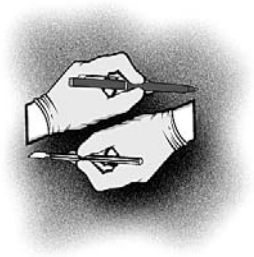

The Ages and Stages Questionnaires: feasibility of use as a screening tool for children in Canada

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Objective: To determine the accuracy and feasibility of a monitoring tool completed by parents for screening at-risk and community infants and children for developmental problems.

Methods: We assessed 43 children following open-heart surgery and 68 community children (aged 4–36 mo) at prescribed intervals using the Ages and Stages Questionnaires (ASQ). Subjects were followed 3 years later (at age 5–6 yr) via telephone interview with their parents concerning developmental delay identified by physicians. Responses were confirmed by telephone interviews with family physicians. We then compared the results of the ASQ with the physician assessments.

Results: Nine at-risk and 9 community children were lost to follow-up. The ASQ identified 4 of the 25 at-risk children as having developmental delay, while 2 of the 6 children assessed by a neurologist were identified as having developmental delay. The ASQ identified 2 of the 59 community children as having developmental delay, 1 of whom was assessed by a neurologist as having developmental delay. The ASQ had sensitivities of 75% in the at-risk group and 100% in the community group, and specificities of 95% and 90%, respectively. The parents were unanimous in their willingness to complete the assessments.

Conclusion: The ASQ is feasible, inexpensive, easy to use, and was appreciated by the parents. It is a sufficiently sensitive and specific monitoring tool that its use in cardiac follow-up programs and in community programs for healthy children is warranted. Although this tool should not be used to replace clinical assessment, it can be used to rationalize access to specialist developmental assessment services.

Objectif : Déterminer l'exactitude et la faisabilité d'application d'un outil de surveillance complété par les parents pour le dépistage des problèmes de développement chez les nourrissons et les enfants à risque et en milieu communautaire.

Méthodes : Nous avons évalué 43 enfants à la suite d'une intervention chirurgicale à cœur ouvert et 68 enfants en milieu communautaire (âgés de 4 à 36 mois) à des intervalles prescrits en utilisant les questionnaires sur les âges et les stades (Ages and Stages Questionnaires – ASQ). Nous avons suivi les sujets trois ans plus tard (à 5–6 ans) en interviewant par téléphone leurs parents au sujet du retard de développement identifié par les médecins. Nous avons confirmé les réponses en interviewant les médecins de famille par téléphone. Nous avons ensuite comparé les résultats des ASQ aux évaluations des médecins.

Résultats : Neuf enfants à risque et 9 enfants en milieu communautaire ont été perdus au suivi. Les ASQ ont permis de déterminer que 4 des 25 enfants à risque et 2 des 6 enfants évalués par un neurologue avaient un retard du développement. Les ASQ ont établi que 2 des 59 enfants des milieux communautaires avaient un retard du développement, dont un a été évalué par un neurologue qui a conclu qu'il avait un retard du développement. Les ASQ avaient une sensibilité de 75 % dans le groupe des enfants à risque et de 100 % dans le groupe des enfants des milieux communautaires, et des spécificités de 95 % et 86 % respectivement. Les parents ont consenti à l'unanimité à remplir les évaluations.

Conclusion : Les ASQ sont applicables, peu coûteux, facile à utiliser et appréciés par les parents. C'est un outil de contrôle suffisamment sensible et spécifique pour que son utilisation dans le contexte de programmes de suivi cardiaque et de programmes communautaires à l'intention d'enfants en bonne santé soit justifié. Même si cet outil de ne devrait pas remplacer l'évaluation clinique, on peut l'utiliser pour rationnaliser l'accès aux services d'évaluation du développement offerts par des spécialistes.

