

Themes in daily life of adolescents and young adults with congenital bleeding disorders: a qualitative study



emma kinderziekenhuis AMC



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Background

- Adolescents and young adults (AYA) with chronic illnesses: more trouble in reaching developmental milestones.
- Transition into adulthood: critical phase of life.
- Important to include the lived experiences of AYA.
- Qualitative research provides an opportunity for patients to inform professionals about their experiences.



Aims

- To capture the perspectives of AYA with congenital bleeding disorders.
- To identify relevant themes in their daily life.

Methods

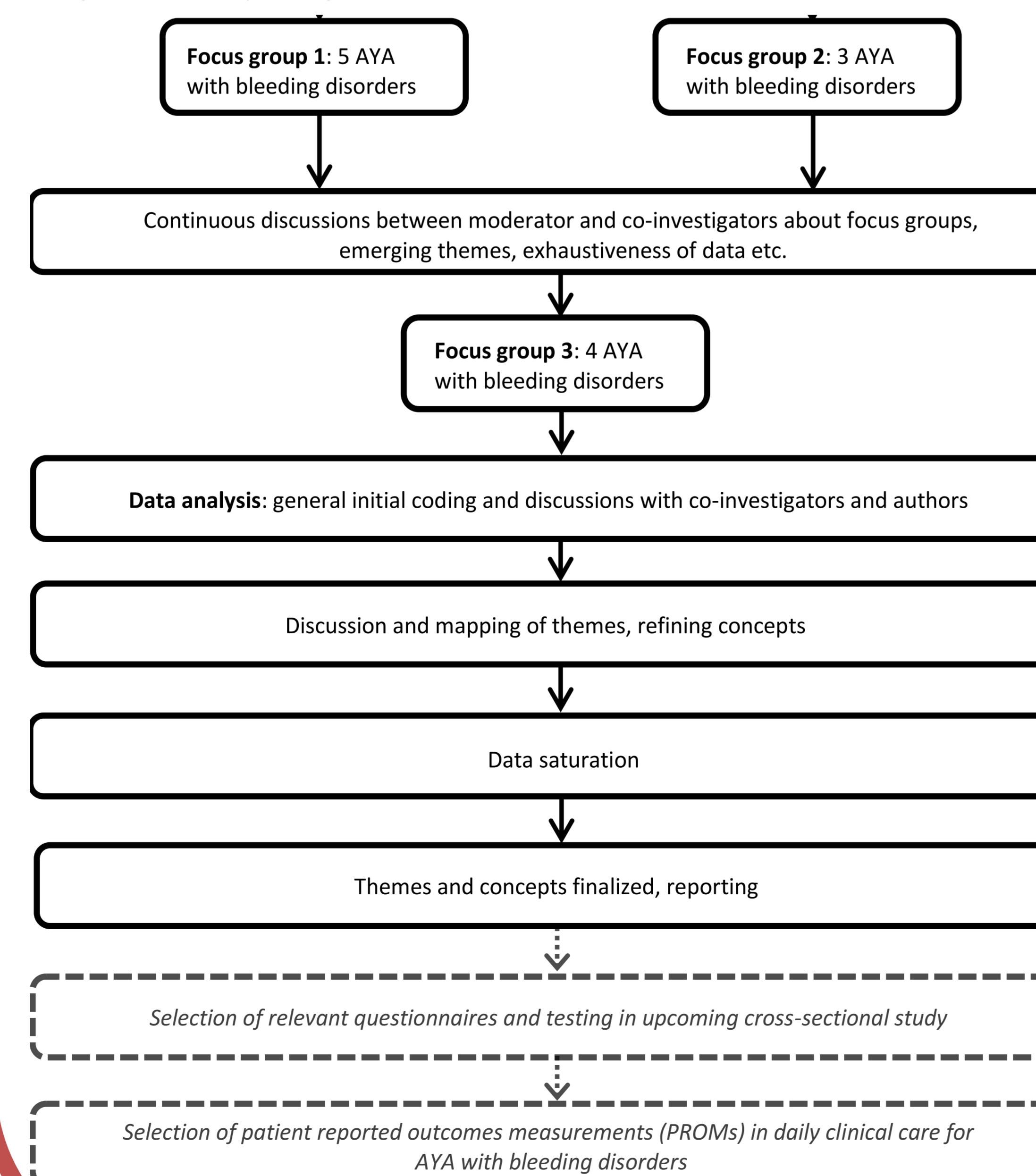
Design

- Focus groups
- Socio-demographic questionnaire
- Audio recordings

Participants

- AYA 16-30 years
- Severe congenital bleeding disorders
- Recruitment from Academic Medical Center and Dutch Hemophilia Patient Society

Figure 1: Study design



Thematic analyses:

- Verbatim transcription
- Open coding using Nvivo analytical software
- Discussion of general initial codes in team meetings
- Grouping codes into themes
- Consensus
- Re-checking data for saturation

Results

Socio-demographics

- N=12 AYA (9 male)
- Mean age: 24.0 years (SD 4.32)
- 59% hemophilia A
- 41% other severe bleedings disorders

Key themes

- Relationship with parents
- Capabilities in sports
- Capabilities in outings/travelling
- Self-management
- Illness perception and acceptance
- Capabilities in education and employment

Conclusions

Paradoxes

- Being able to live life to the fullest VS limitations and negative consequences from bleeding disorder.
- Grateful to live in a country and time with treatment VS suffering from a chronic illness, arthropathy etc.

Clinical implications

- Despite growing up in a developed country, AYA still experience obstacles and issues in daily life.
- The themes identified should be included when discussing and monitoring psychosocial consequences in daily clinical practice.



Reference

Limperg P, Peters M, Gibbons E, Coppens M, Valk C, Grootenhuis M, Haverman L. (2016) Themes in daily life of adolescents and young adults with congenital bleeding disorders: a qualitative study. *Haemophilia* (4).



Poster Presented at:

DOI: 10.3325/gaeb.wfah.2016.20.16

Psychosocial Issues
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