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Delirium screening anchored in child development: The Cornell Assessment for Pediatric Delirium

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Abstract

Objective—The recently validated Cornell Assessment for Pediatric Delirium (CAPD) is a new rapid bedside nursing screen for delirium in hospitalized children of all ages. The present manuscript provides a “developmental anchor points” reference chart, which helps ground clinicians’ assessment of CAPD symptom domains in a developmental understanding of the presentation of delirium.

Method—During the development of this CAPD screening tool, it became clear that clinicians need specific guidance and training to help them draw on their expertise in child development and pediatrics to improve the interpretative reliability of the tool and its accuracy in diagnosing delirium. The developmental anchor points chart was formulated and reviewed by a multidisciplinary panel of experts to evaluate content validity and include consideration of sick behaviors within a hospital setting.

Results—The CAPD developmental anchor points for the key ages of newborn, 4 weeks, 6 weeks, 8 weeks, 28 weeks, 1 year, and 2 years served as the basis for training bedside nurses in scoring the CAPD for the validation trial and as a multifaceted bedside reference chart to be implemented within a clinical setting. In the current paper, we discuss the lessons learned during implementation, with particular emphasis on the importance of collaboration with the bedside nurse, the challenges of establishing a developmental baseline, and further questions about delirium diagnosis in children.

Significance of Results—The CAPD with developmental anchor points provides a validated, structured, and developmentally informed approach to screening and assessment of delirium in children. With minimal training on the use of the tool, bedside nurses and other pediatric practitioners can reliably identify children at risk for delirium.

Keywords

Delirium; Child psychiatry; Pediatric critical care; Developmental anchor points

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CONFLICTS OF INTEREST

The authors state that they have no competing interests to declare.

INTRODUCTION

Early identification of delirium in children is an urgent medical matter, as recognition and treatment of its underlying causes may minimize long-term consequences. Although pediatric delirium (PD) research has lagged behind adult studies, it has been established that delirium in children is a significant problem, with acute and potentially long-term effects (Colville et al., 2008; Schievelde et al., 2013; Schievelde et al., 2007; Smith et al., 2009; 2013), and presents similarly as in adults (Leentjens et al., 2008; Turkel et al., 2006). As delirium is a clinical diagnosis, it is extremely important to standardize assessment and develop clinical screening tools for detection of delirium in critically ill patients of all ages (Girard & Ely, 2008; Schmitt et al., 2012).

Even with recent progress, there is still a lack of consensus around the diagnosis of delirium in very young or developmentally delayed children, as this requires a developmentally informed assessment. Mastering developmental assessment of the healthy child is a core pediatric skill, yet the pediatric and child psychiatry literature is scant on assessment of development or cognition in ill children. It is generally taught that children temporarily regress behaviorally and emotionally during illness. A child's newly acquired, and therefore precariously anchored, developmental achievements may be temporarily lost. Assessment must take into account such potential fluctuations in milestones and changes in attachment behavior due to the stress of illness and hospitalization (Smith et al., 2011). Complicating assessment further is the presence of pain, fatigue, anxiety, and sedation in a hospitalized or ill child (see Table 1).

Observational and retrospective studies of referred populations have included small numbers of cases of infants and developmentally delayed children (Janssen et al., 2011; Schievelde et al., 2007; Turkel et al., 2003), likely because of under-recognition of delirium and under-referral in these populations. In a four-year observational study of patients referred to psychiatry, Schievelde and colleagues reported a 3% rate of delirium in children aged 0–3 years (Leentjens et al., 2008; Schievelde et al., 2007). The pediatric confusion assessment method for the ICU (pCAM–ICU) has been validated for children aged 5 years and older, but children with developmental or psychiatric comorbidities were excluded (Smith et al., 2011). Nevertheless, concern about delirium in children aged 0–5 years has led to the development of a preschool version (psCAM–ICU) (validation currently in progress), and the Pediatric Anesthesia Emergence Delirium (PAED) scale has been validated for children aged 12 months and older (Sikich & Lerman, 2004; Janssen et al., 2011).

