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PII: S0891-5245(22)00332-7
DOI: <https://doi.org/10.1016/j.pedhc.2022.11.001>
Reference: YMPH 2040



To appear in: *Journal of Pediatric Health Care*

Please cite this article as: Jiwon Lee , Patricia C. Clark , Regena Spratling , Transitioning a Research Protocol for Videosomnography to Assess Sleep and Nighttime Caregiving Activities in School-Aged Children with Developmental Disabilities during the COVID-19 Pandemic, *Journal of Pediatric Health Care* (2022), doi: <https://doi.org/10.1016/j.pedhc.2022.11.001>

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Title: Transitioning a Research Protocol for Videosomnography to Assess Sleep and Nighttime Caregiving Activities in School-Aged Children with Developmental Disabilities during the COVID-19 Pandemic

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Disclosures and Acknowledgement: This research was supported by Lewis College Intramural Grant at Georgia State University

The authors would like to thank mothers and children for their participation in our study.

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Abstract

Sleep problems are commonly reported among children with developmental disabilities (DDs), and the COVID-19 pandemic significantly affected children with DDs' sleep. While sleep is a multidimensional construct that can be measured in various ways, most studies on children with DDs rely on parent reports. Videosomnography is a non-invasive, portable time-lapse video recording system used to objectively obtain a child's sleep-wake behaviors and parents' caregiving activities in a natural environment. During the height of the COVID-19 pandemic (September 2020 to February 2021), we conducted a feasibility study using actigraphy (in mothers) and videosomnography in children with DDs for 7 consecutive nights to assess sleep and nighttime caregiving activities. Because of the pandemic, we developed and implemented alternative data collection strategies, such as delivering a "study package" that contained the study equipment with easy-to-follow written instructions and emailed video-recorded instructions on how to record a child's sleep. We aimed to enroll 10 mothers and 10 school-aged children with DDs and achieved this goal. Nine out of 10 mothers completed video recordings of their child's sleep, with only 10% missing data for videosomnography. This paper shared adaptations to our videosomnography protocol and lessons learned.

Keywords:

videosomnography, research protocol, sleep, children, developmental disabilities

Videosomnography is a portable time-lapse video recording system used to obtain a child's sleep-wake behaviors and parents' caregiving activities in children with developmental disabilities (DDs), including autism (Moore et al., 2017). During the height of the COVID-19 pandemic (September 2020 to February 2021), we conducted a feasibility study using actigraphy (in mothers) and videosomnography in children with DDs for 7 consecutive nights to assess sleep and nighttime caregiving activities. In the initial protocol, we planned to make home visits for the research team to set up the videosomnography equipment and give instructions for its use. Due to the pandemic, we had to revise and implement alternative data collection strategies. This article presents how we adapted the research protocol to ensure continued rigor in the data collection process and study completion during the pandemic. We include lessons learned and

suggestions for future research for pediatric advanced practice nurses, pediatric and family researchers, and all healthcare professionals caring for children and their families.

Sleep problems are commonly reported among children with DDs, life-long conditions that result in substantial limitations in language, cognition, self-care, and/or mobility (Developmental Disabilities Assistance and Bill of Rights Act of 2000). Compared to typically developing children, children with DDs are more likely to report shorter sleep duration, greater bedtime resistance, and more night wakings (Köse et al., 2017; Reynolds et al., 2019). The COVID-19 pandemic significantly affected children with DDs' sleep; children with DDs reported reduced sleep quality (Masi et al., 2021) and increased sleep disturbances and daytime sleepiness (Bruni et al., 2022).

