Evaluating the impact of the diagnosis and management of children with type 1 diabetes on parents/carers

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Introduction:
- Glycaemic control of children with diabetes is often adversely affected due to the psychological impact of the disease upon parents/carers.
- The health of a child partly depends upon the psychological status of the parent.
- Assessment of parental psychological wellbeing is a useful technique to determine those families who require further support.

Aim and Objective:
1. To determine the psychological impact upon parents/carers caring for a child with diabetes
2. To identify interventions which provide support to parents
3. To improve parent/carer and child/family relations
4. To improve patient metabolic control

Methods:
- 252 children with type 1 diabetes were identified from SHSCT Twinkle database
- 2 Paediatric Inventory questionnaires (PIP) were sent to each household to identify stressors among parents caring for a child with type 1 diabetes
- 2 parental focus groups were held to discuss concerns raised in the questionnaire and explore the main difficulties faced by parents/carers caring for a child with diabetes

Participants:

Focus Group Themes:

Main concerns:
- Responsibility of ‘24 hour care’
- Reaction from other children
- Society’s misconceptions about Type 1 diabetes

Main difficulties:
- ‘Trial and error’ management of diabetes
- Lack of support in hospital
- Lack of education in wider public

Impact upon parents:
- Lack of social life
- Disturbed sleep
- Making compromises
- Career changes
- Less quality time with partner
- Siblings’ needs overlooked

Interventions:
- Psychological input
- Increased education at diagnosis
- Regular information sharing e.g. Monthly newsletters
- Parental peer support
- Differentiating child and adolescent services

Conclusions:
1. Caring for a child with diabetes has a major psychological impact on parents/carers
2. This impacts family relations and glycaemic control
3. Further psychological support is required for parents/carers
4. Parents are in favour of a psychology service

Results Questionnaire:
- Emotional distance category scored the largest numbers of high scores across both domains of frequency and difficulty
- Role function category scored the largest numbers of low scores across both domains of frequency and difficulty

References: