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SCIENTIFIC FORUM: COMMENTARY

Early identification and intervention in autism spectrum disorders: Some progress but not as much as we hoped

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Abstract
Camarata's (2014) review summarizes the progress that has been made in the field of early identification and early intervention in autism spectrum disorders (ASD) over the past few decades, but also provides a salutary reminder that much still needs to be done. Whilst it is possible to prospectively identify cases of ASD using screening instruments; it is critical that those using such screens in clinical practice understand how to interpret data from published studies and consider how screening information is communicated to parents. After several decades when few randomized controlled trials of early intervention in ASD were conducted, the last decade has seen an explosion of new studies. Despite initial optimism, as more trials are published they have highlighted the limits of, and challenges to, early intervention in ASD. Given the complex nature of ASD these sobering lessons are perhaps not surprising. Rather than promote despondency, they need to inspire and inform the next decade of clinical research to move the field forward to the benefit of young children with ASD and those who care for them.

Keywords: *Autism spectrum disorder, early identification, early intervention, screening, treatment, randomized controlled trials.*

Introduction

Camarata (2014) does the field a service by highlighting the many challenges to early identification and early intervention for young children with autism spectrum disorders (ASD). Some commentators might feel that his overview is rather pessimistic, preferring to highlight challenges and potential obstacles rather than celebrate successes. The limitations of the evidence base are illustrated by the very different positions on universal screening advocated by the US American Academy of Pediatrics (Johnson & Myers, 2007) and the UK National Institute for Health and Care Excellence (NICE, 2011)—with the former advocating routine use of screens at 18 and 24 month well-baby checks, and the latter not recommending systematic, universal screening. Another critical area is the accuracy and stability of early diagnosis in the toddler and pre-school years, although even in older children it is well established that reliability of diagnosis of the sub-types of pervasive developmental disorders listed in Diagnostic Statistical Manual of Mental Disorders–IV (DSM-IV; American Psychiatric Association (APA), 2000) is low, and this was one rationale for moving to a spectrum ASD diagnostic category in the Diagnostic Statistical Manual of Mental Disorders–V (DSM-5; APA, 2013). Finally, the rather mixed evidence base for early intervention is reviewed.

In my response I will focus on two areas. First, I will review recent studies on the most widely used and researched instrument, the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001). Second, I will review recent randomized controlled trials (RCTs) of early intervention programs that target the core social communication impairments that characterize many young children with an ASD.

Early screening using the M-CHAT

Whilst a relatively large number of studies have been conducted looking at the performance of ASD screens in referred samples, only a handful of population ASD screening studies have been conducted (see Charman & Gotham, 2013; for a review). Further, with one exception (Baird, Charman, Baron-Cohen, Cox, Swettenham, Wheelwright, et al., 2000), none have undertaken the long-term follow-up required in order to ascertain sensitivity—identifying cases missed by systematically re-visiting the whole sample at a later age point.

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Robins et al. (2001) developed a modified version of the Checklist for Autism in Toddlers (CHAT; Baird et al., 2000) as a parent report instrument measuring aspects of early social communication impairments characteristic of autism (e.g., poor joint attention, response to name, imitation) as well as repetitive behaviours (e.g., unusual fingers mannerisms) and sensory abnormalities (e.g., oversensitivity to noise). A pass/fail cut-off was set as failing two from six "critical items" or any three items from the total of 23 items (Robins et al., 2001). A 2-stage screening procedure was implemented, with a follow-up repeat screen being administered by telephone if a child was screen positive on the first administration. In their initial reports, Robins and colleagues (Kleinman, Robins, Ventola, Pandey, Boorstein, Esser, et al., 2008; Robins et al., 2001) combined relatively small samples (3793 and 1293, respectively) of unselected children attending well-child visits with "high-risk" children such as those referred for early intervention services. In these studies most children identified who went on to receive a diagnosis of ASD were from the high-risk and not the general population samples. The positive predictive value (PPV) for the one-stage administration was 0.36 in both the Robins et al. (2001) and Kleinman et al. (2008) studies, increasing to 0.68 and 0.74, respectively, following the telephone follow-up.

