Sleep, 2005; Mastin et al.,

2006). Scores range from 0 to 55, with higher scores representing poorer sleep hygiene.

Based on psychometric analysis, scores of 41 and above are in at least the 75th percentile

(Mastin et al., 2006), and for the purposes of this research were considered to be "poor"

sleep hygiene. The SHI has demonstrated acceptable internal consistency ($\alpha = 0.66$) and

reliability ($r = 0.71$, $p < 0.01$) (Mastin et al., 2006).

Data Analysis

Quantitative data were analyzed using the IBM Corp. SPSS Version 24 software.

Descriptive statistics were calculated using frequency counts for categorical data while

percentages, means, standard deviations, and ranges were used to summarize numerical

data. Unpaired t-tests were used to compare the means between pain and pain-free

adolescent and stakeholder groups.

Inductive content analysis was followed to identify subthemes within each of the

main discussion questions, across all focus groups (Moretti et al., 2011). Two reviewers

(M.T., L.K.) independently reviewed the transcribed data, with each reviewer identifying

subthemes for the main focus group questions when a topic was introduced by more than

one participant. The reviewers discussed their themes to arrive at a consensus of what label

and type of information should be applied to each subtheme. Reviewers discussed

discrepancies until consensus was reached and revised the coding as needed. The reviewers

then reviewed all transcripts, and the process continued until no new subthemes were identified and coding agreement of at least 80% was reached. Both reviewers then reviewed and coded each of the focus groups using the final coding guide. Reviewers discussed discrepancies in the final coding, with resolution by a third reviewer as needed (G.R., or P.C.). The coded transcripts were imported into NVivo 12.0, a qualitative analysis program that was used to help organize and review the coded data.

Results

Participants

Of 177 potential individuals who completed the online eligibility questionnaire, 58 consented to participate (36 adolescents, 22 stakeholders). A total of 24 adolescents participated across 6 focus groups, 14 pain-free (4 male, 10 female) and 10 with pain (6 male, 4 female). A total of 22 stakeholders participated across 7 focus groups, 12 pain-free (8 male, 4 female; 4 parents, 8 school professionals) and 10 pain-related (2 male, 8 female; 4 parents, 1 school professional, 5 health care professionals). Focus groups ranged from 2 to 9 participants.

The ages were $M = 16.64$, $SD = 1.21$ for pain-free and $M = 16.40$, $SD = 1.43$ years for pain adolescents, and $M = 41.56$, $SD = 10.85$ for pain-free and $M = 41.20$, $SD = 10.56$ for pain stakeholders. A range of ethnicities was reported with the most common being Caucasian (54% of adolescents, 59% of stakeholders).

There were no significant differences between the pain-free and pain groups in terms of sex, age, ethnicity, ISI, or SHI. All adolescent participants had at least mild insomnia symptoms, with 75% ($n = 18$) reporting clinical insomnia range (Morin et al.,

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2011). The ISI scores for the pain and pain-free groups were $M = 19.8$, $SD = 2.78$ and $M = 17.29$, $SD = 6.60$, respectively. Based on the SHI, adolescent sleep habits were moderately good (pain $M = 37.10$, $SD = 6.64$; pain-free $M = 39.93$, $SD = 5.92$), where scores of at least 41 were considered 'poor' (Mastin et al., 2006). Adolescents with pain ($n = 10$) reported experiencing headaches ($n = 7$), or musculoskeletal pain ($n = 3$), with pain intensity rated on a 10-point scale of $M = 5.38$, $SD = 1.06$, and the duration of experienced pain was $M = 6.63$ months, $SD = 4.62$. Of the 14 adolescents who reported being pain-free at the eligibility assessment, 6 reported experiencing recurrent pain in the demographic questionnaire (intensity: $M = 4.50$, $SD = 2.34$); length: $M = 3.5$ months, $SD = 4.04$). The self-selected pain-free group was maintained for these participants, despite their reports of pain as well as considering that the pain levels were reportedly lower in the non-pain group.

Focus Group Themes

Focus groups discussed two main topics based on the research objectives: 1) perception and use of healthy sleep practices; and 2) eHealth intervention development. These objectives were structured into specific questions asked to all participants during each focus group.

1. Perception and Use of Healthy Sleep Practices

Focus group moderators introduced several healthy sleep practices (see Table 1.1) and asked participants about: 1.1) Following healthy sleep practices, and specifically (a) Which healthy sleep practices are reasonable to implement? and (b) Which healthy sleep practices are most difficult to implement? 1.2) Barriers and facilitators to these healthy sleep practices, and specifically (a) What are the barriers to following healthy sleep

practices? and (b) What are the facilitators to following healthy sleep practices? Responses to these questions were summarized based on how often they were discussed across participants as well as any group differences (e.g., discussed only by stakeholders and not adolescents, or discussed only by pain-related groups and not pain-free).

1.1 Following Healthy Sleep Practices

a) Sleep Practices Considered Reasonable to Implement. All types of participants were generally familiar with each of the healthy sleep practices recommended for adolescents, and the majority of these were perceived as reasonable for adolescents to try to implement. The healthy sleep practice of <u>engaging in calming activities before bed</u> was discussed most often, with participants describing using many different calming strategies including reading, mindfulness, relaxation, drinking caffeine-free tea, listening to quiet music, snuggling with a pet, and coloring. Participants acknowledged that "*winding down is key*" and an adolescent identified "*for that half hour before bed I'm really relaxed and I'm just focusing on my reading. That's helpful to get me ready to go to bed.*"

<u>Following a bedtime routine</u> was the healthy sleep practice discussed next most often, where many participants reported having a routine or being interested in starting one. Participants were aware of the helpfulness of routines, with one teen stating: "*I know that routines really, really, do help because it kind of tells my body that it is time to go to sleep and makes me look forward to going to bed at night.*" Participants were also consistently aware of the connection between <u>regular physical activity</u> and healthy sleep, with one stakeholder identifying "*if they get active and exhausted, when they come home, they will crash and get that much needed sleep*".

The other healthy sleep practices perceived as reasonable for adolescents to implement included eating a healthy diet, keeping the bedroom quiet and dark for sleep, and sleeping 8-10 hours at night. Only pain-related adolescents and stakeholder groups discussed the importance of having no caffeine in the few hours before bed. Further, only adolescents with pain discussed knowing to avoid large meals before bed. Notably however, these last two healthy sleep practices were discussed infrequently and were not identified by any participants as factors that would be difficult to change.

b) Sleep Practices Considered Difficult to Try or Change. Adolescents were reported to have difficulty keeping technology out of the bedroom at night, resulting in a negative influence on sleep. One adolescent reported that "*I always use my phone before bed. I know most people my age do, I know it's bad, and I don't know if it is possible for me to not have in my room.*" The other healthy sleep practice that was identified as difficult to change was using the bedroom only for sleep. Stakeholders and adolescents acknowledged that the bedroom is where adolescents spend a lot of personal time, and it is difficult to expect them to use their room only for sleeping. One parent highlighted that "*it is important for teenagers to have a space that is their own where they can express themselves, for a lot of teenagers, their bedroom kind of becomes that sort of space.*" No group differences were identified for practices perceived as difficult.

1.2 Barriers and Facilitators to Healthy Sleep Practices

a) Barriers to Following Healthy Sleep Practices. Although participants identified that many healthy sleep practices felt manageable to try, they identified that several factors get in the way of being able to follow recommendations successfully and

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consistently. The most common barrier was <u>inconsistent schedules due to lifestyle</u>. Stakeholders and adolescents themselves highlighted that they have busy, variable schedules due to school, extracurricular activities, social engagements, or employment that interfere with consistent bedtime or getting a full night's sleep. One adolescent acknowledged that: *"My extracurricular activities end at different times, so I have to go to bed later some nights. It is hard for me to find an exact time to go to bed."* A parent stakeholder reported that: "*Sometimes it feels like they're fighting a losing battle. It's complicated to find a consistent bed and wake time that accommodates both a school and activity schedule.*"

The use of <u>technology at night</u> was the next most common barrier. Participants discussed using social media, watching videos, and playing video games before falling asleep. One teen highlighted "*I love going to bed late because I always chat with my friends and watch some YouTube videos. It's not good for my health, but it's like an addiction.*" Another common barrier to falling asleep was having <u>an active mind</u>. A health professional noted that "*bedtime is when they are together with their thoughts and if they haven't had the opportunity to learn strategies to manage those thoughts, it can be overwhelming.*"

The barrier of <u>motivation</u> was discussed mostly by stakeholders. One parent indicated that "*it's a really tricky age to try and enforce boundaries around things in your household, all you can do is give that information and try to motivate them as best as you can.*" How <u>academics</u> can interfere with sleep was mostly discussed by adolescents, with one teen highlighting that "*because school is so busy and important, you kind of prioritize school over sleeping.*" Only in the pain focus groups was <u>pain</u> mentioned as a barrier to following healthy sleep practices, with a health professional noting that "*pain-related*

fatigue can contribute to naps during the day or when they get home from school," and an adolescent reporting "*Pain is pretty much the only thing that gets in the way of my sleep.*"

b) Facilitators to Following Healthy Sleep Practices. Three facilitators of following healthy sleep practices were commonly discussed. Participants described how knowledge about both the negative impacts of sleep problems, and the benefits of healthy sleep can facilitate healthier sleep practices. A health professional acknowledged that "*we need to tell them the benefits of going to bed and having decent sleep, and the impacts it will have on their future.*" Focus group discussions also highlighted the importance of modeling healthy sleep practices by parents, friends, or celebrities to motivate adolescents. One parent acknowledged that: "*another good motivator is leading from example. If parents are following a healthy sleep schedule, then maybe the teenager will follow this as well.*" Only stakeholders (and no adolescents) identified setting goals as an important facilitator to healthy sleep practices, with a parent noting: "*you somehow have to find a way to get them to realize and want to take back the control that they have over their lives.*"

2) eHealth Intervention Development

Focus group moderators discussed planning the development of an adolescent eHealth sleep intervention. Discussions explored: a) desired content for an online sleep intervention, b) appealing features and visual presentation for an eHealth intervention, and c) barriers and facilitators to using an eHealth intervention.

a) eHealth Sleep Intervention Content. When participants discussed what content they perceived as most important to include in an eHealth sleep intervention, they provided suggestions from their own experiences and knowledge for how others can overcome barriers to specific healthy sleep practices. The most common suggestions were strategies

to <u>engage in regular physical activity</u>, which included trying activities that are not sports, setting alarms to schedule activity, being active early in the day, and trying short bursts of exercise. Other strategies that participants identified as valuable to include in the intervention were suggestions for <u>avoiding technology in the bedroom at night</u>, including charging phones away from the bed or bedroom, shutting off the internet, and informing peers when turning off the phone. Finally, all types of focus group participants highlighted that the intervention should include recommendations for achieving <u>consistent bedtimes and waketimes</u>; however, the only specific suggestion was to set a daily alarm.

Only pain-related adolescent and stakeholder groups discussed ideas for <u>tailoring content to recurrent pain</u>, with most suggestions provided by health professionals. Suggestions included recommending moderate rather than strenuous physical activity, encouraging mild physical activity even when pain is present, pacing activities to avoid a pain flare-up that interferes with sleep, being aware of pain medications that may interfere with sleep, and incorporating pain management strategies into a daily bedtime routine.

b) eHealth Features and Visual Presentation. Participants highlighted the importance of including <u>interactive features</u> within an eHealth intervention. Activity suggestions included games, quizzes, fillable forms, and customizable personal bedtime or physical activity routines. Participants consistently identified that a <u>reward system</u> such as collecting points or meeting personal achievements would motivate engagement. A <u>sleep diary</u> was often recommended as a feature that would help participants track progress. The majority of these discussions were provided by adolescents with the exception of delivering an eHealth intervention as an <u>app rather than a website</u>, recommended by both stakeholders and adolescents. Almost all comments regarding visual presentation were also provided by

adolescents, with a focus on minimizing text through the use of <u>videos, audio, and pictures</u>. Adolescents also recommended <u>bright colors</u> and a <u>simple design</u> for easy navigation.

c) Barriers and Facilitators to Using an eHealth Intervention. Participants consistently reported that having an intervention that <u>feels like school or is too much work</u> would deter adolescents. Participants also discussed the importance of <u>first impressions</u> and how a negative first experience could quickly turn adolescents away from use of the intervention. Only adolescents, and not stakeholders, reported that <u>generic or stagnant information</u> would stop them from returning to the intervention. Specifically, one adolescent stated: "*If we end up getting similar material every day, then to be perfectly honest, I don't think a lot of people would be drawn to it.*"

The only facilitator to using an eHealth intervention that was discussed across focus groups was <u>accessibility</u>. Participants agreed that having relevant information about sleep problems and healthy sleep practices all in one place would encourage using an eHealth intervention. One teen acknowledged that "*it saves people from looking about the internet for their information and if we have this program that it will all be there in one place.*"

Discussion

This paper describes the first step of a user-centered process for the development of an eHealth sleep intervention for adolescents with sleep problems, with and without recurrent pain. Adolescents and stakeholders provided opinions through online focus groups that discussed healthy sleep practices and preferences for an eHealth sleep intervention. Most healthy sleep practices were considered to be reasonable for adolescents to implement, with the exception of avoiding technology before bed and using the bedroom

only for sleep. However, many barriers to implementing and following sleep practices were identified, the most common being having a variable schedule. Participants recommended information to include within the content of an eHealth sleep intervention, primarily being suggested strategies for overcoming barriers to following healthy practices. Desirable components suggested to include in an eHealth sleep intervention were interactive features, videos, audio, and pictures to present information. Participants identified a program appearing too educational as a common barrier to using an eHealth sleep intervention, with accessibility as a common facilitator. Most discussions were consistent across groups, with a small number of group-specific topics.

Participants were generally aware of most healthy sleep practices presented during the focus groups (Allen et al., 2016), the majority being perceived as reasonable for adolescents to implement, with the exceptions of avoiding technology before bed and using the bedroom only for sleeping. Despite perceiving most practices as reasonable to implement, multiple barriers to successfully and consistently following these in terms of implementation were identified, with the most common being a variable schedule due to timing of activities. These results are consistent with those of other focus groups exploring adolescents' perceptions of sleep behaviour, with common barriers to following healthy sleep practices including time demands, variable schedules, use of technology, difficulty switching off minds at bedtime, and distracting bedroom environment (Godsell & White, 2019; Paterson et al., 2019). These common barriers are therefore important to consider when developing an eHealth intervention for adolescent sleep, with recommendations for overcoming adolescent barriers in conjunction with teaching healthy sleep.

Interestingly, participants in the current study were not aware of many facilitators

for changing sleep behaviours, aside from having information about the positive and negative impacts of sleep. This finding is in contrast with existing research in which adolescents have identified parental involvement as a facilitator to following healthy sleep practices (Gaarde et al., 2020). Given that adolescence is a time of increasing autonomy of sleep behaviours, provision of a sleep intervention at this important developmental stage may help to buffer the shift away from parent support (Randler & Bilger, 2009; Short et al., 2011). To facilitate self-directed change in sleep behaviours, it is therefore imperative that an eHealth sleep intervention integrates clear information about the negative impacts of poor sleep and the positive impacts of healthy sleep, particularly when covering healthy sleep practices that are considered to be most difficult to change.