The Cornell Assessment for Pediatric Delirium

The Cornell Assessment for Pediatric Delirium (CAPD) was developed to be a rapidly and easily administered screening tool for nurses to identify critically ill children of all ages and developmental stages who are at risk for delirium (see Figure 1). It was piloted and validated against the gold standard: an evaluation based on the Diagnostic and Statistical Manual (DSM) by child psychiatrists in two previously published studies (Silver et al., 2012; Traube et al., 2013). It was adapted from the PAED scale, which is an observational scale requiring no patient participation. The PAED tends to select for hyperactive delirium, likely due to its intended use in children emerging from anesthesia. Prior efforts to adapt the PAED for the

pediatric intensive care unit (PICU) setting showed its suitability and feasibility as an observational scale, but also noted its limitations with respect to detection of hypoactive delirium and a lack of identification of cognitive changes (Blankespoor et al., 2012; Janssen et al., 2011). The CAPD scale was designed to address these needs. It consists of eight items that correlate with the diagnostic domains of awareness and cognition from the DSM-5, and also includes psychomotor symptoms. In extensive testing, it has proved to be highly feasible to administer by bedside nurses and takes less than two minutes per patient. Because it is based on behavioral observations of the patient during routine nursing care, it also does not require patient participation at time of administration, making it universally well tolerated.

Improving Reliability

Reliability of a diagnosis of pediatric delirium in young children depends on (1) the ability of the examiner to identify age-appropriate and developmental stage-expected behaviors; (2) the ability of the rater to assess whether deviations from expected behaviors are (a) a consequence of developmental delay (an atypical baseline), (b) a change from baseline as a consequence of regression associated with illness, or (c) a change from baseline due to delirium (Silver et al., 2014); (3) the ability of the examiner to explore and understand how a child may experience and express pain, and how this may be expressed at different developmental stages; and (4) the ability of the examiner to elicit concerns and ideas that may be associated with anxiety, and how to understand this in children in a developmental context.

The physician examiners on the research team addressed these issues of accuracy and reliability of assessment through frequent interdisciplinary meetings to discuss difficult cases, where delirium was on the differential diagnosis but not clearly manifest. Anecdotally, the consistency of psychiatrists' diagnostic approaches improved and in an early phase of the study showed good interrater reliability (Silver et al., 2014). "Thinking developmentally" about each diagnostic symptom domain allowed the clinician to differentiate the delirious child from a child experiencing pain, anxiety, or regression (Schieveld et al., 2009; Smith et al., 2013).

In the early phases of CAPD development, reliability between nurse screeners varied, and it became clear that ratings differed based on nurses' comfort and understanding of child development and behavior, particularly for preverbal children. With minimal psychoeducation (little more than reminding nurses about their knowledge and clinical experience assessing developmental stages in children), interrater reliability improved. For example, item #1—"Does the child make eye contact with the caregiver?"—evaluates a behavior that indicates awareness, and delirious children are frequently observed to have an unfocused and wandering gaze. Nurses questioned how to evaluate "eye contact" in an infant or young child. It was stressed to "think developmentally," to compare current assessment with the developmentally expected level. One can expect an 8 week old to look at the examiner, to follow objects past midline, or to regard their own hand (Ball, 1977; Shapiro & Hertzog 2003). If the child's gaze is floating around the room, never focused, this is considered altered eye contact, and the nurse would report how frequently that alteration was

noted. These discussions demonstrated that a standardized assessment for delirium in young children needed to be explicitly anchored in a framework of developmental milestones. Similar observations were also recently noted by Turkel and colleagues in regard to psychiatric diagnosis of delirium in infants (Turkel et al., 2013).