Introduction

Over the past 3 decades, the benefits of early intervention — therapy for young children identified as having or being at risk of developing a handicap, before it interferes with their growth and development — have been shown in randomized controlled trials.[1–4] It is the role of family physicians and pediatricians to promptly identify children who are developmentally delayed and refer them to the necessary resources for full assessment and an intervention program. The current guidelines for family physicians and pediatricians stress the need for identification of developmental delays and disabilities,[1] and steering of affected children to appropriately trained teams that can offer full assessment and early management.[2] Despite the need for regular and accurate developmental assessment, few pediatricians use formal developmental screening instruments in their offices, with most relying on informal surveillance through the history and physical examination.[5]

Today's physicians face unprecedented challenges of time constraints, budget cuts and inadequate resource allocation, which may impede their ability to provide effective developmental assessment. In addition, there is a lack of consensus on which instruments are the most reliable and cost-effective for screening the general pediatric population.[6] As a result of these barriers, it has been estimated that only 50% of children with developmental disabilities are identified through assessments initiated by physicians.[7] Developmental delay in many children, particularly mild or moderate delay, goes undetected by parents and professionals during the first few years of life and is finally identified when the deficits result in problems in school. Since it is believed that the greatest benefits for early intervention are achieved when it is initiated between the ages of 3 and 5 years,[2] the opportunities to ensure optimum motor, language and social development for these children are likely being missed.

The Ages and Stages Questionnaires (ASQ) constitute a screening system that was developed by the University of Oregon's Center on Human Development.[8,9] It is a developmental assessment tool kit for parents, who complete the questionnaires at prescribed intervals: 4, 8, 12, 16, 20, 24, 30 and 36 months of age. Each questionnaire consists of 30 clearly described and illustrated questions divided into 5 domains: gross motor, fine motor, language, social and adaptive. Parents are asked to report the occurrence of certain behaviours and skills by checking the appropriate box to indicate whether the child has the skill ("yes," "sometimes," or "not yet"). The questionnaires take about 10 minutes to complete and are then sent back to the administrative body to be scored and interpreted. The Centre on Human Development determined the validity (0.86 to 0.91) and reliability (interrater > 0.85, test–retest > 0.90) of the system.[8,9] The tool was developed as an accurate, cost-effective method of monitoring children who are at risk for developmental delay to identify developing problems before they interfere with a child's growth.

Although the efficacy of this tool has been established, the feasibility of its use in an at-risk population has not. Further, the Canadian health care model, the centralized nature of Canadian secondary and tertiary health care, and Canada's vast geography lead to unique conditions. Particularly for parents in rural or remote areas, or those at high risk for developmental delay, concerns about development may go unaddressed. Children in rural and remote First Nations communities are at particular risk, as noted by the Kirby Commission in its report on the status of the health care system in Canada, which stated that

> the health of Aboriginal Canadians is a national disgrace. There is a … completely unacceptable large gap in health indicators between Aboriginal and non-Aboriginal Canadians.[10]

Therefore, we felt that a mailed (or even electronic) questionnaire system might lend itself to the practical realities of Canadian health care delivery.

Children with heart disease are at increased risk of lower than average intelligence quotients and poorer than average perceptual and gross motor

function owing to prolonged cyanosis and central nervous system damage during and immediately after cardiac surgery.[11] We examined the feasibility of having parents complete the ASQ to monitor the developmental status of their at-risk child. We also considered the utility of the ASQ in a community-based population.

Methods

Our study was conducted at the British Columbia Children's Hospital (BCCH) in Vancouver, British Columbia. The study was approved by the University of British Columbia Clinical Research Ethics Board.

Parents whose children were under the age of 4 months and who were diagnosed with congenital cardiac disease in the Cardiac Sciences Group at BCCH were invited to participate. Parents of infants being seen in community public health centres in Upper Island, North Shore and Burnaby Health Districts were invited to participate as community control subjects. Informed consent was obtained.

We obtained information about the child and his or her family and entered it into a database developed for the ASQ. The results from each questionnaire were later added to each child's individual file.

The questionnaires were sent to the families' homes 1 week before the children's 4-, 8-, 12-, 16-, 20-, 24-, 30- and 36-month birthdays, with the request that they be returned within 2 weeks. If the questionnaires were not returned within the allotted time, parents were reminded via telephone up to 3 times. If the questionnaires still had not been received, notes were made in the children's files and the next age-level questionnaires were sent out at the scheduled time.

Analysis

The scoring system for the ASQ uses statistically determined cut-off points that were developed for both children with normal and children with elevated risk. The cut-off points are calculated as 2 standard deviations below the mean score in each of the 5 developmental domains. When a child's questionnaire was received, the score was determined for each of the 5 domains and then compared with the cut-off scores. A child's overall score was deemed to be in the abnormal range if he or she scored at or below the cutoff

- in 2 domains within the same questionnaire;
- in the same domain on 2 consecutive questionnaires.