Participants provided suggestions for content, features, and presentation as well as barriers and facilitators to using an eHealth sleep intervention. The content perceived as most important to include was primarily suggestions about overcoming barriers to healthy practices (e.g., charging phones away from the bed to minimize technology use at night). Regarding features, the need for an interactive and engaging intervention was identified, with suggestions for activities like games or quizzes to hold interest. Participants also recommended integrating reward systems and diary tracking to maintain engagement. For visual presentation, adolescents identified the need for minimal text, simple design, and information presented in bright colors over a range of formats including audio, video, and pictures. These results are in line with previously reported adolescent focus groups addressing other health conditions that have also identified the importance of options for how an eHealth intervention is delivered (Thabrew et al., 2018). Listening to feedback and integrating these suggestions into the content, features, and visual design of an eHealth

sleep intervention is critical to create a program that will be used (Lyon & Koerner, 2016).

Participants identified that an accessible program with relevant information about sleep problems and healthy sleep practices contained all in one place will facilitate using an eHealth intervention. A program feeling too educational or requiring a lot of work were common reported barriers to using an eHealth sleep intervention. Adolescents in previous research have also suggested using minimal text in eHealth intervention delivery (Thabrew et al., 2018; Werner-Seidler et al., 2017). Notably, in pilot testing of an app-based adolescent eHealth sleep intervention, only 33% of adolescents completed all components of the program, with the main reason for discontinuing cited as too much text and repetitive information (Werner-Seidler et al., 2019). Following end-user recommendations of an accessible intervention that does not feel too educational will enhance the likelihood of adolescents overcoming barriers to using an eHealth intervention and following sleep intervention recommendations (Stojmenova et al., 2012).

The secondary aim of this study was to compare responses between adolescent and stakeholder participants, and between groups related to pain and pain-free discussion topics to identify potential differences that may need to be considered for implementation in an online sleep intervention. Discussions about healthy sleep practices were mostly consistent across focus groups with only a small number of subthemes specific to participant groups. When discussing barriers to following healthy sleep practices, adolescent participants identified schoolwork as interfering with following healthy practices, a concern that was not raised by many stakeholders. Stakeholders instead identified motivation as something that may be holding adolescents back, a topic that did not come up in the adolescent groups. Perhaps to address this barrier, only stakeholders further identified setting goals to facilitate

motivation in adolescents to improve their sleep behaviour. In current sleep education literature, programs that have incorporated a motivational theoretical foundation have been found to be most successful in improving sleep behaviours (Rigney, Watson, et al., 2021). Including motivational components within an eHealth sleep intervention is important to implement despite this suggestion being identified by only stakeholders.

When exploring differences between pain and pain-free participants, adolescents with pain and stakeholder pain-related focus group members noted that recurrent pain is a barrier to following healthy sleep practices, highlighting the important relationship between pain and sleep that was not raised by the pain-free participants (Chambers et al., 2008; Dick, 2013). Two healthy sleep practices were discussed by only adolescent and stakeholder pain-related focus group members (having no caffeine in the few hours before bed and avoiding large meals before bed). However, these topics were addressed by few participants and were not discussed in the context of recurrent pain. Finally, when discussing what content was perceived as most important for an eHealth intervention, only pain-related groups recommended tailoring content to be pain specific. The perceptions of adolescent and stakeholder pain-related focus group members are consistent with those of adolescents with long-term health conditions who reported desiring that multiple aspects of their health conditions be addressed within an eHealth intervention (Thabrew et al., 2018).

Strengths and Limitations

While this study collected a range of perspectives from adolescents with and without pain and associated stakeholders, these results reflect these participants' opinions and not necessarily those of all adolescents and stakeholders. The adolescent samples were

difficult to retain, with many individuals failing to attend focus groups despite confirming availability. This resulted in some focus groups that were smaller than the recommended minimum of three participants (Tuttas, 2015), which may have resulted in fewer suggestions than a larger group. Focus groups were held entirely online without any face-to-face contact, potentially influencing the sample composition by limiting participation to only those comfortable participating online. This online platform, however, allowed for recruitment of individuals Canada-wide. The focus group guide was used to provide structure and in doing so may have limited the topics discussed as moderators did not ask about any additional topics. Although the focus groups did not follow a systematic approach for obtaining agreement on all subthemes from all participants, there was consistency across participant groups on most topics discussed, as well as adolescents with pain in the pain-free discussion groups.

Conclusions

This study was the first step in a user-centered approach to the development of an eHealth sleep intervention; that is, gathering opinions from adolescents with and without pain and their corresponding stakeholders (parents, educators, and health professionals). Results from these focus groups have provided meaningful insights from a range of perspectives on guiding adolescents to follow healthy sleep practices and providing that information through an eHealth intervention. The information gathered from these groups will be incorporated into an eHealth sleep intervention, with the aim of tailoring the program to enhance adolescent engagement. While these results were specific to the development of an eHealth sleep intervention, many of the recommendations could provide a foundation for development of eHealth interventions for other adolescent health concerns.

Chapter 3. Development of *Better Nights, Better Days – Youth*

Overview of *BNBD-Youth* Development

This Chapter provides an overview of developing *Better Nights, Better Days - Youth* (*BNBD-Youth*), an eHealth sleep intervention, including the theoretical and evidence-based foundations, integration of focus group feedback (see Chapter 2), and description of the intervention's structure and visual design. *BNBD-Youth* was developed for adolescents 14-18 years old experiencing symptoms of insomnia; that is, frequent and chronic difficulties initiating sleep, maintaining sleep, or early morning waking. *BNBD-Youth* was developed by researchers with expertise in adolescent sleep problems and recurrent pain with the intention of being tested and used by youth recruited from the general population both with, and without recurrent pain, a condition that is often comorbid with adolescent sleep problems (Owens, 2008; Palermo et al., 2011). *BNBD-Youth* development followed a user-centered approach, with its first iteration informed by focus groups held with adolescents (with and without recurrent pain), and relevant stakeholders (parents, educators, health care professionals). Along with clinical best practices, existing evidence, results from the focus groups directly informed *BNBD-Youth* development regarding its content, presentation of information, visual design, and consideration of barriers and facilitators to following healthy sleep practices as well as recommendations for engaging and using an eHealth sleep intervention.

BNBD-Youth and Behavioural Sleep Treatments

BNBD-Youth is a behavioural intervention that includes strategies shown to be effective in managing adolescent sleep problems (Åslund et al., 2018; Blake et al., 2017).

The aim of *BNBD-Youth* is to educate adolescents on healthy sleep practices as well as improve sleep behaviours and associated sleep outcomes. *BNBD-Youth* contains psychoeducation about sleep, effective healthy sleep practices (previously referred to as sleep hygiene), behavioural sleep recommendations, and a daily diary to encourage tracking sleep over time. Content was informed by existing literature, evidence-based healthy sleep practices, national sleep recommendations, and cognitive-behavioural strategies.

Treatment of behavioural sleep problems consists of four stages of intervention: 1) psychoeducation, 2) implementation of healthy sleep practices, 3) specific behavioural interventions, and 4) medication (Taylor & Roane, 2010). *BNBD-Youth* is comprised of the first three stages, wherein the intervention uses psychoeducation to educate adolescents throughout the intervention about sleep, factors contributing to poor sleep, consequences of poor sleep, and benefits of healthy sleep. Although sleep education alone has not been found consistently to produce improvements in sleep behaviour (Blunden & Rigney, 2015; Rigney, Watson, et al., 2021), the knowledge provided through sleep education is considered to be foundational for motivation and engagement when applied with other behavioural sleep strategies (Rigney, Keys, et al., 2021).

Education about the implementation of healthy sleep practices is integrated throughout *BNBD-Youth*, with one session focusing specifically on applied strategies for implementation. Healthy sleep practices include a range of recommendations aimed at increasing behaviours that promote healthy sleep and reducing behaviours that influence poor sleep (Allen et al., 2016). These healthy sleep practices are described in Chapter 1 (see Table 1.1).

In terms of behavioural treatment, common psychological strategies used for sleep management are addressed within *BNBD-Youth*. Behavioural strategies are based on psychological principles of learning and focus on changing patterns of behaviour that influence sleep (Meltzer, 2010). The behavioural strategies included in *BNBD-Youth* are sleep scheduling (scheduling consistent bedtimes and waketimes that allow sleeping 8-10 hours as recommended for adolescents), stimulus control (strategies for using the bed and bedroom only for sleep), and relaxation training (guided diaphragmatic breathing, imagery, progressive muscle relaxation). Although traditionally delivered in-person by a trained therapist (Weiss & Corkum, 2012), these strategies have been adapted for *BNBD-Youth* to be provided through interactive (e.g., relaxation audio) and tailored features (e.g., bedtime calculator, sleep routine builder) to engage adolescents and guide specific goal setting for these important behavioural changes.

Medication is not a component of *BNBD-Youth*, as there is minimal research on its use in adolescents and is considered to be the last stage of the hierarchy of sleep treatment (Owens & Moturi, 2009). The program therefore encourages participants to seek additional information if they would like to learn more about sleep and further sleep treatment once they have completed the intervention, if their sleep remains problematic.

BNBD-Youth Intervention Content

BNBD-Youth is an entirely adolescent-based self-guided intervention, with no interaction or feedback from professionals or parents. The program comprises four main sessions and each session is divided into short and interactive lessons. The sessions each contain 4-10 lessons for a total of 31 lessons included in *BNBD-Youth*. Session 1, "What is

Sleep" describes through 10 lessons the physiology of sleep, how sleep changes in adolescence, and the role of sleep on daily living. Session 2, "Your Sleep", contains 7 lessons that describe the importance of measuring sleep, introduce youth to tracking daily sleep, provide information about common sleep disorders, and guide adolescents to calculate their ideal bedtime. Session 3, "Healthy Sleep Practices", provides detailed information over 10 lessons about healthy sleep practices and guides adolescents to identify the specific areas that they would like to work on, as well as goal setting for these. Session 4: "Looking Forward", includes information over 4 lessons to help adolescents anticipate potential setbacks and provides additional resources for adolescents to explore if they are interested in seeking more information beyond that provided in *BNBD-Youth*. Table 3.1 provides a detailed overview of the content included in *BNBD-Youth*. Automatic one-week delays between sessions 2 and 3 as well as between sessions 3 and 4 are built into the program to encourage implementation of the strategies learned. A video describing *BNBD-Youth* and providing an overview of using the program can be viewed via:

https://drive.google.com/drive/folders/1kVOwvuc3frT4l1KVN-cBFnFsWWpqtWTY?usp=sharing.

Both adolescent and stakeholder participants from focus groups highlighted recurrent pain as a potential barrier to following healthy sleep practices, and also suggested tailoring sleep-related content for adolescents with recurrent pain (Chapter 2). To address this potential barrier, optional tips about the role of recurrent pain and how to consider it when managing sleep were integrated as a component of this research throughout *BNBD-Youth* for youth to explore (e.g., including pain-relieving strategies such as mindfulness or relaxation into a bedtime routine). When pain-related information is included about a topic, an icon is presented within the session, to indicate the option to click on the icon and

review the pain-specific content. Table 3.1 highlights which lessons within the intervention included pain-related information.

Presentation of Information

It is crucial for an online intervention to maintain adolescent engagement and motivation to continue returning to the platform, particularly when considering that protocol compliance is one of the most common barriers to success of adolescent behavioural sleep interventions (Ruiter Petrov et al., 2014). Further, the only web-based adolescent sleep interventions either have included therapist involvement via written feedback (de Bruin et al., 2015), included adolescents in only 24% of the testing sample, or reported poor retention of participants during pilot testing with only one third of participants completing the intervention content (Werner-Seidler et al., 2019). Therefore, developing an engaging and interactive self-guided intervention that maintains adolescent interest was imperative in the *BNBD-Youth* development process.

Microlearning

With the purpose of maintaining adolescent engagement, a micro-learning delivery approach is used for *BNBD-Youth*, a system of providing content through short, interactive, and engaging methods. Microlearning breaks content down into a series of quick interactions aimed to reduce information into manageable units for processing information (Dingler et al., 2017). Shortening new knowledge into fragments that accumulate over time is an important component of critical thinking and reasoning and well-suited for individuals working on behaviour change (Kummervold et al., 2008). Further, microlearning is ideal

for eHealth intervention implementation, as it allows users to interact with the information at their own pace when it is most convenient (Wang et al., 2020).

Interactive Features

Focus group participants highlighted a desire for interactive and engaging features to maintain their interest, with minimal text and a variety of video, audio, and images to convey information. As presented in Table 3.1, a range of features was used to provide information within and across lessons. Careful attention was paid to ensuring that several features were implemented throughout a session with particular emphasis on reducing and simplifying text.

Several videos were created for *BNBD-Youth*, using VideoScribe, a whiteboard animation software that integrates image, text, animation, and voiceover audio. Videos were created for concepts that would benefit from a thorough explanation (e.g., the regulation of sleep; the relationship between sleep and pain), or when a lot of information about a topic was relevant (e.g., what is sleep; the relationship between electronics and sleeping). Audio-format was included for the option of listening to relaxation and mindfulness strategies in session 3, with written transcripts of those audios also provided.

Other interactive features of *BNBD-Youth* included fillable quizzes for participants to complete (e.g., find out if you are a morning or night person), and interactive diagrams or hotspots that allow participants to view an image and hover the cursor over specific areas of the image to learn more (e.g., what happens in the body when you do not get enough sleep). Features also include a sorting game to match newly learned definitions with their labels, slideshows to scroll through with images and text (e.g., learning about sleep and mental

health), a bedtime calculator based on age, sleep duration, and weekday wake-up time, and a personalized bedtime routine builder.

Throughout session 3: Healthy Sleep Practices, participants are prompted to identify if they are currently engaging in each of the healthy sleep practices, and to decide whether they would like to work on each practice. Participants are guided to create a set of personalized goals about managing healthy sleep practices. The goal-setting information is saved both within the session and also imported into a "My Stuff" folder on the *BNBD-Youth* homepage. In addition to the personalized goals set in session 3, the "My Stuff" folder includes a Session Plan that is automatically imported when each session is completed. Session plans highlight the main information learned in a session, and also include any tailored information that was completed during that session (e.g., the results of quizzes along with a summary of the quiz topic).

In line with another common recommendation from focus group participants, a daily sleep diary is included in the program, as well as specific lessons within session 2 about sleep variables and tracking sleep using a sleep diary. Participants are guided to identify their areas of problematic sleeping based on data from their sleep diaries and the graphs that are provided to show trends over time. Pediatric eHealth interventions that include self-monitoring have been found to be more effective for changing health behaviours than those that do not and rely only on education (Cushing & Steele, 2010).

Visual Design and Navigation

In addition to a wide range of interactive features, adolescents' recommendations included that *BNBD-Youth* contain bright colors with a simple design and easy navigation.

