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Addressing the Challenges of Recruitment and Retention in Sleep and Circadian Clinical Trials

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Abstract

Objective/Background: Sleep and circadian disorders are prevalent worldwide and frequently comorbid with physical and mental illnesses. Thus, recruiting and retaining samples for sleep and circadian research are high priorities. The aims of this paper are to highlight barriers to recruitment and retention for participants with sleep and/or circadian dysfunction, and to share strategies used across two randomized controlled trials (RCTs) testing the efficacy of the Transdiagnostic Intervention for Sleep and Circadian Dysfunction (TransS-C) to address these challenges.

Participants: The first RCT recruited 176 adolescents with an evening circadian chronotype, who were ‘at-risk’ in at least one of five health domains: behavioral, cognitive, emotional, physical, and social. The second RCT recruited 121 low-income, racial/ethnic minority adults diagnosed with severe mental illness (SMI) and comorbid sleep and/or circadian dysfunction.

Methods: The current study examined participant, environment, and research factors that impacted recruitment and retention of participants with sleep and/or circadian dysfunction, and identified strategies to enhance recruitment and retention.

Results: Strategies used to recruit participants included: community-based recruiting, reducing stigma, and alleviating burdensome sleep data collection. Strategies used to retain participants in our studies included: flexible scheduling, mitigating participant barriers, building rapport with participants through empathic and positive interactions, creative problem-solving, consulting participant networks, and utilizing incentives and other positive engagement tools.

Conclusion: Both at-risk adolescents and low-income, minority adults with comorbid SMI and sleep and/or circadian dysfunction experience significant barriers to research participation. Recruitment and retention strategies were creatively tailored to meet the unique barriers of these diverse populations.

Keywords

recruitment; retention; sleep and circadian dysfunction; at-risk adolescents; community mental health

Successful recruitment and retention of participants in clinical trials is vital to internal and external validity (Gul & Ali, 2009; Kim et al., 2014). Substantial attrition can result in inadequate statistical power and selection bias (Haley et al., 2014; Herbert et al., 2016). Yet, recruiting and retaining participants in clinical trials is challenging. Several reviews reported that 50% or fewer randomized controlled trials (RCTs) recruited their target sample sizes (Bower et al., 2014; Fletcher et al., 2012).

To address this concern, researchers have identified strategies for recruiting and retaining participants from diverse populations, such as ethnic minority adults and at-risk adolescents. Effective strategies targeted participant-specific barriers like transportation, economic constraints, and disease burden (Greene et al., 2016; Wells et al., 2015). This paper extends the literature by examining recruitment and retention in sleep and circadian treatment research.

Sleep and circadian disorders are prevalent. Lack of sleep is reported in 20 – 41.7% of adults worldwide, while 4 – 26% report excessive sleepiness (Ohayon, 2011). Evidence suggests that sleep and circadian dysfunction contribute to poorer health outcomes and increased risk of chronic conditions (e.g., diabetes, cardiovascular disease, cancer) (Grossman et al., 2017; Laposky et al., 2016). Sleep and circadian dysfunction also predate and predict mental illness (Harvey et al., 2016; Van Dyk et al., 2016). Clearly, recruiting and retaining participants for sleep and circadian research are high priorities.

Unfortunately, “gold standard” sleep and circadian data collection methods can be burdensome for participants (Farabi et al., 2017; Mandrell et al., 2017). For example, actigraphy – which monitors rest and activity cycles – is collected via actimetry sensors worn 24 hours/day, usually in a wristwatch, or actiwatch (Buxton et al., 2017). Sleep diaries require participants to report daily sleep data that may be difficult to remember (Carney et al., 2012; Jungquist et al., 2015). Measurement of dim light melatonin onset (DLMO) – or melatonin secretion in dim light – requires overnight saliva sampling every 30 minutes in dim light, until 30 minutes after average bedtime (Kantermann et al., 2015).

Unsurprisingly then, sleep intervention trials have reported recruitment challenges, highlighting the need to identify effective strategies (Gleason et al., 2014). We describe our approach in two sleep and circadian treatment RCTs: 1) our “Teen Sleep Study,” in which we delivered the Transdiagnostic Intervention for Sleep and Circadian Dysfunction – Youth (TranS-C Youth) to at-risk adolescents, and 2) our “Community Sleep Study,” in which we delivered TranS-C to low-income, racial/ethnic minority adult patients of community mental health clinics (CMHCS) with severe mental illness (SMI).

