Where did we start? Where do we want to go?

Katrin Marfurt-Russenberger RN, MScN, Pain Specialist SPS® Head of Nursing Development



Content

Where did we start?

- Evolution of Family Centered Care FCC
- Evolution Family Integrated Care FIC

Where do we want to go?

• What happens in the clinical setting



I want to thank: experts in FCC

All the families that request it

All the experts that teach and implement it

- Barbara Preusse-Bleuler, RN, MScN
- Ellen Bonvin RN, MAS
- FCC specialised nurses on all the wards

All the leaders that cultivate the culture and understand that it

- costs time and money
- requires structural changes and commitment

I want to thank the pathfinders of FIC

- Nicole Kaufmann, Speech Therapist, PL
- Ellen Wild, Clinical Nurse Specialist, PL



- all the families
- FINE 2 crew
- the crew at the bedside

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Cantonsspital St.Gallen

Project group FIC developmental care

Steering commitee

A. Malzacher/N. ThaqiF. von Arx-SträsslerK. Marfurt (+Coaching)

Projekt Co-Leitung

N. Kaufmann (speech therapy, IBCLC, OKS) E. Wild (PP Neo; clinical nurse specialist Neo, KSSG)

coregroup (FINE 1 + 2)

Bozana Agustoni (PT) Simone Bartunek (PP IPS; LTT) Michelle Fehr (PP IMC/C) Nicole Fichtinger (PP IPS) Markus Hahn (OA IPS/Neo) Sabrina Keller (PP Neo) Susan Rieben (PP Neo) Jacqueline Schlatter (PP WoBe) Christine Siegenthaler (SB KSSG) Carina Treibig (SB OKS) Sandra Wiget (PP IMC/C; LTT)



Charta für Kinder im Spital

EACH: EUROPEAN ASSOCIATION FOR CHILDREN IN HOSPITAL (1988)

«Das Recht auf bestmögliche medizinische Behandlung ist ein fundamentales Recht, besonders für Kinder.» (EACH)

ARTIKEL 1



Kinder sollen nur dann in ein Krankenhaus aufgenommen werden, wenn die medizinische Behandlung, die sie benötigen, nicht ebenso gut zu Hause oder in einer Tagesklinik erfolgen kann.



ARTIKEL 2



Kinder im Krankenhaus haben das Recht, ihre Eltern oder eine andere Bezugsperson Jederzeit bei sich zu haben.

ARTIKEL 3

Bei der Aufnahme eines Kindes ins Krankenhaus soll allen Eltern die Mitaufnahme angeboten werden, sie sollen ermutigt und es soll ihnen Hilfe angeboten werden, damit sie beim Kind bleiben können. Eltern dürfen daraus keine zusätzlichen Kosten oder Einkommenseinbussen entstehen. Um an der Pflege ihres Kindes teilnehmen zu können, müssen Eltern über die Grundpflege und den Stationsalitag informiert und ihre aktive Teilnahme daran soll unterstützt werden.

ARTIKEL 4



Kinder und Eltern haben das Recht, Ihrem Alter und ihrem Verständnis entsprechend informiert zu werden. Es sollen Massnahmen ergriffen werden, um körperlichen und seelischen Stress zu mildern.

ARTIKEL 5



Kinder und Eltern haben das Recht, in alle Entscheidungen, die ihre gesundheitliche Betreuung betreffen, einbezogen zu werden. Jedes Kind soll vor unnötigen medizinischen Behandlungen und Untersuchungen geschützt werden.



kind+spital To de la de la con Contano - 11 i constituires in Gaucetabaltes

Kinder müssen mit Takt und Verständnis behandelt und ihre Intimsphäre muss jederzeit respektiert werden.

Text original: @17ACH Charts 1988, liberariut 2007 Titlar: @177



durch ein möglichst kleines Team sichergestellt werden.

ARTIKEL 10



Kinder sollen gemeinsam mit anderen Kindern betreut werden, die von ihrer Entwicklung her ähnliche Bedürfnisse haben. Kinder sollen nicht in Erwachsenenstationen aufgenommen werden. Für Besucher dürfen keine Altersgrenzen festgelegt werden.