The intervention is presented as a dark blue sky and starlight background, with neon blue and white accents and icons, as well as bright, colorful text, images and videos providing high color contrast throughout. Although adolescents have the option of exploring lessons in whatever order they choose, the lessons are labeled clearly with numbers and titles to provide a suggested order in which to complete the content, as well as a quick indication of what content would be covered in the lesson. Arrows are included at the bottom of every page within each lesson for navigation throughout the lesson and a "back to session" button on the last page of every lesson to indicate completion of that content.

Next Step: Testing *BNBD-Youth* with End-Users

Addressing adolescent needs and targeting their preferences was integral to this development process and informed each component of *BNBD-Youth*, including its content, features, and visual design. Once *BNBD-Youth* was developed, the next steps were to gather user feedback about each of the individual sessions as well as the overall program through usability testing (Chapter 4), and conduct pilot testing to explore user engagement and retention with the aim of informing future larger-scale efficacy testing (Chapter 5).

Table 3.1. *BNBD-Youth* Content for Sessions 1-4.

Lesson	Content	Presentation of Information
Session 1: What is Sleep		
1	Facts and fiction about sleep	Fillable quiz
2	What sleep is, and the relationship between sleep and pain	Videos
3	The sleep cycle, and stages of sleep	Text, interactive diagram, sorting game, slideshow
4	Regulation of sleep	Video
5	Are you a morning, or night person?	Fillable quiz with images
6*	How sleep changes in adolescence	Video
7	Sleep duration recommendations	Interactive diagram, text, image
8	Sleep and mental health	Slide show, images
9*	Relationship between sleep and mental health	Text, images
10*	What happens in the body when we do not get enough sleep	Interactive diagram
Session 2: Your Sleep		
1	Important variables for measuring sleep	Slideshow
2*	Understanding sleep diaries, starting to track your own sleep	Text, image, checklist
3	Different ways to measure sleep	Interactive diagram
4	Common sleep disorders	Interactive diagram
5	Understanding and measuring sleep quality	Text, image, fillable quiz
6*	Understanding and measuring healthy sleep practices	Text, image, fillable quiz
7*	Bedtimes and waketimes	Text, personalized bedtime calculator
Session 3: Healthy Sleep Practices		
1*	The ABCs of SLEEPING	Text and image
2	Consistent age-appropriate bedtimes and waketimes	Text and fillable questions
3*	Schedules and routines	Text, personalized routine creator
4*	Location	Fillable questions interactive image, personalized feedback
5*	Electronics	Video, fillable questions, personalized feedback
6*	Exercise and diet	Text, fillable questions, personalized feedback
7*	Positivity toward sleeping, going to bed relaxed	Text, slideshow, audio, fillable questions, personalized feedback
8	Independence	Text, fillable questions, personalized feedback

Lesson	Content	Presentation of Information
9*	Meeting needs during the day	Text, image, fillable questions, personalized feedback
10	Great sleep	Personalized goal setting
Session 4: Looking Forward		
1	Checking in	Text, checkboxes, fillable questions
2*	Troubleshooting roadblocks	Text
3	Extra resources	Text, links
4	Congratulations	Text

Note. *Lesson includes short tips about the lesson content for youth with recurrent pain.

Chapter 4. Usability Testing of a User-Centered eHealth Sleep Intervention for Adolescents with and Without Recurrent Pain

The manuscript based on this study is presented below. Readers are advised that Michelle Tougas, under the supervision of Dr. Penny Corkum, and in consultation with her dissertation committee members (Dr. Christine Chambers, and Dr. Isabel Smith) participated in the initial conceptualization of the research study, helped to develop the study protocol and prepared submissions for ethical review, was responsible for recruitment, completed and oversaw data collection, scoring, coding, data analysis/interpretation for all components included in this study. Michelle Tougas also applied for and was successful in obtaining funding to support this research. Michelle Tougas was responsible for all aspects of the writing process and received editorial feedback from dissertation committee members. The following manuscript is being prepared for publication submission as:

Tougas, M.E., Chambers, C., Smith, I.M., Rigney, G., Mugford, J., Corkum, P. (2021). *Usability testing of a user-centered eHealth sleep intervention for adolescents with and without recurrent pain.* [Manuscript in preparation].

Abstract

Objective: Evaluate usability of an eHealth sleep intervention for adolescents to inform readiness for future testing. Methods: Adolescents 14-18 years old with insomnia symptoms, some of whom experienced recurrent pain, were provided access to an eHealth sleep intervention for a maximum of 5 weeks. Participants completed usability measures for each of four intervention sessions, as well as the overall intervention. Quantitative usability responses were analyzed using descriptive statistics, whereas qualitative responses were coded using directed content analysis. Repeated measures analysis of variance was used to examine differences in usability ratings. Bivariate correlations were used to explore the relationship between baseline pain frequency and usability ratings. Results: A total of 22 adolescents participated (15 reported experiencing recurrent pain), with generally positive feedback such that 80% of the quantitative usability ratings were positive and the remaining 20% were neutral. Only 6% of ratings were associated with higher levels of baseline pain frequency. Qualitative comments about how 'desirable' and 'accessible' the program was identified that the intervention would benefit from improved functionality of features (e.g., viewing videos) across devices, and by minimizing text prior to future testing. Conclusions: In this research, we followed a user-centered approach to evaluate usability of an adolescent eHealth sleep intervention. The positive results highlight readiness of the program for randomized controlled trial testing once minor modifications based on usability feedback are introduced. Further, many of the identified strengths, challenges, and suggestions for improvement may be applicable to eHealth interventions for other adolescent health concerns.

Introduction

Difficulty sleeping is common among adolescents, with approximately 30%

reporting problems falling or staying asleep (Luntamo et al., 2012), and up to 75% of grade

12 students reporting sleeping less than the recommended 8-10 hours at night (Foundation,

2006; Gariepy et al., 2020). Poor sleep is known to influence several areas of life, including

academic performance, cognitive processing, mental health, and physical functioning

(Chaput et al., 2016; Shochat et al., 2014). Poor sleep is often comorbid with other mental

and physical health conditions and is common in youth experiencing recurrent pain.

Recurrent pain (pain experienced at least once per week for at least three months)

often starts in adolescence and impacts multiple areas of functioning (Stanford et al., 2008).

Up to 30% of adolescents report experiencing recurrent pain (King et al., 2011), and up to

54% of adolescents with recurrent pain also report sleep problems (Palermo et al., 2011).

Further, a reciprocal relationship has been suggested between the two conditions, with sleep

problems influencing pain, and pain influencing sleep problems (Valrie et al., 2013).

Several biopsychosocial factors contribute to the onset of sleep changes in

adolescence (Crowley et al., 2018). Biological changes in adolescence affect sleep timing,

leading to later bedtimes and later waketimes (Gradisar et al., 2011), as well as less

physiological pressure to sleep (Feinberg et al., 2006). Psychosocial factors include

adolescents taking more control over daily activities that interfere with sleep (e.g., caffeine

intake, social media use at night) (Short et al., 2011), and more autonomy for choosing

when they go to bed and fall asleep (Crowley et al., 2018). Adolescence is a time with

increases in peer activities that occur at varied times of day, often influencing bed or wake

times (e.g., extracurricular activities, sports, time with friends, employment, and social media use) (Paksarian et al., 2015).

Despite its high prevalence and negative effects on many aspects of daily life, adolescent problematic sleeping can be treated effectively, most often through targeted strategies to manage healthy sleep practices (Åslund et al., 2018). Traditional delivery methods include individual and group-based approaches, with studies of in-person cognitive behavioural interventions for adolescents either with, or without recurrent pain reporting significant improvement in sleep efficiency, total sleep time, sleep onset latency, sleep quality, daytime sleepiness, and depression (Blake et al., 2017; Bruni et al., 1999; Law et al., 2018). School-based approaches have been found to be effective in improving adolescents' sleep knowledge; however, they have shown limited improvement in sleep behaviour (Rigney, Watson, et al., 2021).

Although in-person delivery has been the typical mode of adolescent sleep treatment, access can be obstructed by cost, available professionals, and time (Reardon et al., 2017). Further, adolescent compliance with protocols has been reported as one of the most common barriers to adolescents' success with in-person behavioural sleep treatment (Ruiter Petrov et al., 2014). The translation of adolescent sleep interventions to online delivery can potentially improve accessibility and adherence to effective treatment.

Despite these advantages, only three eHealth web-based sleep interventions for adolescents (one web-based, two app-based), and none for adolescents with pain, have been published, with all studies reporting improved sleep, including in sleep hygiene, insomnia symptoms, and sleep quality (de Bruin et al., 2015; Carmona et al., 2020; Werner-Seidler et al., 2019). No significant differences were identified between web-based versus in-person

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delivery of a CBT-based intervention, which included written personalized feedback from sleep experts in the web version (de Bruin et al., 2015). The app-based interventions were entirely participant-driven, and authors also reported including adolescents in intervention development (Carmona et al., 2020; Werner-Seidler et al., 2019). However, only 24% of one sample were adolescents (15-18 years old, vs. 76% 19-24 years old, Carmona et al., 2020), and only one third of the other sample completed the entire intervention during pilot testing (Werner-Seidler et al., 2019). The authors reported that too much text and repetitive information were participants' main reasons for discontinuing.

User-centered designs focus on understanding and identifying treatment barriers by systematically and meaningfully involving end-users throughout treatment development, with the purpose of creating a useful and valuable program for the target population (De Vito Dabbs et al., 2009). The success of healthcare applications depends not only on the information provided, but also on how users interact with the application. Involving end-users in design and testing increases the likelihood of promoting intended health outcomes (De Vito Dabbs et al., 2009). Despite a plethora of eHealth applications, only a small number of studies report including end-users in empirical testing and development (Higgins et al., 2018; Majid et al., 2010). Adolescent involvement in eHealth sleep intervention development is critical to understanding the barriers and facilitators to intervention use for development of an engaging and desirable end-product.

eHealth treatments hold promise for providing accessible treatment for adolescent sleep problems. However, focused integration of user input at every stage is necessary to create an intervention that will be used and helpful. For this research, a series of studies was conducted following a user-centered approach in the development and testing of an eHealth

behavioural sleep intervention for adolescents with insomnia symptoms, *Better Nights, Better Days for Youth (BNBD-Youth)*. First, focus groups were held with adolescents and stakeholders to inform barriers, facilitators, content, design, and presentation of *BNBD-Youth* (reported in Chapter 2). Once the intervention was developed incorporating focus group feedback (reported in Chapter 3), usability testing was conducted (reported here) as well as simultaneous pilot testing of pre-post intervention (reported in Chapter 5). Along with the usability study reported in this paper, these studies will determine readiness of testing *BNBD-Youth* with a larger-scale randomized controlled trial (RCT).

The focus of the current study was to test the usability of *BNBD-Youth* for adolescents 14-18 years old who experienced symptoms of insomnia, to evaluate readiness of the intervention for RCT testing. Specifically, to explore: 1) which usability components meet user needs for the *BNBD-Youth* sessions and overall intervention, and 2) which usability components need improvement to meet user needs for *BNBD-Youth* sessions and overall intervention. Further, given the common comorbidity of recurrent pain and sleep, the secondary focus of this study was to explore: 3) whether experiencing recurrent pain influence usability of an eHealth sleep intervention.

Methods

Design

A single arm, pre-post usability design was followed. This research was approved by the local research ethics board.

Participants

Participants were eligible if they were 14-18 years old, experienced symptoms of insomnia (difficulty initiating sleep, maintaining sleep, or early morning waking), attended junior high or high school, resided in Canada, had access to the internet and email, were proficient in English, and had no diagnosed medical or mental health disorders that would interfere with participation. Participants were recruited from May through June 2019 across Canada via online advertisements, print materials, word of mouth, and by contacting participants who participated in focus groups informing intervention development (see Chapter 2). Some recruitment materials advertised that adolescents with recurrent pain were welcome to participate; however, this was not an eligibility criterion, nor specifically targeted through different avenues of recruitment.

Procedure

Interested participants completed an online eligibility and consent form. Consenting participants were emailed an online questionnaire to collect demographic characteristics. Once completed, participants were provided with access to the online intervention, *BNBD-Youth,* for a maximum of five weeks in order to review and complete the program content. After participants reviewed each of the four *BNBD-Youth* sessions, they were automatically emailed a link to a questionnaire to gather specific usability feedback about the session. Reminder emails were sent if participants did not complete the questionnaire prior to starting the next session. A link to the final online usability questionnaire about overall experiences with the program was emailed five-weeks after beginning the program. Participation honorarium was an emailed $20 gift card.

Intervention

BNBD-Youth is an eHealth sleep intervention developed for adolescents with insomnia symptoms that comprises four sessions, with each session divided into 4-10 microlessons. Participants were encouraged to track daily sleep habits using an online sleep diary within the program. Session 1 introduced what sleep is and sleep's important role in daily living. Session 2 provided information about types of sleep disorders, methods for measuring sleep, as well as guidance for tracking sleep quality, healthy sleep practices, bedtimes and waketimes. Session 3 focused on healthy sleep practices, guided youth to understand their own sleep practices, and identified which sleep habits adolescents would like to change. Session 4 focused on reviewing what was learned, potential roadblocks for healthy sleep practices, and additional resources for continuing to learn about and manage sleep. Throughout the intervention, optional brief strategies were included for applying information to individuals with recurrent pain. Program content was delivered through videos, text, images, infographics, quizzes, interactive games, and personalized goal setting. Automatic one-week delays between sessions 2 and 3 as well as between sessions 3 and 4 were built into the program to encourage implementation of the strategies learned.

Measures

Eligibility Questionnaire

The eligibility questionnaire was created by the study authors and was previously used for a focus group study examining adolescents' and stakeholders' perceptions of adolescents' use of healthy sleep practices and using an eHealth sleep intervention (Chapter 2). The questionnaire asked whether participants were 14-18 years old, attended junior high

or high school, resided in Canada, had access to internet and email, were proficient in English, and had no hearing or cognitive deficits.

Insomnia Severity Index (ISI)

The ISI is a 7-item questionnaire developed to detect insomnia, rated on a 5-point Likert scale (0 = no problem; 4 = very severe problem) (Morin et al., 2011). Scores range from 0-28, with 8-14 considered to be subthreshold insomnia symptoms, 15-21 moderate symptoms, and 22-28 severe symptoms. Participants with scores of 7 and lower were excluded from the study. The ISI shows high internal consistency in adolescents without pain ($\alpha = 0.90$) (Chahoud et al., 2017) and in adolescents with recurrent pain ($\alpha = 0.85$) (Bromberg et al., 2020).

Demographic Questionnaire

The demographic questionnaire was created by the study authors and used for the focus group study (Chapter 2). The questionnaire asks about age, sex, ethnicity, grade, and information about recurrent pain experience including the type of pain, intensity (on a 10-point rating scale), duration, and frequency.

Usability Questionnaires

The Session Usability Questionnaire assessed each of the four *BNBD-Youth* sessions, with the Program Usability Questionnaire assessing the overall program. The questionnaires were based on Peter Morville's "user experience honeycomb" (Morville & Sullenger, 2010) and adapted from previous usability studies evaluating other sleep interventions (Orr et al., 2019; Speth et al., 2015; Tan-MacNeill et al., 2020). The

questionnaires consisted of closed- and open-ended questions asking about the usability dimensions including useful (e.g., how useful the program is, and does the program help users achieve their goals), usable (e.g., ease of use, efficiency, errors in use), findable (e.g., navigation and ease of finding information), desirable (e.g., how satisfying the program is to use, desire to come back to the program), accessible (e.g., is the program accessible for all users), credible (e.g., do users trust and believe the information), and valuable (e.g., meeting goals for using the program). Participants were asked to indicate on a 5-point scale (1 = strongly disagree, 3 = neither agree nor disagree, 5 = strongly agree) how much they agreed with each statement with the option to elaborate using open-ended responses. Based on how the response options were worded, ratings of 2 or less were considered negative, above 2 and less than 4 were considered neutral, and 4 or greater were considered positive.

Data Analysis

Descriptive statistics were used to report frequencies, ranges, means, and standard deviations. T-tests and chi-square analyses were conducted to evaluate differences in demographic characteristics between participants who did and did not complete any usability questionnaires. Repeated measures analysis of variance (RM-ANOVA) was used to examine differences in usability ratings across sessions and the overall program. Bivariate correlations were performed to explore whether baseline pain frequency was correlated with usability ratings. Pain frequency was selected as this variable was used to identify the presence of recurrent pain (frequency of once per week or more).

Open-ended questions were analyzed and coded using directed content analysis, which allows coding to be made within an existing framework (Assarroudi et al., 2018).

The data were coded according to a framework developed from Morville's dimensions of user experience (Morville & Sullenger, 2010). Two coders (M.T., J.M.) independently coded 25% of the data, with 88% inter-rater agreement. The remaining data were coded by one reviewer (M.T.). The coded data were then divided into two categories: *Strengths,* which referred to positive aspects of the program, and *Challenges*, which referred to barriers to usability and suggestions for improvement. To identify what program components should be modified based on user feedback, proportions of strengths compared to challenges about a specific topic were calculated for each usability dimension. Similar to previous sleep intervention usability research, a 10% threshold of support for change of a specific topic within a usability dimension was required once strengths and challenges were weighed against one another (Ali et al., 2021).

Results

Participants

A total of 28 participants received the intervention, with 4 participants (14%) who completed only session 1, 4 (14%) who completed only session 2, and the remaining 20 participants (72%) who completed all sessions of *BNBD-Youth*. At least one usability questionnaire was completed by 22 participants (20 completed all four sessions, 1 completing only session 1, and one completing sessions 1 and 2), see Figure 4.1 for participant flow. The 22 youth who completed at least one usability measure were a mean of 15.9 years old ($SD = 1.4$, range = 14-18), the majority were female (79%), Caucasian (71%), attended grades 8-12 ($M = 10.3$, $SD = 1.2$), lived in 5 provinces across Canada. According to the ISI, mean insomnia symptoms were of moderate severity ($M = 18.2$, $SD =$

4.3, range 11-25). Recurrent pain was reported by 15 participants (68%) with an average

frequency of 13.0 days over the previous month ($SD = 9.22$, range 0-31 days), an average

pain intensity of 4.2 out of 10 ($SD = 1.5$, range $= 2$-7), and average pain duration of 4.9

hours ($SD = 8.7$, range 0-24). Pain types included headache ($n = 8$), musculoskeletal ($n =$

8), abdominal ($n = 7$), and facial pain ($n = 1$). The 22 who participated were more likely to

be female and experience recurrent pain than the remaining 46 individuals who completed

the consent and demographics but no usability measures. Participation was not significantly

associated with age, ethnicity, grades, pain intensity, frequency, or duration.

Quantitative Usability Testing

Mean usability ratings ranged between 3.61 and 4.70 (on a scale of 1-5). No mean

ratings from any of the four sessions or overall program were negative (below 2). Neutral

ratings (greater than 2 and less than 4) were identified for 20% (n=7) of dimension ratings

for sessions 1, 2, and 4 for both the "useful" and "desirable" user experience as well as for

session 2 "valuable" (ranging from 3.61-3.98). The remaining 80% of ratings (n=28) were

positive (4 and greater). See Table 4.1 for quantitative usability results. No significant

differences were identified across sessions for any user experience dimension, except

"useful", $F(4, 15) = 8.58$, $p = .001$, where session 1 was rated significantly lower than

sessions 2 and 3, and the overall program.

Qualitative Usability Testing

The open-ended responses of strengths and challenges are summarized for each

usability dimension: 1) useful, 2) usable, 3) findable, 4) desirable, 5) accessible, 6) credible,

and 7) valuable. The proportion of strengths compared to challenges for each dimension is

described and the decision to modify *BNBD-Youth* when the proportion of challenges is 10% or higher is reported.

1) Useful

Of the 135 comments made about how "useful" the sessions and overall program were, the majority (79%, *n* = 107) were *strengths* that highlighted the adolescents' increased understanding about sleep and personal sleep problems. One participant stated about session 3, "*I found it useful in general, seeing what my habits are and how to improve upon them.*" Expressed *challenges* (21% of comments, *n* = 28) noted that some participants were already aware of the content, particularly session 1, "*Some of the information was a bit more "common knowledge" than stuff I didn't actually know.*" Other challenges included some participants being uncertain if the content would help meet sleep goals, and a few participants wishing to learn different information than what was provided (e.g., seeking more applied skills in early sessions). When the proportion of challenges to strengths was assessed, there were not enough reported challenges about specific topics (10% of comments or more) to meet support for changing any component of the intervention to improve the "usefulness" dimension.

2) Usable

From 125 comments about how usable the program was, participants indicated in 84% of comments (*n* = 105) that the program *strengths* included being easy to understand, quick to complete, and ready to be used. A participant noted about session 2 that "*The lessons were easy to use and quick. I was able to complete them in a reasonable amount of time when I had a bit of free time.*" Some participants reported *challenges* in the remaining

12% (*n* = 20) of comments about length of time to complete the sessions as well as wanting reminders to complete sessions. Regarding session, 3 a participant expressed "*This session took a fair amount of time but was easy to get through.*" A small number of participants indicated login issues and wanted access to all material at once rather than waiting for it to be unlocked. The proportion of challenges to strengths did not support making usability changes to *BNBD-Youth*.

3) Findable

Participants agreed in 89% (*n* = 105) of 118 comments that program *strengths* included being well organized, clearly labeled, as well as straightforward to find and return to specific information. When responding about session 4, a participant indicated "*Everything was in the appropriate place and labeled so that I could find what I needed.*" In 11% (*n* = 13) of comments some participants indicated particular *challenges* finding specific information within the program (e.g., information that they had entered into interactive features). One participant noted that "*Sometimes there would be missing back to session prompts at the end of a lesson. You'd have to click to go home or press restart, instead of a "back to session" button which was confusing at first.*" The proportion of challenges to strengths did not support changing *BNBD-Youth* based on "findability".

4) Desirable

Qualitative feedback was mixed for discussing how "desirable" the program was. Of 147 comments, 52% described *strengths* of the program being interactive, eye-catching, appealing, well-designed, and presenting desired information. A participant's comment about session 4 highlighted that "*The lessons were intriguing, and the website also looked*

well put together which wanted me to do it more." However, in 48% (*n* = 70) of comments, *challenges* included a desire for more interactive features, fewer paragraphs, and shorter or faster-paced videos. One participant stated about session 1, "*The visuals and mini games were very useful. Having more of those would make it the most successful!*" Participants also indicated a desire for more color and visually appealing design (e.g., improve the font color or size, increase contrast between font and background, and improve graphics). The proportion of challenges compared to strengths reached threshold for modifying *BNBD-Youth* to improve the "desirable" dimension based on user comments for more interactive features, fewer paragraphs, and improved visual design.

5) Accessible

Participants reported in 62% (*n* = 83) of 134 comments that program *strengths* included being easy to navigate and comprehend, straightforward, intuitive, with clear and simple language. Feedback from one participant about the overall program was, "*The sessions were simple to use, and everything was explained well.*" While some participants highlighted the program as mobile friendly, participants identified in 33% (*n* = 51) of comments that most *challenges* included difficulty using the program on mobile and tablet devices. Specifically, videos and interactive features were reported to be incompatible with most mobile devices, as highlighted by one participant about session 1, "*for a few lessons I was using my phone and found it a bit difficult to move the screen or pause a video etc.*" Another participant noted about the overall program that "*I would rather be able to use my phone instead of laptop.*" The proportion of challenges compared to strengths reached threshold for modifying *BNBD-Youth* to improve the "accessibility" dimension by addressing compatibility of interactive features and videos with varying media devices.

6) Credible

Participants highlighted *strengths* of the program in 91% ($n = 80$) of the 88 comments as appearing professional and being developed from reputable sources with consistent and trustworthy information. One participant noted about the overall program that "*I feel like everything was credible and professional in a way that I would feel comfortable using it to help my life.*" Very few *challenges* about credibility were raised, with only 9% ($n = 8$) of comments suggesting that participants would like to see more websites and cited sources. The proportion of strengths to challenges did not support changing *BNBD-Youth* based on "credibility" comments.

7) Valuable

Participants indicated in 82% ($n = 84$) of 102 comments that program *strengths* included learning new information to help understand and improve sleep habits while moving toward sleep goals. About session 3, one participant highlighted "*The session helped me figure out how to better manage my time prior to going to bed.*" *Challenges* related to the value of the program identified that sleep problems had not been addressed or improved in 18% ($n = 18$) of comments. Interestingly, half of the challenges targeted session 2, where one participant noted, "*I have learned a lot, but if you had a lesson on how to use the things we learned, it would be better.*" A small number of comments distributed across the remaining sessions and program noted that participants desired to learn more specific information (e.g., sleep and mental health). There was not enough support for changing *BNBD-Youth* based on "valuable" comments.

Correlation between pain and usability ratings

Pain frequency was significantly correlated with session 1 ratings for how "usable" the session was ($r = -.49$, $p = .02$), indicating that higher pain frequency was associated with lower ratings (see Figure 4.2). Pain frequency was also significantly correlated with session 3 ratings for how "valuable" the session was ($r = .76$, $p = .00$), indicating that higher pain frequency was associated with higher ratings (see Figure 4.3).

Discussion

This paper describes following a user-centered approach in evaluating usability of an eHealth sleep intervention for adolescents experiencing insomnia symptoms with and without recurrent pain. The ability of *BNBD-Youth* to meet user needs was strongly reflected in the overall positive quantitative and qualitative feedback. The usability dimensions received only a small proportion of comments about challenges, with no modifications identified for the "useful", "usable", "findable", "credible," and "valuable" dimensions. Based on qualitative feedback, minor modifications are warranted to improve *BNBD-Youth's* usability dimensions for "desirable" and "accessible". Of the 35 usability ratings, higher baseline pain frequency was correlated with lower session 1 "usable", and higher session 3 "valuable" ratings.

Of the mean quantitative ratings for the seven assessed usability dimensions, 80% were rated positively, 20% rated as neutral, and none rated negatively. These data demonstrate the perceived usability for each intervention session, as well as the intervention as a whole, across a range of usability dimensions. These positive ratings were also supported by qualitative feedback, with the majority of all comments discussing

strengths of the program rather than challenges. The high usability ratings for *BNBD-Youth* are consistent with existing usability studies evaluating other on-line sleep interventions for different populations created within our research laboratory using a user-centered design (insomnia and obstructive sleep apnea (Orr et al., 2019); children with insomnia (Speth et al., 2015); insomnia and neurodevelopmental disorders (Tan-MacNeill et al., 2020)).

To continue following a user-centered development and testing approach, the challenges provided in feedback were evaluated for potential modifications to improve the next program iteration. The usability dimensions "accessible" and "desirable" received feedback in which 10% or more of the participant comments were about specific challenges. Participants consistently raised accessibility concerns across sessions regarding performance of interactive features (e.g., viewing videos) on tablets and phones. The next iteration of *BNBD-Youth* will need to improve functionality across media devices.

The "desirable" dimension received feedback concerning limitations in visual design, with constructive suggestions to reduce text, add interactive features or videos, and increase visual appeal. Modifications to *BNBD-Youth* should introduce 1) features to minimize text such as providing text-to-audio options and relevant images, 2) strategies to improve videos such as including captions or scripts, or cutting out repetitive content, and 3) improved visual appeal through changing font color, increasing contrast between font and background, and including more colorful pictures. An existing review of usability studies for adolescent eHealth interventions reported similar findings, with adolescent preferences for interactive content such as games and quizzes, as well as for videos and images over text (Reen et al., 2019). The current findings are consistent with existing usability research and may also be transferrable to other adolescent eHealth interventions.

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Higher pain frequency was associated with lower session 1 "useful" ratings, and higher session 3 "valuable" ratings. Session 1 (*Introduction to what sleep is*) may benefit from including more targeted information about the relationship between sleep and pain and how the program can be used by individuals with comorbid recurrent pain. Session 3 (*Healthy sleep practices*) included many pain-specific recommendations for applying healthy sleep practices. The attention to recurrent pain in session 3 may have been particularly valuable for participants with higher pain frequency. Overall, these results are encouraging for use of *BNBD-Youth* by adolescents with recurrent pain, without needing to develop a separate intervention for this population. Possible future research could explore the use and perception of *BNBD-Youth* by other adolescent populations that experience conditions often comorbid with sleep problems, such as depression (Short et al., 2013).

Strengths and Limitations

This study collected a range of perspectives from a combined population of adolescents with and without recurrent pain, recruited on-line from across Canada. These results, however, may not reflect opinions of all adolescents experiencing insomnia symptoms. Qualitative feedback was optional and may not reflect opinions of all adolescents who participated in this study. However, the positive quantitative ratings show consistency with the overall qualitative findings. Only pain frequency, and not pain intensity or pain type was used when exploring the relationship between pain and usability ratings. Further, no sample size calculation was conducted for this research. Recruitment, screening, and all communication was conducted entirely online without any face-to-face contact, potentially influencing overall participation in the study, while also recruiting participants who were most likely to reflect end-users. Although a large number of

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participants consented but did not participate (83%), once participants accessed and began using the intervention, retention rates were high.

Conclusions

This research study utilized a user-centered approach to evaluate usability of an eHealth sleep intervention for adolescents with insomnia symptoms, with and without recurrent pain. Overall, both quantitative and qualitative feedback about *BNBD-Youth* usability was positive across the assessed usability dimensions. Based on qualitative user comments, these results highlighted the need for minor modifications to enhance the *BNBD-Youth* "desirable" usability dimension by integrating video scripts and captions, text-to-audio options, colorful images and fonts, and more contrast between font and background, and to improve the "accessible" dimension through improving function of intervention features across devices. Once modifications to *BNBD-Youth* are addressed, these usability results support readiness for an RCT. While these results were specific to *BNBD-Youth*, many identified strengths, challenges, and suggestions for improvement may be applicable to eHealth interventions for other adolescent health concerns.

Acknowledgements

Table 4.1. Averaged usability ratings of each *BNBD-Youth* session and overall program.