If a child's overall score was in the abnormal range, the parents were telephoned to inform them that the screening tool had identified possible concerns with their child's development and permission was obtained to contact the child's primary care physician. Contact with the physician consisted of a brief summary of the child's test performance and a request for further developmental assessment. If a child scored within the normal range a letter was sent to the parents to inform them that their child was developing normally.

Parental feedback was obtained through a series of open-ended questions on individual questionnaires, in addition to a parent evaluation survey distributed after the second year of the study. The results from these evaluations were used to assist in the determination of the feasibility of this tool's use.

Three years after the end of the study, the families were contacted by telephone interview to determine their child's developmental status. The parents were asked if their child had ever been assessed by a developmental specialist and if either the specialist or the child's family doctor had ever raised concerns about the child's development. We compared these results with the results that were obtained via the ASQ. The sensitivity and specificity of the ASQ were calculated. The feasibility of using the ASQ was assessed by combining the feedback from the evaluation surveys and the total cost of administering the tool.

Results

Parents of 43 children from the Cardiac Sciences Group and 68 children from the community (an upper-middle class area) were enrolled in the study. Of the cardiac group, 5 dropped out, 4 infants died, and 9 were lost to follow-up. Of the community group, 9 were lost to follow-up.

Children's development

At the end of the 36-month ASQ trial period, results had been consistently obtained from 25 children in the cardiac group and 59 children in the community group. Four of the children from the cardiac group had scores within the abnormal range, while 7 children scored within the abnormal range in the community group. After the follow-up telephone interview at the end of the third year, 25 children remained in the cardiac group and 59 children

remained in the community group. Of the parents who were contacted from the cardiac group, 4 reported that their child had been assessed by a specialist or family doctor as having a developmental delay, while 1 child from the community group had been identified in this manner. Of the 4 children in the cardiac group who were identified by the ASQ as having developmental delay, 3 were also assessed by a specialist as having developmental delay. One child with developmental delay was missed by the ASQ, and 1 child was picked up by the ASQ unnecessarily. Of the 7 community children who were identified by the ASQ as having developmental delay, 1 child was found by a specialist to be developmentally delayed and the parents of the remaining 6 children did not report them seeing specialists. No children were missed by the ASQ in the community group. The sensitivity of the ASQ was 75% in the cardiac group (95% confidence interval [CI] 0.22–0.99) and 100% in the community group (95% CI 0.05–1.00). The specificity of the ASQ was 95% in the cardiac group (95% CI 0.74–1.00) and 90% in the community group (95% CI 0.78 to 0.96).

Parents

The feedback obtained from the parents via individual questionnaires and following a parent evaluation survey was overall very positive. Of the 143 surveys that were distributed to parents, 85 were returned (33 from the cardiac group, 52 from the community group), for a total return rate of 59.4%. Both groups of parents indicated that the questionnaires were easy to fill out (100% of the cardiac group, 88% of the community group), that the questionnaires helped them to learn more about their child's growth and development (87% of the cardiac group, 72% of the community group) and that they would recommend the questionnaires to other parents (87% of the cardiac group, 76% of the community group).

Costs of screening

We analyzed the cost of performing the ASQ compared with the cost of having each child screened by a developmental specialist. The total cost of performing the ASQ was less than Can$100.00 per child for mailing and return postage (8 questionnaires at $2.50 per questionnaire, total $20.00 per child); up to 3 reminder follow-up phone calls for about 20% of families; receipt, scoring and reporting abnormal results back to parents; data entry; and filing (20 min per questionnaire at $18.00/h or about $60.00 per child). A very generous estimated total cost of following 100 children is about $10 000.00 over 3 years.

Cost of seeing a developmental specialist

The prevalence of developmental delay among at-risk children has been estimated at 13%–16%.[8] Using this as our rate of abnormal findings and based on a sample of 100 children, 16 would have developmental delays; 12 of those children would be identified by the ASQ; and 4 would be missed. If each of the 12 children were then referred to a specialist for further developmental testing at a cost of $44.45 per 20-minute session,[3] the total cost for identifying and testing those 12 children would be $10 533.40 (ASQ $10 000.00 plus follow-up of $533.40). If, instead, those same 100 children were screened by a developmental specialist via 6 20-minute visits over 3 years, the cost of the assessments alone (if it were feasible to conduct assessments on all children) would be $26 670.00. Additional costs (not calculated) would be incurred either by the parents or by the health care system for transportation of about 15% of the children and parents from rural areas and about 2% from remote locations[12] to a centre providing specialist assessment or for the specialist to travel to rural and remote locations.