Both adolescents and low-income, minority adults face significant barriers to research participation. Barriers for adolescents include family/parental conflict, psychosocial stressors, time constraints, and peer stigma (Kapungu et al., 2012; Kealey et al., 2006; Rait et al., 2015). Barriers for low-income, minority adults include mistrust of research, economic and time constraints, unstable housing, lack of childcare, disease burden, and transportation (Ejiogu et al., 2011; Kim et al., 2014). Furthermore, sleep and circadian

dysfunction are linked to additional barriers, such as cognitive impairment and reduced activity (Gradinger et al., 2011).

Despite these barriers, our team achieved high recruitment and retention rates. The Teen Sleep Study recruited 176 participants, with 14% attrition. The Community Sleep Study (ongoing) recruited 121 participants and currently has 9.92% attrition. The first aim of this paper is to describe primary barriers to recruitment and retention we encountered. The second aim is to describe how several strategies maximized recruitment and retention.

Methods

In our Teen and Community Sleep Studies, we examine the efficacy of TranS-C – a sleep and circadian treatment incorporating elements from cognitive behavioral therapy for insomnia (CBT-I), interpersonal and social rhythms therapy (IPSRT), chronotherapy, and motivational interviewing (Harvey & Buysse, 2017).

Teen Sleep Study.

TranS-C Youth was delivered in six 50-minute, weekly individual sessions. It aimed to shift modifiable contributors to evening circadian chronotype – or preference for later bedtimes and wake-times – and improve five health domains: behavioral, cognitive, emotional, physical, and social (Harvey et al., under review). A sample of 176 adolescents (10–18 years) with evening circadian chronotype, who were ‘at-risk’ in at least one of the five domains, was randomly assigned to: a) TranS-C Youth (n = 89) or b) psychoeducation (n = 87). Psychoeducation, a comparison treatment associated with sleep improvement (Harvey et al., 2015), was also delivered in six 50-minute sessions. Eligibility was determined by phone screen, three-hour in-person assessment, and seven-day sleep diary. A parent or guardian also completed a three-hour in-person assessment. Participants then completed an overnight assessment to have saliva samples collected for DLMO. Afterwards, our team collected another seven-day sleep diary concurrently with actigraphy and ecological momentary assessment (EMA), which repeatedly assesses participants’ behaviors and experiences in their natural environments (Stefano et al., 2016).

Participants repeated overnight assessments and two-week sleep diary, actigraphy, and EMA collections post-treatment. Participants and their parent/guardian also repeated in-person assessments post-treatment. At six-month and 12-month follow-ups, participants repeated in-person assessments and seven-day sleep diaries, while parents repeated in-person assessments.

Community Sleep Study.

TranS-C was delivered in eight 50-minute, weekly individual sessions. This study aimed to improve functional impairment, disorder-specific symptoms, and sleep and circadian functioning in underserved, minority patients of CMHCs (Harvey et al., 2016). A sample of 121 adult patients of Alameda County Behavioral Health Care Services (ACBHCS), diagnosed with SMI and comorbid sleep and/or circadian dysfunction, was randomly assigned to a) TranS-C (n = 61) or b) 8-months of usual care followed by delayed treatment with TranS-C (n = 60). Eligibility was determined by a phone screen, three-hour in-person

assessment, and seven-day sleep diary with concurrent actigraphy collection. Participants repeated assessments, sleep diaries, and actigraphy collection at post-treatment and six-month follow-ups. Participants in the delayed treatment group completed two additional assessments, scheduled 9 – 14 weeks and eight months after randomization with concurrent sleep diary and actigraphy collection, before receiving Trans-C.

In both studies, participants completed self-reported sleep diaries on paper to monitor sleep during treatment.

Barriers and Effective Strategies

We describe recruitment and retention barriers we faced, and provide strategies to address these challenges.

Recruitment Strategies

In the Teen Sleep Study, we elected to complete study procedures only during the school year, when participants experience greater negative effects of poor sleep (e.g. falling asleep in class) (Millman, 2005). Thus to meet recruitment goals, we recruited cohorts of approximately thirty participants per semester, across seven semesters.

In the Community Sleep Study, we initially projected that we would successfully recruit all 121 participants from a single CMHC with 477 open cases. Yet, our team had to expand recruitment to 12 additional CMHCs to meet recruitment goals.

Four core strategies addressed challenges in both studies (see Table 1).

Strategy 1: Community-Based Recruitment.—Building community partnerships established valuable recruitment networks, while presentations and widespread flyer distribution augmented referrals.

Teen Sleep Study: We were deterred from social media recruitment by prior literature reporting high costs and lower participant yields (Moreno et al., 2017; Rait et al., 2015). Thus, we focused on in-person advertising in schools, homes, and communities. We submitted an application to the Oakland Unified School District to recruit from approximately 24 middle and high schools. This process took about two months. After receiving permission, we contacted principals. Because principals were exceedingly busy, we often relied on school secretaries to leave messages or inform us when principals would be in the office. Once we attained principals' approval to recruit in schools, each had different recruitment suggestions. We presented in health classes, assembled informational tables during lunches, distributed brochures in health centers, and provided recruitment packages for teachers and counselors.

