

Establishment of a Family-centred Care Programme with Follow-up Home Visits: Implications for Clinical Care and Economic Characteristics

Erfahrungen im Aufbau eines Elternberatungskonzeptes mit ambulanter Nachsorge: Auswirkungen auf klinische-ökonom. Kenndaten und Akzeptanz der Eltern

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Key words

- family-centred care
- preterm infants
- length of hospital stay
- social medical aftercare

Schlüsselwörter

- Elternberatung
- Frühgeborene
- stationäre Aufenthaltsdauer
- sozialmedizinische Nachsorge

Bibliography

DOI <http://dx.doi.org/10.1055/s-0032-1327620>
 Published online: 2012
 Klin Padiatr
 © Georg Thieme Verlag KG
 Stuttgart · New York
 ISSN 0300-8630

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Abstract

Background: Elternberatung Frühstart is a family-centred care programme for very preterm infants and seriously ill neonates and their parents. The uniqueness of this programme is in its consistency and continuity in parental counselling from pregnancy at risk to follow-up home visits.

Patients and Methods: Family-centred care is provided by specialised nurses, a social education worker, a case manager, a psychologist and neonatologists. They give support and information to parents and facilitate transition to home including co-ordination of health care services and support networks. The programme starts with information for parents at risk of preterm delivery to lessen their anxieties and worries. After birth, parental bonding is encouraged and parents are involved in daily care procedures. The following weeks focus on communication, information and education in order to enhance parental competence. Discharge planning and coordinated follow-up visits involve the family doctor and several members of the welfare and health care system. One of the key objectives is to prevent re-hospitalisation. Over a 4 year period 330 families participated. Funding is provided by: 1) the hospital, from admission to discharge equivalent to one full-time nursing staff, 2) charity donations for follow-up visits and 3) health care insurance for social medical aftercare (Bunter Kreis) following §43, 2 SGB V in severe cases.

Results: As a result of this programme, the median length of stay was reduced by 24 days; the number of patients that stayed longer than average were reduced by 64% in the group of patients born <1500g. At the same time the patient throughput increased from 243 to 413.

Conclusion: To conclude, a family-centred care programme with coordinated follow-up increases parental satisfaction, reduces the length of the hospital stay and is therefore profitable.

Zusammenfassung

Hintergrund: Die Elternberatung „Frühstart“ betreut Eltern Frühgeborener und kranker Neugeborener. Die Einzigartigkeit des Konzepts liegt in der Kontinuität der Betreuung durch das gleiche Team von der Risikoschwangerschaft bis in die Häuslichkeit.

Patienten und Methoden: Das Team besteht aus (Fach-) Kinderkrankenschwestern, einer Case Managerin, einer Sozialpädagogin, einer Psychologin und Neonatologen. Sie unterstützen die Eltern durch Begleitung, Information, Vernetzung und Organisation. Vor der Geburt werden Ängste durch Information genommen, nach der Geburt das Bonding unterstützt, die Eltern in Pflegemaßnahmen einbezogen und die elterliche Kompetenz gestärkt. Das Entlassungsmanagement umfasst die Organisation und Koordination der ambulanten Versorgung und Vernetzung aller an der Versorgung beteiligten Akteure mit dem Ziel, Wiederaufnahmen zu verhindern. Über einen Zeitraum von 4 Jahren wurden 330 Familien betreut. Die Finanzierung bis zur Entlassung erfolgt durch 1) das Krankenhaus (eine Vollzeitpflegestelle), 2) die amb. Nachsorge durch Spenden, 3) und als Mitglied des Qualitätsverbundes Bunter Kreis ist sozialmedizinische Nachsorge in schweren Fällen über die Krankenkassen finanzierbar (§43, 2 SGB V).

Ergebnisse: Die mediane Verweildauer der sehr kleinen Frühgeborenen konnte um 24 Tage verkürzt werden, die Anzahl der Fälle, über der oberen Grenzverweildauer (OGV) wurde um 64% reduziert bei gesunkener Wiederaufnahmerate. Gleichzeitig konnten die Fallzahlen von 243 auf 413 gesteigert werden.

