



Adapted Delivery of Cognitive-Behavioral Treatment for Insomnia in Adolescent and Young Adult Cancer Survivors: A Pilot Study

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Adolescent and young adult cancer survivors (AYACS) are at risk for the development of insomnia, though it remains vastly undertreated. Limited research has evaluated cognitivebehavioral treatment for insomnia (CBT-I) in AYACS. The present study piloted adapted CBT-I designed to improve treatment accessibility by delivering a three-session intervention in person and via videoconference. AYACS with insomnia (N = 12) enrolled in the study. Ten AYACS completed the intervention, with six in person and four via videoconference. Sleep variables improved immediately postintervention and were sustained at two-month follow-up. Within sample effect

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sizes of the adapted intervention for sleep, variables were large, and there were no noted differences on sleep outcomes between the in-person and videoconference participants. These pilot findings indicate that an adapted CBT-I intervention is feasible and promising in AYACS populations.

As a result of improved medical treatment, five-year event-free survival rates for adolescents and young adults (AYA) diagnosed with cancer exceed 80% (American Cancer Society, 2015; Bleyer, O'Leary, Barr, & Ries, 2006). This has led to increasing numbers of AYA survivors (Howlader et al., 2013; Mariotto et al., 2009). Because of their cancer treatment, this growing population is at risk for a variety of medical and psychosocial late effects that can impair health even years after completion of therapy (Oeffinger et al., 2006; Oeffinger, Nathan, & Kremer, 2008; Zebrack & Chesler, 2002; Zeltzer et al., 2009).

Insomnia is one of the most common problems associated with cancer treatment, with up to 75% of young cancer patients experiencing insomnia symptoms while undergoing treatment (Hinds, Hockenberry, Rai, et al., 2007; Zupanec, Jones, & Stremler, 2010). During cancer therapy, pediatric cancer patients are exposed to a myriad of factors that place them at elevated risk for the development of sleep disruption. Prior research has suggested that the unfamiliar and disruptive hospital environment, resulting in frequent nocturnal awakenings, loss of daily routines, and family separation, can all worsen a pediatric patient's sleep function (Boman, Lindahl, & Bjork, 2003; Dogan, Ertekin, & Dogan, 2005; Hinds, Hockenberry, Rai, et al., 2007; Jacob et al., 2006; Jarman, Jacobs, Walter, Witney, & Zielinski, 2002; Walker, Johnson, Miaskowski, Lee, & Gedaly-Duff, 2010; Whitsett, Gudmundsdottir, Davies, McCarthy, & Friedman, 2008), to the point where sleep medications must sometimes be used (Meltzer, Mindell, Owens, & Byars, 2007). Furthermore, once active cancer treatment has ended, young cancer patients may continue to endure maintenance therapy and chronic treatment-related side effects (e.g., pain and anxiety) that can cause their symptoms of insomnia to persist (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; Hinds, Hockenberry, Gattuso, et al., 2007; Vallance et al., 2010). If this insomnia is left untreated it can persist, with up to 28% of adult survivors of childhood cancer reporting clinically significant insomnia symptoms up to 10 years posttreatment (Zhou, Manley, Marcus, & Recklitis, 2015; Zhou & Recklitis, 2014).

For clinicians treating adult cancer survivors suffering from insomnia, evidence-based treatment is available. Cognitive-behavioral treatment for insomnia (CBT-Insomnia) has a well-established evidence base supporting its efficacy in the general adult population as well as in several studies of survivors of adult cancers (Garland et al., 2014). Despite this compelling efficacy evidence, the ability for cancer survivors to access this proven treatment is hampered (Savard & Savard, 2013), and the adolescent and young adult cancer survivor (AYACS) population faces unique obstacles to receiving insomnia treatment. First, this treatment approach has not been widely applied in AYACS, with some evidence indicating that it can be effective in adolescent populations (Clarke et al., 2015). Despite the prevalence of insomnia in this population, we are not aware of any trials that have evaluated the delivery of CBT-Insomnia interventions in the underserved AYACS group. Next, access to treatment for survivors is made more difficult by the six to eight in-person sessions of traditional treatment (Perlis, Smith, Benson-Jungquist, & Posner, 2005), which can prove to be an even greater burden for AYACS, as some struggle to obtain health care coverage (Park et al., 2005). Even when a survivor has the means to receive treatment, he or she is confronted with a critical shortage of trained CBT-Insomnia providers (Kraus & Rabin, 2012). This limited availability of CBT-Insomnia for cancer patients has led to a call for alternative delivery methods in "the treatment of insomnia in patients with cancer" (Savard & Savard, 2013).

