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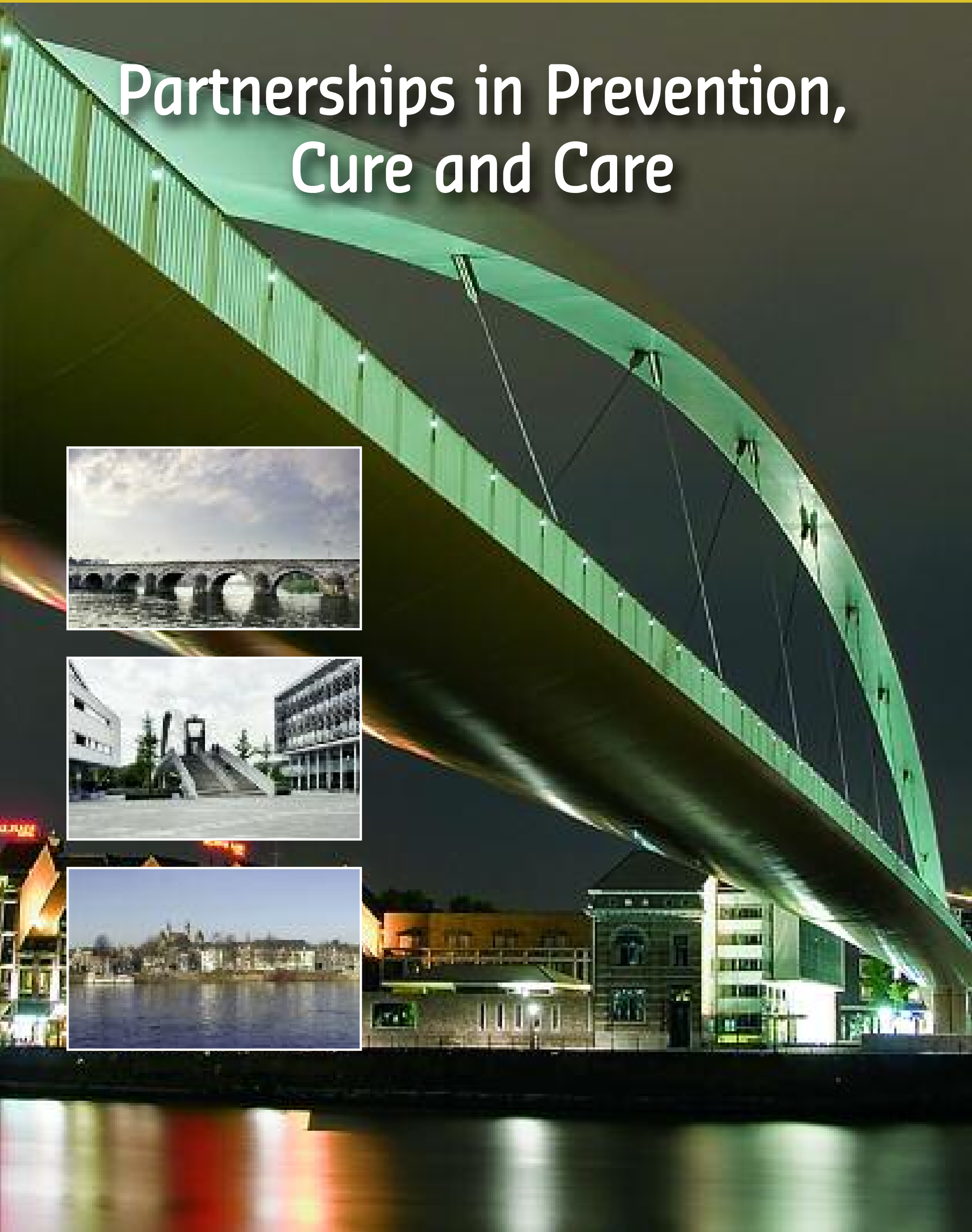
Annual Meeting

Partnerships in Prevention, Cure and Care



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Partnerships in Prevention, Cure and Care

Editors:
J.C.M. Jansen and A.W.P.M. Snijdewind

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Preface

Dear colleagues,

We are very proud to welcome you to the annual meeting (September 28th - 30th 2011) of the European Society for Social Pediatrics and Child Health in Maastricht, the Netherlands.