METHODS

Creation of CAPD Developmental Anchor Points

The “developmental anchor points” (previously un-published) were initially taken from developmental texts and established scales for the behavioral domains addressed by CAPD items (Ball, 1977; Bayley, 2005; Frankenburg et al., 1990). These were then reviewed by a panel of experts that included experienced child psychiatrists (from psychoanalytic, infant, and consult–liaison psychiatry subspecialties), pediatric intensivists, pediatric nurses, developmental psychologists, and a psychometrician in order to evaluate for content validity and include consideration of sick behaviors in a hospital setting. For example, an early version of the developmental anchor points for item #2—“Are the child’s actions purposeful?”—included motor milestones for a 2 year old such as “jumps, kicks a ball, builds a tower of seven blocks.” Considering the constraints of the hospital and the fatigue and malaise of a sick 2 year old, this was changed to “Tries to change position; if mobile tries to get up and walk.” Building towers would require blocks and the child’s willing participation, so it was eliminated. For item #6—“Does the child communicate needs and wants?”—the 2-year-old guideline originally stated, “50+ words, uses *I* and *you*, 3–4 word sentences, uses plurals.” Taking into account that the child may be intubated, or regressed, not feeling well, weak or uncomfortable, it was changed to “uses 3–4 word sentences or signs to communicate needs.” These changes were intended to capture the normal developmental expectations in the context of an ill, hospitalized child.

RESULTS

The resulting developmental anchor points at the key ages of newborn (NB), 4 weeks, 6 weeks, 8 weeks, 28 weeks, 1 year, and 2 years (Figure 2) served as the basis for the training of nurses to score the CAPD in the validation trial (Traube et al., 2013). The developmental anchor points also served as a multifaceted bedside reference chart for the two blinded nurses when scoring the initial 70 CAPD screens. As previously reported, reliability was excellent, with kappa ranging from 0.68 to 0.78 for each individual item and a kappa of 0.94 for the overall screen result (positive score >9).

DISCUSSION

Considering Each Child’s Developmental Trajectory

Developmental milestone charts are useful for education and screening. However, each child is a “moving target” on his or her own trajectory, which can occur at various normal paces, with normal temporary plateaus. Furthermore, differential development of particular domains (e.g., gross motor, social, language) is normal and expected. While the presence of delays should be noted in a child’s medical record, it is common for these comorbidities to be minimized or glossed over in the discussion of complex critical illness. In the PICU

setting, if parents are absent, the child's pre-hospitalization baseline eye-contact or language abilities are often unknown. In psychiatric assessment, determination of baseline is usually a first step, along with questioning of the parent or caregiver (e.g., "Is this his/her normal self?" or, per Schievel, "Is this still your child?") (Creten et al., 2011).

Input from staff and bedside caregivers (aides and companions) can help in reaching a consensus as to whether there is a change from baseline. It is helpful to ask about temperament, regulation (baseline sleep and feeding behaviors), recent developmental milestones, previous hospitalizations, favorite comforts and interests, and baseline relationships with caregivers, in order to inform assessment of the other diagnostic domains.

In the hands of the primary bedside nurse, the CAPD can reliably account for individual variations in development. The experience of pediatric nurses with ill children of all ages is invaluable. Their bond with and knowledge of a particular child's family members and caregiving style, particularly in units that employ a primary nursing model, helps establish the child's baseline both pre- and in-hospital.

The CAPD is designed to be utilized by a nurse who has been caring for a patient, completing the scale mid to late shift, reflecting the nurse's experience of the child for that day. It was designed as such to account for (1) a lack of baseline information if the parent was not available at the time of screening, often a limitation and obstacle for accurate assessment of mental status and behaviors in children, and (2) fluctuating mental status over the shift, a hallmark of delirium. Designed as an observational tool, the CAPD benefits from the patient-caregiver interaction (Smith et al., 2013), as the bedside nurse is usually the person with the most cumulative knowledge and experience of the patient on that day. This can be contrasted to the PAED, which was developed for use by an anesthesia nurse accompanying a waking patient postanesthesia. As such, the CAPD, when implemented as recommended, is not a cognitive "test" the patient must pass, like the pCAM-ICU, nor is it a "snapshot" of behavior at a single point in time, like the PAED. Rather, it is an assessment by a trained observer with cumulative experience of the patient over time and across many interactions.