Robins (2008) found a much lower (0.06) PPV in an unselected sample of 4797 children aged 14–30 months attending well-child visits, but following the telephone interview the PPV increased to 0.57. A recent larger study of 18 989 unselected children aged 16–30 months at well-child paediatric visits again reported a PPV for ASD for the one-stage M-CHAT of .06 which increased to .54 following the M-CHAT follow-up (Chlebowski, Robins, Barton, & Fein, 2013). Chlebowski et al. (2013) also recommend that an initial screen M-CHAT score of ≥ 7 can warrant immediate evaluation since $>70\%$ of toddlers scoring at this level remain M-CHAT positive following the telephone follow-up screen. However, until these samples are systematically followed-up, sensitivity remains unknown.

Clinical issues in screening and surveillance

A number of important clinical recommendations emerge from these studies. First, whilst in some studies the M-CHAT has satisfactory PPVs this is *only* after re-administration following an initial fail. PPV following the initial screen is unacceptably low. Several factors likely explain the improvement in prediction following the repeat screening: the contact is by a knowledgeable researcher; some maturation may have occurred in the interval; parents are oriented to and notice behaviour they had not previously seen following exposure to the initial screen?

If screening is universal, for example at a well-child check-up, some parents' first recognition that something might be wrong may follow "failure" of a screen and consequent discussion about their child's development with the professional involved. For a parent to make use of information about their child it first has to make sense and they have to be ready to agree on it. Recognition, belief, and acceptance can be particularly difficult when the professional is giving completely unexpected information. One of the benefits of active, ongoing surveillance is the opportunity to discuss "risk status" with parents and what it means when a particular child fails a screen. In practice, being screened as positive does not constitute a diagnosis, even when tests have a high PPV. Rather, the initial screening process should be seen as the beginning of a dialogue between the parent and professional about the child's development, with additional assessments being couched as helpful checks to make sure things are progressing appropriately.

Another caution is that screening results are sample-specific and the utility of any particular screening instrument and the application of any particular cut-point for further assessment depend both on the sample characteristics and on the intended purpose of screening. The choice of which screen to use, and for which purpose, critically depends on the relative costs of false positives and false negatives. These costs tend to fall on different parties. False positives involve costly further investigation and parental anxiety. False negatives may deprive children of clinical and education resources or place the burden of provision entirely on parents.

RCTs of early social communication interventions

Camarata (2014) cites the Warren, McPheeters, Sathe, Foss-Feig, Glasser, and Veenstra-Vander Weele (2011) *Pediatrics* systematic review of early intervention studies that soberly concluded that "The strength of the evidence [to support early intervention] overall ranged from insufficient to low" (p. 1303). This is not because early autism interventions have not been studied, but rather because most of the research evidence published to date has been poor quality so does not come out strongly from rigorous systematic reviews (see NICE, 2013). However, the field of early intervention research is on a cusp due to an improvement in trial study design in the past decade (Charman, 2011). Until recently, few autism early intervention studies employed randomized designs that protect against bias and spurious findings. In the past few years several approaches have been more rigorously tested in randomized controlled trials (RCTs) of interventions focused on promoting and enhancing social communication and language skills in infants and toddlers with ASD. These are based on a

variety of developmental and behavioural strategies, including the promotion of joint attention, imitation, and joint social engagement skills both directly delivered by therapists and by training parents in these methods.

Kasari and colleagues (Kasari, Freeman, & Paparella, 2006; Kasari, Paparella, Freeman, & Jahromi, 2008) demonstrated the effectiveness of a short-term (6-week) intervention to enhance joint attention or symbolic play in children who were already receiving early, intensive behavioural intervention. After 6 weeks, there were improvements in both the intervention groups in aspects of child joint attention and play in interaction with experimenters and with their mothers (Kasari et al., 2006). One year later both intervention groups had significantly higher scores on structural language measures than the controls (Kasari et al., 2008). This program has recently been replicated with similar findings in Europe (Kaale, Smith, & Sponheim, 2012).

