

The Psychologic and Disease Burden Assessment in Hemophilia Children with Arthropathy: a Single-center Study in China

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OBJECTIVES

To compare with the modern hemophilia care and (near) normal Quality of Life of hemophilia children in developed countries, the poor status is existing in China. To explore the psychologic status and disease burden in Chinese hemophilia children with arthropathy are need.

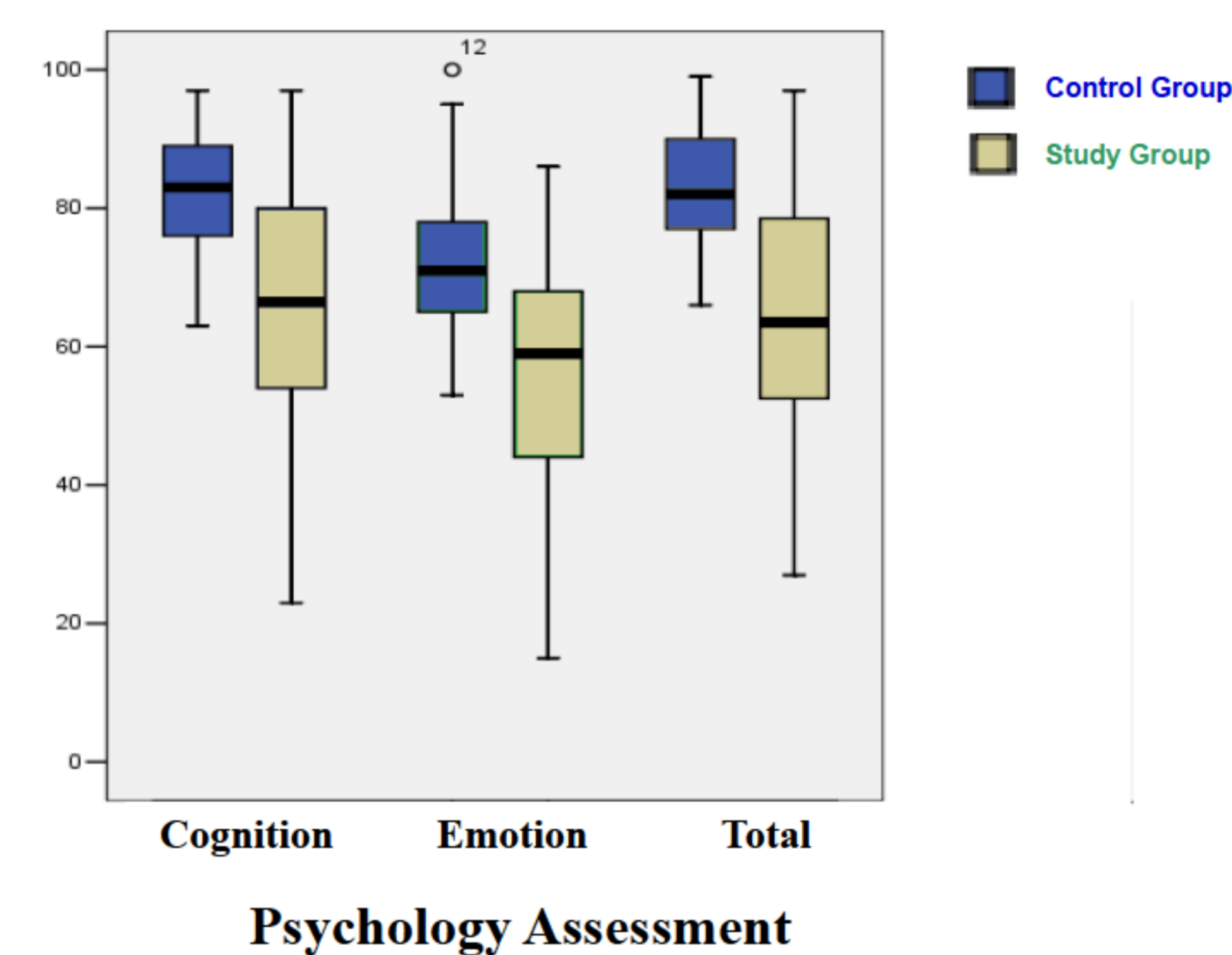
To assess the psychologic status and disease burden for Chinese hemophilia children with arthropathy and analyze the potential affected factors.

METHODS

Using two Chinese tools: Inventory of Subjective Life Quality (ISLQ) and Family Burden Scale of diseases (FBSD) to assess the study group (hemophilia children with arthropathy and their parents) and the Control group (normal children and their parents) in a single pediatric hemophilia center of China.

Table: Different of psychological assessment between the study and control group

| | Number of Patients | Cognition | | Emotion | | Total assessment | |
|---------------|--------------------|-----------|--------------|---------|--------------|------------------|-----------|
| | | range | mean± SD | range | mean± SD | range | mean± S |
| Study group | 42 | 23-97 | 66.45± 17.62 | 15-86 | 55.08± 16.62 | 27-97 | 63.38± 18 |
| Control group | 62 | 63-97 | 81.6± 8.44 | 53-100 | 71.81± 10.62 | 66-93 | 81.91± 8. |
| P | | | P < 0.01 | | P < 0.01 | | P < 0.01 |



RESULTS

- (1) Psychologic assessment (ISLQ): 62 hemophilia children and 52 normal children were enrolled (patients' age $P > 0.05$). Study group had the worse result than Control group (all in Cognitive, Emotional and General assessment, $P < 0.01$). Age, hemorrhage frequency, school drop-out days every month, number of diseased joint, Bathel score and Gilbert score hadn't shown as the potential affected factors for the worse result in Study group ($P: 0.096 \sim 0.859$).
- (2) Disease burden (FBSD): 91 parents in Study group and 11 parents in Control group were enrolled (patients' age $P > 0.05$). Study group had the worse result than Control group (23.87 ± 10.90 vs. 5.36 ± 3.10 , $P < 0.01$). Age, hemorrhage frequency were not ($P: 0.141 \sim 0.858$) but school drop-out days every month, number of diseased joint, Bathel score, Gilbert score ($P: 0.007 \sim 0.011$) were the potential affected factors for the heavier disease burden in Study group.

CONCLUSIONS

Hemophilia children with arthropathy in China have the worse psychologic status and a heavier disease burden. The poor daily life's condition and bad disease joints' function might be the causes.

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