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Short communication

Autism Behavioural Interventional Research in low–resource settings: Overcoming prevailing challenges an Asian perspective

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ABSTRACT

Acceleration of Autism interventional research is evident in high-income countries (HIC), however, remains limited in low-resource settings. Though studies have established efficacy of behavioural interventions for Autism spectrum disorder, conducting behavioural interventional research in low resource setting poses unique challenges in economic, ethical and cultural facets. This brief communication discusses the prevailing challenges in low resource setting in designing and testing the efficacy of behaviour interventional model that is generalizable to primary care settings.

1. Introduction

The prevalence of Autism Spectrum Disorder (ASD) has been increasing globally (Matson and Kozlowski, 2011), with an estimated global prevalence of 0.5–1% (Elsabbagh et al., 2012). In South Asia, ASD is said to affect about 1.4% of the population (Minhas et al., 2015).

The rising global prevalence has fueled interest into various facets of research in ASD. Earlier, research in ASD primarily focused on comprehensive and intensive behavioural interventions (Lovaas, 1987; Reichow et al., 2012). Recently, there has been a paradigm shift of research focus from behavioural interventions to biological aspects including genetics, neuroimaging, biomarkers, molecular research, immunological dysfunction and novel pharmacotherapeutics (Matson and LoVullo, 2009; Rossignol and Frye, 2012; Singh et al., 2009). This shifting landscape of research trends is evident not only in high-income countries (HIC), but also in low-and-middle-income countries (LAMIC), highlighting the trend towards biological and etiological research internationally (Abubakar et al., 2016; Li et al., 2015; Vijay Sagar, 2011).

2. Interventions for Autism spectrum disorder

Current available interventions for ASD are diverse in nature, ranging from early behavioural, pharmacological, dietary interventions to complementary and alternative methods. Systematic reviews of studies on dietary interventions show no high quality evidence of efficacy (Millward et al., 2008; Nye and Brice, 2005). Current reviews of studies on novel pharmacotherapeutics like intravenous secretin, chelation therapy raise concerns regarding potential risks over expected benefits (James et al., 2015; Williams et al., 2012). Complementary and alternative therapies for children with ASD did not yield promising results (Cheuk et al., 2011; Xiong et al., 2016).

The importance of etiological research lies in informing potential intervention strategies. Though various interventions have been proposed, evidence to support them as standard treatment of care is lacking. Given the 'ubiquity of therapeutic misconception', families of children with ASD often end up subjecting their child to unproven and experimental interventions (Daley et al., 2013). This highlights the urgent need to translate novel research findings to effective, feasible and most importantly evidence-based interventions in the clinical and community settings.

In the current scenario, early intensive behavioural interventions and parent-mediated interventions have shown 'some evidence' of efficacy based on systematic reviews and meta-

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analysis (Oono et al., 2013; Reichow et al., 2012). Early detection and initiation of early interventions for children with ASD has been emphasized to achieve optimal outcome (Dawson, 2008). Early intervention models like Early Start Denver Model have been found to be efficacious in improving cognitive, adaptive and pragmatic skills (Dawson et al., 2010).

Intensive intervention models are designed to be delivered over extended time frames (20–40 h per week over 1–2 years), requiring a team of medical and non-medical professionals. Though many international studies have shown that developmental interventions bring about an optimal outcome, evidence of its efficacy is limited in the low-resource settings (Hastings et al., 2012; Oono et al., 2013).

Here, we discuss the challenges involved in conducting behavioural interventional studies in non-funded low-resource settings and the potential strategies to overcome them.

3. Challenges in conducting interventional research

Behavioural interventional research poses challenges irrespective of the setting and availability of resources. Major challenges include designing and conducting methodologically sound RCTs. Systematic reviews which have focused on studies predominantly from resource-rich settings have recommended quality RCTs in future for more conclusive results (Oono et al., 2013; Reichow et al., 2012). Rigorous methodology, good sample size, blind rating of outcome measures, use of standardized tools for outcome measures become essential to improve the quality of evidence (Weitlauf et al., 2014). Interventional studies are longitudinal and attrition is inevitable. Moreover, demonstrating statistically significant improvement over short term and sustained improvement over long term are major challenges encountered.

