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Daily living pain assessment in children with autism: Exploratory study

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ABSTRACT

This study aims to broaden knowledge about pain expression and assessment in daily life situations in children with Autism Spectrum Disorder (ASD). The goals are to provide a description of the responses of the GED-DI, the French version of the NCCPC, and to test the internal structure validity of this scale. Thirty five children with ASD were included in this study (mean age = 58 months; mean developmental age = 32 months). The French version of the NCCPC was filled in by parents. Descriptive analysis of responses shows that children with ASD express pain through varied and common behaviours, related to different expressive markers (vocal, facial, activity, etc.). Behaviours more specific to the symptomatology and disturbances of ASD are also displayed. A four-factor solution (negative emotional reaction, idiosyncratic expression, hyper-vigilance reaction, pain expression) emerges from an exploratory factor analysis that explains 54.4% of the total variance. Correlation coefficients show good psychometric qualities in terms of internal consistency, factorial validity and discriminant validity.

This study provides new data about pain expression in daily life situations and shows that the French version of NCCPC adjusted to ASD children is relevant to assess pain in daily life situations.

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1. Introduction

Autistic Spectrum Disorders (ASD) are characterized by a set of specific features and disturbances (WHO, 1993) which may have direct outcomes on the experience, expression and assessment of pain in daily life (Baghdadli et al., 2008; Dubois, Rattaz, Pry, & Baghdadli, 2010; Rattaz, Dubois, & Baghdadli, 2016). Children with ASD have to deal with pain more often than the general population due to co-occurring behavioural problems – agitation, self-injury, aggression, etc.- (Baghdadli et al., 2008; Emerson et al., 2001; Matson & Nebel-Schwalm, 2007) and somatic comorbidities – epilepsy, gastro-intestinal disorder (Coury, 2010; Gillberg & Coleman, 1996; Kral, Eriksen, Souders, & Pinto-Martin, 2013; Molloy & Manning-Courtney, 2003). These comorbidities are prevalent in this population and are potential sources of pain. Lee, Harrington, Chang, and

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Connors (2008) also show that children with ASD have 2–3 times more injuries requiring attention to potential pain sources than control children (see Moore, 2014 for a review on this area).

Autistic Spectrum Disorders are defined by cognitive disabilities and impairments in verbal and non-verbal communication and social interaction in all aspects of daily life (Fombonne, 2003; Matson & Shoemaker, 2009). These disturbances interfere with this population's ability to effectively use traditional pain assessment tools (Ely, Chen-Lim, Carpenter, Wallhauser, & Friedlaender, 2016). For the children with ASD who are not able to accurately verbalize and describe their pain, assessment of painful experience requires a proxy-report using behavioural assessment tools.

No pain assessment tool has been specifically validated for children with ASD. Nevertheless, some scales have been validated for children unable to communicate verbally and with cognitive impairments: the Non-Communicative Children Pain Checklist (NCCPC; Breau, McGrath, Camfield, Rosmus, & Finley, 2000; Breau, Camfield, McGrath, Rosmus, & Finley, 2001; Breau, Finley, McGrath, & Camfield, 2002; Breau, McGrath, Camfield, & Finley, 2002) and the Face, Legs, Activity, Cry, Consolability Scale – Revised (FLACC-R; Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006) which included children with ASD (between 12% and 16%) in the validation studies. Only the NCCPC has been validated in English (Breau et al., 2000, 2001; Breau, Finley et al., 2002; Breau, McGrath et al., 2002; Massaro et al., 2014; Voepel-Lewis et al., 2008) and in French (*Grille d'Evaluation Douleur – Déficience Intellectuelle*; GED-DI; Zabalía et al., 2011). This scale is validated to assess pain in a post-operative context. The English version has also shown good reliability in daily life pain of people with severe cognitive disabilities. The items of the GED-DI consist of a wide range of behaviours and some opposite behaviours (e.g. agitation or inactivity, becoming withdrawn or seeking comfort and physical closeness, wide open eyes or narrowed eyes). This is an interesting factor because current studies have not succeeded in formalizing and theorizing pain expression in ASD children (Allely, 2013; Dubois, Rattaz et al., 2010). Some authors have shown a low reactivity to pain (Militermi et al., 2000; Tordjman et al., 1999, 2009) and a lack of reactivity (Gilbert-MacLeod, Craig, Rocha, & Mathias, 2000), but others report the presence of a significant facial and behavioural reactivity similar to typically developing children (Nader, Oberlander, Chambers, & Craig, 2004; Rattaz et al., 2013). This lack of consistency could be explained by the heterogeneity of autistic spectrum disorders and the wide range of items in the GED-DI allows us to inventory all the pain expressive range of children with ASD. Moreover, this scale is composed of unexpected and paradoxical behaviours (e.g. clenching one's teeth, thrusting tongue out, a specific word or sound, laughing) occasionally observed in ASD children (Tordjman et al., 1999, 2009) and people with severe intellectual disabilities (de Knecht et al., 2013; Defrin, Lotan, & Pick, 2006; Dubois, Capdevila, Bringuier, & Pry, 2010; Malviya et al., 2006; McGrath, Rosmus, Canfield, Campbell, & Hennigar, 1998).

The GED-DI has already been used in a study on pain expression in ASD children during a venipuncture (Rattaz et al., 2013). Results show that the mean score on the GED-DI increases significantly at the needle insertion. This result indicates that behaviours in the scale can identify and assess acute pain linked to a medical procedure in these children. Nevertheless, in this study, behaviours were rated in a dichotomic manner (absent/present) and not on a graduated scale (0, 1, 2, 3) such as the initial version of GED-DI. Thus, these results cannot be used to test the validity of the scale in this context and with this population. Nader et al. (2004) have previously used this scale and shown a negative correlation between the parents' retrospective pain assessment at home and the behaviours displayed during the venepuncture. The children who were the most reactive to pain during the painful situation are those who were described as less reactive to pain by their parents at home. To explain these results, the authors assume that the pain expression may differ depending on the environment (home, hospital) and the type of painful experience (procedural pain, daily living pain). While children with ASD express atypical behaviours in a daily life situation, they express pain in a common manner during a medical procedure. To explain this difference, we need to focus on the emotional component of pain. The context of a medical procedure could be a greater source of anxiety and negative emotion in ASD children than a painful event at home. Rattaz et al. (2013) suggest that the stress induced by a venepuncture and, probably, by the whole context (hospital, nurses, lack of understanding, sensory stimuli, etc.) has a greater impact for children with ASD than for children with intellectual disability or control children. These results highlight the necessity to validate scales for a target population in specific contexts.

In this way, our study aims to broaden knowledge about pain expression and assessment in daily life situations in children with ASD. Goals are 1) to provide a description of the responses to the GED-DI (French version of the NCCPC) filled in by parents of children with ASD, and 2) to study the psychometric qualities of the scale in this population, with an analysis of its internal structure validity.

2. Method

This study has been approved by an independent ethics committee (IEC South Mediterranean IV). Prior to participation in the study, parents and children were informed and asked to sign a consent form. Data from this study were a part of a larger study describing the painful behavioural and physiological reactions in children with ASD (Rattaz et al., 2013), in a Hospital Clinical Research Program (inter-regional HCRP) and with a grant from the *Fondation de France*.

2.1. Participants

The families were recruited from four units of the University Hospitals of Montpellier and Marseille (France). To be included in the study, children with ASD had to be aged between 3 and 8 years old, with a diagnostic of Autistic Spectrum Disorder assessed by a proficient multidisciplinary team and according to the International Classification of Diseases criteria

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