

Abstract

Introduction: Developmental delay can be identified in the early pre-school years. The benefits to be gained by intervention at this period of life are far greater than at any other time. It was considered cost-effective and feasible to use parents to screen for early identification of risk of developmental delay. Hence, it was considered appropriate to validate the Parental Assessment Score (PAS), a screening tool using parents exclusively, to screen for risk of developmental delay at the age of eighteen months. The validated PAS (S-PAS) was used to estimate the prevalence of being at risk for developmental delay within the district of Colombo. It was also considered important to ascertain parents' views as caregivers of preschoolers with developmental delay and to study the facilities currently available for such preschoolers.

Objectives: To adapt the PAS cross-culturally for use within Sri Lanka, to estimate the prevalence of children aged eighteen months at risk of developmental delay within the district of Colombo, to describe parents' perceptions as caregivers and to describe the facilities currently available for these children

Methods: In component 1 of the study, the PAS was adapted and validated for use in the Sri Lankan cultural context by parents who could understand and read Sinhala. Adaptation was performed with a panel of experts using the Delphi method, while concurrent validation with the Bayley Scales of Infant and Toddler Development (BSID-III) was performed. In component 2, the prevalence of children aged eighteen months at risk of developmental delay within the Colombo district was estimated using the validated PAS (S-PAS) with cluster sampling within all twelve Medical Officer of Health (MOH) divisions of the Colombo district. Component 3 of the study overviewed the perceptions of parents of preschoolers with developmental delay through the use of Focus Group Discussions (FGD), while component 4 overviewed the facilities currently available for preschoolers with developmental delay within Colombo through contacting and visiting such facilities and by conducting a FGD with professionals involved in service provision at these facilities to obtain their views on these facilities.

Results: Cross-cultural adaptation and concurrent validation of the S-PAS was performed, with a correlation coefficient of .226 between the S-PAS and Cognitive Scale of the BSID-III, which was significant at the level of 0.05 and a correlation coefficient of .235 between the S-PAS and

Language Scale of the BSID-III, which was also significant at the level of 0.05. There was no significant correlation between the S-PAS scores and Motor Scale of the BSID-III. However, the sensitivity of the S-PAS was moderate at 50%, while the specificity was high at 94.9%. The prevalence of being at risk of developmental delay among those aged eighteen months in the Colombo district was 1%. The main problems perceived by parents as caregivers were those of transporting their children with developmental delay, lack of resources to provide their children with necessary assistive devices and discrimination against their children when they were accepted into preschools. They also expressed a desire for domiciliary services and more information on optimizing their children's development. The fact that there are yet families that hide away their children with developmental problems was also expressed. Early detection of children with developmental delay was perceived to be unsatisfactory, although the situation has improved in the last few years. Interventions for developmental delay were deemed to require to be more specific to conditions. The quality of services was considered to need improvement together with co-ordination of services which is currently very poor. There are many centres scattered throughout Colombo offering different service modules for developmental delay. However, there is no standard mode of management of specific conditions at these centres. The knowledge of centres regarding other such centres and their services is poor, although sharing of resources does occur to an extent in the government health sector. Parent groups were identified to be strong support systems. However, there are only two such groups in operation and there is no co-ordination between these, even though they share common objectives.

Conclusions: The S-PAS is a reliable and valid instrument for identification of eighteen month old children at risk of developmental delay. However, considering that the sensitivity is only 50%, it is recommended that this tool be simplified to include a pictorial base to aid interpretation of items. It is also considered that parent education on basic developmental skills be improved, both in interpreting the presence or absence of skills and in creating a conducive environment for optimizing skill development. Co-ordination between sectors and facilities need to be greatly improved. This is particularly relevant with regard to social services as there are many parents who do not have the resources to procure necessary assistive devices for their children. Early identification of developmental delay needs to be further improved and intervention services for such children need improvement in both qualitative and quantitative aspects.