Schlussfolgerung: Eine familienzentrierte Betreuung mit ambulanter Nachsorge steigert die Zufriedenheit der Eltern, reduziert die Aufenthaltsdauer kleiner Frühgeborener und lohnt sich daher auch aus ökonomischer Sicht.



Abbreviations

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NICU	neonatal intensive care unit
GA	gestational age
wks	weeks
OGV	obere Grenzverweildauer
BW	birth weight
ICD	international classification of diseases and related health problems

Background

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The overall prematurity rate in Western Society is between 5.5–11.4%. In Germany, the prevalence is 9%. As more very low birth weight patients survive, the number of infants at risk of short and long-term complications increases and becomes a burden, not only for their families but also for social systems [9].

Giving birth is a critical life event. Preterm birth places more strain and psychological distress on mothers than term births [10,16,21]. The natural process of bonding is therefore more challenging. Bonding between mother and child [13] is vital for the infant's future health and adaption and has been shown to be a protective factor in a child's development [2].

There are several issues impeding the parent child attachment in preterm births:

The technical environment of a neonatal intensive care unit (NICU) and separation of mother and child are described as the most severe issues [14,18,19].

In addition, there are feelings of guilt and sadness, daily concern for the child, combined with joy and hope. Therefore, family-centred care programmes should aim at promoting parental bonding as this reduces the mother's stress and anxiety [5,7].

The principles of NIDCAP (Neonatal Individualized Developmental Care and Assessment Programme) [1] have been in place at this centre for 5 years, with parents being allowed to visit their child 24h a day. However, insecurities and anxieties have still been noticed among parents, especially those close to discharge. In 2007, a family-centred care programme was established by neonatal intensive care nurses and neonatologists to improve parental support and counselling provided by one team over a long period of time. The key objective was to create competent and sensitive parents and secure early discharge.

Preterm infants are more often exposed to infections and at a higher risk for malnourishment and abuse than term born infants. These risk factors in the context of a high percentage of families with migration background, single mothers and with other social problems at this centre made us aware of the special needs of these families in order to cope with every day life with a preterm or sick born baby. This was an important motivation for the development of a programme with follow-up home visits.

In 2011, the Department Neonatology, of this centre, became a member of the "Bunter Kreis", a certified quality network for social medical aftercare in Germany.

This family-centred care programme is based on the method of case management. This enables professionals to evaluate the individual resources of the family and their needs and to organise and coordinate a programme that involves all members of the health care system including the family doctor [15].

Patients and Methods

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Family-centred care programme – the "Elternberatung Frühstart"

The uniqueness of this programme is that it offers consistency and continuity in parental counselling provided by the same team of specialised neonatal nurses, a social education worker, a psychologist (Paediatric psychiatrist), a case manager and neonatologists who extend support to the family from pregnancy to their home for the first 12 weeks after discharge. The team is also involved in daily routines on the ward. The team regularly attends educational training e.g. crisis intervention, bereavement counselling, supervision and medical training.

The programme is offered to families with preterm infants <32 weeks gestation (GA), multiple preterms and neonates with congenital malformations or severe illness.

Parental counselling is delivered throughout the entire perinatal period. There are 3 phases: 1. Prenatal support, 2. Counselling after birth until discharge, 3. Discharge planning and follow-up home visits.

1. Prenatal Support

In the first consultation, the neonatologist offers support to parents, including counselling and guidance to the neonatal intensive care unit. The first meeting provides parents with medical background information about premature birth, focuses on supporting them emotionally and psychologically and mothers are encouraged to prolong pregnancy.

They are introduced to the specific materials used to care for their infant either by images or live examples e.g. blood pressure cuffs, positioning pillow and incubator. A tour of the NICU is also arranged for a separate date where, if possible, a preterm baby can be seen. Further consultations are organised on a case-by-case basis.

2. Counselling after birth until discharge

As a first introduction to parenthood, both parents are congratulated and accompanied for their first visit to their baby. The parents are taught how to make specific contact and pacify the infant through touch.

Once the infant is stable, early kangarooing is practiced and breast-feeding is established. In the following days and weeks, parents are involved in daily care procedures.

As in the prenatal stage further consultations are organised on a needs basis.

Support is extended to parents of preterm infants by means of them attending a weekly meetings with other parents or in "parents-support-parents" programmes. During this time, a specialist nursery educator is available to offer assistance to any siblings of the preterm infants in an attempt to alleviate any worries they may have as they witness their parents' distress whilst allowing them to experience some fun activities.

In the event of an infant's death, parents are offered bereavement counselling and to attend a monthly support group in cooperation with the Children's Palliative Care Programme.

3. Discharge Planning and Follow-Up Visits

The main outcome of the discharge process is that parents are enabled to cope with the realities of every day life with a preterm infant or sick newborn at home. This process involves reassuring parental competence and sensitivity to their child.



The planning actually begins 2–3 weeks before the infant is discharged in order to have a safe and timely discharge. A major objective of ambulatory aftercare is to plan a seamless transition to home. This can be achieved by creating a network of professionals including the family doctor, midwife, members of the health and welfare system in addition to extended family. In addition, any medical equipment, medication and nutrition is organised along with any necessary nursing care. Ambulatory appointments are coordinated.

Follow-up home visits occur for a maximum 12 weeks after discharge. Visits take place more frequently in the first few weeks after discharge. As they understand the medical history, the family-centred care team provides continuity in treatment and are therefore best placed to judge the medical condition of the infant to give relevant advice to the family doctor, home care nurses and parents.

The notable value of these visits is that parents gain a sense of security, reduced anxiety, reinforcement of competence, optimisation of available resources and help in creating a family unit. Practical advice to access needed services is also given.

When the parents are deemed to have the necessary competence and are sensitive to their child and they can rely on the network that has been built up for them, responsibility is then transferred from “Bunter Kreis” to them and their family doctor. The family-centred care programme was delivered in German and English. As long as one parent was fluent in German, the entire programme was offered. If both parents did not speak any German, parts of the programme (prenatal support, the first counselling after birth, discharge planning and first appointment with the family doctor) were offered with the help of an interpreter. The support and counselling is adjusted to the individual needs of the family. Families with a migration background, different socio-economic and educational context have a variety of needs and attitudes towards family-centred care that have to be considered.

Evaluation of the introduction of the family-centred care programme

This family-centred care programme was introduced in stages over a 4-year period (April 2008–April 2012). Initially, prenatal support and counselling during the hospital stay was given. Gradually, discharge planning was introduced and since November 2009, funded by charity donations, enabling our centre to offer follow-up home visits to be included in the programme.

The next stage involved becoming an associated member of the quality network „Bunter Kreis” which is recognised by health insurance providers as a provider of social medical aftercare (§ 43, 2 SGB V), at least in severe cases.

Evaluation of the 4-year period of introduction of the programme included: number of participants in the programme, composition of patients and distribution of indications (inclusion criteria) for the family-centred care programme. The “Elternberatung” database was reviewed in order to classify each case for participation in “Elternberatung” (including prenatal counselling), follow-up visits (excluding Bunter Kreis), Bunter Kreis and bereavement counselling or more than one participation. Each case was then assigned to one group based on the major indication for participation: preterm infants <32 wks GA neonates with serious illnesses, neonates with congenital malformations, multiples >32 wks GA, late preterm infants >32 and <34 wks GA and others. Total annual numbers for each group were identified.

Main target group for the family-centred care programme were families of preterm infants <32 wks GA. In order to evaluate the demand of the programme among these families, total annual numbers of infants <32 wks GA treated in our institution were reviewed from our neonatal database (Neodat, PaedSoft, Tübingen, Germany) and compared with the participants of the programme.

Evaluation of economic impact of the programme

In order to evaluate the economic impact of the family-centred care programme information from our neonatal database and medical controlling was gathered: i.e., number of cases during the past 5 years, patient throughput, number of infants born preterm with a birth weight less 1500g, number of decedents, mean and median length of stay, exact days of hospital stay, number of stays longer than average (obere Grenzverweildauer, OGV), gestational age at discharge and re-hospitalisation rate for patients in – and outborn. Due to the diagnose related group system (DRG) in Germany, an economic-medical classification of hospital cases, it was only possible to identify cases by birth weight and not by gestational age. The group of infants born with a birth weight <1500g was considered to match best the target group for family-centred care those born <32 wks GA.

The group of newborns with congenital malformations or seriously ill newborns were considered too inhomogeneous for the comparison of duration of hospital stay.

Before calculation, patients that were transferred or died before discharge were excluded.

For the evaluation of the re-hospitalisation rate all hospitalisations to the pediatric clinic from April 2007–2012 were gathered (excluding decedents). Patients were then filtered by their lifelong case number (Lebensfallnummer) and screened for their weight and department of hospitalisation in order to identify all cases treated in the centre for neonatology. All identified cases were then screened for re-hospitalisation within the first 28 days after discharge. The main reason for re-hospitalisation was identified for each case either by the ICD-code (International classification of diseases and related health problems) or by the individual record or letters.

Re-hospitalisation was further classified: planned re-hospitalisations for vaccinations, MR imaging at term equivalent age or surgery and unexpected re-hospitalisations due to complications or infections. Rates were calculated for infants born <1500g and all other neonates >1500g birth weight separately.

Results



Over the 4-year introductory period, 330 infants were included in the programme. The numbers grew by 219% from years 1 to 4. The demand for family-centred care was 53% in the first year and 100% in the fourth year of the programme (● **Table 1**). A total of 158 infants received follow-up visits (● **Table 2**), 47 infants qualified for social medical aftercare by “Bunter Kreis” (● **Table 3**).

Following the inclusion criteria, 63% of patients were born <32 wks, 14% were neonates with congenital malformations or seriously ill and a further 9% were multiples born >32 wks. The remaining 7% consisted of only prenatal counselling. 4% included infants that had been consulted prenatally and pregnancy had been prolonged into late prematurity. A small percentage of other exceptions were included mainly relating to social issues (See ● **Table 1, 2, 3** for details of the inclusion criteria).



Elternberatung	total no.	1 st year	2 nd year	3 rd year	4 th year
infants receiving Elternberatung	330	36	82	97	115
preterm infants <32 wks. GA	207	32	63	51	61
seriously ill neonates	12	1	0	3	8
neonates with congenital malformations	35	2	7	9	17
multiples >32 wks. GA	31	0	7	15	9
late preterm infants >32 <34 wks. GA	14	1	3	6	4
other reasons	8	0	2	3	3
prenatal counselling only	23	0	0	10	13
bereavement counseling	29	0	3	5	21

Table 1 Total and annual numbers of patients who participated in Elternberatung and their distribution to different indications.

Follow-up Visits (excl. Bunter Kreis)	total no.	1 st year	2 nd year	3 rd year	4 th year
infants receiving Elternberatung	158	0	37	67	54
preterm infants <32 wks. GA	101	0	33	33	35
seriously ill neonates	2	0	0	1	1
neonates with congenital malformations	13	0	2	9	2
multiples >32 wks. GA	28	0	2	15	11
late preterm infants >32 <34 wks. GA	8	0	0	6	2
other reasons	6	0	0	3	3

Table 2 Total and annual numbers of patients who received follow-up visits (excluding those participating in social medical aftercare by Bunter Kreis) and their distribution to different indications.

Bunter Kreis	total no.	1 st year	2 nd year	3 rd year	4 th year
total no infants in Bunter Kreis	46	0	0	12	35
preterm infants <32 wks. GA	20	0	0	7	14
seriously ill neonates	1	0	0	0	1
neonates with congenital malformations	20	0	0	5	15
other reasons	5	0	0	0	5
reimbursement by insurance	44	0	0	12	32

Table 3 Total and annual numbers of patients who participated in social medical aftercare by Bunter Kreis and their distribution to different indications.