The paucity of evidence-based treatments to guide practice presents a significant clinical challenge for medical providers seeking to treat AYACS who present with insomnia. Chronic, untreated insomnia in AYAs is associated with significant physical and psychosocial consequences, including an elevated risk for behavioral and psychiatric problems, substance use, and obesity (Blank et al., 2015). This is a significant issue for the population of AYACS already at increased risk for chronic medical conditions and psychosocial late effects as a result of their cancer treatments (Brinkman et al., 2013; Gurney et al., 2009; Robison et al., 2005), and who may not regularly access medical care (Oeffinger et al., 2004).

Recent trends in the literature have explored shortening treatment length (Buysse et al., 2011) and establishing novel treatment delivery methods (Ritterband et al., 2009) as means of more efficiently disseminating CBT-Insomnia. To address the need for the "establishment of an evidence-based understanding of appropriate treatment choices for insomnia" (Owens, Rosen, Mindell, & Kirchner, 2010) in this unique population, we conducted a pilot study of the feasibility of an abbreviated CBT-Insomnia intervention for AYACS delivered over the course of three sessions, with delivery both in person and via videoconference.

METHODS

Participants

Participants were recruited from survivorship clinics that provide long-term follow-up care for AYACS at a regional cancer center. To be eligible for this study, participants had to be between the ages of 15 and 40 years with a history of cancer diagnosed before age 30 years, not actively receiving cancer therapy, and currently experiencing primary insomnia as defined by the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-V; American Psychiatric Association, 2013) diagnosed through a screening interview conducted by a clinical psychologist. Potential participants were excluded if they endorsed active substance abuse, psychotic symptoms or bipolar disorder, significant cognitive impairment that would interfere with their ability to understand intervention content, a history of a seizure disorder diagnosis or having experienced a seizure within the past 12 months, or shift work employment. Potentially eligible participants were identified either through direct referral by their oncology provider or through a targeted mailing to individuals who had previously reported insomnia symptoms as part of their participation in a study examining health and quality of life outcomes in childhood cancer survivors (Bober et al., 2013). The study was approved by the cancer center's institutional review board, and informed consent of patients (or parents for those less than 18 years of age) was obtained for all participants.

In the current study, a total of 12 AYACS enrolled in the study, though two failed to complete the intervention. The 10 survivors who completed the intervention were predominantly female (60%), non-Hispanic White (100%), never married (60%), and had an average age of 28.1 years (range = 15-40 years; Table 1). The majority had completed some postsecondary education (60%). Their cancer diagnoses were varied, and included hematologic malignancies (60%) and solid tumors (40%; including neuroblastoma, sarcoma, and brain tumors). Survivors were an average of 12.5 years postdiagnosis (range = 2-25 years) and 10.9 years posttreatment (range =

	N or \overline{x} (SD)
Demographic	
Age (years)	28.1 (7.4)
Gender	
Male	4
Female	6
Marital status	
Married	4
Single, never married	6
Education	
\leq High school diploma	4
\geq College education	6
Household income	
< \$50,000	3
\geq \$50,000	7
Cancer-related	
Primary diagnosis	
Leukemia/lymphoma	6
Solid tumor	4
Time since diagnosis (years)	12.5 (8.6)
Chemotherapy	
Yes	10
No	0
Radiation therapy	
Yes	3
No	7
Stem cell transplant	
Yes	2
No	8

TABLE 1Demographic and Cancer-Related Descriptives (N = 10)

0.5–24 years). For our current analyses, we examined the 10 participants who completed the three session intervention (6 in person and 4 via videoconference).