Mean (SD)					
	Session 1 (*n* = 22)	Session 2 (*n* = 21)	Session 3 (*n* = 19)	Session 4 (*n* = 20)	Program (*n* = 22)
Useful[a]	3.61 (.63)	3.98 (.64)	4.37 (.62)	3.95 (.87)	4.29 (.59)
Usable	4.36 (.54)	4.17 (.68)	4.26 (.69)	4.32 (.65)	4.07 (.69)
Findable	4.59 (.50)	4.50 (.70)	4.60 (.52)	4.70 (.44)	4.48 (.54)
Desirable	3.98 (.47)	3.79 (.60)	4.08 (.69)	3.92 (.78)	4.14 (.69)
Accessible	4.41 (.53)	4.29 (.68)	4.53 (.56)	4.65 (.49)	4.39 (.71)
Credible	4.50 (.71)	4.50 (.77)	4.66 (.50)	4.57 (.49)	4.59 (.67)
Valuable	4.16 (.56)	3.98 (.77)	4.29 (.56)	4.25 (.80)	4.20 (.80)

Note: Rating scale from 1-5 (1 = strongly disagree; 3 = neither agree nor disagree; 5 = strongly agree). Dimensions were derived from Morville's user experience honeycomb (Morville & Sullenger, 2010). [a]Significant differences identified across session and program ratings for usability dimension.

Figure 4.1

BNBD-Youth Usability and Pilot Testing Participant Flow

Assessed for eligibility (n = 232)		Ineligible/did not consent (n = 71)

| Eligible & consented (n = 161) | |

	Did not complete demographics (n = 94)
	No response to emails (n = 27)
	Did not log-in (n = 9)
	Withdrawal (n = 3)

Accessed intervention[a]   (n = 28)
-   Did not complete usability   (n = 6)
-   **Completed usability measures   (n = 22)**
    -   Session 1   (n = 22)
    -   Session 2   (n = 21)
    -   Session 3   (n = 19)
    -   Session 4   (n = 20)
    -   Overall program (n = 22)
-   Completed pre-post pilot testing (n = 19)[b]

Note. [a]One of whom was recruited from previous focus groups (Chapter 2). [b]Pilot testing of this sample is reported in Chapter 5.

Figure 4.2

Correlation Between Baseline Pain Frequency and Session 1 Usable Ratings

Figure 4.3

Correlation Between Baseline Pain Frequency and Session 3 Valuable Ratings
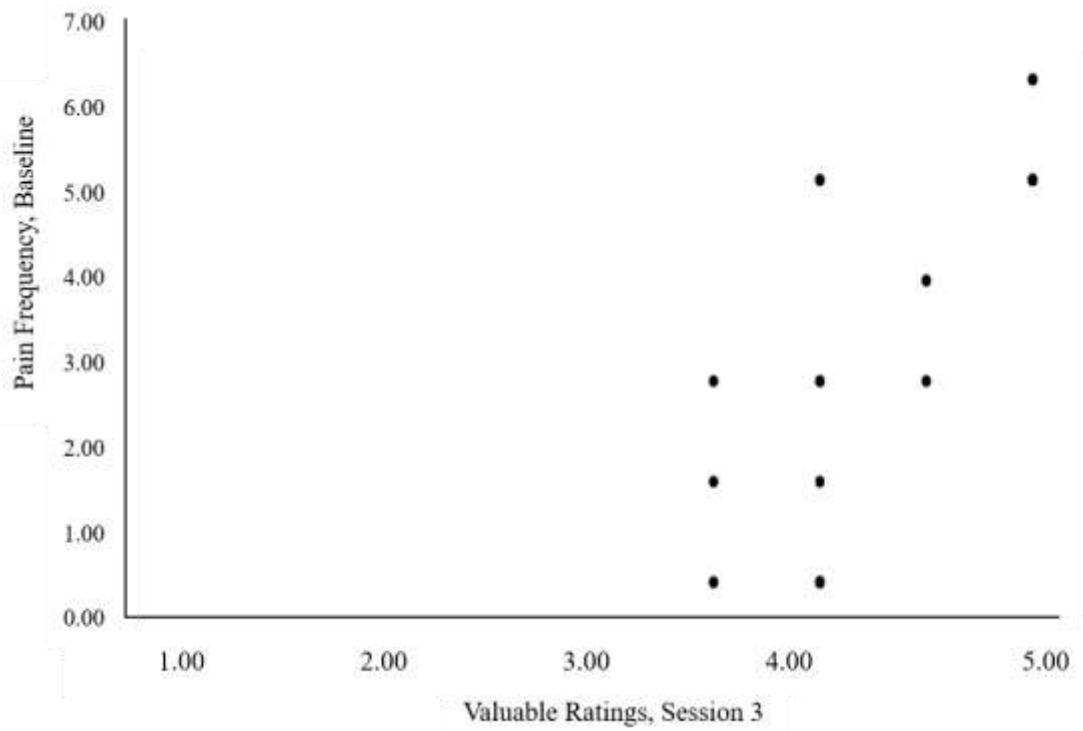
Chapter 5. Non-randomized Pilot Testing of an eHealth Sleep Intervention for Adolescents With and Without Recurrent Pain

The manuscript based on this study is presented below. Readers are advised that Michelle Tougas, under the supervision of Dr. Penny Corkum, and in consultation with her dissertation committee members (Dr. Christine Chambers, and Dr. Isabel Smith) participated in the initial conceptualization of the research study, helped t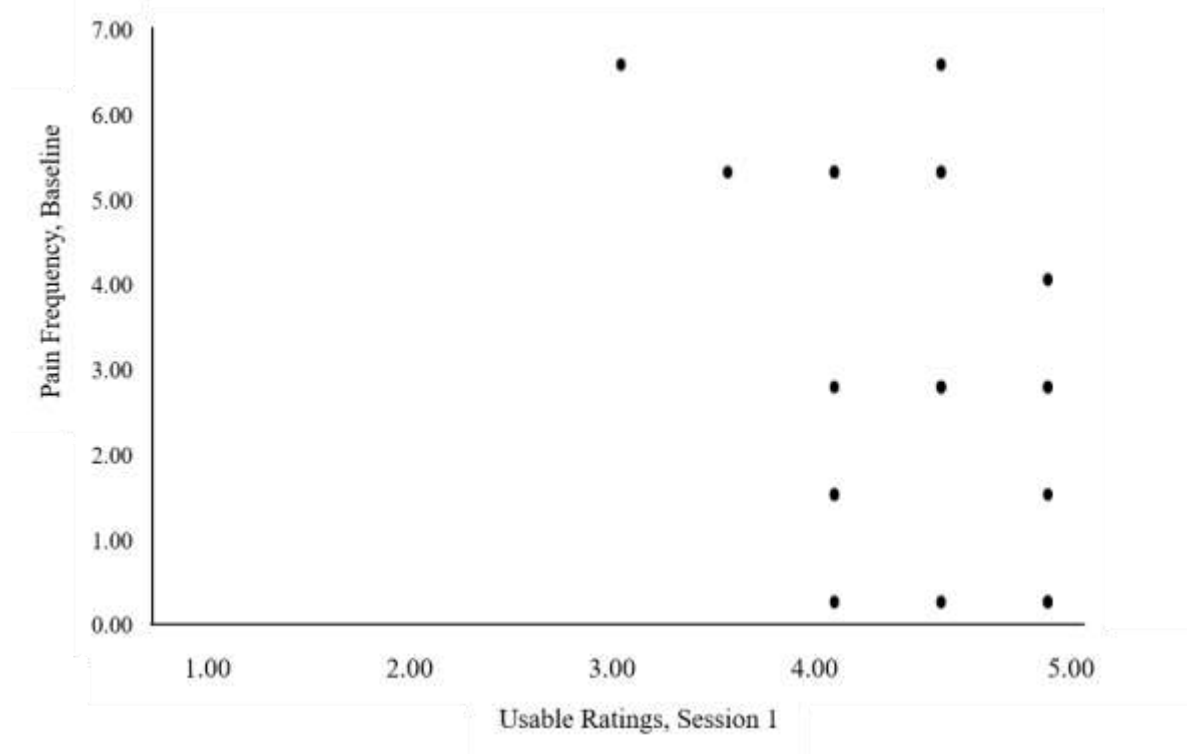o develop the study protocol and prepared submissions for ethical review, was responsible for recruitment, completed and oversaw data collection, scoring, coding, data analysis/interpretation for all components included in this study. Michelle Tougas also applied for and was successful in obtaining funding to support this research. Michelle Tougas was responsible for all aspects of the writing process and received editorial feedback from dissertation committee members. The following manuscript is being prepared for publication submission as:

Tougas, M.E., Chambers, C., Smith, I.M., Rigney, G., Mugford, J., Corkum, P. (2021). *Non-randomized pilot testing of an eHealth sleep intervention for adolescents with and without recurrent pain.* [Manuscript in preparation].

Abstract

Objective: The objective of this non-randomized pilot study was to evaluate the process, and preliminary efficacy, of delivering an eHealth sleep intervention for adolescents to inform future randomized controlled trial (RCT) testing. Methods: Adolescents 14-18 years old with insomnia symptoms, some of whom experienced recurrent pain, were given 5-week access to a 4-session microlearning eHealth sleep intervention, *Better Nights Better Days-Youth (BNBD-Youth)*. Pre-post intervention daily diary measures and questionnaires were collected to assess changes in sleep variables (e.g., total sleep time), healthy sleep practices, recurrent pain, functional disability, and depressive symptoms. Engagement and retention rates for intervention use and pre-post diary and questionnaire testing were collected. Outcome changes were evaluated using paired t-tests. Bivariate correlations evaluated the relationship between pain frequency and outcome variables. Results: Testing demonstrated acceptable levels of participant engagement, with 20 (71%) adolescents completing all four intervention sessions, and 19 (68%) completing all pre- and post-measures including 97-99% completion of daily diaries. Significant improvement post-intervention was identified for most of the sleep and daytime functioning variables. Pain frequency significantly decreased at post-intervention with no other significant changes identified for other pain variables (e.g., pain duration). Pain frequency at baseline was not correlated with any other baseline variables or pre-post changes. Conclusions: This research shows promise for testing the efficacy of *BNBD-Youth* on adolescents experiencing sleep problems with and without recurrent pain through an RCT.

Introduction

Worldwide, significant changes in sleep timing and duration occur in adolescence (Gradisar et al., 2011). It is estimated that 30% of adolescents either meet criteria for insomnia, or report some insomnia symptoms; that is, frequent and chronic difficulties with initiating sleep, maintaining sleep, or early morning waking (Dohnt et al., 2012). Up to 65% of adolescents report taking more than 30 minutes to fall asleep (Hysing et al., 2013), and up to 80% of adolescents report sleeping less than the recommended 8-10 hours each night (Asarnow et al., 2014; Foundation, 2006).

Poor sleep quality and quantity in adolescents has been found to be associated with impaired physical health including being overweight, cardiovascular risk, acute illness, and recurrent pain (Orzech et al., 2014). Approximately 30% of adolescents experience recurrent pain (Luntamo et al., 2012) and 54% with recurrent pain also report sleep impairment (Palermo et al., 2011). A proposed model of pain and sleep suggests a bidirectional relationship, with each factor negatively impacting the other (Valrie et al., 2013). Poor sleep has also been found to impair psychosocial and daytime functioning. Sleep restriction in adolescents impairs a variety of cognitive functions including attention, working memory, executive functioning, and alertness (Lo et al., 2016). Further, adolescents reporting diagnosis of a sleep disorder are considered to be at an increased risk of depressive symptoms (Inkelis et al., 2021).

Adolescent sleep changes have been described as being triggered by a perfect storm of biopsychosocial factors (Carskadon, 2011). Biological changes cause adolescents to have less physiological pressure to fall asleep, as well circadian rhythms

that naturally shift bedtimes and waketimes to later (Feinberg et al., 2006). Psychosocial changes occur at a time when parental control over bedtime and daily activities lessens (Short et al., 2011). Variability in adolescent sleep schedules is influenced by employment, academic commitments, extracurricular activities, and socializing with friends (Owens, 2014). Further, up to 97% of adolescents report using electronics before sleep, which interferes with sleep (Hale & Guan, 2015). Conversely, following healthy sleep practices (previously referred to in the literature as sleep hygiene) has been associated with earlier bedtimes and longer sleep duration (Bartel et al., 2015).

The most common treatment approaches for adolescent sleep problems are targeted behavioural strategies to manage healthy sleep practices. As reported in recent systematic reviews, cognitive behavioural sleep interventions for adolescents have been found to significantly improve sleep efficiency (proportion of time in bed spent asleep), sleep onset latency (time it takes to fall asleep), total sleep time, sleep quality, as well as other variables such as depression (Åslund et al., 2018; Blake et al., 2017). Despite the demonstrated effectiveness of in-person interventions, there are numerous barriers, including cost, time, and access to trained providers (Gradisar & Richardson, 2015).

eHealth interventions offer accessible, potentially cost-effective, and timely resources that address many barriers restricting adolescents from receiving in-person treatment (Cushing & Steele, 2010). Only three studies report development of adolescent eHealth sleep interventions, one of which reports RCT testing that demonstrated improved sleep efficiency, sleep onset latency, total sleep time, night wakings, and symptoms of psychopathology (de Bruin et al., 2015). This intervention, however, was not entirely adolescent-led and included weekly written feedback from a professional.

The second and third eHealth sleep interventions, *Sleep Ninja*, and *Delivering Online Zzz's with Empirical support (DOZE)* are entirely participant-driven apps that reported improvement sleep and daytime functioning outcomes during pilot testing (Carmona et al., 2020; Werner-Seidler et al., 2019). However, the *DOZE* intervention was tested in a sample with only 24% adolescents (n=20) (the remaining 76% participants were 19-24 years old) (Carmona et al., 2020). Further, the *Sleep Ninja* intervention revealed poor retention rates with only one-third of participants completing the program, and users reporting too much text and repetitive information as main reasons for discontinuing. Considering that protocol compliance is one of the most common barriers to success of adolescent behavioural sleep interventions (Ruiter Petrov et al., 2014), it is critical to develop a stand-alone product that will engage adolescents and retain their interest.

The focus of the current study was to evaluate the online process of delivering *BNBD-Youth* for adolescents 14-18 years old who experience symptoms of insomnia, with and without recurrent pain. The research questions are:

1) Is *BNBD-Youth* ready for future RCT testing regarding participant recruitment, engagement, retention, and data collection?

2) Does using *BNBD-Youth* result in significant pre-post sleep and daytime functioning changes as measured by diary and questionnaire assessment?

3) Do higher levels of baseline pain frequency influence pre-post changes in sleep outcomes?

4) What is the effect size estimate for sleep efficiency to inform future RCT testing of *BNBD-Youth?*

Methods

Participants

Adolescents between the ages of 14 and 18 years were eligible if they experienced insomnia symptoms (difficulty initiating sleep, maintaining sleep, early morning waking), resided in Canada, attended junior high or high school, had access to the internet and an email account, proficient in English, and no cognitive/visual/hearing impairment. Participants were recruited across Canada via online advertisements, posters, word of mouth, and by contacting participants from previous focus groups held to inform intervention development. Some recruitment materials advertised that adolescents with recurrent pain were welcome to participate; however, this was not an eligibility criterion.

