

Psychosocial care for children with congenital bleeding disorders and their parents in the Netherlands



emma kinderziekenhuis AMC



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Background

- Psychosocial factors may have a significant impact on health related quality of life (HRQOL).
- Providing psychosocial care and support to patients with congenital bleeding disorders and their families is indispensable.
- The Emma Children's Hospital in Amsterdam is a specialized Hemophilia Comprehensive Care Centers (HCCCs) in the Netherlands (\pm 230 children under treatment).
- Multidisciplinary team: 3 pediatric hematologists, 2 pediatric hemophilia nurses, 1 pediatric psychologist, 1 social worker and 1 physiotherapist.



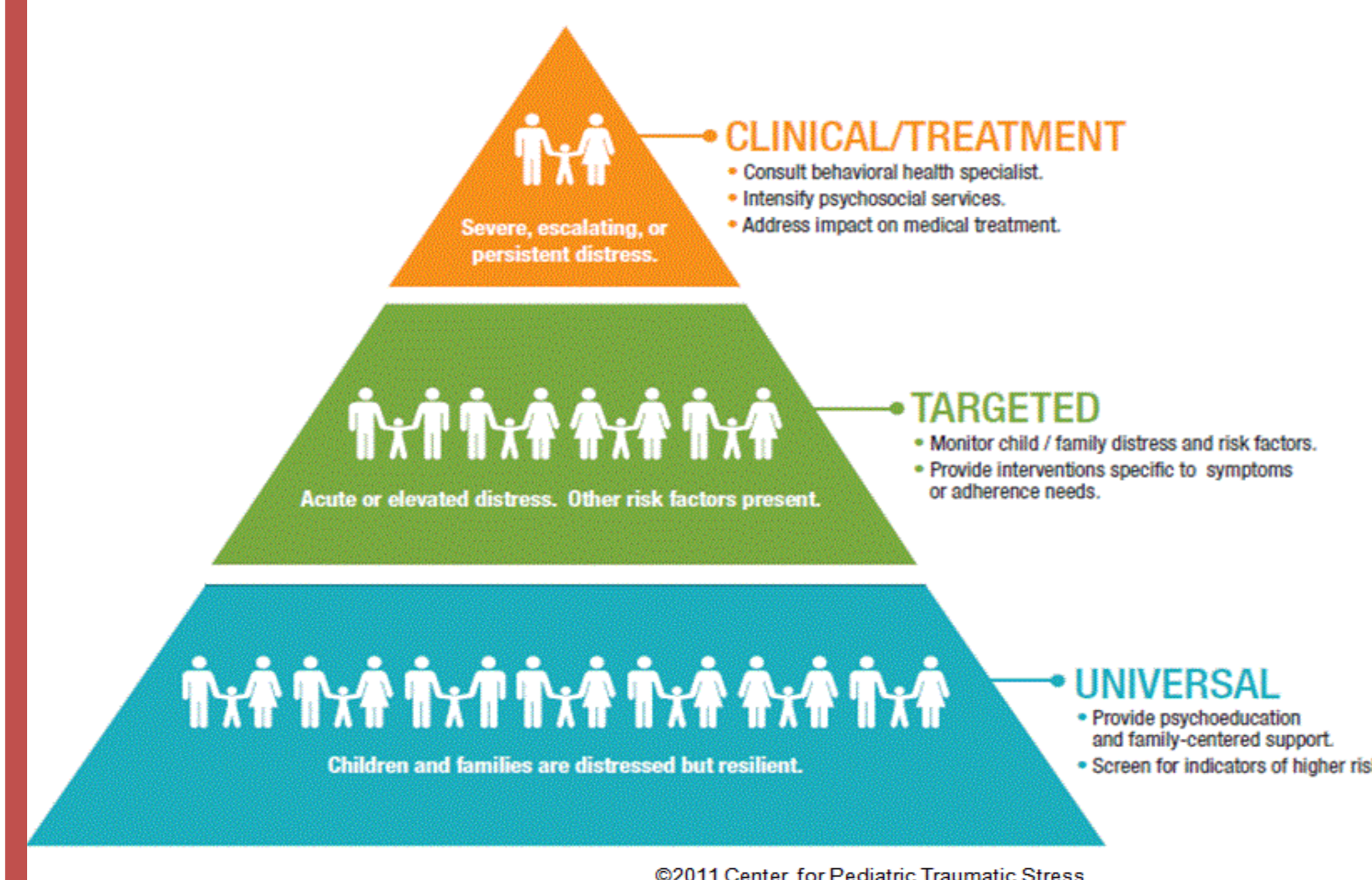
Aim

- To give a description of psychosocial care provided by the multidisciplinary team of the HCCC in Amsterdam.

Methods

The Pediatric Psychosocial Preventative Health Model (PPPHM)

- The PPPHM (Kazak, 2006) was used as a framework.
- Three tiers:
 - *Universal* (low risk; general support, psycho-education)
 - *Targeted* (moderate risk; psychosocial interventions and support for specific symptoms)
 - *Clinical* (high risk; behavioral health specialist interventions)
- To describe psychosocial care and interventions available for all patients and parents under treatment at the HCCC with varying levels of risk.



Results

Universal psychosocial care

- Innovative system for monitoring HRQOL in daily clinical practice 'KLIK' (www.hetklikt.nu). 
- *Self-management, psycho-education and peer contact:*
 - Hemophilia Camp (boys 5-12 years)
 - Hemophilia School (boys 12-13 years)
 - Disease-specific activities (boys 12-18 years)
 - Girls meeting (girls 11-14 years)
 - Parent meeting
 - On-demand visit to school/daycare
 - Emma at Work (employment agency 15-25 years)

Targeted psychosocial care

- The Haemophilia Coping and Perception Test (Limperg et al., 2015).
- On Track group intervention program (Scholten et al., 2013).

Clinical psychosocial care

- Individual psychological counselling and treatment.
- Referral services.

Conclusions

- Psychosocial care across all tiers of the PPPHM is available.
- We are aware of the fact that our HCCC is a privileged center and that it has resources to use for psychosocial care.
- Still, the overview of psychosocial support offered may be helpful to others in forming psychosocial care.
- Important to share existing (evidence-based) interventions to improve patient care outcomes.
- When resources are scarce, there are opportunities for psychosocial care by other healthcare providers than psychologists or social workers (e.g. facilitating peer support).

References

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Psychosocial Issues
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