One school allowed us to hold a focus group to identify barriers and facilitators to research participation. We learned that one deterrent was fear of being hooked up to wires, or being videotaped while sleeping. Thus, we emphasized no wires or videotaping in recruitment materials.

We sent letters to pediatricians, adolescent psychologists, and other family health professionals. We advertised to an online parent community and delivered presentations to parent groups. We distributed flyers throughout the east Bay Area in cafes, libraries, restaurants, commuter rail stations, etc. Most effectively, we purchased mailing lists from a direct mail company to identify households in family-abundant zip codes. We mailed over 12,000 recruitment postcards to these addresses. While this was our most expensive recruitment effort at approximately \$5,000, it accounted for 39.77% of recruitment. Tables 2 and 3 roughly compare each recruitment method's yield against their financial and time costs, respectively.

Community Sleep Study: The principal investigator made contact with ACBHCS behavioral health directors, proposing a partnership to implement TranS-C in ACBHCS clinics. With directors' approval, we presented our research study to clinic staff (e.g. case managers, psychiatrists) of 13 ACBHCS clinics during our 28-month recruitment period. We implemented a referral process with minimal disruption to clinic workflow. Clinic staff either submitted short referral forms or gave patients our phone number. Ongoing collaboration was essential to recruitment success. We updated ACBHCS partners on milestones with annual newsletters and bi-yearly reports, while cultivating positive relationships.

Furthermore, we hosted focus groups consulting ACBHCS patients on how to make the study more engaging. For example, we learned that Target and Walmart were popular stores, which determined our choice of Target and Walmart gift cards as compensation.

Afterwards, we delivered recruitment presentations to ACBHCS patients in CMHCs, board and cares, residential treatment facilities, and support groups, bringing snacks and sleep-themed t-shirts to generate excitement. We also greeted patients in clinic waiting rooms, where brochures advertised the study.

Table 4 describes the distribution for how participants were recruited in both studies.

Strategy 2: Reducing Stigma.—Stigma and mistrust of researchers are commonly cited barriers to research participation (Kim et al., 2014; Woodall et al., 2011). Reducing treatment or research-related stigma can facilitate recruitment (Woodall et al., 2011).

In both studies, we reduced stigma towards the word “therapist” by calling providers “sleep coaches.” Additionally, we used non-threatening language to describe research procedures. For example, “EMA” became “activity calls,” and assessments became “interviews.” In the Community Sleep Study, we called our program the “Sleep Team” to invoke positive connotations of being part of a team, rather than research subjects.

Strategy 3: Alleviating Burdensome Sleep Data Collection.—Both studies required effortful data collection that deterred participation. Our team instituted protocols to alleviate as much participant burden as possible.

Teen Sleep Study: Overnight DLMO collection was highly effortful for participants. Participants began saliva sampling 5.5 hours before average bedtime and remained in dim

light for the entire collection, starting 30 minutes before the first sample. Thirteen samples were collected per assessment in 30-minute intervals, until 30 minutes after average bedtime. These requirements, along with safety concerns, deterred some adolescents and parents. To allay concerns, parents were assured that an adult supervisor was always present. We offered tours of the sleeping room to reassure participants. We created personal bios of all research assistants present at overnight assessments and sent these to families to familiarize them with their DLMO team.

Community Sleep Study. Several participants found actigraphy collection uncomfortable. Approximately three developed rashes from the actiwatch bands. Our team provided cloth wristbands for these participants to wear under the actiwatch to increase comfort.

Participants in both studies experienced challenges with the daily sleep diary. Our team collected all eligibility, post, and follow-up assessment sleep diaries daily over the phone to facilitate collection. Furthermore, our team personalized a sleep diary for one participant who had difficulty understanding the order of the sleep diary questions. These strategies alleviated participant burden, rendering participants more likely to enroll.

Retention Strategies

Participants reported numerous retention barriers, summarized in Table 5. Most participants who dropped out faced multiple barriers. Our team developed five core strategies to combat these barriers, listed in Table 1.

Strategy 1: Flexible Scheduling.—Time conflicts are frequently cited retention barriers (Kapungu et al., 2012; Pescud et al., 2015). Flexible scheduling is vital and at times requires staff willing to work evenings and weekends.

Teen Sleep Study. All appointments were held after school or on weekends to accommodate students' and working parents' schedules. Sleep diary collectors called participants before school, but after their wake-up time. DLMO collection required flexible scheduling of overnight assessments and staff willing to stay overnight.