This is the second time this meeting has been held in our country. An extensive and varied scientific programme has been prepared for you, but there will also be enough time to renew old friendships and meet new people.

We hope you will enjoy the beautiful scenery in the province of Limburg (and perhaps even one of the adjacent countries) as well as the beauty and culture of the historic city of Maastricht.

We gratefully acknowledge the support of the University of Maastricht and the Maastricht University Medical Centre which has made this meeting possible.

The province of Limburg will welcome you to a reception in its Provincial Government House where the Maastricht treaty was signed and we gratefully appreciate their hospitality.

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PROGRAMME ANNUAL MEETING ESSOP 2011, MAASTRICHT

Programme Annual Meeting ESSOP 2011, Maastricht

WEDNESDAY, September 28

14.00 – 18.00	Registration
20.00 – 23.00	Official Opening: Nick Spencer, president ESSOP and Thea van Zeben-van der Aa, Programme Committee

Welcome Dinner

THURSDAY, September 29

Chair: Thea van Zeben-van der Aa

07.45 – 08.30	Registration
08.30 – 09.00	Opening: Nick Spencer and Thea van Zeben-van der Aa
09.00 – 10.30	Plenary session: Staffan Janson: Child Maltreatment – Our Common Responsibility Merian Bouwmeester: Supportive Parenting: Primary Prevention of Parenting Problems in the Netherlands
10.30 – 11.00	Coffee and Tea
11.00 – 12.30	Workshops: A: Rachel Levi and Noor Landsmeer: Children, Sex and Internet

B: Stuart Logan: Research on and with Children: Epidemiological and Ethical Issues
Wim Pinxten: The Moral Limits of Medical Research with Children

C: Ellen Kohnhorst: Medically unexplained Symptoms; unexplained?
Andrieke C. Knottnerus:
Approach for severe Invalidating medically unexplained Symptoms
Patrick Luyten: An attachment and mentalizing Approach to the Treatment of Patients with functional Somatic Disorders

12.30 – 14.00 Lunch

12.30 – 14.00 ESSOP Executive Committee Meeting (members only)
12.30 – 14.00 Huishoudelijke Vergadering SSPK (members only)

14.00 – 15.00 Free papers:
Meta van den Heuvel:
Comparison of early Child Health and development services of Canada and the Netherlands.
Jónína Einarsdóttir and Geir Gunnlaugsson:
Excluded groups to Health Services in Monkey Bay, Malawi and global Partnership
Helma van Gameren-Oosterom:
Prevention of recurrent Respiratory Tract Infections in Down Syndrome: what could potentially be gained?
Erika Sievers and A. Dietrich:
Introducing cultural competence Training into paediatric Public Health Services

15.00 – 16.30	Plenary session: Ulrike Ravens-Sieberer: Quality of life questionnaires for children and adolescents – the kidscreen approach Symone Detmar: The Usefulness of quality of life Assessment in Pediatrics
16.30	Leaving for visit to the Provincial Government House, Maastricht
17.00 – 18.30	Reception at the Provincial Government House

FRIDAY, September 30

Chair:	Anne Marie Oudesluys- Murphy	
08.15 – 08.45	Registration	
08.45 – 09.00	Opening and review of yesterday	
09.00 – 10.30	Plenary session: Anne Marie Oudesluys and Paul de Cock: Disabilities and Handicaps	
10.30 – 11.00	Coffee and Tea	
11.00 – 12.30	Workshops	
	D:	Emma Van Daalen: Early Signs of Autism, ADHD and Psychomotor Disorders Petra Hurks: Using our current Understanding of Preschool Children at risk of ADHD to Support early Identification and Intervention Paul de Cock

E: Stuart Logan: Research on and with Children: Epidemiological and Ethical Issues
Wim Pinxten: The Moral Limits of Medical Research with Children

F: Ellen Kohnhorst: Medically unexplained Symptoms; unexplained?
Andrieke C. Knottnerus:
Approach for severe Invalidating medically unexplained Symptoms
Patrick Luyten: An attachment and mentalizing Approach to the Treatment of patients with functional Somatic Disorders

