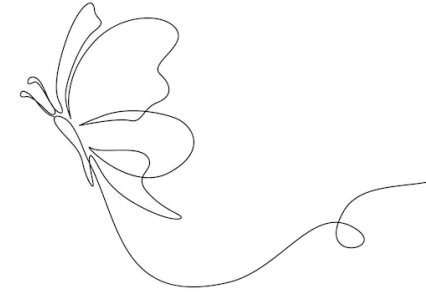




UZ
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Psychological support for patients and their families

Experience & current state-of-the-art options

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18-10-2024

EB Clinet Conference 2024, Vienna

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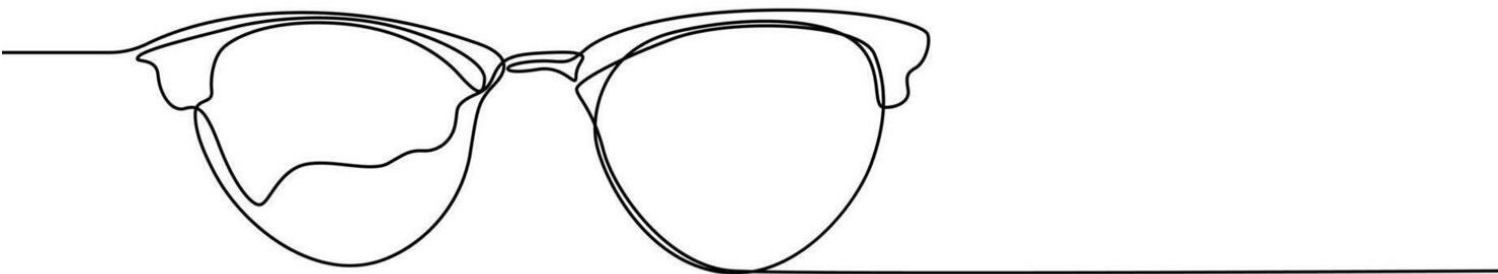
UNIVERSITY HOSPITALS LEUVEN

- University Hospitals Leuven, Belgium
- Multidisciplinary EB team
 - 0-18 years old
 - 18-... years old
 - Multidisciplinary consultation every 3 months
 - Cooperation with KITES home care team



Approach of psychological support in chronic illness

1. Psychosocial development by Erikson
2. Biopsychosocial model by Engel
3. Ecological system of development by Bronfenbrenner



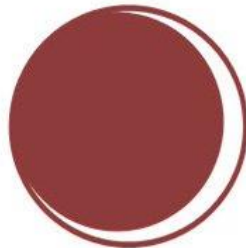
1. Psychosocial development by Erikson

Stage	Basic Conflict	Virtue	Description
Infancy 0–1 year	Trust vs. mistrust	Hope	Trust (or mistrust) that basic needs, such as nourishment and affection, will be met
Early childhood 1–3 years	Autonomy vs. shame/doubt	Will	Develop a sense of independence in many tasks
Play age 3–6 years	Initiative vs. guilt	Purpose	Take initiative on some activities—may develop guilt when unsuccessful or boundaries overstepped
School age 7–11 years	Industry vs. inferiority	Competence	Develop self-confidence in abilities when competent or sense of inferiority when not
Adolescence 12–18 years	Identity vs. confusion	Fidelity	Experiment with and develop identity and roles
Early adulthood 19–29 years	Intimacy vs. isolation	Love	Establish intimacy and relationships with others
Middle age 30–64 years	Generativity vs. stagnation	Care	Contribute to society and be part of a family
Old age 65 onward	Integrity vs. despair	Wisdom	Assess and make sense of life and meaning of contributions

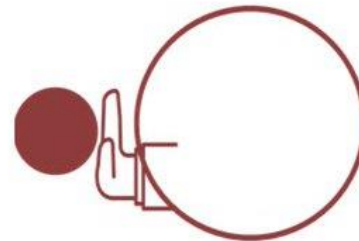
12-18 years old: identity vs. confusion

Illness identity

Engulfment



Rejection



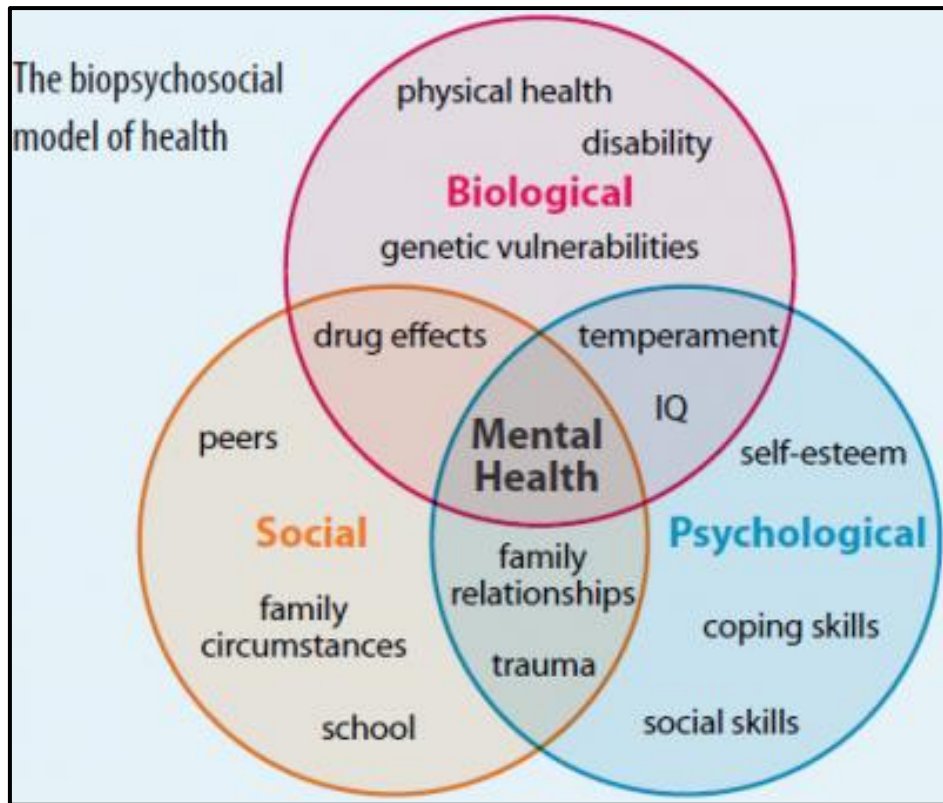
Acceptance



Enrichment



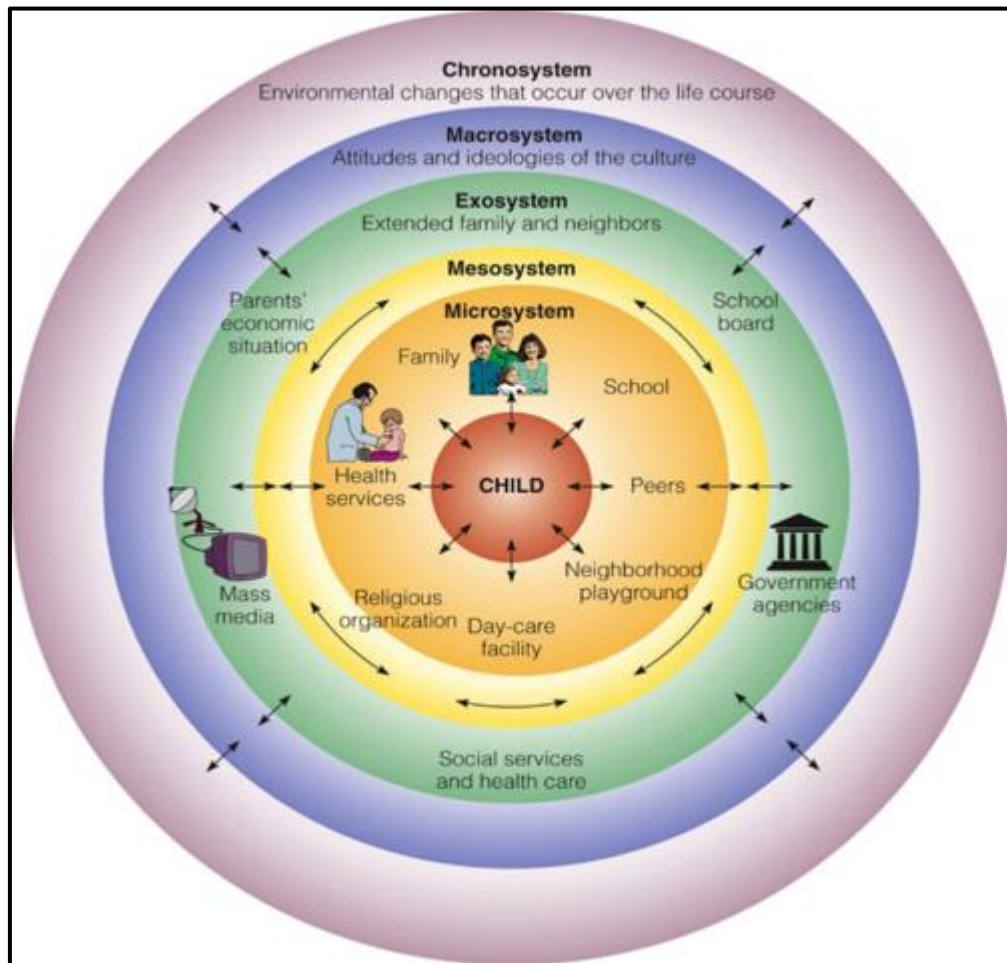
2. Biopsychosocial model by Engel



'We believe a multidisciplinary and bio-psychosocial approach to EB management, in which the perspectives of people living with EB are considered, should be at the centre of professional practice.'

'Parents caring for children with EB face emotional, physical, psychosocial and financial challenges. Addressing parents' needs and concerns will go a long way in decreasing this burden. A biopsychosocial approach with an awareness of cultural context is essential for family-centred holistic EB care.'

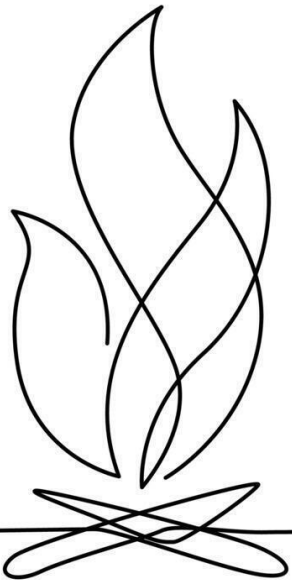
3. Ecological system of development by Bronfenbrenner



'Few studies exist that explore the support needs of parents of a child with EB. More attention should be paid to the support needs of parents to provide adequate care to those diagnosed with EB as well as their families.'

'Hot topics' in psychological support in EB

1. (Giving) birth & attachment
2. Wound care & pain management
3. School & other transitions
4. The family