Community Sleep Study. When possible, we scheduled appointments with participants immediately before or after existing appointments (e.g. with their psychiatrists) to reduce additional travel. Furthermore, participants frequently lost and/or damaged actiwatches, requiring flexibility in staff schedules to provide participants new actiwatches immediately to maintain concurrence with the sleep diary. Nearly all participants who lost actiwatches were successful in their second or third attempts.

In both studies, participants received reminder letters, calls, and/or texts the week before, day before, and – if needed – day-of appointments. Appointments were rescheduled as many times as necessary.

Strategy 2: Mitigating Participant Barriers.—Mitigating modifiable barriers whenever possible can maximize retention (Gul & Ali, 2010; Woodall et al., 2011).

Teen Sleep Study.: Although treatment was only administered in English, bilingual research assistants provided translation to non-English speaking parents in Spanish and Mandarin, and IRB-approved consent forms were also supplied in these languages. Parental buy-in was occasionally difficult to obtain, most commonly due to privacy and time concerns. Research staff personally addressed each parents' concerns to troubleshoot issues. For example, one parent tested all clinic doors to ensure they were locked before an overnight assessment.

Community Sleep Study.: We minimized transportation barriers through monetary support and in-home treatment. Participants may find it physically and mentally taxing to travel to new locations (Silver et al., 2012). Thus, our team offered several locations, including participants' ACBHCS clinics, our campus clinic, and our Oakland CMHC office. We provided bus passes, commuter rail passes, paratransit passes, and even taxi services to 57 participants to offset transportation costs. We printed directions and maps as needed. During actigraphy collection, we frequently picked up actiwatches from participants' homes to reduce travel burden. Even with these accommodations, 22 participants found it too physically difficult (e.g. chronic pain) or mentally distressing (e.g. agoraphobia) to travel. Staff administered assessments and treatment in 20 participants' homes, while four received phone treatment sessions.

Strategy 3: Empathic and Positive Interactions.—Our team strove to establish rapport with participants through warm, positive interactions. Building patient rapport through empathy and compassion is integral to therapeutic treatment (Overholser, 2016; Rogers 2007); as such, it is integral to treatment research. In general, people are more likely to persevere in a study when they are treated with respect and kindness (Kim et al., 2014; Wells et al., 2015).

Teen Sleep Study.: We implemented a buddy system by matching participants to research assistant “buddies” for the sleep diary, EMA collection, and overnight assessments, aiming to make these study components more enjoyable. Participants and “buddies” were frequently paired based on shared interests. During overnight assessments, participants and “buddies” played games, listened to music, etc. after completing research tasks. One research assistant was even able to re-engage her participant “buddy” after the participant initially dropped out of the study.

Community Sleep Study.: Developing strong rapport may be especially critical when working with underserved and/or minority participants (Overholser, 2016; Wells et al. 2015). This was particularly important when participants faced obstacles to completing treatment (e.g. psychiatric hospitalization, housing instability, etc.). If participants reported hardship deterring them from completing treatment, we expressed empathy and postponed the next appointment until the participant was ready, increasing likelihood of retention. On a free response task specifically asking participants what they learned in treatment, 41.35% of participants voluntarily expressed enjoyment or appreciation for specific staff members or our entire staff team, using words such as “patient,” “kind,” “friendly,” “caring,” and “helpful” to describe them.

Strategy 4: Creative Problem-Solving.—Our team generated creative solutions to resolve specific participant issues. We offer several examples of problem-solving for issues that commonly occurred.

Teen Sleep Study.: One participant initially declined follow-up assessments because he was overwhelmed with college applications. To accommodate, we conducted part of the assessment by phone and sent the remaining questionnaires and actiwatch to complete by mail.

Community Sleep Study.: Offering assessments and actigraphy collection by phone and mail enabled five Community Sleep Study participants who moved out-of-county or out-of-state to be retained. An additional six participants, who lacked time or interest, were also retained through phone/mailed assessments.

One participant consistently missed in-home treatment sessions (not at home when the sleep coach arrived). While re-engaging him, we discovered that he found the self-report sleep diaries stressful. We enlisted a research assistant to collect his sleep diary by phone for the remainder of treatment. Research assistants collected 8-week sleep diaries via daily phone calls, for 20 participants who struggled to complete self-report paper sleep diaries during treatment.

Another participant struggled to understand the sleep diary and became irritated when her sleep coach asked to review it. We designed an illustrated sleep diary depicting each question visually for her. Adapting written materials with images can be highly useful in supporting participants with limited literacy (Pastrana et al., 2017).

Strategy 5: Consulting Participant Networks.—We identified participant networks to draw upon when participants struggled to complete the study (Ejiogu et al., 2011).

In the Community Sleep Study, our ACBHCS partners were integral to retention efforts. When our team was unable to reach participants, we consulted ACBHCS clinic staff with whom we had signed releases of information. Clinic staff provided updated contact information when participants lost phones or moved. Clinic staff also shared insights about patient hardships impeding study participation, such as housing instability, health problems, etc. Thus, we were better apprised of whether to reach out to absentee participants, or postpone contact. With clinic staff support, our team re-engaged 22 participants. This strategy can be replicated with other members of a participant's network – such as family members or other providers – as long as consent is obtained (Kim et al., 2014).

Strategy 6: Incentives and Other Positive Engagement Tools.—Most clinical trials employ incentives to encourage recruitment and retention (Kapungu et al., 2012; Kim et al., 2014). Compensation levels had to be high enough to motivate participants through long assessments, but low enough so as not to compel them to complete treatment only for money. In addition, we developed fun, enjoyable incentives.

Teen Sleep Study.: Participants received \$20 for the eligibility assessment and \$10 for the eligibility sleep diary. At post-treatment, participants received \$1 per sleep diary call and 50¢ per EMA call; at six-month and 12-month follow-ups, they received \$5 for assessments and \$5 per sleep diary call. Parents received a \$15 Amazon gift card for eligibility and post-treatment assessments, and \$20 gift cards for six-month and 12-month follow-ups. Furthermore, we offered positive engagement tools such as colorful calendars illustrating study milestones and magnets with our lab’s sleeping bear logo, inspired by UC Berkeley’s beloved bear mascot. For completing treatment, participants received customized t-shirts depicting a sleeping bear, the UC Berkeley bell tower, and the statement “I participated in research at Cal!” (see Figure 1).

Community Sleep Study.: Participants received \$30 Target or Walmart gift cards for each assessment, and two \$10 gift cards for seven-day sleep diaries and actigraphy collection. Participants also received a “UC Berkeley Sleep Team” t-shirt for completing treatment, and a “Certificate of Achievement” for completing the study. Additional incentives – including a “Sleep Team” membership card (see Figure 2) and “Sleep Team” water bottle – were offered to delayed treatment participants to increase retention during the waiting period. Finally, we regularly sent handwritten birthday cards and seasonal greeting cards.

Discussion

The combination of recruitment and retention strategies was effective across two sleep and circadian treatment RCTs. However, when employing individual recruitment methods, it is important to consider each study’s specific needs. For example, mailing postcards was most effective for our time-limited recruitment in the Teen Sleep Study, though the trade-off was high financial cost. Meanwhile, other methods had low to medium financial cost, but only recruited handfuls of participants at a time and required weekly time commitments. These methods may be suitable for studies with longer, ongoing recruitment periods. We offer all strategies in hopes that they will assist other researchers in their recruitment and retention efforts.

There were several limitations. First, participants dropped out of both studies for unknown reasons and reasons for dropout were only collected by our team. Thus, some participants may have dropped out due to barriers other than those described, and may have been better served by different retention strategies. Second, transportation was not an obstacle in our Teen Sleep Study because of our clinic’s central location and extensive public transportation; however, other research teams may need to address transportation barriers for adolescents. Third, we did not collect quantitative data on success rates of specific retention strategies or whether these strategies were more or less successful for certain participant barriers. Future studies should collect quantitative data on successful versus unsuccessful applications of retention strategies, while examining their impact on explicit participant barriers.

Participants face abundant barriers and researchers should design studies to account for these obstacles, while creatively tailoring retention strategies to meet the unique barriers of diverse

populations. Patience, persistence, and compassion for participants are key to successfully implementing these strategies (Brannon et al., 2013).