The CAPD, along with the developmental anchor points, was validated in both typically developing children and developmentally delayed children. Sensitivity in developmentally delayed children remained high (96.2%). Specificity was decreased (51.2%) from the overall cohort (79.2%), which was still acceptable for a screening tool (Mehler et al., 1978). Further research is needed to determine how to improve the specificity of this tool in this group. For immediate clinical implementation in the PICU setting, however, this should not be a barrier to utilization of the CAPD. A positive screen should result in referral to psychiatry, as is appropriate in this at-risk population. The psychiatrist can then further investigate the child's developmental baseline, assess the current mental status, and support the PICU team in the holistic care of a developmentally delayed, critically ill child.

Infant Consciousness and Cognition

The CAPD, with the associated developmental anchor points, was designed to assess an infant's mental status using observable behaviors in a PICU setting. The most challenging

aspects of assessment of infants and young children are the domains of *consciousness* (also *awareness*, in the DSM-5) and *cognition*.

Normal consciousness may be described as having appropriate alertness, eye contact, awareness of surroundings, communication, and orientation (Ball, 1977; Shapiro & Hertzog, 2003):

- Normal alertness in a newborn includes a significant part of the day spent sleeping, with some periods of crying, and periods of calm wakefulness (Holditch-Davis, 2005; Mirmiran et al., 2003). A hypoalert infant would not wake to feed, or when disturbed, or in pain. Such infants may lack a crying response when bedside procedures like venipuncture or arterial puncture are done. A hyperalert infant may be too distracted to feed and unable to settle into sleep even when fatigued.
- Appropriate eye contact develops from a newborn's soft focus on a caregiver's face, to holding a gaze at 6 weeks, to following an object across midline at 8 weeks, to holding a gaze and preferring to watch a parent at 28 weeks.
- Awareness of surroundings begins in newborns as having calm, awake time; by 4 weeks turning to the primary caregiver's voice or smell; and by 8 weeks frowning or turning to a bell, and demonstrating a social smile.
- Normal infant communication of needs and wants includes crying when hungry or uncomfortable. At 28 weeks, infants begin to vocalize and point. At 1 year of age, a child may use single words that indicate his awareness of himself and his needs.
- Normal orientation in an infant develops with increasing daytime wakefulness and nighttime sleep. Even a newborn will respond preferentially to mother or father's face and voices, and will be soothed by their voices and touch. This will generalize to the increasing soothability of a familiar song, rocking, or holding, and then a preference for primary caretakers over others. In the later months of the first year of life, an infant will clearly indicate an awareness of their own name/nickname (Newman et al., 2013).

Normal *cognition* involves the developmentally appropriate ability to learn, remember, and apply knowledge. Elements of cognition include: attention, memory, the production and understanding of language, reasoning, problem solving, and decision making. A cognitively intact infant is one whose actions are purposeful, whose distress is consolable when needs are met, and who utilizes verbal and nonverbal communication to express and manipulate her environment:

- Attention can be assessed by evaluating an infant's ability to hold a gaze with a caretaker or focus on a novel object. An 8-week-old infant who cannot hold the gaze of its caretaker or focus on a novel object will not be able to respond appropriately to that person or object (Bushneil et al.,

1989; Field et al., 1984; Mehler et al., 1978; Newman et al., Chatterjee, 2013; Pascalis et al., 1995).

