Paediatric ambulatory and home care for chronically ill children and adolescents

What do we provide and what do children and their families need?

Barnesykepleierforbundet NSF
Vårseminar 2014, Oslo, Norway
29th April 2014

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Hannover/Germany
1980 established as Arbeitskreis der Kinderkrankenschwestern (AKK) e.V. in Hannover

1982 Journal „Kinderkrankenschwester“

1991 Berufsverband für Kinderkrankenschwestern und Kinderkrankenpfleger (BKK) e.V.

1998 Member of Deutscher Pflegerat (DPR) since its foundation

2000 Berufsverband Kinderkrankenpflege Deutschland (BeKD) e.V.

represents today nearly 2000 Paediatric nurses and nursing students (membership is voluntary)
Professional Nursing in Germany

- about 50 000 Paediatric Nurses (2009)
  - about 38 000 in hospitals (2009)
  - about 6 500 students (2010/2011)

- about 485 000 Nurses for adults (2009)
  - about 324 000 in hospitals (2009)
  - about 60 000 students (2010/2011)

- about 195 000 Nurses for elderly people (2009)
  - about 52 000 students (2010/2011)

no compulsory registration for nurses
Professional Paediatric Nursing in Germany

- specific education programme
- 3 years of vocational training
  - nursing schools recognised by the government
- state-controlled examination
  - regulated by federal law
"Childhood is entitled to special care and assistance"

(UN Convention on the Rights of the Child, 1989)
Children are a highly vulnerable group of the population because ...

... there is no other period of time within the lifespan when the human development in all dimensions is as fast and complex as during childhood

... of the physical and mental vulnerability of children

... of the child's absolute dependence from the parents or legal guardians
Children in Germany

Zahl der minderjährigen Kinder 2000 und 2010

Quelle: Mikrozensus

Abb. 1: Zahl der minderjährigen Kinder 2000 und 2010 (Statistisches Bundesamt)
"Ageing society"

Bevölkerungsentwicklung in Altersklassen

1950

- Männer: 32%
- Frauen: 55%

69,3 Mio./1950

2008

- Männer: 20%
- Frauen: 55%

82,2 Mio./2008

2040

- Männer: 17%
- Frauen: 46%

73,4 Mio./2040

Quelle: Statistisches Bundesamt 2006
"While only a few things can be predicted with certainty, one thing that seems certain is that the future of health care will be dominated by the challenge of complex chronic disorders."

(Nolte et al. 2008, 1)
"The Red Thread"

1. ... the situation of chronically ill children and adolescents and their families
2. ... the concept of care dependency in children and adolescents
3. ... the providing of adequate professional paediatric nursing care
"The Red Thread"

1. ... the situation of chronically ill children and adolescents and their families
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chronic or long-term illness

... diseases

... which are not (yet) curable

... remain for a longer period in life

... permanent and continuing care needs
Family (system)
"The family is a unit with structure and organization that interacts with its environment. The family is a system ... defined by emotional bonds and common responsibilities. ... Members of the family do not need to be biologically related or live in a single household. The family is defined as all persons an individual considers to be family. The family includes all persons who carry family functions and are emotionally connected to the individual."

(Friedemann 1995, 18)
Family (system)
Children and adolescents with Cystic Fibrosis

1985
median age of the patients 11 years
-> 18,7% older than 18 years

2006
median age of the patients 20 years
-> 54,5% older than 18 years

(SVR Gesundheit 2009)
Children with chronic conditions

German Health Interview and Examination Survey for Children and Adolescents (RKI KIGGS, 2003 - 2006)

- the various chronic diseases have different lifetime prevalence rates

- about 13 - 14 % of all children aged 0 - 17 years have special health care needs
Figure 11-1 Adequacy values of self-care related to therapeutic self-care demand may vary over time.
**Abbildung 5-5:** Konzeptuelles Rahmenwerk der Selbstpflegedefizit-Theorie (SPDT) für die Dependenzpflege.