12.30 – 14.00 Lunch

12.30 – 14.00 ESSOP Annual General Meeting (members only)

14.00 – 15.30 Free papers:
Florence Noirhomme-Renard:
Children of teenage Mothers: delayed psychomotor and language Development
Eveline Louwers:
Effects of changing Policy on Screening and Detection of Child Abuse in Emergency Departments
Selda Bülbül:
Behaviours of Health Sciences Faculty Students in the road of developing healthy lifestyle
Nick Spencer, Clare Blackburn and Janet Read:
Social Disadvantage and Childhood Limiting Longterm Illness/disability: Cause or Consequence?

15.30 – 17.00	Plenary Session: Anders Hjern: Long term Outcomes of Foster Care: Lessons from Swedish National Cohort Studies Douglas Eric Simkiss: Promoting Quality of Life for looked after Children and Young People Barbara Rubio and José A. Diaz Huertas: Children in State Care: Spain
17.00 – 17.15	Closing Remarks
17.15	Lobby: Refreshments

POSTERS

Serpil Ugur Baysal, Selda Bulbul, Guzide Kurt
The first children's rights congress in Turkey: Children's rights for children's republic

Selda Bülbül
Care and nutritional status in children with cerebral palsy

Selda Bülbül
Additional health problems and functional status in children with cerebral palsy

Selda Bülbül
Factors affecting the satisfaction levels of patients applying to a newly established University hospital and the pediatrics clinic

Geir Gunnlaugsson and Jónína Einarsdóttir
Prevalence of disciplinary measures for Children in Iceland

Harmen B.Haanstra, Anne-Claire Bosmans, and
Thea van Zeben – van der Aa
Consultation team for high risk pregnancies: Prevention of (intra-uterine) child Maltreatment

Lubomír Kukla
Elspac as an Example of a longitudinal epidemiological Study on Children and Adolescents

Florence Noirhomme-Renard, Tancredi Annalisa, Christiane
Gosset Perinatal depression in adolescent mothers : a public health concern

Tessa Sieswerda
Interdisciplinary hospital-based child abuse and neglect team in an academical centre; Overview of interventions

Gonca Yilmaz, Nilgün Caylan and Candemir Karacan
Abusive head trauma: report of 3 cases

PLENARY SESSIONS

WORKSHOPS

FREE PAPERS

POSTERS

Drawings: Annabella Rijksen

PLENARY SESSIONS

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CHILD MALTREATMENT – OUR COMMON RESPONSIBILITY

Staffan Janson MD, PhD, Pediatrician.
Professor Karlstad and Örebro Universities, Sweden.

Abstract

Child abuse is common worldwide and has severe consequences for children's´ health, development and later function in adulthood. WHO has estimated (Pinheiro 2006) that more than 50 000 children are killed every year due to maltreatment, 150 million girls and 75 million boys are sexually abused, 3 million girls are sexually mutilated and that 125 million children are working in dangerous workplaces risking their lives and normal development. Child abuse is unfortunately still quite common in the western world and as register data gives very unsafe estimates self reported data from young people are more trustworthy. In a report published in the Lancet 2009 (Gilbert et al 2009), the following estimates were done about child abuse in industrialised countries:

Self-reported:

- 5 – 35 % of all children in different countries report severe corp. punishment at home
- 4 – 9 % severe psychological abuse and one in three severe offences (particularly in Eastern Europe)
- Sexual exploitation 15 – 30 % of girls and 5 -15 % of boys, whereof 1/3 are penetrations
- 1,5 – 15 % severe neglect
- 8 – 25 % family violence

The figures are overall lowest in Scandinavia and highest in the East European countries.

In the same study a great number of articles were scrutinised concerning risk factors for child abuse. The following risk factors are established:

- Weak economy and low level of parental education
- Economic inequality particularly increases the risk for mortal abuse
- Ethnic factors are mainly explained by socio-economic background factors
- Drug problems increase the risk for family violence
- About 10 % of the risk is explained by the social position and "climate" in the neighbourhood

The long-term consequences of child abuse and severe neglect are, with high degree of association: Behaviour problems, PTSD, Criminality and Obesity! This is an association that has not been realised before the results of greater prospective studies with long time follow up of abused children have been published.