The above factors are common to both HIC and LAMIC settings. However research on behavioural interventions in LAMIC poses significant and unique challenges. The major limitations to behavioural interventions for ASD are fewer resources for service delivery, lack of hierarchical health system and poor health-economics. In addition, factors such as existence of varied and alternative health care systems, lack of awareness and misconceptions regarding the disorder and role of behavioural intervention, delay in diagnosis and initiation of intervention (Preeti et al., 2017) are also important adversities.

International studies have shown that 75–85% of individuals with mental health care needs in LAMICs do not receive any treatment (Reichow et al., 2013). Disorder specific interventions are delivered by trained personnel in some tertiary care centres as well as centres of National importance. However, majority of the patient population visiting the easily accessible, resource-limited, primary care settings are deprived of such opportunities.

Behavioural interventional research therefore needs to consider the above limitations inherent to low resource settings to enhance generalizability apart from other considerations such as lack of access to gold standard tools, ethical and cultural concerns. On one hand, there is focus on addressing the lack of existing interventional models by adapting established models from HIC and attempting task-shifting to suit the resource needs in LAMIC (Hastings et al., 2012; Rahman et al., 2016; Wallace et al., 2012). On the other hand, given the lack of a hierarchical referral system in LAMIC (Saraceno et al., 2007) and the first contact personnel often being pediatricians, a model deliverable at primary care settings is essential to address the treatment gap.

4. Prevailing challenges in resource-limited settings

With the background of prevailing challenges and limitations, we propose an interventional model applicable for delivery in resource-limited settings. Before conceptualizing and designing interventions, different sets of assumptions and precautions based on understanding of issues of relevance were considered as a prerequisite to enhance sustainability.

The key aspects to be addressed were narrowed down to:

a Need for a brief early interventional model deliverable by primary care physicians.
b Emphasis on addressing parental stress from a cultural perspective.

The module included components based on the theoretical underpinnings of the core deficits in ASD which are suitable for delivery through a parent-mediated model, in a non-specialist setting in the initial few weeks following diagnosis. The components were narrowed down to joint attentional skills, imitation and adaptive behaviour which have been in practice in the treatment of Indian children denoting acceptability and feasibility and most importantly have evidence base (Oono et al., 2013).

The intervention was structured and designed to be delivered in outpatient settings within a limited time frame of 5 visits spread over 12 weeks to enhance generalizability of findings to primary care settings.

Phase 1: Educating parents and addressing stress (psychoeducation; assessing and addressing parental stress and coping).

Table 1
Potential strategies to overcome prevailing challenges.

S. no	Prevailing challenges	Potential strategies to overcome challenges
1.	Fewer resources for service delivery on a therapist-child basis	Delivery through a 'Parent-mediated' model
2.	Paucity of available specialists across levels of health care systems	Interventions applicable to primary care setting or a pediatric setting
3.	Economic concerns – lack of funds for compensation	Model applicable for delivery on out-patient basis as part of routine care. Limited time frame to enhance feasibility.
4.	Lack of public access to 'gold-standard' scales and observation schedules, need for formal training	Adapting pre-existing validated tools whenever feasible and applicable. Subjective rating on visual analogue scales to capture micro gains over short term.
5.	Parental stress and cultural beliefs	Addressing parental stress from a cultural perspective as an essential and foremost component of behavioural intervention. Division of responsibilities, involving both parents and significant other member of extended family.
6.	Fidelity of Intervention and Implementation	Intervention checklist for the therapist and a simple take-home log for the parents, applicable across educational background. Fine-tuning of interventions and flexibility for delivery based on parental literacy, stress and competence.
7.	Long term follow up and attrition	SMS or phone calls to serve as gentle and cost-effective reminders.