- Memory can be assessed by recognition of caregivers and responses to familiar objects, routines, or comforts. At birth, infants recognize a caregiver's voice; with early development the infant will remember routines. They will repeat such learned efforts as kicking a mobile or ringing a bell (Gulya et al., 1998).
- Psychomotor activity can affect or disrupt multiple areas of cognition. An infant or child with hyperactive delirium may be moving in a badly coordinated fashion, or so constantly that no purpose can be gleaned from her actions. A hypoactive infant may be so delayed and slow in hypoactivity that minimal or no benefit can be gained from his actions.
- Even a newborn infant can effectively communicate needs, and her awareness of them, by crying when hungry, or in pain, and stopping crying when fed or soothed. An older child of 1 or 2 years may symbolize nonverbally, or verbally, that she is hungry or uncomfortable, and then be able to symbolize relief or satisfaction. Even an intubated 2-year-old child will be able to point to his stomach in order to communicate pain.
- Perceptual disturbances are usually noted by caregiver observations of a child commenting on, or interacting with, something that is not real, for instance, a 5 year old who is swatting nonexistent flies.

Further Questions

Further research is needed to improve our understanding of delirium presentation in the developmentally delayed child. One possible solution to further “anchor” the CAPD for each child's developmental trajectory is a basic developmental screen, done on admission, designed to assess the baseline developmental domains most meaningful in delirium. As thoughtfully suggested by Schievelde and colleagues (2014), it is possible that an initial CAPD, where parents/caregivers answer questions according to the child's behaviors prior to the current illness, can establish the baseline, but this needs to be validated in delayed children. Additionally, closer examination of subpopulations of developmentally atypical hospitalized children, such as formerly premature infants, may help identify particular risk factors for delirium. Future studies may be useful in determining whether increased frequency (more than twice per day) of screening will improve detection in cases of fluctuating mental status and possibly assist in tracking of delirium response to treatment or changing illness factors.

SUMMARY

Diagnosing delirium in children, particularly infants and children with developmental delay, can be challenging. However, “thinking developmentally” makes it possible to reliably and accurately interpret alterations in behavior, communication, and emotion in the critically ill child of any age. The developmental anchor points, added during piloting of the CAPD,

embeds this developmental framework into the tool. As the core diagnostic features of delirium are thought to be the same at all ages, it is reasonable and practical to use an observational scale like the CAPD for all ages and developmental stages. The *differential presentation* of these symptoms in children of different ages and developmental stages is accounted for with the developmental anchor points reference tables, making the CAPD a valid and versatile tool for delirium screening for all children hospitalized in the PICU. Furthermore, implementation of the CAPD can be an opportunity for training pediatric providers of all disciplines, deepening our assessment skills and diagnostic acumen when evaluating children for delirium.

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RASS Score ____ (if -4 or -5 do not proceed)						
Please answer the following questions based on your interactions with the patient over the course of your shift:						
	Never 4	Rarely 3	Sometimes 2	Often 1	Always 0	Score
1. Does the child make eye contact with the caregiver?						
2. Are the child's actions purposeful?						
3. Is the child aware of his/her surroundings?						
4. Does the child communicate needs and wants?						
	Never 0	Rarely 1	Sometimes 2	Often 3	Always 4	
5. Is the child restless?						
6. Is the child inconsolable?						
7. Is the child underactive—very little movement while awake?						
8. Does it take the child a long time to respond to interactions?						
TOTAL						

Fig. 1.
Cornell Assessment of Pediatric Delirium (CAPD) revised.

