# Has the quality of life improved for children haemophilia A?

[1]VK Williams, [2]G Antoniou, [3]A Jackson, [4]A Atkins

*[1]SAPathology, Adelaide, South Australia. [2]Public Health research Unit, Women's and Children's Hospital, Adelaide, South Australia. [3]Haemophilia Centre, Women's and Children's Hospital, Adelaide, South Australia. [4]Haemohpilia Centre, Royal Adelaide Hospital, Adelaide, South Australia.*

## Introduction

Understanding and treatment of haemophilia have advanced considerably over the last 50 years due to:

- extensive knowledge of genetic mutations
- the use (access to) of recombinant factor replacement
- reduction in transmissable disease from treatment
- increased collaboration with surgical teams, rheumatology, physiotherapy, dentistry and social work

An important question however is whether these advances have translated to improvements in the quality of life of persons with haemophilia.

It could be anticipated that children of the current era, with the improvements that have been made, would report a much better quality of life than their counterparts of 20 plus years ago.

However it also possible that in comparing their situation with an unaffected person, children with haemophilia may still feel that their quality of life is reduced.

This study aimed to compare the reported quality of life of current children with haemophilia with that of adults with haemophilia, recalling their childhood.

## Methods

The HAEMO-QOL questionnaire for ages 8-12 years was mailed to all eligible persons with haemophilia (PWH) in the relevant age range and to all registered PWH aged 18 years or older.

Possible ratings and responses for all subscales except global health were-: 1=never, 2=seldom, 3=sometimes, 4=often and 5=all the time. For 'global health' possible responses were-: 1=excellent, 2=very good, 3=good, 4=fair and 5=poor. Higher ratings represented lower quality of life.

Transformed scale scores were used in the statistical analyses. The two groups were compared using the non-parametric Kruskall Wallis Rank Sum Test – due to skewness in some of the data and the ordinal nature of ratings.

## Results

Overall, responses were higher in the adults, indicating a generally lower quality of life. Fig 1

Responses in two subscales, family and treatment were comparable for both adults and children.

A significant difference between the two groups was noted for view of yourself, friends, sports and schools, dealing with haemophilia and global health. (Table 1)

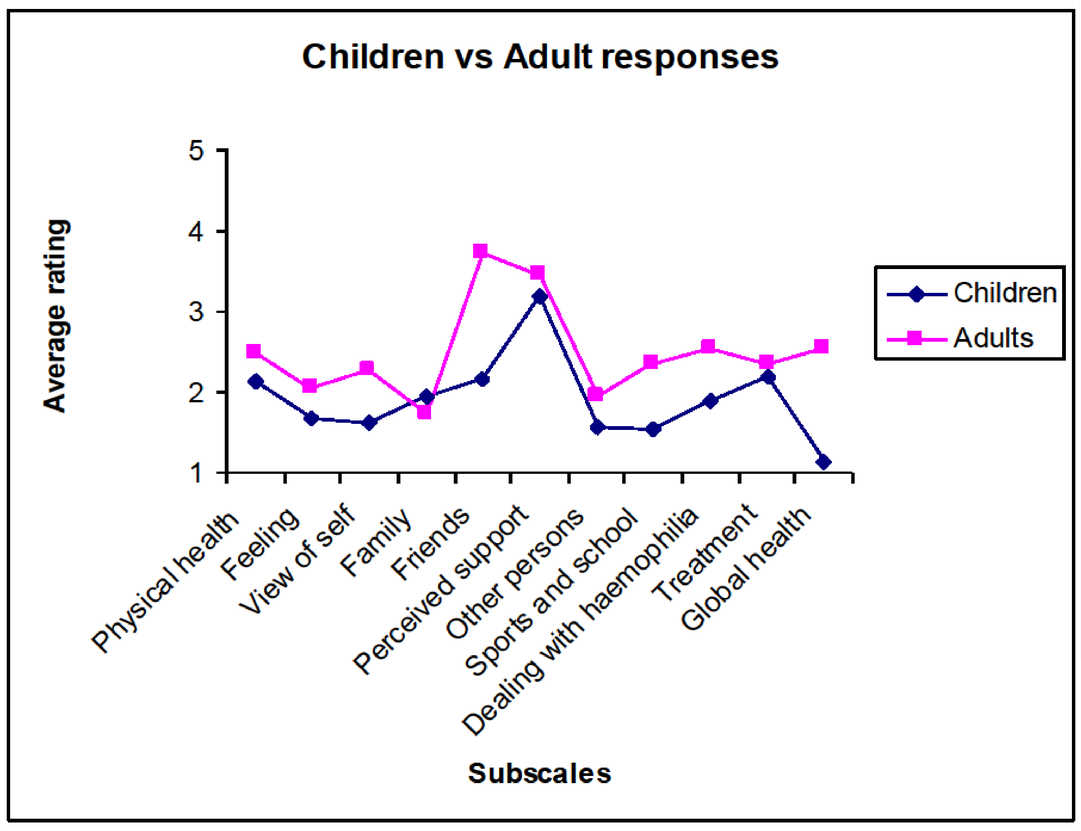


Fig 1 Average ratings of each subscale for adults versus children

Table 1

Statistical significance of subscale comparisons between adults and children

| Subscale | *p* value (Kruskall-Wallis Rank Sum Test) |
|---|---|
| Physical health | 0.56 |
| Feeling | 0.23 |
| View of self | 0.04 |
| Family | 0.61 |
| Friends | 0.003 |
| Perceived support | 0.61 |
| Other persons | 0.20 |
| Sports and schools | 0.06 |
| Dealing with haemophilia | 0.05 |
| Treatment | 0.78 |
| Global health | 0.0006 |

## Discussion

### In summary

- the areas of friends and considerable disparity –

-the adults generally inc network of friends for childhood

-overall health was cons adults but excellent in the

- perceived support was consistently higher ra generations. In this subsc to others about proble consideration and haemophilia, outside of fa appears to be an area t upon

- family support and disru having haemophilia do changed with time, but in children the scores were family support was strong

- the remaining subscales in the responses indicating for each across the genera responses higher and in s statistically significant -:

- the adult group felt mor happy and at a disadvanta peers

- the adult group also v sporting activities and s and were treated differentl

## Conclusion

The quality of life has i with haemophilia A.

Perceived support is still a room for improvement.

A larger scale study m conclusions.

Quality Pathology supporting Training and Research



DOI: 10.3252/pso.eu.WFH2012.2012