Additional therapy for young children with spastic cerebral palsy: a randomised controlled trial

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Executive summary

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Executive summary

Objectives

It has been suggested that children with cerebral palsy should not only have their physical needs addressed, but also that there should be support for the family.

This study separated these functions by investigating whether in the short and medium term additional support by (a) a physiotherapy assistant improved physical function in young children with spastic cerebral palsy and (b) a family support worker improved family functioning; children in all groups received standard physiotherapy in addition to the study interventions. In addition, the study examined the needs of the families and the factors affecting child and family functioning in relation to services received and outcome.

Design

This was a multi-centre randomised controlled trial (RCT) with blinded assessments and a cost-effectiveness analysis. The children studied had spastic cerebral palsy that was the consequence of perinatal adversity. All were less than 4 years old on entry to the study.

Randomisation was to: (a) a group who received extra physiotherapy from a physiotherapy assistant; (b) a group who received standard physiotherapy; and (c) a group where the child received standard physiotherapy and the family was also visited by a family support worker. Children in all groups continued to receive standard physiotherapy in addition to the study interventions.

Both quantitative and qualitative methods were used in this trial.

Participants

Seventy-six families completed the intervention period. Forty-three families were reassessed 6 months after the end of the intervention and 34 of these after a further 6-month period.

Main outcome measures

The child outcome measures were:

- motor functioning (Gross Motor Function Measure)
- developmental status (Griffiths Mental Developmental Scales)
- adaptive functioning (Vineland Scales).

The family outcome measures were:

- self-reported maternal stress (Parent Stress Index)
- level of family needs
- parental satisfaction.

Results

The RCT found that:

- There was no evidence that additional physical therapy for 1 hour per week for 6 months by a physiotherapy assistant improved any child outcome measure in the short or medium term.
- Intervention by a family support worker did not have a clinically significant effect on parental stress or family needs.
- Over the 6-month period the total cost of services for each child ranged from £250 to £6750, with higher costs associated with children with more severe impairments.

The multivariate analyses found that:

- There was no significant relationship between measures of intensity of services received by the children and families and the main outcome measures.
- Low-functioning children, in terms of both motor and cognitive function, were more likely to receive more services in terms of variety and frequency.

The qualitative analysis found that:

- Parents generally reported high satisfaction ratings after all interventions and some

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stated that the interventions had benefited the child and/or the family. There was therefore a discrepancy between the perceptions of these parents and the objective, quantitative measurements.
- The family support workers identified a small number of families who were experiencing considerable family problems, but who had not been referred for appropriate support by any other agency.

Conclusions

The findings of this study provide support for the current literature that there was no evidence that additional intervention (in this case by a physiotherapy assistant or family support worker) helped the motor or general development of young children with spastic cerebral palsy. Nor was there any quantitative evidence that providing extra family support helped levels of parental stress and family needs. The implication was that the provision of extra physical therapy does not necessarily improve the motor function of a young child with cerebral palsy and additional family support should not automatically be assumed to be beneficial. In addition, no significant association was found between the intensity of the local services provided and any outcome measure, other than a slight association with lowered family needs.

The provision of local services was related to the severity of the child's impairments and not to family difficulties. A small group of families with complex family problems needed more service input.

There was a wide range in the costs of services.

Implications for health care

Physical therapy services were largely child focused. No evidence of significant provision of family support was found, other than in one area that offered wider support in facilitating contact between services and referral to other services. The qualitative methodology showed that there were some families which benefited from the family support worker intervention. These families of children with cerebral palsy had little input from other sources. They were experiencing high stress levels and had high levels of unmet needs. Support for these families was at a relatively superficial level and there was no indication of support by social or psychological support, that is, the focus appeared to be on physiotherapy services directed towards the child.

It appears that more funds are not needed. However, families who might particularly benefit from family-focused intervention were not appropriately targeted.

There was some evidence of over-provision and/or of a sub-optimal service mix for some of these children and their families. There should be specific focus on avoiding duplication and defining the criteria that are used to decide on service provision for individual children and their families.

If the physiotherapist is to be the key professional (key worker) for a child with cerebral palsy, guidance should be given on how to explain to parents that more intensive or more frequent physical therapy may not necessarily be warranted. A key worker for the child with cerebral palsy and his or her family needs to understand what family support entails, and their role in providing it and acting as gatekeepers for referral to other agencies. If this really is an important part of the paediatric physiotherapist's role, appropriate training and resources need to be provided.

Recommendations for future research

Research is needed to examine what 'sufficient' levels of provision or therapy might be for which children and which families. Key issues are:

- How the allocation of resources to individual children and families is decided
- The variability among child development centres in relation to how families are assessed, the formulation of a family plan, referrals to other agencies and interagency working. One approach might be to compare the effectiveness of a service with a key worker who has clear management protocols and develops an individualised care plan with the present less structured approach.

A time series of different levels of input and outcomes would provide valuable information for practitioners.

Various methodologies were used for this study. It is recommended that future assessments of

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therapies of this type adopt a similar multifaceted approach, which is likely to be more suitable than a simple RCT for the evaluation of clinical interventions where the effects are complex. The most appropriate measures of outcome should be used, including assessment of provision of information and emotional support for families.

Publication

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