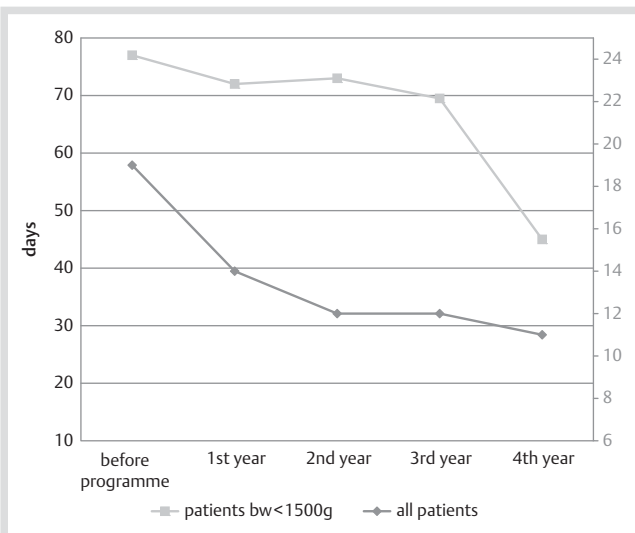


Fig. 1 Median Length of hospital stay in days for all patients on the NICU and neonatal ward and for preterms < 1500 g birth weight respectively.

It is worthy of note that at this centre, investing in one full-time nursing staff dedicated to the family-centred care team, led to a reduction of the median length of hospital stay by 24 days. (◉ Fig. 1)

The number of patients (<1500g birth weight) that stayed over the average length (obere Grenzverweildauer, OGV) was reduced by 64% (◉ Fig. 2) which enabled greater resources to be allocated to increase the patient throughput of all neonatal patients by 70% (◉ Fig. 3). The rate for unexpected re-hospitalisation decreased significantly for both groups whereas planned re-hospitalisations increased in the group of patients <1500g birth weight. (◉ Table 4)

The financial viability of this programme is justified due to the 70% increase in patient throughput, which significantly outweighs the cost of one full-time nursing staff. Reimbursement by insurance companies for social medical aftercare was achieved in all cases of the third year and in 91% of the cases to date. Reimbursement had to be negotiated individually for each patient. Those institutions of Bunter Kreis that are recognised as providers of social medical aftercare by the insurance companies, may lay down a fixed amount of reimbursement, which is variable within Germany.

There were no marked differences between the group of all patients born <1500g (including outborn patients) and the group of patients inborn <1500g. Due to small numbers in the group of outborn patients, no comparison was possible to inborn patients. A further advantage of Elternberatung „Frühstart“ is the consistency and continuity in parental counselling. Evaluation of the family needs and the design of care can be tailored to each parent and child. The fact that the nurse visiting the home knows the infant's clinical course, its behaviour and needs offers security for the parents and supports other professionals, e.g. the family doctor and nursing care service.

In the last few years, 3 cases have occurred where follow-up home visits were vital for the infant's well-being. One case discovered malnourishment due to inadequate feeding practice by an extremely challenged single mother. The other 2 cases led to an early detection of severe infections. Detailed observations and judgement of the visiting nurse detected pneumonia in a child with tracheostoma and a severe electrolyte loss and acidosis in a child with short bowel syndrome and anus praeter. These cases show that the transition to home is a critical phase for both infants and their families. The continuity of specific knowledge and information pertinent to this group, sensitivity to the infant's condition and strengthening parental and professional competence is vital for the future course.

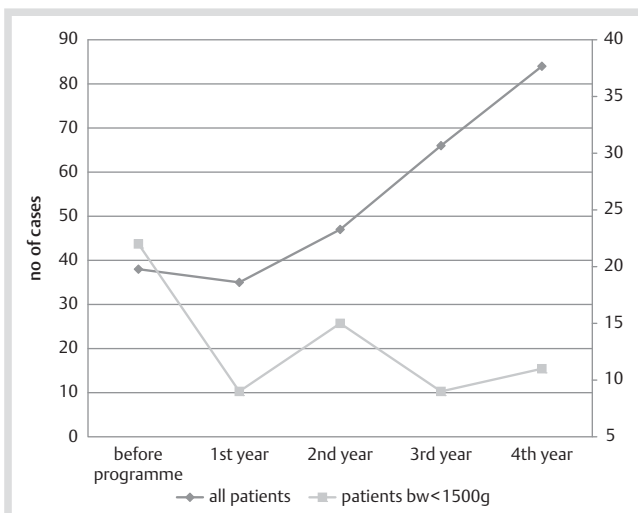


Fig. 2 Number of cases / patients that stayed over average (OGV) on the NICU and neonatal ward, all patients and preterms < 1500 g birth weight respectively.