Intervention

Eligible survivors participated in a three-session (60 min/session) individual intervention, modeled after brief behavioral treatment for insomnia programs that have been proven to be efficacious in adult populations (Buysse et al., 2011; Germain et al., 2006; Germain, Shear, Hall, & Buysse, 2007). Our adapted intervention focused on the core behavioral components of CBT-Insomnia treatment (sleep restriction and stimulus control) as they have been demonstrated to improve sleep and are well-suited for delivery in an abbreviated intervention time frame (Bootzin & Nicassio, 1978; Spielman, Saskin, & Thorpy, 1987). In addition, we also provided a short, focused discussion addressing maladaptive sleep-related cognitions and sleep hygiene to offer participants an understanding of the role these factors play in perpetuating their sleep disruption. The first 5 participants were offered the intervention via in-person sessions, while the next 7 participants were

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offered the option of receiving the intervention as an in-person intervention or as a live videoconference intervention for Sessions 2 and 3. Six of these 7 participants chose to receive the intervention via videoconference. Those who chose to receive the intervention via videoconference attended the first session in person, during which they received their loaner iPad and verbal instructions on how to initiate a videoconference call. All videoconference participants received a padded FedEx box designed specifically to securely encase the iPad for return, and were asked to sign a contract promising that they would return it following the intervention. All session-bysession content is outlined in Table 2 and was identical for in-person and videoconference participants.

Measures

Except where otherwise noted, study measures were collected at three time points: Time 1 (Baseline); Time 2 (Immediately postintervention at Session 3); and Time 3 (2 months after Time 2).

Sleep log

From Sessions 1 through 3, participants maintained sleep logs (Monk et al., 1994) in which they recorded daytime sleep-related events, bedtime, sleep latency, number and duration of night awakenings, and desired and actual wake time. Data from sleep logs were used to calculate total sleep hours and sleep efficiency (a ratio between total actual sleep compared to total desired sleep,

Session	Content			
1	• Conduct a thorough evaluation of sleep history.			
	 Discuss medical factors that influence sleep. 			
	 Discuss cancer-related late effects, including medications, that impact sleep function. 			
	• Instruct on completion of sleep diary.			
	10–14 days between Session 1 & 2			
2	• Review of sleep diary.			
	 Instruct on calculation of sleep efficiency. 			
	 Discuss rationale and instructions for sleep restriction and stimulus control 			
	 Schedule sleep-wake schedule based on sleep diary. 			
	 Help anticipate and prepare for difficulty with adherence. 			
	• Discuss risks of sleep deprivation.			
	 Discuss with family members (if relevant) the intervention rationale and sleep objectives. 			
	10-20 days between Session 2 & 3			
3	• Review of sleep diary.			
	• Discuss sleep expansion.			
	• Identify and address cognitive factors that impact adherence and sleep			
	function.			
	• Discuss sleep hygiene factors that may improve sleep.			
	• Troubleshoot adherence challenges.			

TABLE 2 Intervention Session Structure

with a sleep efficiency score below 85% indicating clinically significant insomnia (Spielman et al., 1987).

Pittsburgh Sleep Quality Index (PSQI)

The PSQI (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) is a commonly used 19-item self-report measure of sleep quality over the past two-week time period. The individual items generate a global sleep score, with scores above 5 indicating poor sleep (Buysse et al., 1989). The PSQI has been used extensively in general cancer populations (Beck, Schwartz, Towsley, Dudley, & Barsevick, 2004), and specifically in adult survivors of childhood cancer (Mulrooney et al., 2008).

Insomnia Severity Index (ISI)

The ISI (Bastien, Vallieres, & Morin, 2001) is a brief screening measure of insomnia symptoms, and has been frequently used as an insomnia measure in oncology research (Garland et al., 2014). A total score of 8 and above is associated with subthreshold insomnia, while a total score of 15 or above is associated with clinical insomnia (Bastien et al., 2001).

Short Form-12 (SF-12)

The SF-12 (Ware, Kosinski, & Keller, 1996) is a 12-item measure that evaluates health-related quality of life, and has demonstrated reliability and validity (Ware et al., 1996). The SF-12 provides both a physical and mental health summary score. It has been used extensively in the cancer literature, including AYACS populations (Mulrooney et al., 2008).

Medical history

Electronic medical records were reviewed for all participants to collect their cancer and treatment history (Time 1 only).