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References

- Bower P, Brueton V, Gamble C, Treweek S, Smith CT, Young B, & Williamson P (2014). Interventions to improve recruitment and retention in clinical trials: a survey and workshop to assess current practice and future priorities. *Trials*, 14, 399.
- Buxton OM, Nahmod NG, & Strayer SM (2017). Studying sleep in family contexts via actigraphy and wearable devices In: McHale S, King V, & Buxton O (Eds.), *Family contexts of sleep and health across the life course*, National Symposium on Family Issues, 8 (pp. 183–199). Cham: Springer.
- Carney CE, Buysse DJ, Ancoli-Israel S, Edinger JD, Krystal AD, Lichstein KL & Morin CM (2012). The consensus sleep diary: standardizing prospective sleep self-monitoring. *Sleep*, 35(2), 287–302. [PubMed: 22294820]
- Ejiogu N, Norbeck JH, Mason MA, Cromwell BC, Zonderman AB, & Evans MK (2011). Recruitment and retention strategies for minority or poor clinical research participants: lessons from the Healthy Aging in Neighborhoods of Diversity across the Life Span study. *The Gerontologist*, 51(1), S33–S45. [PubMed: 21565817]
- Farabi SS, Quinn L, & Carley DW (2017). Validity of actigraphy in measurement of sleep in young adults with type 1 diabetes. *Journal of Clinical Sleep Medicine*, 13(5), 669–674. [PubMed: 28162146]
- Fletcher B, Gheorghe A, Moore D, Wilson S, & Damery S Improving the recruitment activity of clinicians in randomised controlled trials: a systematic review. *BMJ Open*, 2012, 2: e000496.
- Gleason K, Shin D, Rueschman M, Weinstock T, Wang R, Ware JH, Redline S (2014). Challenges in recruitment to a randomized controlled study of cardiovascular disease reduction in sleep apnea: An analysis of alternative strategies. *Sleep: Journal of Sleep and Sleep Disorders Research*, 37(12), 2035–2038.
- Gradinger F, Glassel A, Gugger M, Cieza A, Braun N, Khatami R, Mathis J (2011). Identification of problems in functioning of people with sleep disorders in a clinical setting using the International Classification of Functioning Disability and Health (ICF) Checklist. *Journal of Sleep Research*, 20, 445–453. [PubMed: 20887394]
- Greene JA, Bina R, & Gum AM (2016). Interventions to increase retention in mental health services: a systematic review. *Psychiatric Services*, 67(5), 485–495. [PubMed: 26725290]
- Grossman ES, Shrira A, Bodner E (2017). Enduring sleep complaints predict health problems: a six-year follow-up of the survey of health and retirement in Europe. *Aging & Mental Health*, 21(11), 1155–1163. [PubMed: 27484858]
- Gul RB & Ali PA (2009). Clinical trials: the challenge of recruitment and retention of participants. *Journal of Clinical Nursing*, 19, 227–223.
- Haley DF, Lucas J, Golin CE, Wang J, Hughes JP, Emel L, Hodder SL (2014). Retention strategies and factors associated with missed visits among low-income women at increased risk of HIV acquisition in the US. *AIDS Patient Care and STDS*, 28(4), 206–217. [PubMed: 24697160]
- Harvey AG (2015). A transdiagnostic intervention for youth sleep and circadian problems. *Cognitive and Behavioral Practice*, 23, 341–355.
- Harvey AG & Buysse DJ (2017). *Treating sleep problems: A transdiagnostic approach*. New York, NY: The Guilford Press.
- Harvey AG, Hein K, Dolsen MR, Dong L, Rabe-Hesketh S, Gumport NB, Blum D (under review). Modifying the impact of eveningness chronotype in adolescence: A randomized controlled trial.

- Harvey AG, Hein K, Dong L, Smith FL, Lisman M, Yu S, Buysse DJ (2016). A transdiagnostic sleep and circadian treatment to improve severe mental illness outcomes in a community setting: Study protocol for a randomized controlled trial. *Trials*, 17, 606–617. [PubMed: 27998295]
- Harvey AG, Soehner AM, & Kaplan KA (2015). Treating insomnia improves sleep, mood and functioning in bipolar disorder: A pilot randomized controlled trial. *Journal of Consulting and Clinical Psychology*, 83(3), 564–577. [PubMed: 25622197]
- Herbert LJ, Gillepsie C, Monaghan M, Holmes C, & Streisand R (2016). Factors associated with recruitment and retention in randomized controlled trials of behavioral interventions for patients with pediatric type 1 diabetes. *Journal of Clinical Psychology in Medical Settings*, 23 (2), 112–125. [PubMed: 26661924]
- Jungquist CR, Pender JJ, Klingman KJ, & Mund J (2015). Validation of capturing sleep diary data via a wrist-worn device. *Sleep Disorders*, 2015, 1–6. doi: 10.1155/2015/758937
- Kantermann T, Sung Haerin, & Burgess HJ. (2015) Comparing the Morningness-Eveningness Questionnaire and Munich ChronoType Questionnaire to the dim light melatonin onset. *Journal of Biological Rhythms*, 30(5), 449–453. [PubMed: 26243627]
- Kapungu CT, Nappi CM, Thakral C, Miller SA, Devlin C, McBride C, Brown L, & Project STYLE Study Group (2012). Recruiting and retaining high-risk adolescents into family-based HIV prevention intervention research. *Journal of Child and Family Studies*, 21, 578–588.
- Kealey KA, Ludman EJ, Mann SL, Marek PM, Phares MM, Riggs KR, & Peterson AV Jr.. (2007). Overcoming barriers to recruitment and retention in adolescent smoking cessation. *Nicotine & Tobacco Research*, 9(2), 257–270. [PubMed: 17365757]
- Kim R, Hickman N, Gali K, Orozco N, & Prochaska JJ (2014). Maximizing retention with high risk participants in a clinical trial. *American Journal of Health Promotion*, 28(4), 268–274. [PubMed: 23875989]
- Krystal AD & Edinger JD (2008). Measuring sleep quality. *Sleep Medicine*, 9(1), S10–S17. [PubMed: 18929313]
- Laposky AD, Cauter EV, & Diez-Roux AV (2016) Reducing health disparities: the role of sleep deficiency and sleep disorders. *Sleep Medicine*, 18, 3–6. [PubMed: 26431756]
- Mandrell BN, Avent Y, Walker B, Loew M, Tynes BL, & Crabtree VM (2017). In-home salivary melatonin collection: methodology for children and adolescents. *Developmental Psychobiology*, 60, 118–122. [PubMed: 29152732]
- Millman RP (2005). Excessive sleepiness in adolescents and young adults: causes, consequences, and treatment strategies. *Pediatrics*, 115(6), 1774–1786. [PubMed: 15930245]
- Moreno MA, Waite A, Pumper M, Colburn T, Holm M, & Mendoza J (2017). Recruiting adolescent research participants: in-person compared to social media approaches. *Cyberpsychology, Behavior, and Social Networking*, 20(1), 64–67.
- Ohayon MM (2011). Epidemiological overview of sleep disorders in the general population. *Sleep Medicine Research*, 2, 1–9.
- Overholser JC (2016). When words are not enough: Psychotherapy with clients who are living below the poverty level. *Journal of Contemporary Psychotherapy*, 46, 89–96.
- Pandi-Perumal SR, Smits M, Spence W, Srinivasan V, Cardinali DP, Loew AD & Kayumov L (2007). Dim light melatonin onset (DLMO): a tool for the analysis of circadian phase in human sleep and chronobiological disorders. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*, 31(1), 1–11. [PubMed: 16884842]
- Pastrana FA, Bridges AJ, Villalobos BT, Dueweke AR, & Rodriguez JH (2017). Cognitive behavioral therapy tools for clients with limited functional literacy. *The Behavior Therapist*, 40(4), 137–144.
- Pescud M, Pettigrew S, Wood L & Henley N (2015). Insights and recommendations for recruitment and retention of low socio-economic parents with overweight children. *International Journal of Social Research Methodology*, 18(6), 617–633.
- Rait MA, Prochaska JJ, & Rubinstein ML (2015). Recruitment of adolescents for a smoking study: use of traditional strategies and social media. *Translational Behavioral Medicine*, 5(3), 254–259. [PubMed: 26327930]
- Rogers CR (2007). The necessary and sufficient conditions of therapeutic personality change. *Psychotherapy: Theory, Research, Practice, Training*, 44(3), 240–248.

- Rosal MC, White MJ, Borg A, Scavron J, Candib L, Ockene I, & Magner R (2010). Challenges and successes in recruiting and retaining low-income Latino patients with Type 2 Diabetes into a randomized clinical trial. *The Diabetes Educator*, 36(5), 733–749. [PubMed: 20729512]
- Silver D, Blustein J, & Weitzman BC (2012). Transportation to clinic: Findings from a pilot clinic-based survey of low-income suburbanites. *Journal of Immigrant Minority Health*, 14, 350–355. [PubMed: 22512007]
- Soehner AM, Kaplan KA, & Harvey AG (2013). Insomnia comorbid to severe psychiatric illness. *Sleep Medicine Clinics*, 8(3), 361–371. [PubMed: 25302060]
- Stefano EC, Hudson DL, Whisenhunt BL, Buchanan EM, & Latner JD (2016). Examination of body checking, body image dissatisfaction, and negative affect using Ecological momentary assessment. *Eating Disorders*, 22, 51–54.
- Van Dyk TR, Thompson RW, & Nelson TD (2016). Daily bidirectional relationships between sleep and mental health symptoms in youth with emotional and behavioral problems. *Journal of Pediatric Psychology*, 41(9), 983–992. [PubMed: 27189691]
- Wells A, Lagomasino IT, Palinkas LA, Green JM, & Gonzalez D (2013). Barriers to depression treatment among low-income, Latino emergency department patients. *Community Mental Health Journal*, 49, 412–418. [PubMed: 23054150]
- Wells AA, Palinkas LA, Williams SL, & Ell K (2015). Retaining low-income minority cancer patients in a depression treatment intervention trial: lessons learned. *Community Mental Health Journal*, 51, 715–722. [PubMed: 25544505]
- Woodall A, Howard L, & Morgan C (2011). Barriers to participation in mental health research: Findings from the Genetics and Psychosis (GAP) Study. *International Review of Psychiatry*, 23(1), 31–40. [PubMed: 21338296]



Figure 1. Teen sleep study T-shirt graphic. This figure illustrates the graphic (designed by a research assistant) that was printed on t-shirts given to participants for successfully completing treatment.