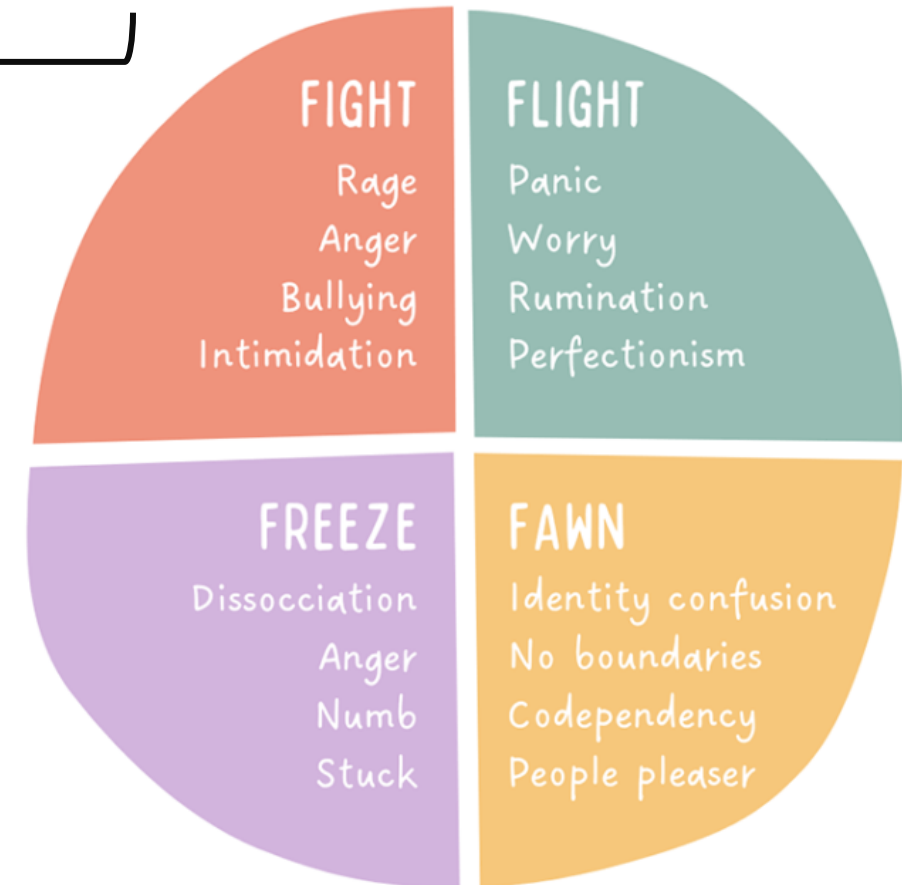


1. (Giving) birth & attachment in EB

Giving birth can be traumatic & Getting born can be traumatic

Impact on attachment

- > Meet the family as soon as possible
- > Start building your therapeutic relationship
- > Estimation of the resilience of the family
- > Pro-active, close follow-up: e-mail, telephone, real-life
- > Referral to psychiatrist when needed (PTSD)



Attachment works in both ways:

> Supporting the child

- Multidisciplinary teamwork to decrease pain
- Kangaroo care: skin to skin contact
- Smell/voice/availability of parents during long hospitalizations

> Supporting the parents

- Let parents be with their child as much as possible
- Guide them in finding a balance between developing a safe attachment and medical wound care
- Remind them and show them how they can be parents and not only nurse