Intervention feedback

To evaluate intervention feasibility, participants were asked as part of their Time 3 follow-up study questionnaires to report on their experiences with the intervention. Specifically, they were asked to strongly agree, agree, disagree, or strongly disagree with statements about whether the intervention helped them better understand their insomnia, whether they regretted participation in the intervention, and whether they would recommend the intervention to other survivors with insomnia.

Statistical Analyses

We calculated descriptive statistics to describe our sample's demographic, medical, and health characteristics. To evaluate impact of the intervention on sleep and quality of life measures, Time

2 and Time 3 assessments were compared to Time 1 assessments using paired samples *t*-tests and calculation of Cohen's d_z as a measure of effect size (Cohen, 1988). In order to ensure that results were not influenced by any departures from normality of other assumptions of parametric statistical tests, these analyses were repeated using a nonparametric Wilcoxon matched-pairs signed rank test. The pattern of results using the Wilcoxon was not substantially different from the *t*-test results, and only *t*-tests are reported here.

RESULTS

Of the enrolled subjects, two completed only the first intervention session and baseline study measures. Both were to complete the intervention via videoconference but elected not to continue with the intervention following completion of the first session, and reported that their work or school schedule prevented further study participation. Four survivors completed the intervention treatment via videoconference, while 6 completed the intervention in-person. There was not a statistically significant difference in any of the preintervention or postintervention sleep-related variables between the two groups (ps > .25; not shown in tables). Refer to Table 3 for further participant information.

At Time 1 (Baseline), survivors in our sample reported average ISI (mean = 13.4; SD = 4.1) and PSQI (mean = 10.5; SD = 3.6) scores above cutoff scores conventionally used to indicate significant insomnia symptoms and sleep disruption. In addition, their sleep log data revealed challenges with sleep onset (mean = 54.3 min; SD = 50.1 min), night awakening (mean = 32.7 min; SD = 30.8 min), and early morning awakening (mean = 22.6 min; SD = 16.7 min). The sample slept an average of 6.6 hr (SD = 0.8 hr), and reported a mean sleep efficiency of 78.8% (SD = 9.7%). Finally, the sample reported SF-12 physical health (mean = 51.3; SD = 9.2) and mental health (mean = 43.2; SD = 8.3) scores within the average range.

Following the intervention, statistically significant improvements were reported across all sleep measures (Table 4). The ISI score mean decreased to 6.3 (d = 1.0) at Time 2, and further decreased to 4.2 ($d_z = 1.3$) at Time 3. Similarly, the PSQI score decreased to 5.9 ($d_z = 1.7$) at

Participant	Age Gender		PSQI baseline total score	Intervention delivery format	Study completion? Yes	
1 15 F		F	13	In person		
2	28	М	10	In person	Yes	
3	40	F	5	In person	Yes	
4	34	F	13	In person	Yes	
5	32	М	12	In person	Yes	
6	28	М	12	Videoconference	Yes	
7	22	F	11	Videoconference	No	
8	20	F	14	Videoconference	No	
9	18	М	5	Videoconference	Yes	
10	27	F	7	In person	Yes	
11	24	М	13	Videoconference	Yes	
12	29	F	15	Videoconference	Yes	

TABLE 3 Individual Participant Characteristics

	Time 1	Time 2		Time 3	
	Mean (SD)	Mean (SD)	Effect size (d_z)	Mean (SD)	Effect size (d_z)
Insomnia Severity Index					
Total Summary Score	13.4 (4.1)	6.3 (4.9)*	1.0	4.2 (3.9)*	1.3
Pittsburgh Sleep Quality Index					
Total Summary Score	10.5 (3.6)	5.9 (2.4)*	1.7	3.4 (3.3)*	2.3
Sleep Logs					
Sleep onset latency (min)	54.3 (50.1)	15.5 (23.4)*	1.8	N/A	N/A
Night awakening (min)	32.7 (30.8)	5.8 (4.2)*	.9	N/A	N/A
Early morning awakening (min)	22.6 (16.7)	3.2 (1.0)*	2.9	N/A	N/A
Total sleep duration (hr)	6.6 (0.8)	6.4 (0.7)	.3	N/A	N/A
Sleep efficiency (%)	78.8 (9.7)	94.5 (6.2)*	2.7	N/A	N/A
Short-Form 12					
Physical health summary score	51.3 (9.2)	54.7 (3.6)	.4	54.0 (4.2)	.3
Mental health summary score	43.2 (8.3)	46.3 (6.4)	.3	50.6 (7.6)	.7

TABLE 4 Sleep and Health Function Improvement Pre- and Postintervention

Note. Time 1 = Baseline; Time 2 = Immediately postintervention at Session 3; Time 3 = 2 months after Session 3. *Time 2 and Time 3 values that significantly differ from baseline (p < .05) are shown in bold asterisk.