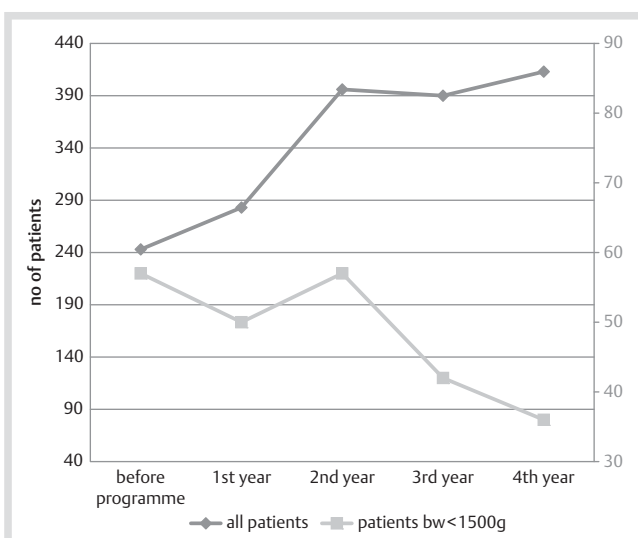


Fig. 3 Number of cases / patients treated on the NICU and the neonatal ward for all patients and preterms < 1500g birth weight respectively.

Discussion

▼ In order to assess the socio-economic impact of this programme, the average length of stay, patient throughput and the re-hospitalisation rates were studied and resulted in having a positive effect. These more than compensates for the costs incurred.

Over average stays were reduced in many centres in Germany following the introduction of the DRG system. However, the number of patients with a birth weight < 1500 g that stayed over average (OGV) decreased abruptly during the introduction period of the family-centred care programme in this institution. Therefore, it can be concluded that this reduction is due to the specific intervention of Elternberatung „Frühstart“.

At the same time, the number of patients treated increased. This is only partly explained by the introduction of the family-centred care programme. The establishment of a pediatric surgery in 2010 and external referrals to our institution accounts.

The median length of hospital stay was reduced in all neonatal patients over the 4-year period. Even those patients who did not participate in the programme benefited from standardised protocols for discharge planning and parental counselling.

Cost efficacy is achieved by early but safe discharge without re-hospitalisation. During the introduction period, the average length of stay decreased at the same time as patient throughput increased and unexpected re-hospitalisations decreased. It is worthy of note that in the third year of the intervention unexpected re-hospitalisations dropped abruptly. We believe that there is a causal relationship between the start of follow-up home visits in November 2009 and the decreased rate of unexpected re-hospitalisations of preterm infants < 1500 g birth weight. The rate of planned re-hospitalisations increased due to introduction of routine MRI-scanning at term equivalent age of all preterm infants < 32 wks GA and/or < 1500 g birth weight.

Economic viability and effectiveness of the aftercare programme, “Bunter Kreis” was proven for preterm infants and neonates in 2005 [20]. In this randomised study, mothers in the intervention group who received family-centred care and aftercare showed greater sensitivity and mother-child interaction and felt less stressed than those without it. The children in the intervention group had improved emotional regulation and needed less hospital and outpatient treatment after their first discharge.

Huppertz-Kessler et al. provide in their survey of 2010 insights in various stressing stimuli of a NICU and their effect on neu-

	Before programme	1 st year	2 nd year	3 rd year	4 th year
all neonates	243	283	396	390	413
< 1500 g bw	57	50	57	42	36
> 1500 g bw	186	233	339	348	377
all re-hospitalisations	34	31	49	49	57
< 1500 g bw	15	18	36	22	24
planned re-hospitalisations	1 (1.8%)	6 (12.0%)	21 (36.8%)	19 (45.2%)	21 (58.3%)
MRI/vaccination	0	5	20	17	18
surgery	1	1	1	2	3
unexpected re-hospitalisations	14 (24.6%)	12 (24.0%)	15 (26.3%)	3 (7.1%)	3 (8.3%)
> 1500 g bw	19	13	13	27	33
planned re-hospitalisations	1 (0.5%)	0 (0.0%)	4 (1.2%)	7 (2.0%)	9 (2.4%)
MRI/vaccination	0	0	4	6	8
surgery	1	0	0	1	1
unexpected re-hospitalisations	18 (9.7%)	13 (5.6%)	9 (2.7%)	20 (5.7%)	24 (6.4%)

