A Successful 9 year Journey by a Canada-China Professional Group to Transfer Current Hemophilia Assessment Tools from Canada to Advance Pediatric Hemophilia Care in China.


(1) Children’s Hospital of Eastern Ontario, Ottawa, Ontario, Canada (2) Foothills Hospital, Calgary, Alberta, Canada (3) Nanfang Hospital, Guangzhou, China (4) Beijing Children’s Hospital, Beijing, China (5) Peking Union Medical College Hospital, Peking, China; (6) Hospital for Sick Children, Toronto, Ontario, Canada (7) Laurentian University, Sudbury, Ontario, Canada.

INTRODUCTION

Hemophilia Treatment Centers (HTC) Development, China: A great leap forward since WFH launched priority project in China in 2000.

2 Landmark Developments

(1) 2004: Inauguration Hemophilia Treatment Center Collaborative Network China (HTCCNC) with 6 core centers, laying the corner stone for development

(2) 2015: Landmark achievement of 50 HTCs established across China creating an urgent demand in professional training.

Cost constraints

- A major road block in treatment
- Estimate 40,000 – 50,000 hemophilia boys at risk for early joint disease by school age.
- Urgent need for lower cost effective replacement treatment intervention.

China/Canada Collaborative Working group

Hemophilia care professionals with specific interest and experiences in China, from Beijing and Guangzhou, China, Toronto, Ottawa, and Calgary, Canada formed a collaborative Working Group to implement teaching and training and transfer current hemophilia care assessment tools from Canada to China thus enhancing care for boys with hemophilia and research within China. (Table 1)

METHODS

The cross cultural adaptation of each tool required four steps:

1. Translate the methods and procedures into Simplified Chinese.
2. Conduct focus group meetings with patients/parents and healthcare professionals to resolve culturally sensitive language and practical issues.
3. Train local professionals to utilize the tools.

RESULTS

The schedule to transfer the assessment tools were prioritized in accordance with the progress of development in China

ADAPTATION AND VALIDATION – HEMOPHILIA JOINT HEALTH SCORE (HJHS) V2.1

2008 - 2009
Forward-backward translation - HJHS V2.1
2009 August
Train the Trainer Workshop on Hemophilia Physiotherapy- 6 Trainers completed training. [1]
2009 November
Reliability study, Guangzhou. 4 Trainers as assessors.
Intra-rater r = 0.85; Inter-rater r = 0.81 Reliability confirmed. [2]

IMAGE STUDY BY MRI AND ULTRASOUND

2011 Dr NN Zhang: 6 month training at HSC Toronto under Dr A Doria. 2012 Validation Study: 4 HTCs across China. BCH (Northern), Nanfang (Southern), Nanfang (Eastern), Chengdu(Western). Child and parent each completed the PEDS-QOL and CHOKLAT twice, 1 - 2 weeks apart. Validity compared to PedsQL r.65 for boys r = 0.66 for parents. Intra-rater (test retest) r = 0.88 for boys r = 0.90 for parents Validation confirmed [3,4]

ADAPTATION AND VALIDATION OF CANADIAN HEMOPHILIA OUTCOMES - KIDS LIFE ASSESSMENT TOOL (CHO-KLAT) V 2.0

2009 – 2010 Focus group meetings by patients/parents from rural and urban.
- All 35 question relevant.
- 3 additional questions related addressing social economical difference in China.
These groups are separately as a module for Socioeconomic conditions (SEC).

2011 A consensus meeting at BCH to adapt the Chinese CHO-KLAT version 2.0
2012 Validation Study: 4 HTCs across China. BCH (Northern), Nanfang (Southern), Nanfang (Eastern), Chengdu(Western). Child and parent each completed the PSD-QOL and CHO-KLAT twice, 1 - 2 weeks apart. Validity compared to PedsQL r = 0.66 for boys r = 0.67 for parents. Intra-rater (test retest) r = 0.88 for boys r = 0.90 for parents Validity confirmed [3,4]

REFERENCES

6. Short term dose low to intermediate dose PK studies in Chinese hemophilia boys. Inter-rater r = 0.9; Intra-rater r = 0.91 Reliability confirmed. [2].

DISCUSSIONS

The challenge to close the gap in Pediatric hemophilia care in China is daunting. 40,000 – 50,000 hemophilia boys are at risk. With the record growth in economy in China, social medical support for the PWH has improved in many developed regions. However, poor support and insurance in rural and poorer regions will remain very suboptimal. A high priority is to develop lower cost effective treatment for urgent interim intervention. Two proposed clinical trials are ready for grant submission:

1. A randomized controlled 2 year long individualized prophylaxis study comparing PK dosing and low dose regimens in CHINESE hemophilia A boys.
2. A two year long randomigostic study on Chinese severe hemophilia boys.

SUCCESSFUL OUTCOMES

PEDIATRIC HEMOPHILIA CARE DEVELOPMENT

BCH team completed training and leads as Chair for Pediatric Forum, 2008 – 2010, Annual WFH Pediatric Workshop and Dr. Wu established Pediatric Hemophilia Working Group, 2014. Recognized by MOH as a model centre for comprehensive pediatric hemophilia care in China.

CLINICAL TRIALS

• 3 pilot low dose prophylaxis studies [5,6,7]

• 3 Quality of Life studies

PROFESSIONAL TRAINING

May 2015: Multidisciplinary team building training on coagulation, HJHS, CHO-KLAT ultrasound and CHO-KLAT at Chengdu to enhance comprehensive care and capacity for clinical research.

CHIP study China, to be launched 2016

A multicentre, long term, 1-year perspective, secondary escalating dose, prophylaxis study on Chinese severe hemophilia A boys using four low dose FVIII regimens.

ACKNOWLEDGEMENTS

We thank the grant and training support from Bayer Canada, BMS, Baxter, Factor 8, Medac, Biochrom, Schering, Stago, the Canadian hemophilia foundations and professional organisations, the patients and parents contributing to the studies.

Preliminary PK studies began on Chinese hemophilia boys at BCH. 2008 - 2009 Forward/backward translation into simple Chinese. 2009 – 2010 Focus group meetings by parents/children from rural and urban. All 35 question relevant. 3 additional questions related addressing social economical difference in China. These groups are separately as a module for Socioeconomic conditions (SEC). 2010 – 2011 Cognitive debriefing session to test wording and interpretation. 2011 A consensus meeting at BCH to adapt the Chinese CHO-KLAT version 2.0 2012 Validation Study: 4 HTCs across China. BCH (Northern), Nanfang (Southern), Nanfang (Eastern), Chengdu(Western). Child and parent each completed the PSD-QOL and CHO-KLAT twice, 1 - 2 weeks apart. Validity compared to PedsQL r = 0.65 for boys r = 0.66 for parents. Intra-rater (test retest) r = 0.88 for boys r = 0.90 for parents Validity confirmed [3,4]