The estimated monetary savings for screening 100 children with the ASQ is $16 140. There would be a cost associated with missing 25% of the children with developmental delay, but this comparison is also based on the assumption that 100% of children could be assessed by health care professionals and that there is 100% sensitivity for identifying developmental delay through assessment by a health care professional and therefore no child with a developmental delay would be missed.

Discussion

Our study found that parental completion of the ASQ was a feasible and cost-effective means of screening for developmental delay among at-risk children as well as community children in Canada. The cost of administration of the ASQ is low (about $100.00 per child), but it would now be possible to lower the costs by using electronic distribution and follow-up, which would improve the level of cost-efficiency, although the impact on compliance

would need to be evaluated. In particular, it is likely worthwhile for at-risk patients in Canada who are currently not followed consistently because of problems with access or cost of follow-up to be monitored with the ASQ.

The prevalence of developmental delay among the children in the cardiac group (4 of 25, 16%) is consistent with other reports.[13] The prevalence in the community group (1 of 59, 2%) is somewhat low compared with other reports.[14] However, research has shown that lower socioeconomic status is associated with increased risk for developmental delay[15] and thus in our sample population from an upper-middle class area, prevalence could be expected to be lower than reported by others.

In Canada, many at-risk children are followed comprehensively within existing programs. However, a significant number of children who are at risk of having developmental delay are not served adequately by the existing systems. The ASQ is simple enough for individual physicians to use to follow all infants. It could also be used routinely for groups of at-risk children such as those who have received specialized care or consultation (e.g., children who have had heart surgery or graduates of premature nurseries who do not meet the criteria for ongoing follow-up), or those with socioeconomic risk factors. However, it may be more rational for institutions or provincial health authorities to move toward coordinating the administration of this developmental monitoring tool. Moreover, if the present belief that early intervention for developmental delay is efficacious is borne out by evidence-based studies, then investment in a provincially administered identification program would be logical, as has been adopted by several states in the United States.

The comments from parents in our study indicated that they appreciated and learned from their involvement while using the ASQ to assess their children. The American Academy of Pediatrics supports the increased involvement of parents and indicates that

> the explicit use of parental reports has the added advantage of parents being active participants in the evaluation of their children, and shows respect for their expertise.[1]

Moreover, Parry[2] concludes that the maximum effectiveness of early intervention is achieved when parental skills (and knowledge) are increased, and parental involvement, in partnership with professionals, is seen as essential for sustained progress from early intervention. Increased involvement of parents, and respect by the medical community for the observations of parents, likely also results in more rational use of health care services in the long term.

Evidence demonstrating important short- and long-term outcome is increasingly required as part of the provision of good health care. Currently, "outcome" data are often limited to survival or length of hospital stay. In particular, specialized clinics may follow the specific medical problem, but the long-term developmental effects of care, both positive and negative, are often not routinely addressed in follow-up. Use of the ASQ screening tool would enable clinicians to identify more at-risk children who would otherwise not be referred for comprehensive assessment by a fully trained team. Many larger communities with secondary level care have such teams, meaning that not all referrals need be to tertiary care. As the health care agenda moves to ensure quality health care, it is increasingly important for clinicians to avail themselves of tools that easily and economically provide relevant follow-up information.

Study limitations

There were some limitations to our study:

- The cost–benefit analysis was theoretical.
- The number of cases of developmental delay identified, either by the ASQ or by physicians, was small, so the CIs, particularly about the sensitivities, are wide.
- The community-based children were largely from the upper or middle economic class and children specifically from lower socioeconomic circumstances, the population most likely to benefit intellectually from early intervention,[2] were not included.

Conclusion

The ASQ may be feasible and economical as a screening tool. It could be used by specialty clinical programs to follow their at-risk populations, particularly those who are excluded from conventional follow-up by geography or limited resources. The ASQ could also be used by public health authorities to screen currently underserved populations.

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