

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

Dr Ciara McCormick Paed Trainee ST3 SHSCT, Dr Sarinda Millar Paed Cons SHSCT

## 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 parents
- Assessment of parental psychological wellbeing is a useful technique to determine those families who require further support

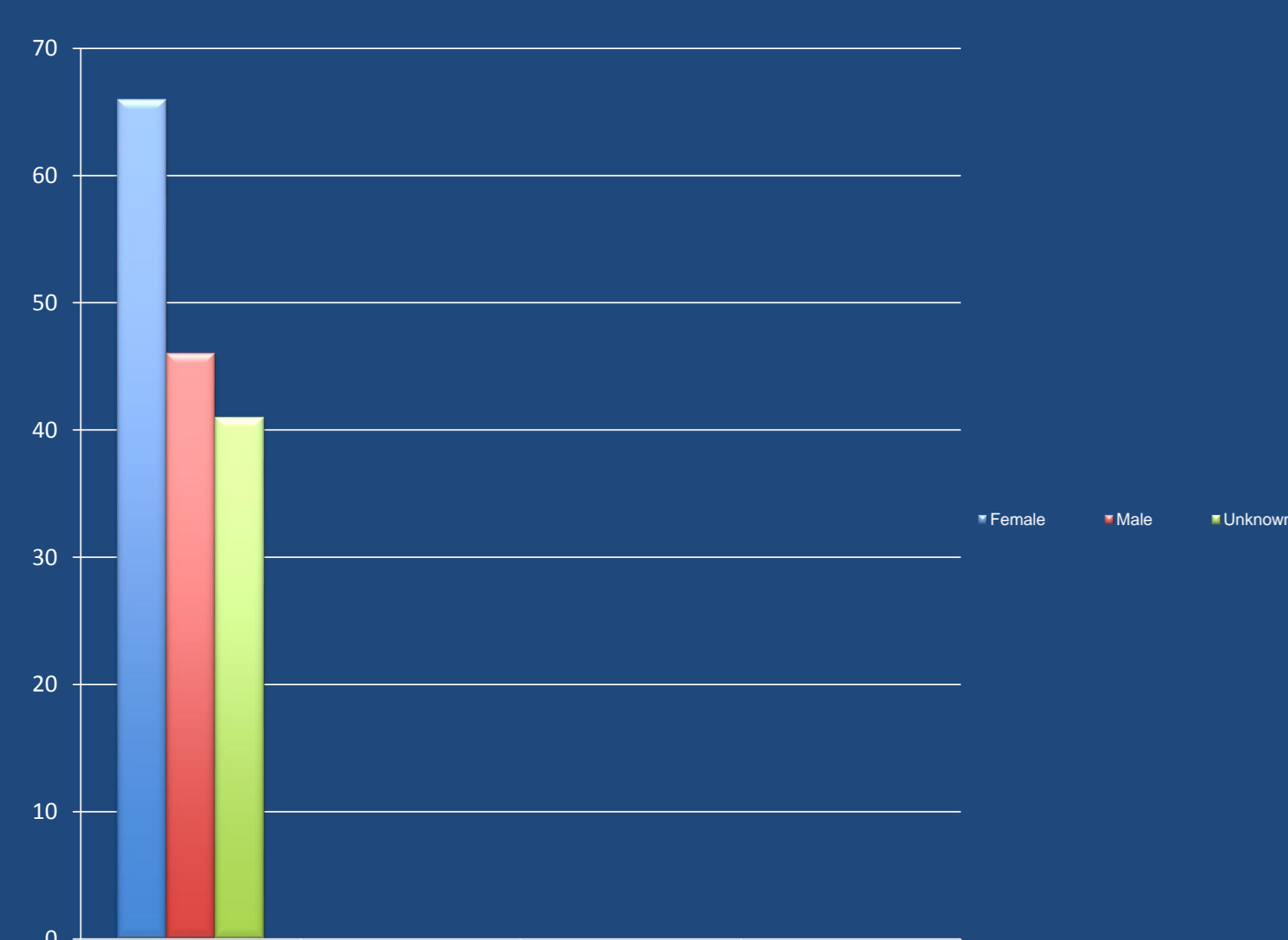
## Aim and Objective:

- To determine the psychological impact upon parents/carers caring for a child with diabetes
- To identify interventions which provide support to parents
- To improve parent/carer and child/family relations
- To improve patient metabolic control

## Methods:

- 252 children with type 1 diabetes were identified from SHSCT Twinkle database
- 2 Paediatric Inventory questionnaires for Parents (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