Table 4 Number of cases treated in this centre (excluding decedents), re-hospitalisation rates (planned and unexpected) for neonates born < 1500 g birth weight all other neonates born > 1500 g birth weight respectively. Total numbers and percentage (%).



development in preterm infants. [8] Although the exact mechanisms of interference in the sensitive process of brain development remain unclear, strong efforts in terms of individualized developmental care interventions are made.

As the highest risk for cerebral insults is in the first 72 h of life, interventions should start prenatally or in the delivery room. However most of the studies recruit their patients later.

In the Netherlands, the effect of a home-based infant behaviour assessment and intervention programme on mother-infant interaction after very preterm birth was studied in a multi-centre randomised control trial. Whilst increased maternal sensitivity interacting with their child was discovered, no effect was found on self-regulatory behaviour at 6 month corrected age. A significant difference between this study and the "Elternberatung Frühstart" is that in this centre, the starting point for intervention is around birth, supporting the bonding process, which is vital for infants' adaption, whereas, in the Netherlands study, intervention started at 35–38 wks [11].

Spittle et al. report on the effects of a preventive care programme for preterm infants and their families after discharge until the end of the first year on infants' and caregivers outcome at 2 years of age. The programme focused on parent-infant relationship, parents' mental health and the infant's development assessed in 9 home visits by a physiotherapist and a psychologist. This intervention improved parent-reported behavioural outcomes for infants and decreased caregiver-reported anxiety and depression but did not find significant effects on cognitive, language or motor development [17].

NIDCAP is the most known interventional programme for neonates and their families and is practised (in parts) in many NICUs. However, with regard to beneficial effects and long-term consequences, data from heterogeneous studies of different designs, sizes and end points shows controversial evidence. [6] Prospective large multicentre trials with standardized interventional protocols and follow-up examinations are needed.

In a decentralised system of perinatal care, like in Germany, it is even more difficult to obtain long-term outcome data.

Since 2008 neurodevelopmental examinations at the corrected age of 2 years became obligatory for very low birth weight infants in Germany. Moll et al. showed an increase in the participation of these examinations since 2008 but in order to identify behavioural problems and cognitive impairment standardised follow-up examinations until school age are required [12].

Furthermore "investigations" also need to focus on cost-efficacy in the long term of any individualised developmental care intervention before recommendations can be made area-wide.

The Elternberatung „Frühstart“ programme was founded following a model that has been established since 1998, at the Department of Neonatology, Charité Universitätsmedizin, Berlin [3], which ends at discharge of the infant and mainly includes patients born prematurely. However, with the help of Charity donations, this model has been expanded to include home visits for up to the first 3 months after discharge with a mobile service. Furthermore, severely ill or neurologically impaired term-born infants have also been included. One major scientific focus at this centre is paediatric and neonatal neurology which includes the treatment of congenital malformations, neuromuscular diseases and asphyxia. In addition to this, paediatric surgery was established in 2010 and this led to an increase of patients with congenital malformations. These families not only require psychological support to enable them to cope with lifelong disabilities and special care for their baby but also a well organised network of health care and welfare professionals for the ambulatory aftercare. In some cases, palliative

care and bereavement counselling become the most important aspect. Therefore, Elternberatung makes it possible to extend care to parents through dedicated nursing staff.

Family-centred care programmes have been proven to enhance the overall quality of NICU care, resulting in less stressed, more informed and confident parents [4].

To conclude, a family-centred care programme with coordinated follow-up has been proven to increase parent satisfaction, reduces the length of the hospital stay with decreased re-hospitalisation rates by investing the costs of one full-time nurse.

Therefore other NICUs should be encouraged to emulate this approach.

Conflict of interest: The authors have no conflict of interest to disclose.

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