ARTIKEL 7

ARTIKEL 6

Kinder haben das Recht auf eine Umgebung, die Ihrem Alter und Ihrem Zustand entspricht und die ihnen umfangreiche Möglichkeiten zum Spielen, zur Erholung und Schulbildung gibt. Die Umgebung soll den Bedürfnissen der Kinder entsprechend geplant und eingerichtet sein und über das entsprechende Personal verfügen.

ARTIKEL 8

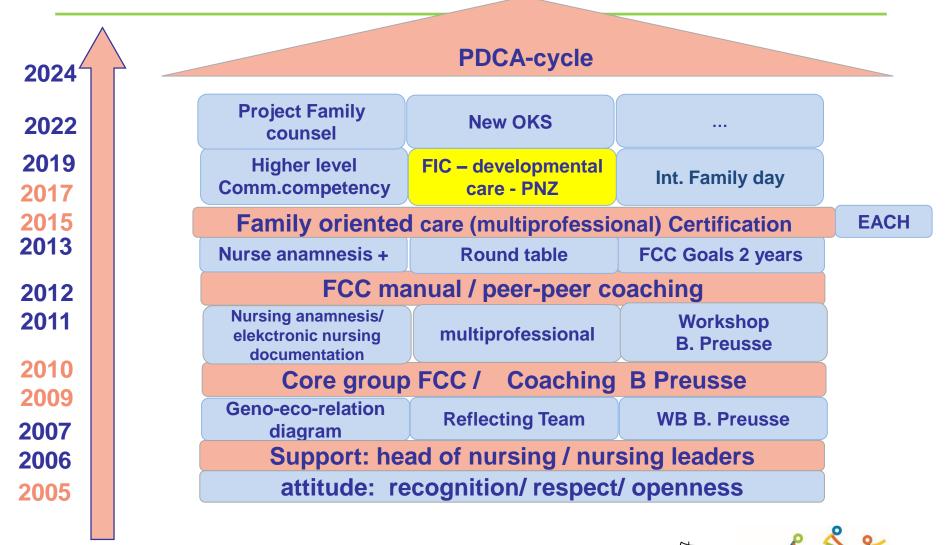
Kinder haben das Recht auf Betreuung durch Personal, das durch Ausbildung und Einfühlungsvermögen befähigt ist, auf die körperlichen, seelischen und entwicklungsbedingten Bedürfnisse von Kindern und ihren Familien einzugehen.

ARTIKEL 9





FCC-FIC development process OKS





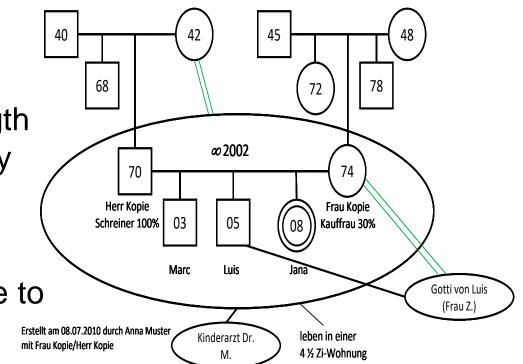
Attitude of FCC

- Building a relationship on trust, respect and openness
- Benevolent curiosity
- Equal partiality
- To understand a family as a system
- "Illness is a family affair" (Wright & Bell, 2009)
- The family and their members are experts for their individual situation
- The health care team attends/supports families with expertise, information and guidance



Geno-eco-relation-diagram (since 2006)

- Family feels recognized and respected in their situation
- Ressources and strength are transparent not only challenges
- Recognition and appreciation encourage to cope with challenges





Building relationships with families

"Give 2"

Recognition and appreciation in the first 10 minutes of an encounter / conversation

Wright, L. & Leahey, M. (2014)