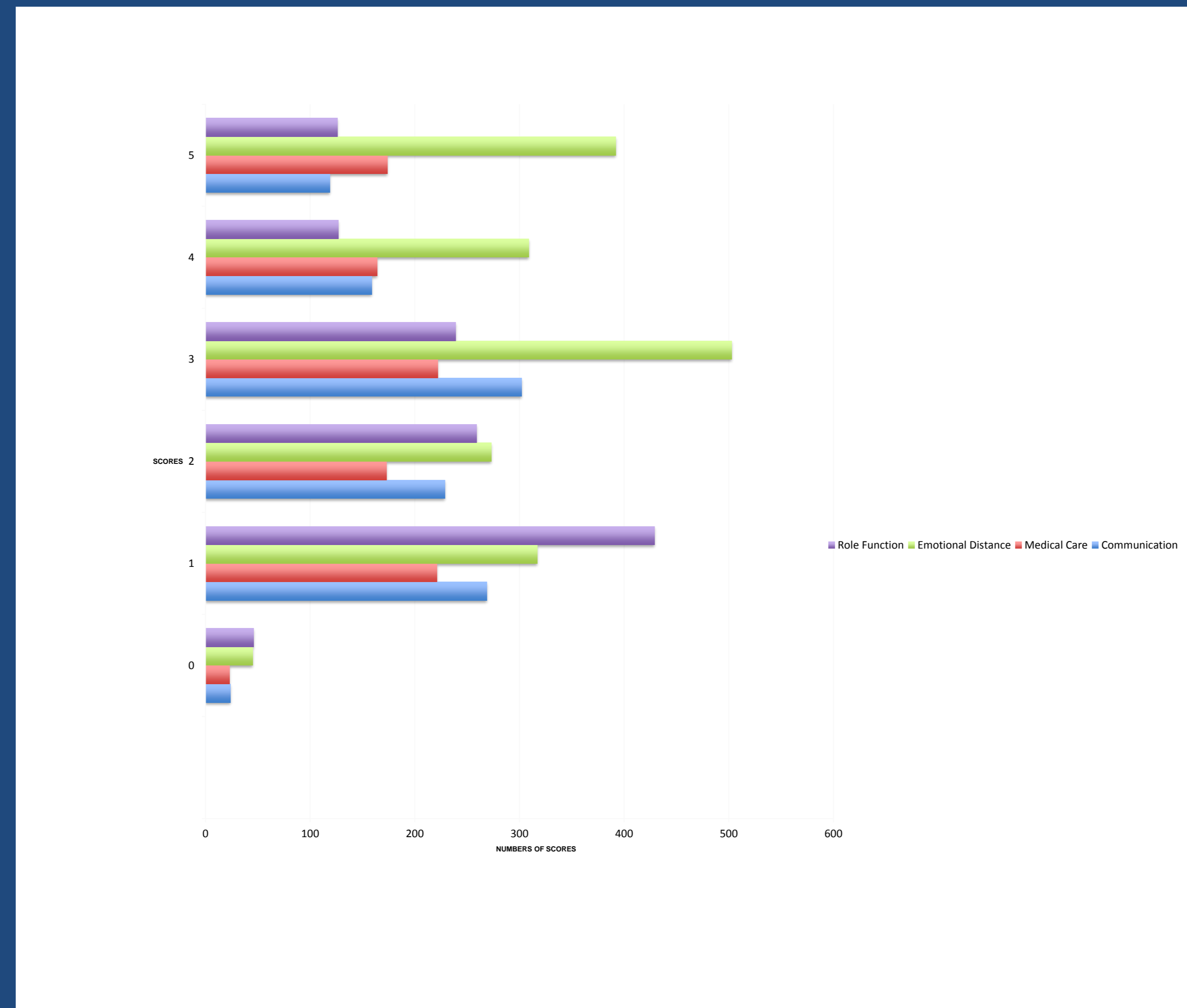
## Participants:



## Results

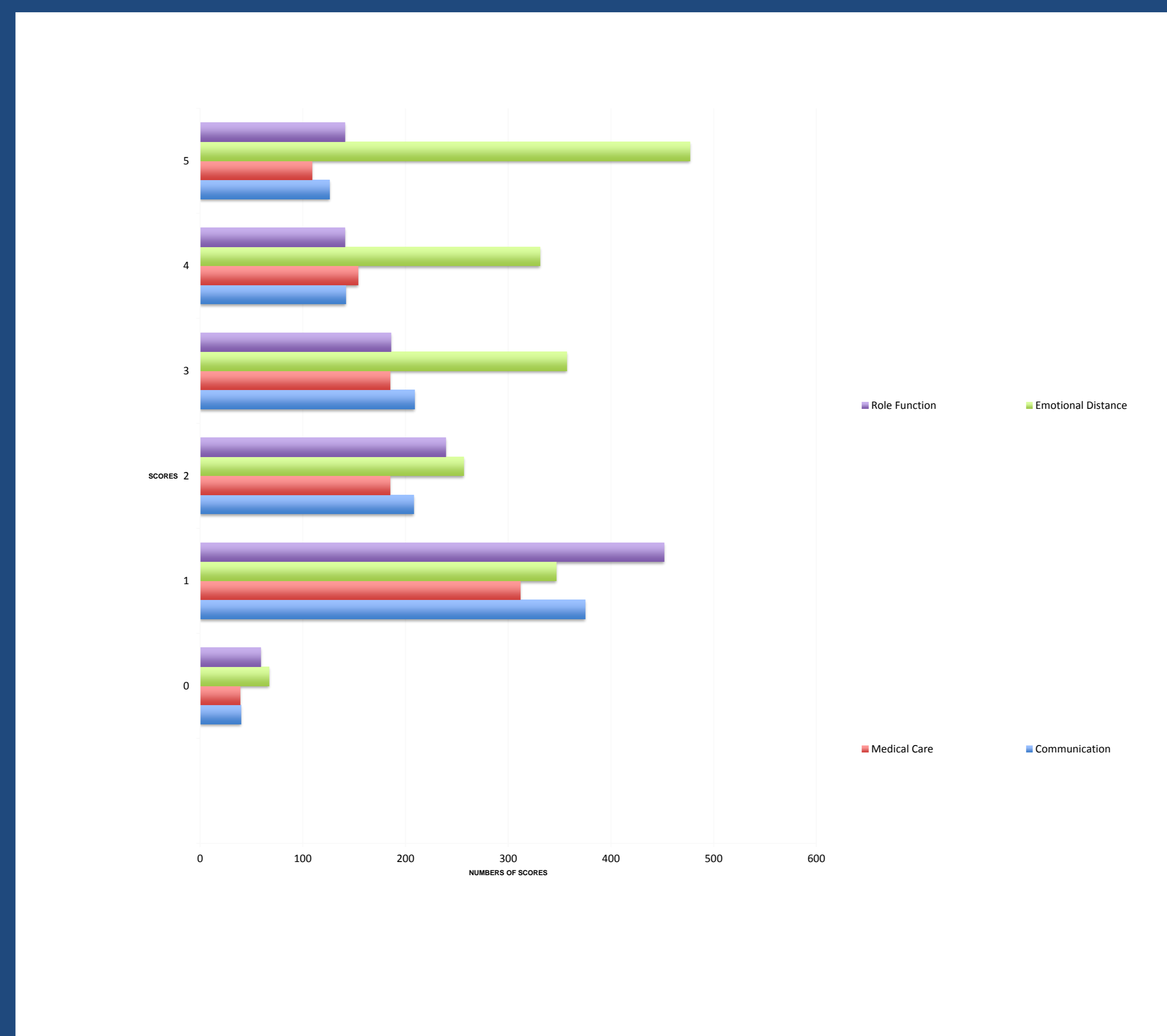
### Questionnaire:

- 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



Graph A above : illustrating the numbers of each score (1,2,3,4 and 5) found in total in each of the 4 questionnaire categories across the frequency domain.

Graph B below: illustrating the numbers of each score (1,2,3,4 and 5) found in total in each of the 4 questionnaire categories across the difficulty domain.



### References:

- Goldbeck L. The impact of newly diagnosed chronic pediatric conditions on parental quality of life. Quality of Life Research. Published online 13.09.2006.
- Northam E et al. Psychological and Family Functioning in Children with Insulin Dependent Diabetes at Diagnosis and One Year Later. Journal of Pediatric Psychology. 1996; 21(5):699-717.
- Landolt M et al. Prospective Study of Posttraumatic Stress Disorder in Parents of Children with Newly Diagnosed Type 1 Diabetes. Journal of the American Academy of Child and Adolescent Psychiatry. 2005; 44:7.
- Mellin A et al. Parenting Adolescent Girls with Type 1 Diabetes: Parents' Perspectives. Journal of Pediatric Psychiatry. 2014; 13(10):221-230.
- Hood K et al. Updated and Revised Diabetes Family Conflict Scale. Diabetes Care. 2007; 30(7):1764-1769.

## 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:

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

## Conclusions:

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