While sleep is a multidimensional construct that can be measured in various ways (Buysse, 2014), most studies on children with DDs rely on parent reports. Actigraphy, a watch-like device that measures sleep-wake patterns using activity-based monitoring, has been widely used in diverse pediatric populations (Meltzer et al., 2012). However, using actigraphy among children with DDs raises tolerance concerns (Moore et al., 2017). Researchers cannot obtain parent-child interactions, including nighttime caregiving activities or child behavior when awake at night. Videosomnography is a non-invasive, objective sleep measure that captures sleep behaviors in a natural environment (Sadeh, 2015). Home-based videosomnography has been increasingly used recently due to technological advances and the increasing use of telemedicine (Schwichtenberg et al., 2018). To our knowledge, videosomnography has not been used in school-aged children with DDs. We wanted to determine the feasibility of using videosomnography to measure a child's sleep-wake variables objectively (e.g., sleep onset/offset time, wake after sleep onset, and night waking) and parents' nighttime caregiving activities.

Identifying video recording device

To identify the hardware (video-recording device) and software system suitable for videosomnography, we conducted a literature review of videosomnography in studies with children with DDs. Few studies provided details (e.g., camera and procedures) about videosomnography for children with DDs. These studies lacked detailed descriptions of the hardware and software systems used. Even if a specific video recording device was noted, the device was either no longer available for purchase or lacked storage capacity for 7 nights of video recordings. Therefore, the principal investigator (PI) and the graduate research assistant (GRA) searched for the best portable video recording device on the market with storage space for 7 nights of video recording. We also consulted with the university's Center for Excellence in Teaching, Learning and Online Education (CETLOE), a resource for technology use in education and research. Ultimately, we identified a portable video recording device with adequate storage (128 GB) and a night-vision camera (CammPro® I826 Camera).

Developing videosomnography protocol

The initial protocol based on a literature review was designed for the PI or GRA to conduct a home visit and set up the camera in the child's bedroom with an adequate height and angle to best capture the child's sleep. The research team member would also instruct the mother on using the camera and a paper-pencil diary to record the start/end child's sleep times. In order to capture sleep onset time and offset time, we asked mothers to start recording when they started the child's nighttime routine and stop recording when the child was up for the day.

Adapting videosomnography protocol during the COVID-19 pandemic for successful data collection

With the COVID-19 pandemic restrictions, we adapted our protocol and used alternative data collection strategies. One change was creating a “study package” that contained the camera, tripod, and other study equipment with easy-to-follow written instructions (available from the first author). We set up a time to deliver the study package outside the participant's home. Before the home visit, we emailed mothers a link to a 4-minute video-recorded instruction that we created on how to set up and record using the camera (video available at https://mediaspace.gsu.edu/media/QLAV1720/1_f3izmkbfb).

The PI or GRA met the mother at a designated area outside the participant's house, such as the porch or driveway, a parking lot/deck, or any open common area at an apartment or condominium where we could maintain social distance. We adhered to the Centers for Disease Control and Prevention's latest infection control guidelines during this visit, including (a) checking research personnel's temperature before the visit; (b) wearing a mask and gloves; (c) disinfecting the video equipment between each use; and (d) social distancing during participant interactions. During this initial meeting, the PI or GRA reviewed the written instructions with the mother and demonstrated how to use the camera. Mothers also were encouraged to practice with the camera and ask questions during this visit.

Since the mothers were being asked to record for 7 consecutive nights, a series of text messages were sent during the week to identify any potential problems with recording. The first text message was sent after the first night of video recording (1st day). Two other text messages were sent at mid-point (3rd day) and fifth day to mitigate any issues with recording the child's sleep. These messages were short and encouraged the mother to let the PI know of any problems or questions.

The study package included all the necessary videosomnography equipment, including a tripod, a metal stand with an attached wedge for the video recording device, and an extension cord. Mothers were asked to set up the tripod at least 40 inches above the foot of the child's bed. In our study planning, we determined that a camera could capture the best video when the camera was placed at a 45-degree angle on a metal plate attached to the tripod. We cut a piece of rectangular-shaped wood at a 45-degree angle and attached it to the metal plate. We attached VELCRO® strips to the bottom of the camera's charging dock and the wedge so the mother could easily attach and detach the camera from the metal plate (all shown in the instructional video). Although the camera had a battery, it was not enough to last overnight. At the visit and in the written instructions, we asked mothers to use the extension cord to plug the charger into an outlet to continue battery charging during the night.

At the end of the 7 days, another appointment was made to pick up the study equipment. This appointment was scheduled during the last text message on the fifth day of the data collection. Mothers were asked to return all study equipment to the provided box and place the box outside at the date and time for a research team member to pick up the study package.

The success of the adapted videosomnography protocol

We aimed to enroll 10 mothers and 10 school-aged children with DDs and achieved this goal. Nine out of 10 mothers completed video recordings of their child's sleep, with only 10% missing data for videosomnography; two mothers could not record the entire 7 nights (only six and four recorded, respectively).

Challenges with data collection

There were unanticipated challenges with obtaining the child's sleep onset time variable, especially for the first few study participants. We noted this problem early because we reviewed

child sleep recordings for video quality soon after retrieving packages from participants. To address this issue, we reinforced that the recording should start at the beginning of the child's bedtime routines when we dropped off the study package. Mothers completed a 7-day paper-pencil sleep diary containing a child's sleep onset/offset time. We used the sleep diary to replace the missing sleep onset times from videosomnography for analysis. About 13 % of the sleep onset time was missing from videosomnography, mainly from the first three participants. The inability to capture sleep onset time was often because the child had fallen asleep outside the bedroom. There was also co-sleeping; a parent or sibling was sleeping with the child with DDs. These challenges created problems with computing sleep parameters, such as total sleep time, sleep latency (time for a child to fall asleep), and nighttime caregiving activities. If the mother is sleeping with a child, the mother's awakenings for caregiving might require either more or less time. However, these challenges were not due to the pandemic. We felt our protocol and video, and written instructions were adequate.

While we did not have any incidents related to videosomnography, one child was able to reach the camera and damage it resulting in missing data and equipment replacement. To prevent any potential trip or fall injuries related to using videosomnography and minimize equipment damage, we asked mothers to set up the camera far away from the standing zone next to the bed to avoid nighttime falls and to move the tripod to the closet or the corner of the child's bedroom during the day.

Recommendations and strategies for future studies

We demonstrated that mothers could obtain video recordings of their child's sleep over multiple nights with adequate instructions and support. We also showed that mothers in other geographic areas could be included in future studies. For example, study packages with

equipment and written instructions can be mailed to the mother, and video or telephone access can be used for further demonstration or questions. The packages could be prepared for an easy return via addressed, postage-paid boxes. Several mothers living in remote areas were interested in participating in the study, but we were unable to include them due to the distance.

In addition, future study considerations with camera battery life and charging are essential. Keeping the camera plugged into a power source all night may be challenging, increasing the chance of a trip and fall incidence for the mother or child. However, as technology improves battery life, this may become less of an issue.

Having a camera on a tripod may cause a safety issue. We believe that having a well-developed safety protocol minimized incidences related to the videosomnography in our study. For some children, cameras and infrared lights can be interesting. We had one camera damaged, which had to be replaced. Research budgets need to include funds for possible equipment damage.

Researchers may consider using multiple cameras or a moving camera for videosomnography. One of the drawbacks of using a single camera for videosomnography is the inability to capture a child's sleep-wake behaviors when the child is out of frame. We noted that some children were in and out of bed multiple times, but we could not see what the child was doing. Having multiple cameras or a camera moving with a child's movement may be beneficial to more fully capture a child's night-waking activities. However, this approach will increase equipment costs, require more funding, and potentially increase protocol complexity. These additions may raise concerns about additional burdens for mothers if they are setting up equipment.

Conclusion

Videosomnography may be a useful objective sleep measure to obtain sleep-wake behaviors and mothers' nighttime caregiving activities for school-aged children with DDs. By adapting our data collection protocol, we successfully completed the feasibility study using videosomnography during the COVID-19 pandemic. The pandemic changed the research environment and challenged many aspects of human research studies. This paper shared adaptations to our videosomnography protocol and lessons learned. Our experience may benefit other pediatric researchers, advanced practice nurses, and clinicians considering using videosomnography to measure a child's sleep.

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