	NB	4 weeks	6 weeks	8 weeks	28 weeks	1 year	2 years
1. Does the child make eye contact with the caregiver?	Fixates on face	Holds gaze briefly Follows 90 degrees	Holds gaze	Follows moving object/caregiver past midline, regards examiner's hand holding object, focused attention	Holds gaze. Prefers primary parent. Looks at speaker.	Holds gaze. Prefers primary parent. Looks at speaker.	Holds gaze. Prefers primary parent. Looks at speaker
2. Are the child's actions purposeful?	Moves head to side, dominated by primitive reflexes	Reaches (with some discoordination)	Reaches	Symmetric movements, will passively grasp handed object	Reaches with coordinated smooth movement	Reaches and manipulates objects, tries to change position, if mobile may try to get up.	Reaches and manipulates objects, tries to change position, if mobile may try to get up and walk
3. Is the child aware of his/her surroundings?	Calm awake time	Awake alert time Turns to primary caretaker's voice May turn to smell of primary care taker	Increasing awake alert time Turns to primary caretaker's voice May turn to smell of primary care taker	Facial brightening or smile in response to nodding head, frown to bell, coos	Strongly prefers mother, then other familiars. Differentiates between novel and familiar objects	Prefers primary parent, then other familiars, upset when separated from preferred care takers. Comforted by familiar objects especially favorite blanket or stuffed animal	Prefers primary parent, then other familiars, upset when separated from preferred care takers. Comforted by familiar objects, especially favorite blanket or stuffed animal
4. Does the child communicate needs and wants?	Cries when hungry or uncomfortable	Cries when hungry or uncomfortable	Cries when hungry or uncomfortable	Cries when hungry or uncomfortable	Vocalizes /indicates about needs, e.g., hunger, discomfort, curiosity in objects, or surroundings	Uses single words or signs	3 to 4 word sentences, or signs. May indicate toilet needs, calls self or me
5. Is the child restless?	No sustained awake alert state	No sustained calm state	No sustained calm state	No sustained awake alert state	No sustained calm state	No sustained calm state	No sustained calm state
6. Is the child inconsolable?	Not soothed by parental rocking, singing, feeding, comforting actions	Not soothed by parental rocking, singing, feeding, comforting actions	Not soothed by parental rocking, singing, feeding, comforting actions	Not soothed by parental rocking, singing, comforting actions	Not soothed by usual methods, e.g., singing, holding, talking	Not soothed by usual methods, e.g., singing, holding, talking, reading	Not soothed by usual methods, e.g., singing, holding, talking, reading (may tantrum, but can organize)
7. Is the child underactive—very little movement while awake?	Little if any flexed and then relaxed state with primitive reflexes (Child should be sleeping comfortably most of the time)	Little if any reaching, kicking, grasping (still may be somewhat disordinated)	Little if any reaching, kicking, grasping (may begin to be more coordinated)	Little if any purposive grasping, control of head and arm movements, such as pushing things that are noxious away	Little if any reaching, grasping, moving around in bed, pushing things away	Little if any play, efforts to sit up, pull up, and if mobile crawl or walk around	Little if any more elaborate play, efforts to sit up and move around, and if able to stand, walk, or jump
8. Does it take the child a long time to respond to interactions?	Not making sounds or reflexes active as expected (grasp, suck, moro)	Not making sounds or reflexes active as expected (grasp, suck, moro)	Not kicking or crying with noxious stimuli	Not cooing, smiling, or focusing gaze in response to interactions	Not babbling or smiling/laughing in social interactions (or even actively rejecting an interaction)	Not following simple directions. If verbal, not engaging in simple dialogue with words or jargon	Not following 1–2 step simple commands. If verbal, not engaging in more complex dialogue

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Fig. 2.
CAPD developmental anchor points for youngest patients.

Table 1

Behavioral changes in illness

Observable Behavior	Possible Causes
Complaining/irritability	Pain, anxiety, mood dysregulation, other physical illness symptoms, side effects of opiates/sedatives
Decreased eating	Decreased appetite, pain, nausea, fear of vomiting
Clinging or demanding with primary parent	Increased attachment behavior, separation anxiety
Thumb sucking, regression in speech, loss of bladder or bowel control, passive in self-care/feeding	Regression (care seeking, feeling helpless)
Nightmares, reacting fearfully	Fantasies of punishment, fear of mutilation, fear of death
Phobic or conversion symptoms	Anxiety
Withdrawn, flat affect	Depression, trauma, side effects of opiates/sedatives

Adapted from Table 84.1, "Distress Signs," in Lewis (1991).