Home Therapy Consensus in an Under-resourced Hemophilia Setting

Johnny Mahlangu,[1] Anne-Louise Cruickshank,[2] David Stones,[3] Christopher Sutton,[4] Alfonso Iorio,[5]

[1]Hemophilia Comprehensive Care Centre, Faculty of the Health Sciences, University of Witwatersrand and NHLS, Johannesburg, [2]Department of Hematology, University of Cape Town, Cape Town, [3]Department of Pediatrics and Child Health , University of the Free State, Bloemfontein, [4]Department of Pediatrics and Child Health, University of Limpopo, Polokwane, [5]Health Information Research, Department of Epidemiology and Biostatics, McMaster University, Toronto

Introduction

- For people with hemophilia, (PWH), the ability to replace clotting factor concentrate(CFC) immediately following a bleed, even if this occurs outside a treatment center, in a home setting is an important component of their successful management(1).
- The benefits of home therapy (HT) in PWH are many and include early pain relief, faster bleed resolution, reduced hospitalization, reduced costs and prevention of arthropathies (2).
- However, uptake of HT in under-resourced settings remains extremely low, as is the case in South Africa, where only a small fraction of PWH in 10 hemophilia treatment centers (HTCs) were found to be on a regular HT program in a pilot study (3)
- There are currently no guidelines supporting implementation of HT in a resource poor setting.

Aim of the study

The aim of this study was to produce principles to guide practice of HT in a resource poor setting by adopting a Delphi consensus process involving local hemophilia experts.

Material and methods

- Through a Delphi consensus process, we convened a meeting of 21 hemophilia experts active in hemophilia care in South Africa.
- The group brain stormed to generate statements and questions on all aspects of HT.
- A core group of the above authors refined the larger group input into a 36 item questionnaire covering all aspects of HT.
- The HT questionnaire was administered electronically using McMaster University data collation tool to the 21 participants.
- Each question in the questionnaire had six options and participants were asked to rank their answers to each question.
- ≥50% agreement on the top ranked items was defined as consensus.
- A single blinded iteration of the questionnaire was administered and responses were analyzed and summarized descriptively.

Results

- The participant response rate to the questionnaire was 100% reflecting the intimate and committed group involved in this project.
- The participants comprised adult hemophilia treaters, pediatric hemophilia treaters, hemophilia nurse practitioners, a hemophilia physiotherapist and a hemophilia pharmacist.
- Participants represented both comprehensive care treatment centers as well as ordinary haemophilia treatment centers in South Africa.
- Consensus was reached in 92%(33/36) of the questionnaire items.
- The top 3 strong agreements were on
  1) prioritizing pediatric patients for HT,
  2) PWH signing informed consent/indemnity for HT and
  3) availability of home support for HT participants.
- Participants did not reach consensus on the following three items
  1) the home environment most suitable for HT,
  2) sizes of needles supplied to PWH for HT and
  3) the number of doses required for patients to take home for HT use.
- There was a strong participant view on the following three items
  1) that product safety is not a barrier to HT,
  2) that arterial lines should not be used for HT and
  3) that spending time investigating funding for HT models will not improve the uptake of HT in the South African setting.

References

1. Srivastava *etal* Haemophilia 2013; 19: e1-e47
2. Darby *etal* Blood 2007; 110: 815-825
3. Mahlangu *etal* Survey of Home Therapy in South Africa-pilot study

Results (continued)

Consensus was reached on a number of practices and principles and these included the following

- Definition of home therapy
- Rationale for implementing home therapy
- Age of starting home therapy
- Factors to consider before starting home therapy
- Compliance in the home therapy setting
- Issues of venous access in the home setting
- Support for patients on home therapy
- Success indicators for home therapy
- Identification of barriers to home therapy

Conclusion

- In hemophilia, evidence based practice is not always possible due to practicality of not being able to generate such evidence in a rare disease.
- However, guidance is required to inform financial, governance and clinical decision practices in hemophilia even in the absence of evidence
- We have shown in this study that it is possible to produce a consensus based guidance document which can be used to inform policy and practice in hemophilia care .

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Self-Infusion and Home Treatment

Johnny Mahlangu

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