Validation of the Choking Risk Assessment and Pneumonia Risk Assessment for adults with Intellectual and Developmental Disability (IDD)

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ABSTRACT

Background: Risk assessments are needed to identify adults with intellectual and developmental disability (IDD) at high risk of choking and pneumonia.

Aim: To describe the development and validation of the Choking Risk Assessment (CRA) and the Pneumonia Risk Assessment (PRA) for adults with IDD.

Methods: Test items were identified through literature review and focus groups. Five-year retrospective chart reviews identified a positive choking group (PCG), a negative choking group (NCG), a positive pneumonia group (PPG), and a negative pneumonia group (NPG). Participants were tested with the CRA and PRA by clinicians blind to these testing conditions.

Results: The CRA and PRA differentiated the PCG (n = 93) from the NCG (n = 526) and the PPG (n = 63) from the NPG (n = 209) with high specificity (0.91 and 0.92 respectively) and moderate to average sensitivity (0.53 and 0.62 respectively). Further analyses revealed associations between clinical diagnoses of dysphagia and choking (p = 0.043), and pneumonia (p < 0.001).

Conclusions: The CRA and PRA are reliable, valid risk indicators for choking and pneumonia in adults with IDD. Precautions for mitigating choking and pneumonia risks can be applied selectively thus avoiding undue impacts on quality of life and unnecessary interventions for low risk individuals.

1. Introduction

Choking and pneumonia are serious health and safety concerns for adults with intellectual and developmental disability (IDD) (Chadwick & Jolliffe, 2009; Guthrie & Stansfield, 2017; Morad, Kandel, & Merrick, 2009). Aspiration is a contributing cause for
pneumonia (Langmore et al., 1998). Choking and aspiration occur as a consequence of failure in airway protection associated with swallowing (Troche, Brandimone, Godoy, & Hegland, 2014) and may be resolved as a non-fatal but harmful event or can be fatal. The mechanisms for this failure are varied. Choking refers to the individual’s attempt to clear an airway obstruction lodged, typically, where the airway narrows at or above the vocal folds or in the trachea below the vocal folds. Furthermore, indirect tracheal obstruction may occur when there is blockage in the esophagus compressing the trachea. The signs of choking are immediate and vary depending on whether the obstruction is partial or complete. They include gagging, coughing, inability to vocalize, cyanosis, anxiety, and loss of consciousness (Samuels & Chadwick, 2006; Sparks, 2016). Aspiration associated with swallowing refers to entry of bolus material below the level of the true vocal folds and into the trachea. This may occur prior to initiating swallowing, during swallowing or directly after swallowing. If the individual is unable to expel aspirated material, the outcome is passage of the material into the lungs and potential pulmonary infection (Martin et al., 1994; Ramsey, Smithard, & Kalra, 2005; Rogers, Stratton et al., 1994). Aspiration may be associated with swallowing food, drink, saliva or medications. In contrast with choking, aspiration related morbidity and mortality are delayed by hours or days from the event and may have cumulative effects over repeated episodes.

Troche, Brandimone, Godoy et al. (2014) proposed a framework for airway protection in which awareness of the sensation of aspiration results in urge to cough, a cortically-mediated response followed by the reflexive cough response. Thus, the cough expels the aspirate from the airway into the oropharynx for swallowing or the oral cavity for expulsion. This model may be expanded to include choking, as penetration into the upper airway may begin in the oropharynx with a gag response and progress to cough as the material moves distally into the larynx (i.e., choking) and thence through the glottis to the trachea and into the lungs as “aspirate.” In healthy individuals, an effective cough clears aspirate material from the airway. However, higher cough reflex thresholds and weaker cough responses, along with absence of cough commonly seen in adult onset dysphagia and individuals with IDD and dysphagia may result in ineffective clearance (Chadwick & Jolliffe, 2009; Troche, Brandimone, Okun et al., 2014). Furthermore, adults with IDD may be at a cognitive disadvantage for timely appreciation of the urge to cough and the cortical to brainstem activation of the reflexive cough (Troche, Brandimone, Godoy et al., 2014; Troche, Brandimone, Okun et al., 2014). It is this link between asphyxiation and aspiration and the high incidence of choking and pneumonia in adults with IDD that motivated this risk management study.

1.1. Incidence of choking and pneumonia in IDD

Reducing choking mortality in individuals with IDD is a frequently occurring topic in health care and disability literature (Carter & Janca, 1994; Samuels & Chadwick, 2006; Thacker, Abdelnour, Anderson, White, & Hollins, 2008). In a study of 9891 deaths of people with IDD, the incidence of choking as a cause of death was 100 times greater than in the typically developed population (Dupont & Mortensen, 1998). Deaths from choking asphyxiation in adults increase with age (Berzlavaich, Fazen-Dorner, Waldhoer, Fasching, & Keil, 2005).

Pneumonia is a health care concern in the field of IDD for its associations with morbidity and mortality, health consequences, quality of life, and costs of care. Pneumonia and other respiratory diseases are the most common causes of death in adults with IDD in large residential care and small group home or community settings. A high proportion of pneumonia-related deaths occur among those with severe and profound IDD (Chadwick & Jolliffe, 2009; Durvasula, Beange, & Baker, 2009; Glover & Ayub, 2010; Heslop et al., 2013; Janicki, Dalton, Henderson, & Davidson, 2009). Additionally, non-fatal episodes of choking and pneumonia have a high incidence within this group (Beange, Lennox, & Parmenter, 2009; Dupont & Mortensen, 1998).

In a community survey, more than 40% of responding caregivers for adults with developmental disabilities (IDD) reported episodes of non-fatal choking episodes (NFCE) (Thacker et al., 2008). Given the risks of choking and pneumonia for adults with IDD, we argue that development of tools to identify risk indicators/factors that detect reliably those at high risk for these life-threatening conditions is critical. Such tools facilitate timely introduction of strategies to mitigate the risk.

1.2. Risk indicators for choking and pneumonia

In order to identify risk indicators for choking and pneumonia, we reviewed the literature relating to physiological and behavioral factors associated with choking and pneumonia in individuals with IDD. Where research studies were absent, we referred to data in the general population of older people, as their cluster of impairments including physiologic, medical, cognitive and psychologic impairments that characterize aging have similarities to the lifelong impairments of adults with IDD (Deb, Thomas, & Bright, 2001; Janicki et al., 2009; Sheppard, 2010a).

1.2.1. Risk indicators associated with choking

NFCEs, defined as “bolus misdirection into the airway” that require assistance to clear, were studied in a cohort of 75 patients with typical development or adult onset disorders (Ekberg & Feinberg, 1998). Choking occurred under varied conditions: on all solid food consistencies and liquids, during all meals and snacks, and in a variety of eating environments. The significant risk factors associated with choking were: being elderly, having a neurogenic condition, being dependent for feeding, and requiring special dysphagia diets. Anatomical or functional swallowing abnormalities (i.e., dysphagia) were noted on subsequent instrumental testing in some subjects (Ekberg & Feinberg, 1998).

Thacker et al. (2008) used a caregiver survey to explore indicators of choking risk in adults with IDD and found in excess of 40% of respondents reported their cared ones had one or more NFCEs that occurred variably on food consistencies and on non-food items. Odds for choking were higher for individuals taking two or more medications, especially if they used tranquilizers. A cluster of “unable to read” (reflecting severity of intellectual impairment), “teeth condition” (cavities and poor oral hygiene), “medication use”,

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