Time 1 and to 3.4 ($d_z = 2.3$) at Time 3. At Time 3, both the ISI and PSQI mean scores for the group were below cutoff scores used to indicate significant insomnia symptoms and sleep disruption. The sleep log data also demonstrated improvements in sleep onset latency, night awakening, and early morning awakening.

In addition, improvements to the participants' physical and mental quality of life scores on the SF-12 were noted ($d_z = .3$ to .7). However, the differences were not statistically significant.

Feedback collected from the participants was consistently positive, with all study participants reporting that they would recommend this intervention to another cancer survivor who had problems with sleep. In addition, all study participants agreed or strongly agreed that the "intervention helped [them] better understand [their] insomnia" and disagreed or disagreed strongly with the statement of regretting "participating in the intervention." However, the delivery of the videoconference intervention was not without technical issues, including WiFi connectivity issues that interrupted intervention sessions for 2 participants.

DISCUSSION

Insomnia is a significant clinical concern for a large proportion of adolescent and young adult cancer survivors (AYACS) who are already at risk for medical and psychosocial late effects of their cancer treatments. At a juncture in their lives when adolescents and young adults (AYA) are already adjusting to developmental challenges (i.e., going to college, seeking their first job, and developing lifelong relationships) it is important that disrupted sleep is not another battle that they must routinely face. Building on the empirical evidence supporting CBT-Insomnia treatment in other populations, we conducted a pilot study to evaluate the feasibility of an adapted CBT-Insomnia intervention in a sample

of AYACS. We addressed previously noted challenges with accessing CBT-Insomnia treatment by piloting an abbreviated CBT-Insomnia intervention delivered both in person and via videoconference.

Our pilot data supports the feasibility of delivering an adapted version of traditional CBT-Insomnia treatment and provides preliminary support for this intervention in the AYACS population. Immediately following the intervention, participants reported improvements in all sleep continuity variables (sleep onset, night awakening, and early morning awakening). Initially it appeared that participants struggled most with sleep onset, reporting that they took an average of almost 1 hr every night to fall asleep. This improved to approximately 15.5 min postintervention. As expected, the group's overall sleep efficiency improved dramatically, well above the cutoff scores generally used in clinical practice (85%). It is important to note that every single participant's sleep efficiency improved over the course of the intervention, demonstrating that the AYA population was able to implement the intervention-specific changes.

Despite the fact that our intervention was abbreviated, the magnitude of the intervention effect on sleep variables after only three sessions was quite robust ($d_z > 1.0$). Perhaps more importantly, we found evidence of continued improvement in sleep measures at two-month follow-up when participants were faced with the challenge of maintaining their new sleep regimen independently. These increasing improvements in insomnia symptoms and sleep quality during a self-maintenance phase provides promising evidence that the intervention program was effective in teaching AYACS the skills necessary to independently manage their sleep.

Though positive changes to physical and mental quality of life were seen in our sample, the size of the intervention effects on quality of life ($d_z = 0.4$ –0.7) were not as large as those seen on sleep measures and were not statistically significant. In other patient populations, improvements to mood and physical outcomes as a result of improving insomnia symptoms have been reported (Fleming, Randell, Harvey, & Espie, 2014; Harvey et al., 2015; Vitiello et al., 2014). However, we note that our study sample reported quality of life scores within the average range and a ceiling effect may partially explain our findings. Future studies with more statistical power will be needed to determine if similar improvements in quality of life will be seen in AYACS after treatment for insomnia symptoms.

As noted previously, problems in accessing CBT-Insomnia treatment are substantial, and play an important role in making the treatment unavailable for many cancer survivors with insomnia. Our novel approach to consolidating program length and offering participants the opportunity to receive treatment via videoconference directly targets critical factors that impede treatment accessibility: treatment length and access to trained providers (Savard & Savard, 2013). The potential for an abbreviated CBT-Insomnia program that can be delivered via videoconference has direct implications for improving treatment access. Our three-session program duration was found to be sufficient to provide participants with the knowledge for sustained improvements in their sleep, and indicated that participants were able to continue to monitor and adjust their sleep without direct, ongoing clinical guidance.