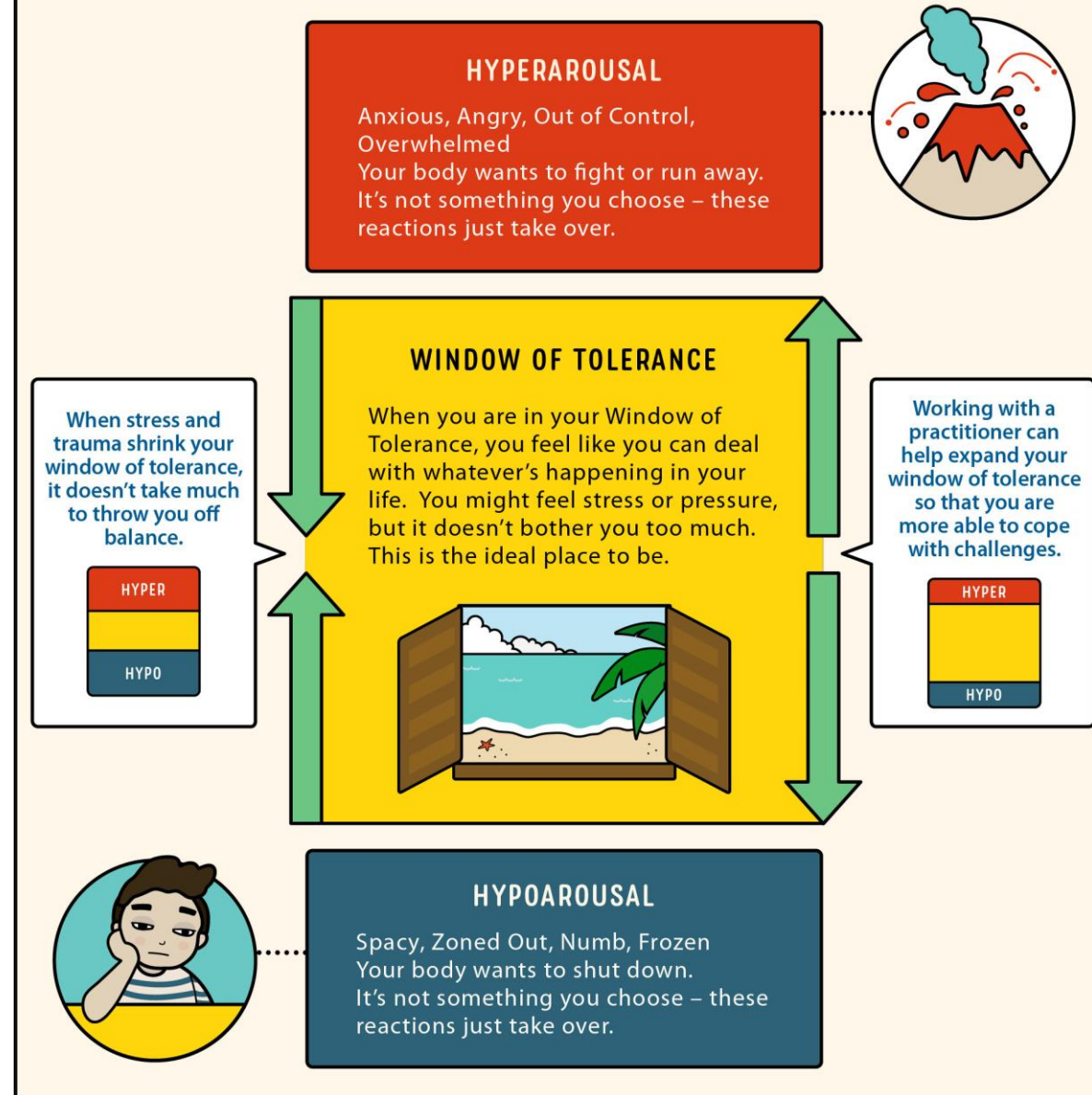
Trauma & Window of Tolerance

Can affect:

- Attachment
- Wound care
- Hospital visits and conversations
- Medical procedures and investigations
- Important decisions
- ...

Everyone has their own window, both children and parents!

How Trauma Can Affect Your Window Of Tolerance



2. Wound care and pain management

- Goes against nature and intuition
- A lot of questions and insecurities

- > Make time and listen
- > If possible, try to be part of the wound care or ask for a video
- > Psycho-education
- > Tailor-made advice for every family
- > Multidisciplinary approach
- > Get professional help
- > Step by step...

3. School & other transitions

- > Inform the environment
- > Take away ignorance & insecurity
- > Strengthen the micro-, meso- and exosystem
- > Encourage the environment
- > Normalize if/where it's possible

CONSULTATION & COMMUNICATION



Optimalisation of the chances/possibilities
for the patient and his/her family

Consultation & communication

- > Do not wait for questions and/or problems
- > Schedule meetings on time and repeatedly
- > Use images: leaflets, DEBRA-brochures and books
- > Tailored to the audience
- > Show them the possibilities
- > Be a TEAM with one shared goal

A large, black, right-facing curly bracket that spans the vertical range of the list items on the left, pointing towards the word 'PREVENTION!' on the right.

PREVENTION!

4. The family

- = the microsystem
- EB is a burden for the whole family
- Parents, brothers/sisters, grandparents,...
- Family under pressure vs. Family in survival mode

- > Try to meet the whole family in the beginning
- > Assessment of resilience
 - Context and SES?
 - Support of family?
- > Parental support: personalised and with respect for the culture
- > Referral if needed

BUT:

- The hustle and bustle of everyday life
- Psychosocial advice is sometimes the least of the worries
- Time: difficult to speak to all family members on a regular basis

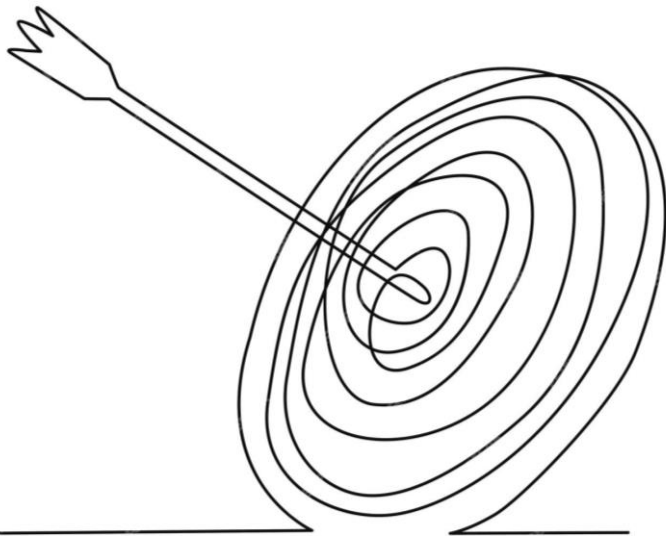
The biggest challenges

- Guarantee safe attachment between patients with EB and their parents
- Minimize trauma and PTSD in patients with EB and their parents
- Medical necessity vs. Quality of life
- Integration in daily life



Psychosocial support...

... is about how to combine psychosocial development through the lifespan with the enormous impact of a disease like EB in different contexts (home, school, peers, work, ...)



... is about WORKING TOGETHER!

Thank you for your attention.

Any questions?