A certain connection with low educational performance and unskilled work, depression and suicide attempts, alcohol problems and prostitution and a weak or uncertain connection to self inflicted injuries, drug abuse, teen age pregnancy and chronic pain as adult. The connection to general bad health or quality of life as adult has not yet been definitely evaluated.

Children´s rights:

The **UN Convention of the Rights of the Child** from 1989 has since 1990 been ratified by all countries in the world except for Somalia and USA. This means that almost all countries in the world actually have approved the articles that protect children from abuse (Articles 5, 18 and **19**). In Europe this has been further ratified by the **Revised European Social charter** in article 16 (promote economic, legal and social protection of the child). A minority of the world´s countries have also taken specific **National Corporal Punishment**

bans, where Sweden was the first country in the world to approve such legislation in 1979. This legislation was however preceded by a number of law promoting people´s and specifically women´s and children´s rights over a period of more than hundred years. The important Swedish lawmaking to prevent corporal punishment is as follows:

1858 prohibited to beat grown up servants. **1920** prohibited to beat all servants, children included. **1928** corporal punishment of pupils prohibited in higher education. **1957** corporal punishment legally equalised to cruelty. **1958** corporal punishment is prohibited in all schools. **196**6 corporal punishment abolished as a method of upbringing of children in the Swedish Parental Act. 1979 Corporal punishment of children is prohibited by the Swedish Parental Act. **1982** Corporal punishment of children incorporated under public prosecution. **1990** Sweden ratifies the UNCRC.

Norway was actually the first country to approve a law against corporal punishment in schools, already in 1936. Banning of corporal punishment in schools always precedes banning of corporal punishment in homes, probably because states have a greater influence over schools than families. Almost 60 % of the world´s children are still not protected from corporal punishment in schools and 97 % are not protected from corporal punishment in the homes.
The Swedish parental act from 1979 has actually taken the protection a little further as it also forbids humiliation.

The Swedish Parental Act Chapter 6 § 1:

- Children have the right to care, safety and a good upbringing. Children should be treated with respect for its person and individuality and shall not be exposed to corporal punishment or any other insult (humiliation).

Thirty countries in the world, whereof 19 in Europe, has banned corporal punishment in homes by October 2011. These countries are:
Europe (22 countries): Sweden 1979, Finland 1983, Norway 1987, Austria 1989, Cyprus 1994, Denmark 1997, Latvia 1998, Croatia 1998

Germany 2000, Bulgaria 2000, Island 2003, Ukraine 2003, Hungary 2004, Rumania 2004, Greece 2006, Holland 2007, Portugal 2007, Spain 2007, Liechtenstein 2008, Luxemburg 2008, Moldavia 2009 and Poland 2010

Middle East: Israel 2000

Latin America: Uruguay 2007, Venezuela 2007, Costa Rica 2008

Oceania: New Zeeland 2007

Africa: Tunisia 2010, Kenya 2010, South Sudan 2011

Police reporting and statements from parents and children

Since 1982 it has been mandatory for professionals working with children to report to the social services and in severe cases to the police authorities in Sweden on suspected child abuse and neglect. These reports have increased for every year since then. This poses a specific problem for Sweden as it is misunderstood abroad, that child abuse increases in Sweden, while it is actually the tendency to report that has been increasing. This was thoroughly checked and verified in 1999 and a new investigation of the reports will be published in the en of October this year (2011).
Attitudes towards corporal punishment and behavior have actually changed profoundly for the better in Sweden during the last 50 years, which can be seen in the diagram below. This diagram concerns positive attitudes to corporal punishment (blue) and actual corporal punishment during the preceding year of a specified child in the family (red). The same method, Conflict Tactic Scale (Straus 1998), has been used on all occasions from 1980 and on, while earlier figures are extrapolated from the parent statement of their own upbringing and compared with figures from studies in Stockholm in the 1950s and 60s.