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Figure 2. Community sleep study delayed-treatment “special reserves” membership card. This figure illustrates the card given to delayed-treatment participants to encourage retention.

Table 1:

Recruitment and Retention Strategies in Sleep and Circadian Treatment Research

Recruitment Strategies	Retention Strategies
1. Community-Based Recruitment	1. Flexible Scheduling
2. Reducing Stigma	2. Mitigating Participant Barriers
3. Alleviating Burdensome Sleep Data Collection	3. Empathic and Positive Interactions
	4. Creative Problem-Solving
	5. Consulting Participant Networks
	6. Incentives and Other Positive Engagement Tools

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Table 2

Financial Cost-Effectiveness of Recruitment Strategies in Teen Sleep Study

Financial Cost	Low Yield	Medium Yield	High Yield
Low	Health or mental health provider (6.82%) Friend or relative (1.7%)	Online parent community (9.09%)	
Medium		School recruiting (14.2%) Community flyering (11.93%)	
High			Mailed postcards (39.77%)

Note. % = percent of participants recruited

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Table 3

Time Cost-Effectiveness of Recruitment Strategies in Teen Sleep Study

Time Cost	Low Yield	Medium Yield	High Yield
Low	Health or mental health provider (6.82%) Friend or relative (1.7%)	Online parent community (9.09%)	Mailed postcards (39.77%)
High		School recruiting (14.2%) Community flyering (11.93%)	

Note. % = percent of participants recruited

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Table 4:

Distribution of Methods for Participant Recruitment

Recruitment Method		Number of Participants Recruited	% of Participants Recruited
Teen Sleep Study			
	Mailed postcard	70	39.77
	School (e.g. counselor, e-mail, flyer, presentation, teacher)	25	14.20
	Flyer in the community (e.g. café, commuter rail station, gym, library, store, restaurant)	21	11.93
	Online parent community (e.g. Berkeley Parents Network)	16	9.09
	Health or mental health provider (e.g. pediatrician, psychiatrist, therapist)	12	6.82
	Friend or relative	3	1.70
	Unknown or did not remember	29	16.48
Community Sleep Study			
	Referred by provider (e.g. case manager, psychiatrist, therapist)	48	39.67
	Presentation at a board & care, supported independent living home, or residential treatment facility	22	18.18
	Presentation at a clinic	12	9.92
	Presentation at a peer support group	11	9.09
	Provider gave patient our phone number	10	8.26
	Saw a brochure	7	5.79
	Met in a clinic waiting room	5	4.13
	Learned about us from a friend/participant already in the study	4	3.31
	Presentation at a clinic event	1	0.83
	Unknown	1	0.83

Table 5:

Self-reported Barriers to Research Participation and Strategies Used to Retain Participants with Drop-out Potential

	Self-reported participant barriers	Number of participants with this barrier	% Participants with this barrier	Strategies used to combat this barrier
Teen Sleep Study	Emotional burden	1	0.01	3
	Time constraints	6	0.03	1, 2, 4, 6
	Found treatment unhelpful	4	0.02	3, 6
	Unknown	16	9.09	n/a
Community Sleep Study	Homelessness and/or housing instability	4	3.33	2, 3, 4, 5, 6
	Family illness	3	2.48	3, 5, 6
	Physical health issue (e.g. surgery, chronic pain, cancer)	9	7.44	1, 2, 3, 4, 6
	Mental health issue (e.g. psychiatric hospitalization, decompensation, relapse, paranoia, avolition, etc.)	22	18.18	2, 3, 4, 5, 6
	Transportation	12	9.92	1, 2
	Scheduling conflicts (e.g. with work, school, family, children)	15	12.40	1, 2, 4, 6
	Difficulty with treatment (e.g. unwilling to change, disliked it, too much work)	10	8.26	3, 4, 6
	Lack of interest after placement in UC-DT	4	3.31	3, 4, 5, 6
	Moved away	6	4.96	1, 2, 4, 5, 6
	Passed away	3	2.48	n/a
Unknown	2	1.65	n/a	

Note. Participants were considered potential drop-outs if they appreciably delayed treatment or assessment, paused treatment for an extended time, fell out of touch with our team for a period, or expressed desire at any point to drop out of the study