GBFs = Grundlegende Bedingungsfaktoren, B = Beziehung, < = Defizitbeziehung. (Verändert mit freundlicher Genehmigung von Orem, D. [1997]; *Strukturkonzepte der Pflegepraxis* [1. Aufl., S. 475], Ullstein Mosby, Wiesbaden)
D.E. Orem states that ...

... health care requirements for persons with self-care deficits related to chronic illness or disability include:

- continuous care to regulate disease processes
- therapy to stabilize or protect functioning
- continuous evaluation of disease progress and recovery
- prevention of complications
- prompt treatment of complications
- general health maintenance and promotion
- assistance with coping
- rehabilitation
- assistance in helping patient and family assume continuing self-care (and dependent-care).

(Orem 2001)
**Figure 11-5** Dual roles of dependent-care agents.

- **Other roles**
  - **ROLE I** Self-care agent
    - Know and meet one's therapeutic self-care demand
  - **ROLE II** Dependent-care agent
    - Mature or maturing person having or assuming responsibility for a dependent person
    - Exercise and continue to develop one's self-care capabilities
    - Conditioning effect of each one on the other
      - Know and meet the dependent person's therapeutic self-care demand in whole or part
      - Continuing dependent-care system
        - Exercise and continue to develop one's dependent-care capabilities
        - A subsystem of dependent-care that articulates with the dependent's system of self-care

- A continuing self-care system
Requirements ...

... to enable sufficient self- and dependent-care

- education in technical measures, e.g. feeding via gastric tube, subcutaneous injection of insulin ...  
- establishment of sustainable routines in daily life 
- prevention and health promotion 
- psychological support 
- relief from time-consuming tasks 
- case-management and company within the health care system 
- ...

(Büker 2008)
Parental competences

Einflussfaktoren:
- Auftreten neuer Erkrankungen
- Zunahme an medizinischen, diagnostischen und therapeutischen Techniken
- Überlebenschance chronisch kranker Kinder und Kinder mit einer Behinderung steigt

Anforderungen an die Dependancepflege

Entwicklung und Stabilität der Dependenzpflegekompetenz

Einflussfaktoren:
- Anstieg der Zahl allein Erziehender
- "Späte Elternschaft"
- Tabuisierung von Krankheit und Tod in der Gesellschaft
- Verlust an Traditionen durch Migration
- Abnahme der Weitergabe von Dependenzpflegepraktiken durch Zunahme von Kleinstfamilien

Abb. 1: Gesellschaftlich relevante Einflussfaktoren auf die Dependenzpflege

(Holoch 2002)
Paediatric Nurses
"The Red Thread"

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"Care dependency can be defined as a subjective, secondary need for support in the domain of care to compensate a self-care deficit"  

(Boggatz et. al. 2007).
31. Tagung der Gesundheits- und Kinderkrankenpfleger/-innen
im Rahmen des deutschen Kinderärztekongresses

Kurzbericht zum Gemeinschaftsprojekt
der GeKinD und des BeKD e.V.

Pflegebedürftigkeit bei Kindern und Jugendlichen
Eine Untersuchung aus Perspektive der Gesundheits- und Kinderkrankenpflege

Dr. Elisabeth Holoch

Mannheim, den 5. Mai 2009
"The Red Thread"

1. ... the situation of chronically ill children and adolescents and their families
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What do the children and their families require?

• a family-centred approach
• an adequate assessment tool for care dependency in children and adolescents
• case-management
• a network that is covering the needs in all regions of the country and in all settings of nursing care
• clinical paediatric nurse specialists in outpatient departments of the hospitals
• structured assessment, discharge management, communication and handover mechanisms and information sharing
• paediatric community nurses
• school nurses
• planned process of transition to adult services
Adolescent Transition Care

Adolescent transition care
Guidance for nursing staff
Today and in future we need ...

• ... to share our expertise and experiences with others so that we can improve our knowledge and our practice.

• ... research and evaluation to be able to establish recommendations for good practice.

WWW PNAE initiative for a survey of situation of outpatient, ambulatory and home care for children and adolescents in Europe ... to discuss recommendations for good practice from the perspective of paediatric nurses WWW
KINDSEIN BRAUCHT

UNSERE PFLEGE