It is actually so that figures from later years are even lower when the statements from immigrant parents are omitted from the statistics. Statements from Swedish School children confirms the decreasing trend in corporal punishment and since 2000 the pupils state

that they have been punished at least once in their lifetime in 15 % and one of ten have been severe punished by a device.
Murder of children under 15 years of age has decreased continuously since the 1970s and during the last 5 years only about 4 children a year have been murdered in Sweden and most of them due to extended suicides or psychotic parents. This is probably the lowest figure in the world at the moment.
The trend in Sweden is on the whole paralleled in the other Scandinavian countries and experiences from the rest of the western world indicate a similar but slower development. Data from USA, England and Germany indicates a decrease of corporal punishment since 1990. According to estimations made by David Finkelhor and his group in the USA 1990 – 2004 the following has happened:

- Sexually abused children: down ~ 50 %
- Child Abuse: down ~ 40 %
- Family violence: down ~ 50 %

Plausible explanations for USA: lower unemployment, generally better economy, higher educational level, changed attitudes, better service for parents with psychiatric diseases, more active social intervention (Finkelhor, Jones: Why have child maltreatment and child victimization declined. J Social Issues 2006;62(4):685-716)

Plausible explanations for the positive development in the Scandinavian countries are:

- The welfare state, technical development making life easier
- Early political consensus, early protective legislation
- Early high educational level of the population
- High awareness of the importance of socio-economic factors – economic equality
- The unique position of the individual rather than the family
- Preventive health care for all, parental education (?)
- Comparably economic gender equity
- The majority of the children early in the "public space" (pre-schools)
- Increased understanding of the connection between family violence and child abuse

The effects of corporal punishment has been summarized by the American Academy of Paediatrics: Guidance for effective Discipline 1998: (Pediatrics 1998;101 (4) 723-728):

- Spanking small children increases the chance of physical injury and the child is unlikely to understand the connection between behaviour and punishment
- Although spanking may result in cessation of undesired behavi our, repeated spanking may cause agitated, aggressive behaviour
- Spanking models aggressive behaviour as a solution to conflict
- It makes discipline substantially more difficult when spanking is no more an option (older children)
- Spanking is not effective as a long term strategy
- the only way to maintain the effects of spanking is to escalate the intensity

An interesting question is then how Scandinavian parents bring up their children nowadays without spanking. What they do is naturally dependent upon the age of the child but they distract, make jokes, support good behaviour, calm down and comforts the child, do not insult consciously and hug the child to make it able to listen. More than 90 % of all Swedish parents state that they think it is strange to use corporal punishment against children and they react with disgust when they see foreign parents using it.

Before ending up I will point at a specific problem. It has been known since long that disabled children have been abused in institutions, but lately this has also been shown to be quite frequent in their families, also in Sweden (Svensson 2011). Disability is not a protection against child abuse – it actually gives an increased risk and the increased vulnerability is due to:

- increased isolation, weaker social networks
- increased dependency
- Less control over the own body
- less risk for discovery
- Behavior understood as provoking
- Indications of abuse misjudged as consequences of the disability

Children with disabilities are less listened to directly, less believed. They live in families with increased parental stress and staff in health care and social service have easier to identify themselves with adults than with children.

Finally: How can we help to make children´s life better?

- Advocacy for Children’s rights and welfare
- Realize where the risks are highest and most frequent
- Increase discovery of abuse and neglect – give children opportunity to talk!
- Make interventions focused on the child´s life circumstances
- Work for gender equity and ”empower” dispriviliged mothers
- Use existing well functioning social networks (neighbourhood, schools etc
- Work with “evidence based” methods, which are defendable from a child rights perspective

References:
(Above references given directly in the text, a few more books and articles are recommended below)

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SUPPORTIVE PARENTING: PRIMARY PREVENTION OF PARENTING PROBLEMS IN THE NETHERLANDS

Merian Bouwmeester

Curriculum Vitae:
Merian Bouwmeester (1976) entered the realm of child maltreatment during her university internship, where she helped prepare the national guideline on secondary prevention of child maltreatment for Youth Health Care (1999), and has never left it since. After writing her PhDthesis on Early Home Visitation in Families at risk for Child Maltreatment at the Leiden University Medical Center and working as an assistant professor at Leiden University she dedicated herself to implementing science into daily practice. She has been involved in the development of Dutch Centers for Youth and Family (CJG) and was projectleader for the Regional Approach to Child Maltreatment (RAAK). Since 2005 she is national coordinator for the method Stevig Ouderschap (Supportive Parenting) which she developed as a PhD and which has been implemented in 36% of the Netherlands over last five years.