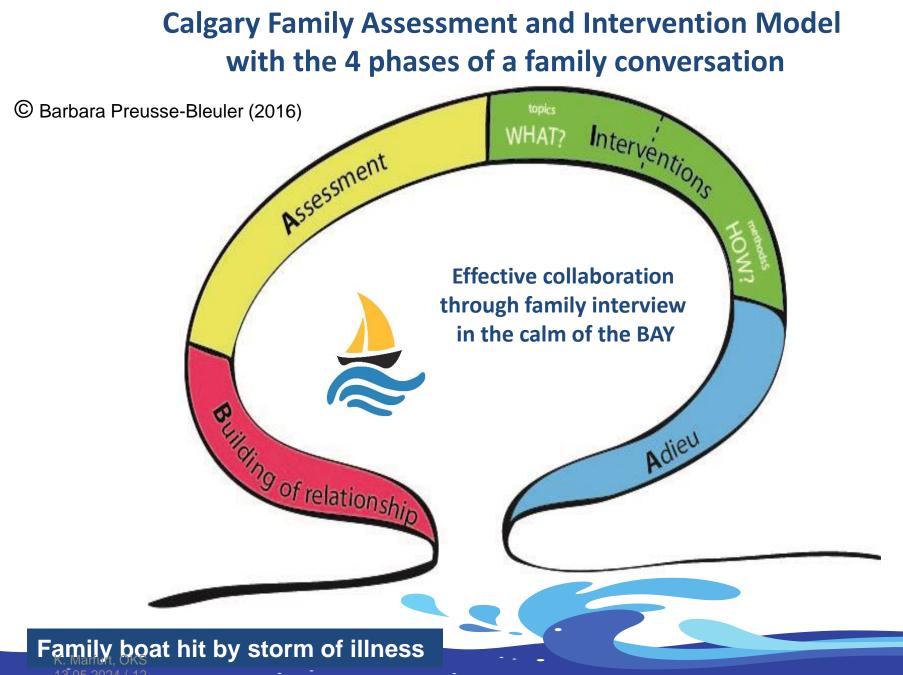
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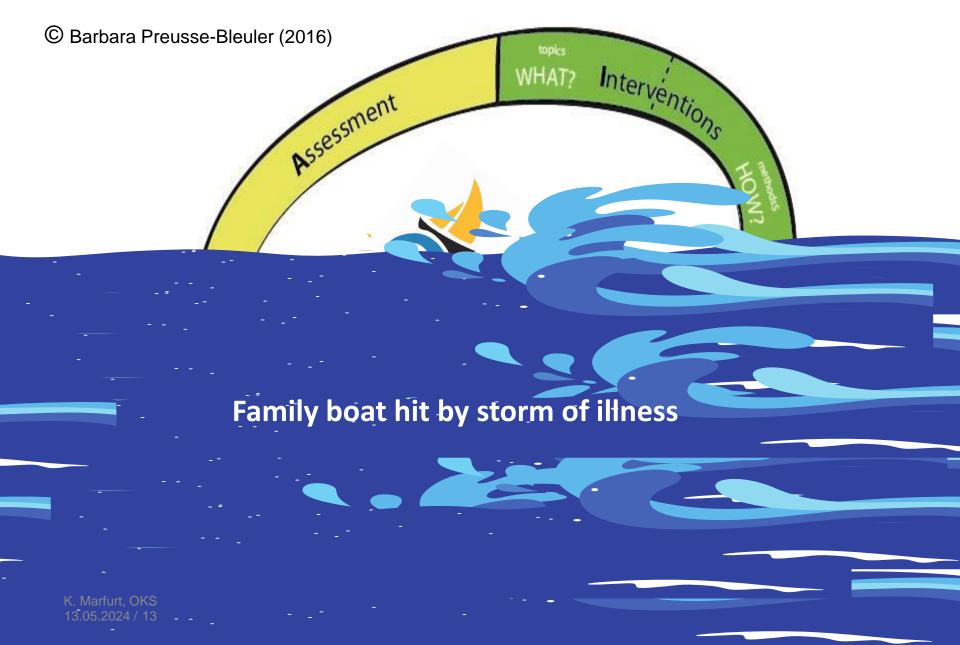
B uilding of relationship A ssessment ntervention A dieu

a safe haven for families

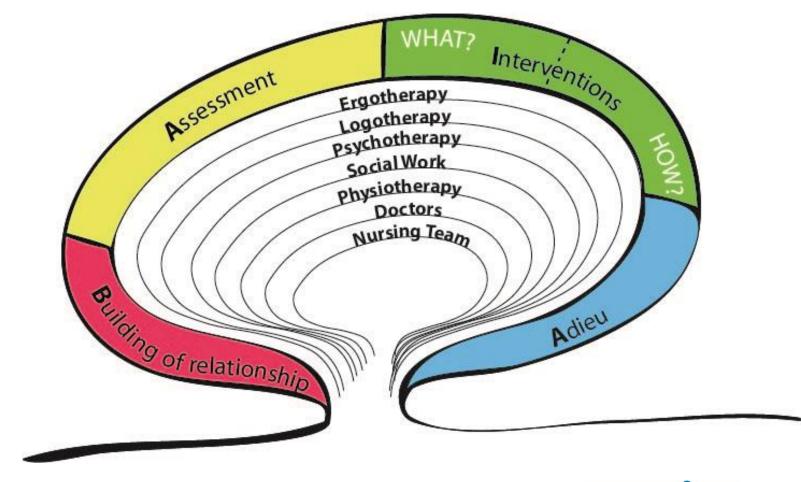


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Missing phases of a family conversation



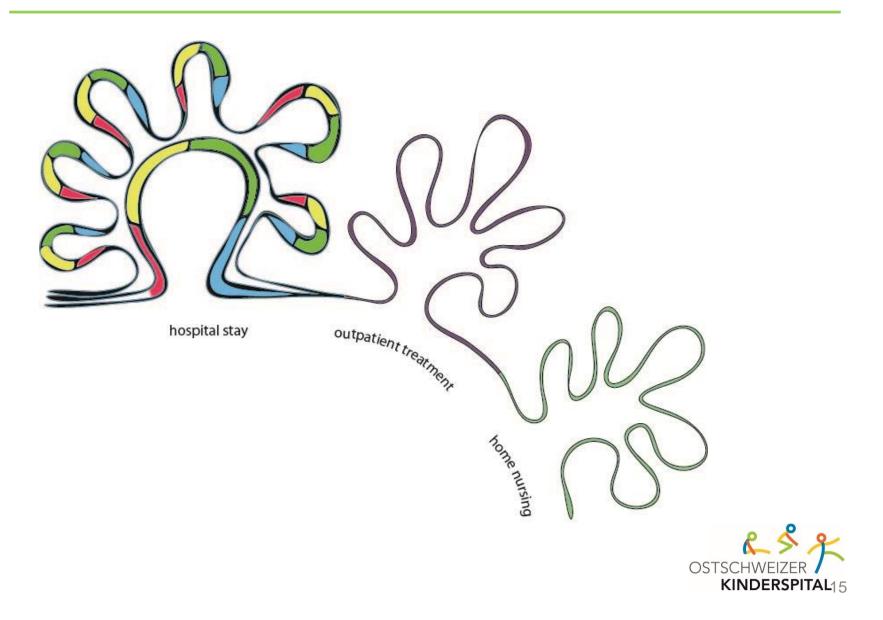
BAIA – all disciplines are required



© Barbara Preusse-Bleuler (2016)



BAIA – series of stopovers © Barbara Preusse-Bleuler (2016)



«Family integrated care (FIC) or family delivered care (FDC) involves providing parents and carers with sufficient education and tools so that they are able to become confident and independent primary carers of their infants under the team's supervision. In order for FIC to become the standard of care within a neonatal unit the basic principles of Family centered Care (FCC) should already be in place. FIC is a step further to FCC as here the parents become integrated as equal partners in the neonatal team.»

Banerjee et al., 2018 p. 10



FIC one step further in perinatal care Banerjee et al., 2018

Structured training empowers HP's to be coaches, mentors and counsellors for parents. Clear training syllabus for staff: FINE 1
Formal training delivered by NNU staff/veteran parents. Clear training curriculum and competency assessment for parents
Encouraged to be present on the unit for at least 6 – 8 h/d and assume most of the primary care of their baby. Facilities in place to support this (kitchen, family room, accomodation for every parent)
Parents are encouraged to be involved in daily and enhanced cares for their baby with level of autonomy following a competency-based training.
Parents are encouraged to be active members of the ward round and present their baby to the HP's
Identify the purpose of routine medication. Administer approved oral medication under supervision of nursing staff
Availability of psychosocial support and peer support from trained veteran parents

HP: health professionals

fully implemented

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implemented

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Neurodevelopmental Care - Perinatal Centre PNZ+ (OKS/KSSG) (|



Analysis 1/2020

Ist-/SWOT-Analysis along NIDCAP Nursery Assessment

Stakeholder Analysis



Compare models 5/2020

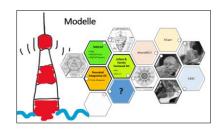


Ab-/Vergleich 2021 – 3/2022

Workshops OKS-KSSG multiprofessional Decision for FINE (family and infant neurodevelopmental education)

Analysis efcni Standards

 \rightarrow Core Measures







Multiprofessional approach

Lactation consultant Lactation and milk bank

Social service Psychological support Spiritual care/counselling Music therapy

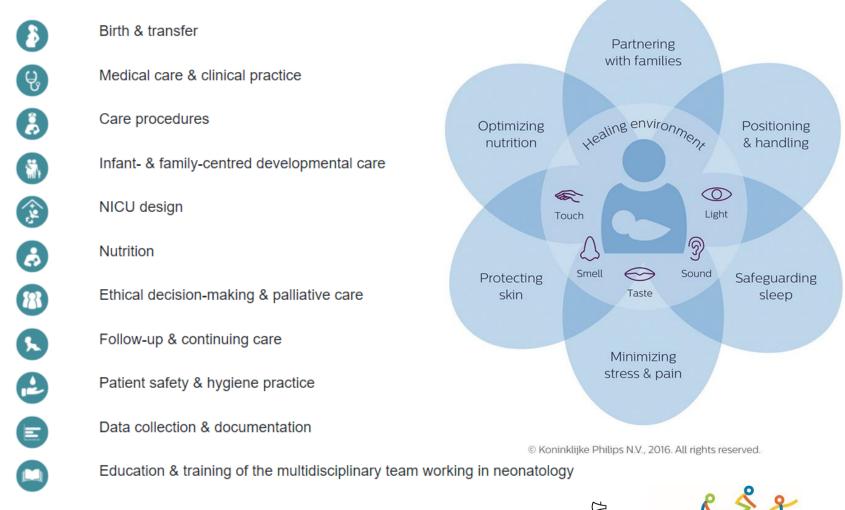
Pediatric Palliative Care Ethical support Physiotherapy Speech therapy (nutrition) Occupational therapy «basal stimulation» / kinaesthetics

Follow-up Developmental pediatrician Other disciplines



European Standards of Care for Newborn Health (EFCNI)





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4 Pillars in a Neuro-Nurturing NICU

'ONE Brain. Four Pillars. EVERY NICU'

K. Marfurt, OKS

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www.synapsecare.com



Neuro Neuro Neuro Neuro **Development** Protection Monitoring Assessment • EKG/SaO2 Clinical assess ventilation parents Position & • FFG Thermoregula- pain Handling tion • aEEG/Brainz metabolic (hypothermia) Sensory NIRS MRI/MRS environment medication Sono/ HeRo sleep • IVH-Ultrasound AEP prophylaxis Pain/stress/ • ROP nutrition separation feeding Follow-Up Ntrainer (NNS) •

Every NICU is NeuroNICU Part 1 of 4Neuro Assessment FREE NICU NurseEducation - YouTubeSt.Gallen



Implemented + all topics ongoing



prenatal, birth & transfer: prenatal visit \rightarrow info, support



Medical care & clin. practice: NEO-Fahrplan "Golden first 2 weeks"



Care procedures: FINE 1+2, neuroprotective & neurocritical care

Infant & family centered developmental care:



- FINE 1+2
- 2 persons (4 hands)
- supporting and enhancing NICU Sensory Experiences through Kangaroo care, skin to skin care



Working together with parents





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Nächster Austausch

Do, 04. April

von 17.30 19.30 Uhr

u n d

Mo, 22. April

von 16.00 -18.00 Uhr

FRÜHCHEN

www.fruehchenschweiz.ch

Du bist Mama oder Papa eines frühgeborenen Kindes?

Wir sind eine Gruppe von Frühchen-Eltern, die die ersten Wochen/Monate mit ihren Kindern hier in St. Gallen im Spital verbracht haben.

Wir wissen, wie hilfreich es sein kann mit betroffenen Eltern über Sorgen, Ängste oder sonstige Gefühle zu sprechen, um so in dieser Zeit Kraft und Mut zu schöpfen.

Wir würden uns über einen Austausch mit dir sehr freuen, damit du einfach mal durchatmen und loslassen kannst.. du bist nicht allein.

Testing of Kangaroo chair





st.ganen

Implemented + all topics ongoing



NICU design: integration in new OKS and couplet care, make it easy to implement skin to skin care and parent integration, couplet care

- NICU Design for the new OKS
- Couplet Care
- Chairs for Kangaroo Mother Care (KMC)





Nutrition: project phase III: lactation centre, milk bank and milk production not yet started



Ethical decision making & pediatric palliative care: specialised team



Follow-up & continuing care: Developmental pediatrician / therapy department

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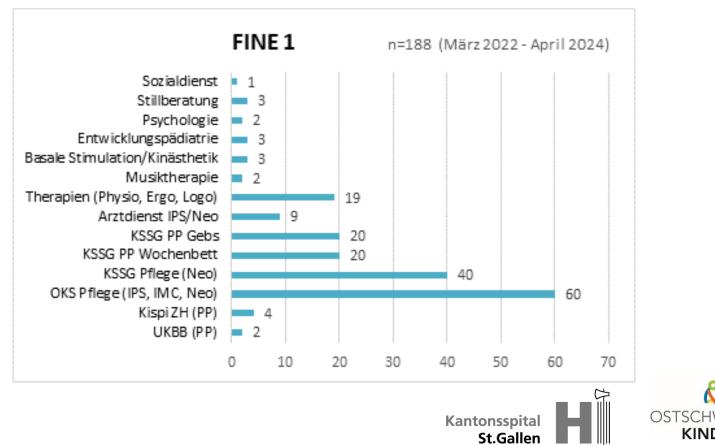


Implemented + all topics ongoing



Education & training of the multiprofessional team working in neonatology

- FINE 1 and 2
- NICU modules $1 8 \rightarrow$ students ICU



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FINE 1 – Basics training 2 days

FAMILY AND INFANT NEURODEVELOPMENTAL EDUCATION April 2024: mother as teacher

- Models of developmental care
- Neurodevelopment in preterm infants/newborns
- synactive theory
- Observation/assessment of infants behaviour
- Perspective of parents and teamwork with family
- Coping with stress and pain
- Infant behavioural states and sleep
- Motor development and mobilisation
- Sensory development and NICU environment
- Kangaroo-care
- nutrition
- Change of nursing care and medical interventions
- intervention plans



FINE 2 – advanced training 12 weeks



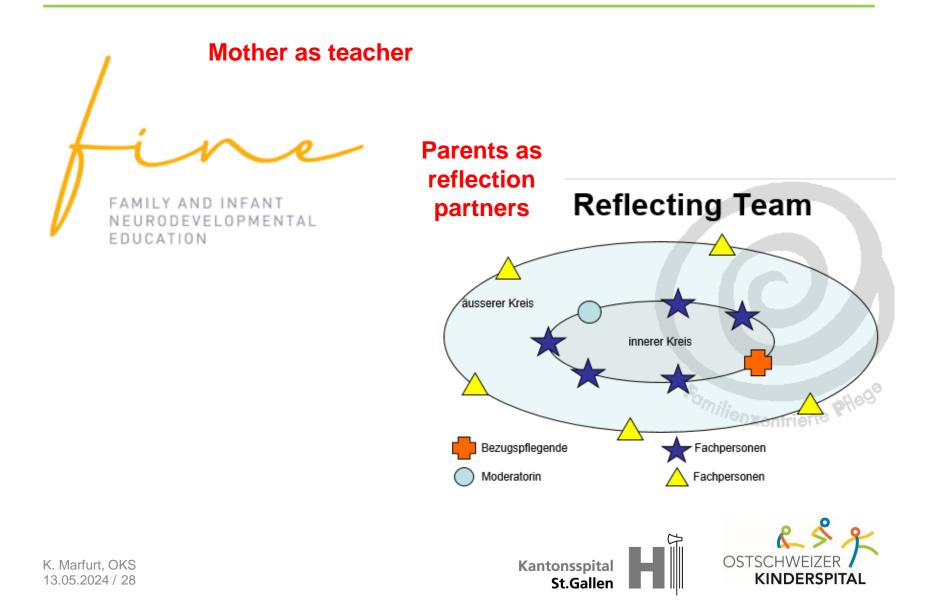
- synactive organisation in the behaviour development
- assessment families as partners reflection
- System change

FINE as transition from a task oriented to a individualized, relation oriented care and support

Interventions \rightarrow *individualised* assessment, care and therapy



Working together with parents



Implemented + all topics ongoing



Patient safety & hygiene practice



Data collection & documentation: KISIM challenge in the new OKS



- «We cannot say when you should come, we listen and look what the child tells us»
- «I am staying with the child during tube feeding, you would never leave a 4 year old eathing by him-/herself»
- «I work a lot slower by opening the cover of the incubator, assessing what the infant is telling me»



Voices that I heard during my hospitation II

- «I work together with the parents in a closer way by leading them and the more they take over I work together like a colleague, ask them what they need or what they want me to do»
- I experience that the infants are less stressed, when we do the rounds with 4 hands, either with the mother/father or another colleague. The infants need less regulation support when I listen to their voice/signs and prioritize what tasks are actually important in that very moment»
- The cleaning staff is aware of our changes and plans her tasks in accord with us and the family.

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Reflexion on nursing rounds March 2024

Szenario	Positive Outcome	Challenge
Round from «A-Z»	 Security for the nurse to assess the infant To be able to schedule Do all in one round, gives flexibility to do other things after the round 	 maximal stress for the infant Reducing of development potential Potentially need of prolonged breaks to activate the infant Possible clinical deterioration for the infant
Round « ¹ / ₂ / ¹ / ₂ »	 Gives partial security «what I have seen, I can assess or evaluate» Less stress for infant Better adapt nursing care 	 The possibility raises to do shorter follow- up nursing care «what I have not seen, I can not assess or evaluate» Requires spontaneity from HP's Requires differentiated thinking process
Round «indivi- dualized»	 Best baseline to promote developmental care/infant and family-centered (IFCDC) develop- mental care to protect, to individualize Maybe? shorter ICU/NICU stay Higher parent satisfaction 	 Might challenge own feelings of security Requires very hight level of differentiated/ experienced thinking process → awareness of «red flags» and ability to prioritize Requires flexibility and ressources → may be challenging in ICU setting with NICU/Ped mixture Requires high level of multiprof. teamwork

References

- Altimier, L. & Phillips, R.M. (2013). The Neonatal Integrative Developmental Care Model: Seven Neuroprotective Core Measures for Family-Centered Developmental care. *Newborn & Infant Nursing Reviews, 13*, 9-22. http://dx.doi.org/10.1053/j.nainr.2012.12.002
- Banerjee, J., Aloysius, A., Platonos, K. & Deierl, A. (2018). Family centred care and family delivered care What are we talking about? *Journal of Neonatal Nursing 24*, 8-12 https://doi.org/10.1016/j.jnn.2017.11.004
- National Association of Neonatal Nurses (2022). Trauma-Informed Care in the NICU. Position Statement #3075. www.nann.org
- Ostschweizer Kinderspital St. Gallen (2018). Konzept ,Familienorientierte Betreuung' sanaCERT Standard 21 Ostschweizer Kinderspital <u>Qualitätskonzept (kispisg.ch)</u>
- Preusse, B. (2018): Empowerment durch Familienzentrierte Pflege mit dem BAIA-Modell, das Calgary Familien Modell und seine Instrumente. *NOVAcura 5/18*. Bern: Hogrefe
- Preusse, Barbara et al. (2012). Familienzentrierte Pflege Handbuch. Arbeitsinstrumente für Familienzentrierte Pflege. Das Calgary Familien Assessment und Interventionsmodell in der Pflegepraxis in Lindenhofspital und Schule, Bern. Eigenverlag.
- Warren, I. (2017). Family and Infant Neurodevelopmental Education: an innovative, educational pathway for neonatal healthcare professionals. *Infant, 5*, 200-203.
- Wright, L.M. & Leahey, M. (2014). Familienzentrierte Pflege. Assessment und familienbezogene Intervention (2te Ed.).
 (B. Preusse-Bleuler, Hrsg., H. Börger, Übers.). Bern: Huber. (Original Buch Nurses and Families, 2009, Philadelphia: Davis Company).



Sources

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Project documents from PNZ-efB, Ostschweizer Kinderspital St. Gallen, Kantonsspital St. Gallen

EACH Charta: <u>EACH-Charta – Kind+Spital (kindundspital.ch</u>) and Ostschweizer Kinderspital St. Gallen: <u>plakat_each_charta_v10_endversion.pdf</u> (kispisg.ch)

Neuro-Nurturing NICU:

- <u>www.synapsecare.com</u>
- Every NICU is NeuroNICU Part 1 of 4 Neuro Assessment FREE NICU Nurse Education - YouTube

Eltern unterstützen Eltern (fruehchenschweiz.ch)