Nineteen youth participated, with a mean age of 15.7 years ($SD = 1.4$, range = 14-18). Adolescents were 79% female ($n = 15$), 74% Caucasian ($n = 14$), and attended grades 8-12 ($M = 10.3$, $SD = 1.3$). Participants also completed usability measures during participation with usability results and participation flow reported in Chapter 4.

Procedure

Interested participants completed an online eligibility and consent form. Consenting participants were emailed a link to a questionnaire to collect demographic and participant characteristics. Participants completed an online diary to monitor pre-treatment sleep patterns and pain levels for 7 consecutive days. A link to the same diary was provided each day for seven days exactly five weeks after initial use of *BNBD-Youth* to monitor one-week post-treatment outcomes. At both pre- and post- intervention, participants were given a maximum of 10 days to complete seven diary entries, with the

ability to complete diaries up to two days prior to the date of entry. Once the first week of diary tracking was completed, participants were provided with access to *BNBD-Youth* for a maximum of five weeks to review and complete the program content. A $20.00 gift card was emailed at the end of the study as an honorarium for participation.

Intervention

Better Nights, Better Days – Youth (*BNBD-Youth*) is an online sleep intervention program developed for adolescents with sleep problems. *BNBD-Youth* comprises four sessions, each divided into multiple microlearning lessons, providing behavioural strategies focused on sleep behaviours, including psychoeducation about healthy sleep practices, stimulus control (strategies for associating bed and bedroom with normal sleep), relaxation techniques, and strategies for applying information to individuals with recurrent pain (Table 5.1). Content is delivered in the form of videos, text, images, infographics, quizzes, interactive games, daily sleep diary, and access to graphs based on diary input. Across all sessions, participants were encouraged to track their sleep habits using an online sleep diary within *BNBD-Youth*.

Measures

Eligibility Questionnaire

The eligibility questionnaire was created by the study authors and used for the focus group study (reported in Chapter 2). The questionnaire asks whether participants were between 14-18 years old, lived in Canada, attended junior high or high school, had access to internet and email, were proficient in English, and did not have any hearing or cognitive deficits.

Insomnia Severity Index (ISI)

The ISI is a 7-item questionnaire developed to detect clinical cases of insomnia, rated on a 5-point Likert scale (0 = no problem; 4 = very severe problem) (Morin et al., 2011). Scores range from 0-28, with 8-14 considered to be subthreshold insomnia symptoms, 15-21 moderate symptoms, and 22-28 severe symptoms. Participants with scores of 7 and lower were excluded from the study. The ISI shows high internal consistency in adolescents without pain ($\alpha = 0.90$) (Chahoud et al., 2017) and in adolescents with recurrent pain ($\alpha = .85$) (Bromberg et al., 2020). The ISI was used to assess adolescents' insomnia symptoms to determine study eligibility.

Demographic Questionnaire

The demographic questionnaire was created by the study authors and used for the focus group study (reported in Chapter 2). The questionnaire asks about age, sex, ethnicity, grade, any recurrent pain, as well as the type, intensity (on a 10-point rating scale), duration, and frequency of pain. The demographic questionnaire was used to assess descriptive participant characteristics.

Sleep Hygiene Index (SHI)

The SHI is a 13-item index that was developed from the diagnostic criteria in the International Classification of Sleep Disorders to assess inadequate sleep hygiene (referred to currently as healthy sleep practices) (American Academy of Sleep, 2005; Mastin et al., 2006). Scores from the SHI range from 0 to 55, with higher scores representing poorer sleep hygiene. Based on psychometric testing (Mastin et al., 2006), scores of at least 41 are at the 75th percentile or higher, and for the purposes of this

research considered to be "poor" sleep hygiene. The SHI was used to assess pre-post change in healthy sleep practices.

Functional Disability Inventory (FDI)

The FDI is a self-report measure validated for use in youth 8-17 years old. The FDI is a 15-item measure that assesses psychosocial functioning associated with physical health over the past two weeks (Walker & Greene, 1991). Items are rated on a 5-point scale to indicate the level of difficulty (0 = no trouble, 4 = impossible) to participate in activities (e.g., walking to the bathroom, attending school). The FDI was used to assess pre-post change in functional disability.

Centre for Epidemiologic Studies Depression Scale (CES-D)

The CES-D was used to evaluate depressive symptoms and has been validated for use in adolescents (Roberts et al., 1990). CES-D is a 20-item measure; items are rated on a 4-point scale to indicate frequency of symptoms over the past week (1 = Rarely or none of the time; 4 = Most or all of the time). The CES-D was used to assess pre-post change in depressive symptoms.

Pre-post Diary

An online daily diary was used to monitor participants' sleep and pain patterns pre- and post-intervention. The daily diary tracked the time of day (hh:mm) that participants got ready for bed, got into bed, were ready to fall asleep, fell asleep, and woke up. Participants also recorded the number and duration (in minutes) of night wakings. Using Likert scales from 1-5, participants recorded perceived sleep quality,

feeling rested after sleeping, and satisfaction with wake-time. Participants also recorded the number and duration of naps taken throughout the day. To record pain, participants indicated daily whether they experienced any pain (frequency), the type of pain, its duration (in minutes), and intensity (on a scale of 1-10). The daily diary was used to assess pre-post changes in daily sleep and pain outcomes.

Data Analysis

Descriptive statistics were used to report frequencies, ranges, means, and standard deviations. Sleep efficiency was calculated by identifying the proportion of time spent asleep versus time spent in bed. Sleep onset latency was calculated by identifying the amount of time it took participants to fall asleep (time the adolescent fell asleep minus the time when the adolescent reported being ready to fall asleep). The means of daily sleep and pain diary values were calculated within and across participants. Sleep and pain diary variables were averaged across participants for each of the pre- and post- treatment weeks. Paired t-tests were conducted to evaluate pre- to post- changes in sleep and pain diary outcomes, as well as healthy sleep practices, functional disability, and depressive symptoms from questionnaire measures. Given that the definition of recurrent pain is based on frequency of at least one pain episode per week for at least three months, bivariate correlations were performed to explore whether baseline pain frequency was correlated with baseline sleep variables and any change post-treatment. To inform the effect size needed to demonstrate significant change for a randomized controlled trial, Hedge's g effect size estimate for sleep efficiency was calculated using results from this study. Sleep efficiency was selected as it includes both sleep quantity and quality, is commonly used as a primary outcome measurement in clinical trials.

Results

Study Participation

A total of 28 participants received the intervention, with 20 participants (71%) completing all sessions of *BNBD-Youth*, and 19 participants (67%) completing all pre-post measures. From the 19 participants, a total of 131 baseline diaries were entered on-line, with an average of 6.9 (99%) diaries (range 5-7) completed per participant, with 59% entered on time and the rest entered one (40%) or 2-3 days after the entry date (1%). At follow-up, 129 diary entries were made, with an average of 6.8 (97%) diaries (range 5-7) completed per participant, with 57% entered on time or one day after the entry date (33%), with the remaining entries (10%) completed 2-3 days after the diary date. The descriptive statistics for pre- and post- intervention diary variables and questionnaire data are presented in Tables 5.2 and 5.3, respectively.

Sleep and Pain Questionnaire Characteristics

Of the 19, participants' scores on the ISI ranged from 11 to 25 ($M = 18.2$, $SD = 4.3$), with 5 participants in the sub-clinical threshold range, 7 participants in the moderate range, and 7 participants in the severe range of insomnia symptoms. At baseline, 15 of the 19 participants (79%) reported experiencing recurrent pain at least once per week for at least three months, with 10 reporting pain-related to sleep problems. Average pain frequency over the past month was 13.6 days ($SD = 9.4$, range 0-31 days), with 2 participants who reported that they were always in pain. Average pain intensity was 4.3 ($SD = 1.5$, range = 2-7), and average pain duration was 5.3 hours ($SD = 9.2$, range 0-24).

Pain types included musculoskeletal ($n = 7$, 37%), abdominal ($n = 6$, 32%), headache ($n = 5$, 26%), and facial ($n = 1$, 5%).

t-Tests between pre- and post- treatment variables

Paired-sample t-tests were conducted to assess mean differences from pre-post intervention for sleep (Table 5.2), pain, and daytime functioning outcomes (Table 5.3).

Sleep Outcomes

Of the sleep variables collected through daily diaries, significant improvement post-intervention was found for sleep efficiency ($p < .01$), the total time that adolescents spent asleep ($p < .001$), as well as the total time spent in bed ($p < .001$). Number of night wakings significantly decreased post-intervention ($p < .001$), while significant increases in positive perception of wake-up time ($p = .001$), and sleep quality ($p < .05$) were identified. The remaining diary sleep outcome variables, sleep onset latency, total time spent awake at night, perception of feeling rested in the morning, and number of naps, did not change significantly. Adherence to healthy sleep practices collected via questionnaire significantly improved post-intervention ($p < .001$). At pre-intervention, scores reporting adherence to healthy sleep practice ranged from 30-47 with 22% ($n = 4$) of participants reporting poor healthy sleep practices (scores of 41 and higher). At post-intervention, adherence scores ranged from 21-42, with one participant (5%) reporting poor sleep.

Pain and Daytime Functioning Outcomes

A significant decrease in pain frequency from 2.79 pain episodes to 1.10 episodes per week was identified ($p = .001$). No significant differences were found for pain

duration or pain intensity. Pre-post questionnaire measures found significant improvement in the ratings of functional disability ($p < .01$) and depressive symptoms ($p = .001$). Pain frequency at baseline was not correlated with changes in pre- to post- sleep outcomes, nor with sleep variables at baseline.

Effect Size Estimate

The Hedge's g effect size calculated to demonstrate significant change in a future RCT was determined to be a small-moderate effect, ($g = 0.47$, 95% CI (0.15 – 0.83)).

Discussion

This paper describes an evaluation of the process of delivering an eHealth sleep intervention for adolescents experiencing symptoms of insomnia, with and without recurrent pain. The results indicate that testing *BNBD-Youth* achieved high rates of retention, pre-post data collection, and diary completion. Further, *BNBD-Youth* led to significant improvement across most measures at post-intervention, including sleep efficiency, sleep duration, time in bed, night waking, sleep quality, perception of wake-up time, healthy sleep practices, functional disability, depressive symptoms, and pain frequency. Finally, these results provided the effect size needed to demonstrate true significant change in sleep efficacy for future RCT testing of *BNBD-Youth.*

Through a non-randomized pilot trial, this study explored the processes that will be carried out in larger RCT testing, including online recruitment, screening, consent, communication, testing an entirely adolescent-driven sleep intervention, pre-post diary and questionnaire measurement. Although the dropout rate was high between completing consent ($n = 161$) and starting the intervention, ($n = 28$; retention of 17%), once

participants accessed the intervention, 71% completed all four sessions of *BNBD-Youth*, and 68% completed all pre-post diary and questionnaire measures, with an average of 6.9 and 6.8 pre- and post- diaries, respectively, completed out of a possible 7. The only existing web-based interventions either had therapist involvement through written feedback and did not report intervention completion rates (de Bruin et al., 2015), were tested in a sample of only 24% adolescents (Carmona et al., 2020), or reported poor retention rates when the intervention was pilot tested (Werner-Seidler et al., 2019). The level of participant engagement with *BNBD-Youth* is encouraging for future testing and further contributes to this field of research in testing adolescent-driven eHealth sleep interventions.

The significant improvements in sleep outcomes and daytime functioning are consistent with results of in-person and online sleep interventions that also demonstrated improved sleep and daytime functioning outcomes (Åslund et al., 2018; Blake et al., 2017). *BNBD-Youth* demonstrated preliminary efficacy in guiding adolescents to improve sleep efficiency from just outside of the normal range (84%) to within the optimal range at 88% (85% and above is considered to be normal sleep efficiency; Lacks & Morin, 1992). The program contributed to improved sleep duration from 7.2 hours to 8.3 hours of sleep nightly, within the lower end of the recommended 8-10 hours of sleep per night for adolescents. Sleep quality and healthy sleep practices also demonstrated an overall improvement, consistent with reported sleep intervention outcomes. Inconsistent with existing literature, however, were the non-significant findings for sleep onset latency, and duration of night waking. The lack of significant outcomes for these two variables were due to high variability in reporting across participants and as such will benefit from

further examination with a larger population. Together, these results provide support for potential improvement in sleep outcomes when testing efficacy of *BNBD-Youth* through a RCT. These preliminary findings also warrant further examination of the association between sleep and daytime functioning to understand potential efficacy of an eHealth sleep intervention for improving functioning beyond sleep outcomes.

While no significant differences were identified for pain duration or intensity, participants reported a significant decrease in pain frequency from an average 2.79 episodes before intervention to 1.10 episodes the week after intervention, a 40% reduction in pain frequency. These results are encouraging support for the suggested bi-directional relationship between pain and sleep (Valrie et al., 2013) and the potential benefits to pain experiences in the context of managing sleep behaviours. While 79% ($n =$ 15) of participants in this study reported experiencing recurrent pain, frequency at baseline did not influence baseline sleep variables or any change at post-treatment. Although pain was not a main area of focus within the intervention content, short tips for applying sleep strategies specifically for individuals with recurrent pain were integrated throughout the intervention and may have contributed to improvement in sleep and pain outcomes for this population. These results provide support for further testing of *BNBD-Youth* as a sleep intervention for adolescents both with and without recurrent pain.

Strengths and Limitations

Participants included adolescents with and without recurrent pain, recruited across Canada. These results, however, may not reflect all adolescents experiencing insomnia symptoms. Given that the sample was primarily Caucasian female adolescents with

recurrent pain, generalizability may be limited due to this lack of diversity. While daily diary measures are an excellent source of pre-post outcome data, in this study diary tracking was limited to seven days for each period. Further, there were no objective sleep measures, such as actigraphy, in which a wrist-worn device (actigraph) is used to track motor activity from which a number of sleep variables can be calculated. Participants were also completing usability ratings throughout participation (see Chapter 4), which is an added burden that may have influenced participant engagement. Recruitment, screening, and all communication were conducted entirely online without any face-to-face contact, potentially influencing overall participation in the study, while also recruiting participants who were most likely to reflect end-users of *BNBD-Youth*.

Conclusions

This research evaluated the delivery and preliminary efficacy of *BNBD-Youth*, an eHealth sleep intervention for adolescents with and without recurrent pain. This research shows promise for participant retention, engagement with the intervention, and following pre-post testing procedures. Significant pre- to post-intervention changes in sleep and daytime functioning outcomes were identified and provided effect size estimate for demonstrating change in future RCT testing of *BNBD-Youth.*

Acknowledgements

Table 5.1. Content delivered in each of the *BNBD-Youth* sessions.

Session	Session content
Session 1 (10 lessons)	- What sleep is - The role that sleep has - Importance of sleep on daily living
Session 2 (7 lessons)	- Different sleep disorders - Methods of measuring sleep - Tracking sleep quality, healthy sleep practices, bedtimes and waketimes
Session 3 (10 lessons)	- Specific healthy sleep practices - Understanding personal sleep practices - Identifying areas of behaviour to change
Session 4 (4 lessons)	- Review of what was learned in previous sessions - Roadblocks for practicing healthy sleep - Additional resources about sleep

Table 5.2. Descriptive statistics and t-tests for pre-post diary and questionnaire sleep variables.

