



## Research paper

# Psychological distress and parent reporting on child health: The case of developmental delay



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## ABSTRACT

**Background:** Caregiver-completed screening questionnaires are a common first step in the identification of developmental delay. A caregiver's mood and anxiety level, however, may affect how he or she perceives and reports possible problems.

**Aims:** In this article, we consider the association between caregiver distress and the accuracy of the Ages and Stages Questionnaire (ASQ), a widely-used screen.

**Methods and procedures:** Our sample includes 857 parent-child dyads drawn from the Psychometric Assessment of the NDDs Study (PANS) and the NDDs Alternate Responses Study (NARS). Parents completed the ASQ and the K6, a brief measure of generalized distress. Children were assessed using the Bayley Scales of Infant and Child Development (BSID). We divided children on BSID result and used logistic regression to examine how distress influenced the ASQ's accuracy in each group.

**Results:** Of our 857 children, 9% had at least one domain below  $-2$  standard deviations on the BSID, and 17.3% had positive ASQ results. Caregiver distress predicted a positive ASQ substantially and significantly more strongly among BSID-positive children than among others. This translates into slightly reduced ASQ specificity but greatly improved sensitivity among caregivers with higher distress.

**Conclusions:** At low to moderate levels of distress, greater distress is associated with greater ASQ accuracy.

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## What this paper adds

Mood and anxiety levels have been shown to affect reporting of symptoms in some medical contexts, and there is some evidence that it also influences caregivers' perceptions of their children's health. This may affect the performance of screening instruments, which commonly ask caregivers to express concerns or to identify problems. In this study, we find that, at the low and moderate levels of distress that predominate in the general population, more distress is actually associated with greater screen accuracy: More-distressed caregivers seem to slightly over-report child problems, but they are also far more

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likely to identify genuine issues. This suggests that moderate anxiety and depression are not barriers to accurate reporting, and may also support the incorporation of parent characteristics into predictive models or clinical judgements.

## 1. Introduction

Identifying developmental delay in young children often requires the reporting of caregivers or other third parties (Glascoe & Dworkin, 1995). Delay usually lacks obvious physical signs that can be directly observed by physicians during clinical appointment; and, although clinical standardized instruments for its assessment exist, they are not often used systematically in the course of standard clinical practice (Guttmann, Klein-Geltink, Kopp, & Cairney, 2011; Limbos, Joyce, & Nguyen, 2012). Instead, identification of developmental delay often depends in part on the information primary caregivers communicate to their primary care provider (Raspa et al., 2015).

Caregivers may raise concerns, or may disclose them when asked about a child's development (Glascoe & Dworkin, 1995). There are also a number of brief parent-completed screening questionnaires. Some of these ask caregivers about their concerns (e.g., the Parents' Evaluation of Developmental Status; PEDS) while others ask them to complete checklists of age-specific developmental milestones (e.g., Ages and Stages Questionnaires; ASQ; Brothers, Glascoe, & Robertshaw, 2008; Squires, Twombly, Bricker, & LaWanda, 2009). Both approaches rely on caregivers' perception and judgement. For measures that elicit concerns, such as the PEDS, responses will necessarily reflect caregivers' beliefs about what constitutes normal development and functioning. Measures that ask about particular milestones, meanwhile, require that parents understand what is being asked of them, and accurately judge whether or not the milestone has been reached.

In both cases, there may be factors that affect the accuracy of reporting. Some caregiver characteristics, such as education and parenting experience, have been evaluated in previous work and have been found not to be strongly associated with accuracy of reports on developmental progress (Glascoe & Dworkin, 1995; Waters et al., 2000). Another possibility, however, is that reporting may be affected by the caregiver's level of *psychological distress*. Distress is a state of psychological discomfort, usually measured in terms of tense, worried, anxious, sad, stressed, and tired mental states. Although distress is highest among people with psychiatric disorders, it occurs in most people at lower levels (Slade, Grove, & Burgess, 2011). Studies in various contexts suggest that mood or anxiety problems can lead to symptom amplification or over-reporting (Barsky, Goodson, Lane, & Cleary, 1988; Henningsen, Zimmermann, & Sattel, 2003; Watson & Pennebaker, 1989). In pediatrics, one particular source of concern is the 'anxious parent' (Kroes, Veerman, & De Bruyn, 2003): Anxiety has been shown to affect mothers' reports of their children's psychopathology (Briggs-Gowan, Carter, & Schwab-Stone, 1996), physical health (Waters et al., 2000), and quality of life (Davis, Davies, Waters, & Priest, 2008). Little research considered the effect of distress on screen accuracy, and we know of none that has tested possible effects on screens for developmental delay specifically. Dulcan et al. noted, however, that parents with psychiatric disorder were more likely than others to consult pediatricians about their children's mental health, and that this resulted in a higher detection rate (Dulcan et al., 1990). Glascoe and Dworkin, while noting the possibility of over-identification, have also suggested that parents with "obvious" distress might offer more, not less, accurate clinical information (Glascoe & Dworkin, 1995).

A relationship between caregiver distress and screen performance is therefore plausible. Such an association could take several forms. More-distressed caregivers might 1) simply over-report children's difficulties; 2) be poorer at ruling problems out when they are absent; and/or 3) be more alert to problems when they are present. Variation of this kind might help to explain the moderate agreement between parent-report tools and clinical assessments of child development, and may also provide an area for improvement in development of new versions of screening instruments (Limbos & Joyce, 2011; Sices, Stancin, Kirchner, & Bauchner, 2009; Veldhuizen, Clinton, Rodriguez, Wade, & Cairney, 2015). Evidence on effects of distress on reporting might also help clinicians to better interpret information from caregivers. Errors related to caregiver distress are also problematic, in that already-distressed parents may see a positive screen result as more reason to be anxious; until a final diagnosis can rule out delay, a distressed caregiver must live with unnecessary stress over their child's development. Scarce resources may also be unnecessarily directed to a costly in-depth clinical developmental assessment of children who will not go on to receive diagnoses (Foster & Wolraich, 1997).

In this report, we consider the association between caregiver distress and the accuracy of the ASQ, a widely-used screen for developmental delay. We also consider some mechanisms that might underlie such a relationship. One possibility is that it is mediated by other variables. For example, if higher education were associated with both low distress and high screen accuracy, then distress and screen accuracy would appear to be inversely related, but only because of the effect of education. Although research to date does not suggest that variables such as education or parenting experience strongly affect the accuracy of parent report (Glascoe & Dworkin, 1995; Glascoe, 1994, 2003; Pulsifer, Hoon, Palmer, Gopalan, & Capute, 1994), it seems prudent to evaluate available covariates in order to provide an accurate estimate of the independent effect of distress on screening accuracy. It is also possible that children's difficulties lead to caregiver distress, in which case distress would be in part simply an indicator of caregivers' awareness of a child's delay. For this reason, we aimed to examine the impact of caregiver distress on the validity of a developmental screening test while controlling for independently-measured child functioning.

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