Finally, the adapted intervention delivered via videoconference is innovative, well-accepted, and feasible and holds promise for the unique AYA population. The potential for the dissemination of an effective clinical intervention through a popular technological device is especially compelling in a generation so attuned to their handheld devices. An estimated 84% of 18–29 year olds have regular access to wireless Internet services (Smith, 2010) and this delivery method is very much a part of the normal day-to-day lives for young adults in general. We acknowledge challenges associated with this delivery format, both on a technical level and having to adjust to the virtual patient–provider environment. It is noted that both study noncompleters had chosen to

receive the videoconference intervention, and it is possible that the lack of in-person connection for subsequent intervention sessions played a role in their withdrawal. Despite these challenges, we note that the feedback from AYACS who received the intervention via iPad was very positive. Specifically, two participants reported that they would not have been otherwise able to receive insomnia treatment, as their commute to the cancer center was too long. It is clear that the convenience of being able to receive treatment without the burden of having to travel to a regional cancer center provided meaningful benefit in an age group often busy with work and school commitments and for cancer survivors who may reside in rural areas without access to in-person CBT-Insomnia providers.

Study Limitations and Future Directions

Several limitations should be considered for these novel findings. First, our sample size was limited and came from a single cancer center. In addition, our sample was comprised entirely of non-Hispanic Whites with the majority having an annual income greater than or equal to \$50,000 per year. Thus, our findings may not be generalizable to the AYACS population as a whole (Ojha et al., 2013). In addition, though it is unlikely that participants experienced a dramatic reduction in insomnia symptoms independent of the intervention, because our study did not include a control condition we cannot exclude this possibility. In planned research, we intend to recruit a larger, less homogenous survivor population to study and to compare the brief CBT-Insomnia intervention to a control condition.

Furthermore, it would be beneficial to develop insomnia interventions for pediatric patients currently undergoing treatment for cancer or early in the survivorship period prior to the insomnia symptoms becoming chronic. Modifications to this intervention for on-therapy patients should include ensuring adequate sleep opportunities in the context of inpatient hospitalizations (such as bundled nursing care and protected sleep periods when no medical interventions are necessary), as well as allowing for rest periods that occur outside of the bed (consistent with stimulus control) when patients are feeling fatigued. In addition, any insomnia intervention delivered to pediatric patients would include instructions delivered both to the patient and parent or caregiver to ensure fidelity to the intervention and ability to evaluate and address barriers to intervention implementation.

Despite these noted limitations, our findings provide novel information supporting CBT-Insomnia in AYACS. Health care providers who encounter an AYACS presenting with insomnia symptoms can be challenged by limited treatment options due to insufficient access to trained CBT-Insomnia providers, or by concerns about the long-term use of sleep medications including lack of United States Food and Drug Administration approval for sleep medication for patients under 18 years of age. Results of this pilot study indicate that a brief CBT-Insomnia intervention can be both efficacious and well tolerated by the AYA population, and has potential in this underserved population. The intervention not only efficiently provided relief from symptoms during the course of insomnia treatment, but also educated survivors on effective self-monitoring and the management of future insomnia. Perhaps most encouraging is the fact the intervention was effective even though it was delivered in an abbreviated form, and when it was delivered inperson or remotely via videoconference.

Despite the development of empirically supported cognitive-behavioral treatment for insomnia, most cancer survivors with chronic insomnia go untreated, often because of treatment accessibility issues. Brief insomnia treatments that can be easily disseminated, like the intervention piloted here, have the potential to address this problem and bring effective insomnia treatment to AYACS and 298 ZHOU ET AL.

others who are at high risk for chronic insomnia but often receive no treatment. Based upon these findings, there are clear needs for future research to complete the next steps necessary to advance this clinical research. Specifically, it is important to examine the effects of this adapted intervention in a larger sample, whether there is a sustained intervention effect beyond the two-month follow-up, and the feasibility of delivering treatment via group-based videoconference.

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