Variable type	Outcome variable	Pre-Treatment Mean (SD)	Post-Treatment Mean (SD)	t-test t	df	p
Daily diary pre-post measures	Sleep efficiency (%)	84.22% (7.09)	88.16% (8.72)	**-3.21**	**18**	**<.01****
	Sleep onset latency (mins)	39.27 (24.53)	37.78 (37.58)	.26	18	.80
	Total sleep time (mins)	432.56 (54.83)	506.72 (61.14)	**-6.12**	**18**	**<.001*****
	Total time in bed (mins)	512.83 (61.86)	580.24 (85.61)	**-4.71**	**18**	**<.001*****
	Night waking (number)	1.64 (1.44)	.77 (1.03)	**5.27**	**18**	**<.001*****
	Night waking (total mins)	20.72 (16.39)	29.16 (56.73)	-.52	13	.61
	Perception of wake-up time (1-5)	2.45 (.64)	3.15 (.66)	**-4.13**	**18**	**.001*****
	Perceptions of sleep quality (1-5)	2.78 (.66)	3.14 (.68)	**-2.39**	**18**	**< .05***
	Perceptions of how rested (1-5)	2.41 (.69)	2.78 (.73)	-1.86	18	.08
	Naps (number)	0.37 (.50)	0.21 (.42)	1.00	18	.33
Questionnaire pre-post measure	Sleep Hygiene Index	37.10 (5.46)	32.05 (.20)	**3.80**	**18**	**.001*****

Note. SD = Standard deviation; mins = minutes; % = percent.

Table 5.3. Descriptive statistics and t-test results for pre-post pain, functional disability, and depressive symptoms.

Variable type	Outcome variable	Pre-Treatment Mean (SD)	Post-Treatment Mean (SD)	t	df	p
Daily diary pre-post measures	Pain frequency (#)	2.79 (2.39)	1.10 (1.82)	**3.89**	**18**	**.001***
	Pain duration (mins)	116.24 (127.33)	84.17 (41.64)	.86	7	.42
	Pain intensity (1-10)	4.42 (1.14)	4.37 (1.36)	.86	7	.42
Questionnaire pre-post measures	Functional Disability Inventory	17.37 (13.31)	9.52 (2.18)	**3.64**	**18**	**.01**
	Depression Scale	14.37 (10.40)	13.67 (3.14)	**-3.88**	**18**	**.001***

Note. SD = Standard deviation; mins = minutes.

Chapter 6: Discussion

Overview of Findings

The goal of this dissertation was to follow a user-centered approach in the development of an eHealth sleep intervention for adolescents with sleep problems, including adolescents with and without recurrent pain. The primary research aims of this work were to: 1) conduct focus groups to identify adolescents' and stakeholders' perceptions of youth about following healthy sleep practices and using an eHealth sleep intervention, 2) conduct usability testing and evaluate user experience with the developed intervention for identifying readiness for future RCT testing, and 3) conduct pilot testing to evaluate the process of delivering the eHealth sleep intervention to adolescents and identify preliminary pre-post efficacy of the intervention on sleep and pain outcomes.

The main results from this dissertation are briefly summarized along with the broad research questions introduced in Chapter 1 (Introduction). After summarizing the main findings, the role of taking a user-centered perspective in the development of an adolescent eHealth intervention is discussed, as well as the implications for managing sleep in adolescents with recurrent pain. Finally, overall strengths and limitations of this program of research reported in this dissertation are reviewed, as well as clinical implications and future research directions.

Research Question 1: **What are adolescents' and stakeholders' perceptions of healthy sleep practices and eHealth sleep intervention use in adolescents with and without recurrent pain?**

Results of the focus groups represented opinions of adolescents with and without recurrent pain and associated stakeholders (e.g., parents, educators, health care professionals). Findings from these focus groups highlight that while adolescents were generally aware of most recommended healthy sleep practices and perceived the majority as reasonable to implement, many barriers are present that prevent consistent and effective implementation of healthy sleep practices by youth. Both adolescent and stakeholder participant groups related to the pain and pain-free discussion topics reported that the most common barriers were inconsistent schedules due to lifestyle, technology at night, and having an active mind. These barriers influence several healthy sleep practices such as going to bed at the same time each night, avoiding exciting activities before bed, and/or sleeping 8-10 hours every night. Participants noted that facilitators to changing sleep behaviour would be awareness about the negative impacts of poor sleep and the benefits of healthy sleep, to help understand the importance of managing sleep practices.

These findings are consistent with existing focus group studies that have reported adolescents' awareness of healthy sleep practices and desire to improve sleep behaviour, while also noting several barriers that interfere with following healthy sleep practices, particularly time demands and variable schedules (Gaarde et al., 2020; Godsell & White, 2019; Paterson et al., 2019).

The perceptions collected from focus group members about manageable and difficult healthy sleep practices as well as facilitators and barriers to following them were integral in development of *Better Nights, Better Days – Youth (BNBD-Youth)*, a behavioural eHealth sleep intervention for adolescents with and without recurrent pain. Content development included consideration of which healthy sleep practices were perceived as most difficult and focused on clearly conveying suggestions for overcoming barriers while also engaging interest with interactive features (e.g., an animated video discussing the relationship between electronics and sleep, a tailored sleep routine builder to help adolescents plan for bedtime). Knowing that focus group members desired information about the benefits and impacts of sleep, this content was integrated throughout *BNBD-Youth* along with a daily sleep diary to continue enhancing motivation for improving sleep behaviours during participation.

The results from these focus groups contributed to the development of *BNBD-Youth* as well as to larger literature about eHealth development through gathering input about content, features, visual design, barriers, and facilitators to use. The main feedback from the focus group participants regarding intervention content perceived as most important to include, were primarily recommendations for overcoming barriers to healthy practices. Adolescents with and without pain reported that an eHealth intervention should include features that are interactive and engaging with content provided through videos, audio, and images to minimize text. Visually, participants recommended a colorful and simplistic design that is easy to navigate and understand. An intervention that feels too educational or time consuming was highlighted as a common barrier to using an eHealth intervention, while an accessible platform was reported as a desirable facilitate to use.

This feedback is consistent with adolescents who participated in focus groups to inform the development of *Sleep Ninja*, an app-based sleep intervention (Werner-Seidler et al., 2017). When participants who pilot tested the app were asked about their reasons for discontinuing use (67% did not complete all sessions of the intervention), the main reasons were that the app contained too much text and was too repetitive (Werner-Seidler et al., 2019). The considerations that were recommended by focus group members for an eHealth sleep intervention were important during the design development of *BNBD-Youth,* leading to developing a program using a micro-learning approach with content provided in short lessons that can be completed within minutes. A focus was placed on minimizing text and including videos, pictures, interactive games and features to maintain interest and engagement during participation. *BNBD-Youth* includes a simple navigational design with colorful accents integrated throughout.

When exploring differences between subgroups (i.e., pain/non-pain; adolescents/stakeholders), discussions about healthy sleep practices were mostly consistent, with only a small number of subthemes specific to participant groups. While adolescent participants identified schoolwork as a common barrier to following healthy sleep practices, stakeholders identified motivation as a potential interfering factor and suggested that an eHealth sleep intervention include goal setting to guide motivation for changing sleep behaviours. This suggestion is supported by current sleep education literature that suggests incorporation of a motivational theoretical foundation increases improvement of sleep practices (Rigney, Watson, et al., 2021). A goal-setting component was integrated into *BNBD-Youth* for guiding adolescents to identify the sleep behaviours that they would like to change.

Regarding differences between pain and pain-free participant groups, two healthy sleep practices (no caffeine or large meals before bed) were raised by only a small number of pain-related adolescent and stakeholder focus group members, and not discussed at all by pain-free group members. Adolescent and stakeholder pain-related focus group members also noted that recurrent pain is a common barrier to following healthy sleep practices, highlighting the important sleep-pain relationship to consider during eHealth sleep intervention development (Chambers et al., 2008; Dick, 2013). When discussing eHealth sleep intervention development, the pain-related adolescent and stakeholder groups both identified that information tailored to adolescents with pain would be beneficial to guide understanding about the interaction between sleep and pain. This suggestion is consistent with feedback from adolescents with long-term health conditions who were reported to desire multiple aspects of their health conditions to be addressed within a targeted eHealth intervention (Thabrew et al., 2018). To address these suggestions, in the development of *BNBD-Youth*, optional tips about the role of recurrent pain and how to consider it when managing sleep were integrated throughout the program for adolescents to explore.

The findings from these focus groups were critical in the design of *BNBD-Youth*'s content, features, and visual design. This focus group research provides several contributions to existing literature. Novel to this field is receiving specific feedback about several individual healthy sleep practices and identifying those that are manageable, difficult, and the common facilitators to their use. These findings also confirmed common barriers to following healthy sleep practices reported in existing studies, as well as common adolescent perceptions about desired features for eHealth interventions (Gaarde

et al., 2020; Godsell & White, 2019; Paterson et al., 2019; Thabrew et al., 2018). Unique to this work is the simultaneous collection of perceptions about healthy sleep practices as well as eHealth intervention development from the same population. Additionally, this research contributes perceptions of both adolescents and stakeholders, and also collected opinions of adolescents with recurrent pain as well as associated stakeholders. These focus groups were the comprehensive first step of a user-centered approach and addressed multiple components related to user needs for consideration in the development of *BNBD-Youth*. Following a user-centered approach aims to overcome barriers of using an eHealth intervention while increasing the chance of success at improving sleep outcomes in adolescents (Stojmenova et al., 2012).

Research Question 2: **Does usability testing of BNBD-Youth support readiness of future RCT testing regarding user experiences?**

Once *BNBD-Youth* was developed based on focus group feedback, the extant literature, and clinical best practices, usability testing of the intervention was conducted with 22 adolescents. Overall usability results highlighted positive feedback from participants about the individual intervention sessions, as well as the intervention as a whole. Usability was assessed using Morville's user experience honeycomb to evaluate the intervention on seven usability dimensions: useful, usable, findable, desirable, accessible, credible, and valuable (Morville & Sullenger, 2010). Participants provided both numerical ratings and written feedback about each of the usability dimensions for the intervention sessions and overall program. Most averaged ratings were found to be positive across the usability dimensions, with only a small number of neutral ratings (7 of 35). No negative ratings were provided.

Similar to the usability ratings, most of the written feedback was positive with a small proportion of written feedback highlighting challenges of the intervention. Comments about challenges of "desirable" and "accessible" usability dimensions across sessions and the intervention were notable and warrant minor modification of *BNBD-Youth* before it is ready for larger-scale RCT testing. To improve the "desirable" user experience, modifications to the next iteration of the intervention could include more integration of color throughout the program as well as introducing additional features to minimize text and improve video, such as providing text to audio options, adding screen captions or scripts for videos, including additional relevant images. To address "accessible" concerns, functionality of features within the program (e.g., viewing videos) will need to be improved across devices (e.g., tablet and phone). These recommendations were not yet integrated prior to pilot testing (Chapter 5) as it ran concurrently with the usability study. The next step of this research will be to implement these changes to improve "desirable" and "accessible" components of *BNBD-Youth*.

This study also considered the influence that recurrent pain may have on user experience when interacting with an eHealth sleep intervention. While the *BNBD-Youth* intervention did not have a large focus on pain, there were optional tips integrated throughout the program about the role of recurrent pain and how to consider it when managing sleep. Across all usability dimensions for each session and overall program, pain frequency was found to be associated with lower usability ratings (ranging from neutral to positive) for the "usable" dimension of Session 1 (what is sleep) and higher ratings (also ranging from neutral to positive) for the "valuable" dimension of Session 3 (healthy sleep practices). This indicated that participants with higher pain frequency at

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baseline reported Session 1 to be less usable, and Session 3 to be more valuable than those with lower pain frequencies. The next iteration of *BNBD-Youth* may benefit from inclusion in Session 1 of more targeted information about the relationship between sleep and pain and how the program can be used by individuals with comorbid recurrent pain.

Once the next iteration of *BNBD-Youth* is finalized, this user evaluation supports readiness in usability for future larger-scale testing of adolescents both with and without recurrent pain. This usability research provides several contributions to existing literature, including an illustration of how a user-centered perspective can be followed for eHealth sleep intervention development. This user-centered development process demonstrates the steps that can be taken in gathering and integrating user input with the aim of meeting user needs. In particular, *BNBD-Youth* is the only existing web-based eHealth sleep intervention that is entirely self-guided by the adolescent and tested by adolescents with and without recurrent pain. Including feedback from adolescents with and without recurrent pain adds a unique contribution to this research area and provides an example of addressing the needs of adolescents with comorbid conditions in a user-centered process. Usability testing of *BNBD-Youth* identified important considerations of intervention strengths that were positively received and meet user needs, as well as intervention challenges to address in the next *BNBD-Youth* iteration for better meeting user needs.

Research Question 3: Does pilot testing of BNBD-Youth support readiness for future RCT testing regarding procedures, outcomes, and effect size estimate?

For this non-randomized pilot testing, a subsample of 19 adolescents who participated concurrently in usability testing completed all pre-post measures and were

included in analysis. Results from this research support using entirely online methods for recruitment, participant engagement, data collection, and intervention delivery. This process successfully identified eligible adolescent participants across Canadian provinces with and without recurrent pain. Although the drop-out rate was high between completing consent ($n = 242$) and starting the intervention ($n = 28$), once participants accessed the intervention 71% completed all four sessions and 68% completed all pre-post diary and questionnaire measures, with 97-99% of the seven-day pre-post diaries being completed.

Results from this process demonstrate retention and adherences rates to the assessment procedures and use of the *BNBD-Youth* intervention that allow for an accurate evaluation of pre-post outcomes. Pilot testing of *BNBD-Youth* produced similar retention rates of participants completing pre-post measures when compared to the only other entirely self-directed (without involvement of parents or trained providers) adolescent eHealth sleep intervention, *Sleep Ninja* (Werner-Seidler et al., 2019). These results are encouraging for using online methods of assessment, and may contribute to a reduced participant burden that facilitates retention during testing (Teague et al., 2018). However, *Sleep Ninja* was reported to have only 33% of participants adhere to completing all components of the intervention, compared to 71% of participants completing all components of *BNBD-Youth*.

Results of the preliminary efficacy testing also provide support for continuing this research and examining the efficacy of *BNBD-Youth* on sleep outcomes through a future RCT. Statistically significant improvements were identified for several sleep and daytime functioning outcomes, consistent with results of testing in-person interventions (Åslund et al., 2018; Blake et al., 2017). Unique to this pilot testing research is also the identified

significant improvement in pain frequency post-treatment (with no significant changes to pain duration or intensity). Considering the suggested relationship between sleep and pain (Valrie et al., 2013), this positive change in pain frequency warrants future exploration. No significant relationship was found between baseline pain frequency and change in sleep outcomes. Given that baseline pain frequency was not correlated with any baseline sleep variables, it is unsurprising that an association was also not present between baseline pain frequency and change in sleep variables at post-intervention.