Landa, Holman, O'Neill, and Stuart (2011) compared two kindergarten programs for children with an ASD. The programs differed only in that one focused on "interpersonal synchrony" (IS)—a range of social communication activities and constructs including joint attention, imitation, turn-taking, non-vernal social communicative exchanges, affect sharing, and engagement. Trained kindergarten staff delivered the program for 6 months and parents attended education classes focusing on the same strategies. Landa et al. (2011) found that the IS group differed from the non-IS group on one variable only: "socially engaged imitation". The groups did not differ in the amount of initiated joint attention or shared positive affect when interacting with an examiner; nor did their scores on a standardized language measure differ.

Several parent-training programs are based on similar principles—a focus on shared attention and parental sensitivity to the child's communicative attempts, with the goal of enhancing communicative exchanges to promote communication understanding and social engagement (Aldred, Green, & Adams, 2004). Kasari, Gulsrud, Wong, Kwon, and Locke (2010) conducted an 8-week (24 sessions) parent training approach focusing on joint engagement, joint attention, and interactive play. Following treatment and at 1-year follow-up, they found improvements in joint engagement (with parent), response to joint attention bids, and the number of functional play acts compared to a waitlist control group. In contrast, a recent trial of the Hanen More than Words (HMTW) program found no main effects on either parental responsivity or children's communication (Carter, Messinger, Stone, Celimli, Nahmias, & Yoder, 2011).

Green et al. (2010) reported on a large, multi-site RCT of the Preschool Autism Communication Trial (PACT) intervention developed from that piloted by Aldred et al. (2004). One hundred and fifty-two children were randomized to receive a parent-training program or community treatment as usual. The parent program was of moderate intensity, involving twice-monthly visits for 6 months and then six further monthly visits. The intervention was a video-aided program designed to increase parental sensitivity and responsiveness to child communication, as well as promoting action routines, the use of pauses and supportive language. Green et al. (2010) found no evidence of a group difference on symptom severity scores measured by the Autism Diagnostic Observation Schedule (ADOS; Lord, Risi, Lambrecht, Cook, Leventhal, DiLavore, et al., 2000), but did find improvements of a large effect in blinded ratings of parental synchrony and child initiations in parent–child interactive play. They also found positive effects on parent-reported measures of language and early social communication skills which, while non-blinded, benefitted from parental knowledge of the child's communicative behaviour in a range of contexts.

Employing a combination of both developmental and behavioural approaches with greater intensity, Dawson, Rogers, Munson, Smith, Winter, Greenson, et al. (2010) randomized 24-month-olds to receive the Early Start Denver Model (ESDM) or local community treatments. They describe the ESDM approach as based on teaching strategies that involve interpersonal exchange, shared engagement, adult responsivity, and sensitivity. Therapists delivered a mean of 15 hours of ESDM over a 2-year period and parents, who were also trained in the approach, reported spending 16 hours per week using ESDM strategies. The ESDM group increased their IQ compared to the control group, with most of the change being the result of improved language skills. Improvements in communication were also found on (non-blinded) parent reported adaptive behaviour. However, Dawson et al. (2010) found no changes in symptom scores as measured with the ADOS. Recently, a briefer 12-week parent-mediated version of ESDM found no significant effects (Rogers, Estes, Lord, Vismara, Winter, Fitzpatrick, et al., 2012).

It is too early to draw firm conclusions from this new wave of studies, but behaviours proximal to the intervention delivered may be more amenable to change, in particular when measured using dyadic interaction measures of joint attention and symbolic play (Kasari et al., 2006, 2008); joint engagement (Kasari et al., 2010); parental synchrony (Green et al., 2010); and socially engaged imitation (Landa et al., 2011). There is a more equivocal pattern when one examines effects on downstream variables such as formal language measures. Improvements on standardized measures of language and communication were found in some cases (Dawson et al., 2011; Kasari et al., 2008), but not others (Carter et al., 2010; Green et al., 2010; Landa et al., 2011). However, in the only studies examining autism symptom severity, this has not been amenable to

change (Dawson et al., 2010; Green et al., 2010). Understanding the mechanisms that underlie this attenuation of treatment effects from directly targeted proximal behaviours (in the child, in the parents) to more distal behaviours of language and social communication and onto autism severity, and how these can be overcome, is a key challenge for future studies.

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