Finally, this research identified that a small-moderate Hedge's g effect size (0.47) is needed for demonstrating significant change of sleep efficiency in a future RCT. This is an encouraging finding for the current and future testing of *BNBD-Youth*. Determining effect size for future testing provides important information for future planning such as sample size determination. The small-moderate effect size needed in future larger-scale testing demonstrates confidence in the findings retrieved from the current pilot study and the ability to detect differences between groups in future testing.

Together, these pilot testing results demonstrate the readiness of *BNBD-Youth* for future RCT in terms of testing procedures and preliminary efficacy. This pilot testing has several important contributions to existing literature, including demonstration of entirely online procedures for delivery of an eHealth sleep intervention, as well as entirely online processes for recruitment and evaluation of participants. Of the three existing web-based sleep intervention studies, one included therapist involvement (de Bruin, et al., 2015), one included only adolescents in 24% of the population (Carmona et al., 2020), and the other reported poor intervention adherence rates (Werner-Seidler et al., 2017). Considering that *BNBD-Youth* is an entirely adolescent-driven intervention without

therapist involvement and maintained high pilot testing adherence rates, the procedures followed in this research are promising for future testing.

The results from testing preliminary efficacy of *BNBD-Youth* on sleep, and daytime functioning outcomes are consistent with the direction of effect from existing in-person sleep interventions and support future efficacy testing (Åslund et al., 2018; Blake et al., 2017; Griggs et al., 2020; McLay et al., 2020). The improvement in pain frequency at post-intervention is also consistent with research that has delivered in-person sleep interventions to adolescents with pain. Unique to the present program of research is the eHealth delivery of a sleep intervention to adolescents reporting recurrent pain. The improvement of pain frequency in this pilot testing supports future larger-scale evaluation of *BNBD-Youth* and its efficacy on improving pain outcomes.

User-Centered Approach in Adolescent eHealth Sleep Intervention Development

There is currently a lack of research reporting development and testing of eHealth sleep interventions for adolescents. eHealth sleep interventions have potential to overcome many adolescent barriers to receiving evidence-based treatment for sleep problems. The development and testing of *BNBD-Youth* as an eHealth sleep intervention is an important contribution to bridging the gap between science and practice. *BNBD-Youth* is an accessible program delivered over the internet, cost-effective without any need for direct professional engagement, and personalized through features integrated across the program. As a web-based program, *BNBD-Youth* is also highly scalable and can potentially be easily modified for other populations (e.g., adolescents with depression) as was done for adolescents with recurrent pain.

An important component of eHealth intervention development is the integration of adolescent input throughout the development process through a user-centered approach. End-user involvement allows for important consideration of user needs. Following adolescents' recommendations will enhance the likelihood of overcoming barriers to using an eHealth intervention and increase the likelihood of following intervention recommendations (Stojmenova et al., 2012). *BNBD-Youth* was therefore developed in consideration of adolescent needs and followed a stepped, user-centered approach with the goal of creating an appealing, usable, and desirable end-product (De Vito Dabbs et al., 2009).

Adolescents need to be interested and engaged with an intervention to benefit from the therapeutic content. Protocol compliance is one of the most common barriers to success of in-person adolescent behavioural sleep interventions (Ruiter Petrov et al., 2014). However, the lack of therapist involvement within eHealth interventions creates an even higher risk of adherence issues, with online adherence rates to adult insomnia interventions around only 52% (Horsch et al., 2015). Including the focus group feedback as a key source of direction during the initial stages of intervention development guided all components of *BNBD-Youth* to be centered around needs, opinions, and values of adolescents experiencing sleep problems. This approach is consistent with recommended guidelines for the development of mental health apps wherein understanding user needs is essential for intervention update and suggested for inclusion during development (Bakker et al., 2016). The aim of this approach was to bridge the knowledge to practice gap and create a sleep intervention that is readily accessible to adolescents while also creating a product that will be used and ultimately improve outcomes.

The overall positive feedback received from usability testing, as well as the adherence rates to intervention and preliminary efficacy results from pilot testing demonstrated that *BNBD-Youth* appears to be meeting most user needs. A contributing factor to these positive findings is likely the user involvement in the intervention's design and development. This usability and pilot testing also allows for continuation of the stepped user-centered approach in the next stages of this research. These outcomes have potential for additional improvement once modifications based on usability feedback are integrated into the next iteration of *BNBD-Youth* that will be assessed through future larger-scale testing.

The involvement of adolescents in the development of *BNBD-Youth* may increase likelihood of intervention uptake and user satisfaction (Kushniruk & Turner, 2011). The findings from this work, particularly concerning the reported strengths and challenges from using the intervention, although specific to *BNBD-Youth*, may also prove to be helpful guidance for researchers to consider when developing future eHealth interventions for adolescents.

Implications for Managing Sleep in Youth With Recurrent Pain

This research also uniquely contributes to existing literature by incorporating input from adolescents who experience comorbid recurrent pain and sleep problems into the intervention design, development, and testing. Although sleep problems and recurrent pain are common comorbid conditions with up to 50% of youth with recurrent pain experiencing sleep problems (Palermo et al., 2011), research focused only on sleep management in this population is scarce. Two in-person studies have explored the role of

managing sleep in recurrent pain adolescent populations and have reported improvement in both pain and sleep outcomes (Bruni et al., 1999; Law et al., 2018). In studies exploring eHealth for pain management through CBT that includes sleep education, positive changes in both pain and sleep outcomes have been reported (Degotardi et al., 2006; Fales et al., 2015; Law et al., 2015; Palermo et al., 2016; Palermo et al., 2009). No studies to date, however, have reported exploring the use of an eHealth sleep intervention with adolescents experiencing recurrent pain.

Including a sample of adolescents with recurrent pain in the user-centered approach of *BNBD-Youth* development allowed for in-depth exploration of potential differences between youth with and without pain. Input from adolescents with recurrent pain and associated stakeholders in the focus group study (Chapter 2) allowed for specific pain-related recommendations for *BNBD-Youth*. Considerations included awareness of recurrent pain being an important barrier to following healthy sleep practices (e.g., having a pain episode that interferes with following bedtime routine) and suggestions for tailoring intervention content to address recurrent pain issues (e.g., being aware of medications that may interfere with sleep). As a result of focus group input, several pain-related tips for applying or elaborating intervention content to youth with pain were integrated in the development of *BNBD-Youth* (see Table 3.1 for an overview of which lessons include pain-specific content).

The experience of recurrent pain continued to be a consideration during usability and pilot testing. Out of a possible 35 usability ratings, higher pain frequency at baseline was associated with lower ratings for the "usable" dimension of Session 1 (what is sleep), and higher "valuable" ratings for Session 3 (healthy sleep practices). Given that there

were not any other differences identified in usability rating between adolescents with and without pain, user needs for accessing an eHealth sleep management intervention may have been equally addressed for adolescents with and without recurrent pain. This potential user experience equivalency between adolescents with and without pain is further supported by positive preliminary efficacy results from pilot testing finding for sleep and daytime functioning outcomes. Through correlation analysis, no significant differences were identified between pain frequency at baseline and changes in sleep outcomes. Across the three dissertation studies, few differences between recurrent pain and pain-free populations were identified. These consistent findings provide support for using *BNBD-Youth* as a sleep intervention for youth regardless of recurrent pain diagnosis, without need of developing multiple diagnostic-specific sleep interventions.

From preliminary pilot testing of pain outcomes, while there was no significant improvement in pain intensity or duration, pain frequency significantly improved from 2.79 pain episodes pre-treatment to 1.10 pain episodes post-treatment. This is a 40% reduction in pain frequency and is close to no longer being classified as recurrent pain (at least once per week or more for at least three months). This finding is promising for continuing efficacy testing with pain populations and warrants future exploration with potential for important implications in further understanding of the relationship between recurrent pain and sleep problems in adolescents. Although change in sleep has been reported to be measured effectively through one-week daily sleep diaries, guidelines for trials of behavioural treatments for recurrent headache in adolescents, however, have suggested at least 28-day measurement to appropriately assess pain-related outcomes (Penzien et al., 2005). A longer period of daily pain measurement for all pain outcomes in

future testing will provide a more accurate representation of the impact an eHealth sleep intervention has on pain outcomes.

Strengths and Limitations

The findings from this dissertation are supported by several strengths that are present across the three individual studies presented in Chapter 2 (focus groups), Chapter 4 (usability testing), and Chapter 5 (pilot testing). First, the development of an eHealth sleep intervention for adolescents addresses the important research to practice gap that exists for adolescent sleep management. This research is novel in its user-centered approach of developing an eHealth sleep intervention that includes input from, and testing of, adolescents with and without recurrent pain. This research provides an illustration of the steps that can be taken to guide intervention development through consultation with end-users and demonstrates how feedback is considered and integrated at each step of the research. Following focus group feedback with first intervention development then usability and pilot testing allowed for an iterative approach in development and testing of *BNBD-Youth*, with intention of modifying the intervention based on this research, prior to future testing. Conducting and reporting these steps is an important contribution to literature in adolescent eHealth sleep intervention development, given that involving end-users in development processes is suggested to enhance the likelihood of creating a useful and valuable intervention that promotes improvement for intended health outcomes (De Vito Dabbs et al., 2009).

Additionally, the impact of using an eHealth sleep intervention was investigated in youth with and without recurrent pain. This is significant since up to 30% of

adolescents experience recurrent pain, and almost 50% of those also experience sleep problems and may therefore be even more influenced by sleep difficulties (King et al., 2011; Palermo et al., 2011; Valrie et al., 2013). While eHealth pain interventions have demonstrated improvement of sleep outcomes in adolescents with recurrent pain, no targeted eHealth sleep intervention studies have reported exploring this population. This dissertation therefore represents an important first step in developing and testing online management of sleep problems in adolescents with and without recurrent pain.

In addition to the strengths of this dissertation, there are also limitations to consider. Across the three dissertation studies, all recruitment, screening, consent, communication, and outcome measurement were conducted entirely online. The entirely online aspect of participation may have contributed to the high drop-out rates between completion of consent and participation in data collection for all three dissertation studies. The samples collected are therefore limited to those who were motivated to participate in this research and may not accurately reflect all adolescents experiencing insomnia symptoms with or without recurrent pain.

No components of the testing procedures involved in-person or phone communication, and all engagement between researchers and participants was through email (for usability and pilot testing, Chapter 5 and 6, respectively), with the exception of focus groups that were conducted entirely online (Chapter 2). The lack of in-person connection limits the subsamples to only those willing to participate in online focus groups in the first study (Chapter 2), and those willing to receive sleep treatment through entirely online means without direct, personal feedback from a trained professional (Chapter 5 and 6).

The online recruitment also limited the sample to those who: actively sought participation via classified ads, followed specific social media groups or email lists to which recruitment posts were shared, or were notified through word of mouth by others who had been reached by the online recruitment methods. Generalizability was also potentially limited due to participant demographics being primarily Caucasian female adolescents with recurrent pain. Targeted recruitment methods (e.g., within schools), would allow for access to a more representative sample of adolescents with sleep problems (with and without recurrent pain).

There were also no objective measures of sleep, such as actigraphy, to support the pre-post findings detected from pilot testing. Usability testing was also conducted using subjective measures and this this information was not completed in parallel with objective tracking of participant usage (e.g., button clicks, time spent on each page, % completion of forms, interaction with pain components). Integration of objective measures within future testing of *BNBD-Youth* can provide additional consideration for the research findings.

Clinical Implications and Future Research Directions

With limited existing eHealth sleep intervention research for adolescents with and without recurrent pain, this dissertation highlights several considerations for future research. The immediate next steps of this work will be to integrate modifications based on usability testing into the next iteration of *BNBD-Youth*. Once finalized, the intervention should be tested through larger-scale efficacy testing to evaluate the use of the intervention with a larger sample of adolescents with and without pain, as well as

examine follow-up effects post-intervention to identify maintenance of change over time. As previously mentioned, holding longer diary measurement periods for recurrent pain populations will likely provide a clearer indication of the role that managing sleep has on pain outcomes. This knowledge will further contribute to understanding the suggested bi-directional relationship between pain and sleep in adolescents and provide important considerations in the management of these often comorbid problems.

While this research targeted adolescents with and without comorbid recurrent pain, future eHealth sleep research could follow a similar approach for targeting other health conditions that are commonly associated with sleep problems, such as depression, anxiety, or attention deficit hyperactivity disorder (ADHD). The pilot testing reported in Chapter 5 demonstrated significant improvement in post-intervention depressive symptoms. This finding is consistent with several in-person studies that have specifically explored the relationship between sleep and depressive symptoms (Blake et al., 2016; Clarke et al., 2015; de Bruin et al., 2015). Other research has demonstrated a bidirectional relationship between sleep and externalizing problems, such as ADHD, from childhood to adolescence, as well as a relationship between childhood sleep and later adolescent internalizing problems, such as anxiety (Quach et al., 2018). As stated above with recurrent pain, understanding the role that treating sleep has in addressing other areas of functioning such as depression, anxiety, or ADHD, may have important clinical implications for managing those conditions.

This field of research would also benefit from evaluation of the specific mechanisms of therapeutic change that contribute to benefits in sleep outcomes in adolescents (Blake et al., 2019). In-person cognitive behavioural sleep interventions have

included a wide variety of treatment components, with consistent improvement in outcomes across studies. Testing the effects of specific treatment components on outcomes through alternative versions of an intervention or collecting measures throughout treatment intervention to identify when change happens, would contribute to understanding the mechanisms of change and contribute to further understanding barriers and facilitators to changing sleep behaviour in adolescents. Where protocol compliance has been a reported issue for adolescent engagement with sleep interventions (Ruiter Petrov et al., 2014), identifying the mechanisms of change may reduce some adolescent barriers to healthy sleep practices.

A potential direction for this work could be the testing of *BNBD-Youth* as an addition to sleep education in schools. Although sleep education in schools is relatively easy to implement and allows for direct and quick access to large numbers of adolescents, research has found that while these school-based programs are effective in improving knowledge about sleep, they are less effective in improving sleep behaviour (Blunden & Rigney, 2015; Chung et al., 2017; Gruber, 2017; Rigney, Watson, et al., 2021). Integration of *BNBD-Youth* with sleep education in schools would allow for access to large numbers of adolescents while also providing a tailored sleep intervention that is typically received through in-person delivery methods.

Conclusions

The literature on adolescent eHealth sleep management is in its infancy and the studies presented within this dissertation are important contributors to this area. The results from this research suggest that following a user-centered approach may contribute

to developing an eHealth intervention that adolescents find usable, will engage with, and may lead to improvements in sleep, pain, and daytime functioning outcomes. This research and development process can be applied specifically to adolescent sleep management, and broadly to eHealth interventions for adolescents. Future research is needed to support the clinical efficacy of the *BNBD-Youth* program through larger-scale testing. Following a user-centered approach in the development of an eHealth sleep intervention, such as *BNBD-Youth*, shows promise for overcoming barriers to offering effective self-guided sleep treatment to adolescents.

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