Summary:
Raising a child may be the most difficult task we face in our lives. It becomes all the more difficult when we are occupied by past or present adversities, causing distraction, doubt and stress and making us a lesser parent than we aspire to be – sometimes even, inadvertedly, a maltreating parent. Although many parents would benefit from additional support in raising their children, this is most true for those facing adversities – those at risk. The additional support that is best suited for this group of parents should focus on helping them learn how to cope with their adversities, it should help them recognize the best interest of their children and it should be easily accessible, that is: it should be provided to them in the trusted environment of their own home.

It was this idea that constituted the foundation for an elaborate research project that started in 2001. The method devised during this project consisted of a questionnaire, administered amongst all

parents with newborns in order to determine which parents would benefit from additional support, combined with a series of six home-visits, provided by a specially trained nurse from the Dutch 'Parent- and Childcare Centers' (PCC's).

These centers provide one standardized home visit within two weeks after the birth of each child and continue their services to families through a series of consultations at the center, to which parents are invited. Since approximately 98% of all new parents use these services the Parent- and Childcare Centers are an excellent base to provide additional services to families at risk for parenting problems.
Questionnaires were addressed during the standardized home visit and, if parents were eligible for additional support a home visiting nurse would contact them. The home visits were provided over a period of approximately 18 months and started around 6 weeks after the birth of a child.

Over the course of the research project during 13 months 8899 families were approached with the questionnaire. This resulted in a population of 1263 families eligible for additional support. Almost half of these parents were interested to participate in the study. Eventually 500 families were randomized into an intervention- and a control-group. Effects of the intervention were evaluated through comparison of a baseline measurement and consecutive measurements at 1 and 2 years of age of the index-child, addressing parental self-reported parameters such as abuse potential as well as information from physicians and the Dutch maltreatment-reporting agency.

A clinically significant reduction of the risk for maltreatment was achieved in almost a quarter of the families visited, over twice as much as in the control group (22% versus 10%). Findings also demonstrated improved parental expectations regarding their children as well as a better child physical and psychosocial development due to the intervention. An analysis of trends revealed particular benefits for families at increased risk as well as families with a first child. No significant between-group differences were found based on the information from consulted physicians except for families in the intervention group being more punctual regarding their PCC-appointments. A significantly larger proportion of successful referrals to psychological care were found in the intervention group. Maltreatment reports were made slightly more often about families in the control group when excluding reports from visiting nurses about few dropout families. Combined reports suggested an increase of the early detection of maltreating families in the intervention group.

These results were deemed promising enough to start implementing the method in daily practice. First, in 2005, a pre-implementation phase was started in the same geographic area where the original research project was based, which allowed for interesting comparisons between a research-setting and everyday life. Although response to the questionnaire was slightly lower in everyday life, more families were eligible for support, indicating an increased willingness to be open about delicate personal information, and most importantly, much more families agreed to participate in the home visits (an increase of 48% to 62%).

Ever since the pre-implementation phase more and more Parent- and Childcare Centers implemented the method which now became known as Supportive Parenting. Today, 10 years after the original research project was started, each year almost 70.000 families, living in over 150 municipalities in the Netherlands (which is 37% of the entire population) are presented with the questionnaire and approximately 4% of them participate in the home visits. Parents are highly appreciative of the home visits, when asked to rate the support they consequently come up with an average of 8+ (with 10 being the highest grade).

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QUALITY OF LIFE QUESTIONNAIRES FOR CHILDREN AND ADOLESCENTS – THE KIDSCREEN APPROACH

Ulrike Ravens-Sieberer & the KIDSCREEN Group Europe

Quality of life (QoL) is an important psychological construct which has been researched intensively over the last decades. The specific construct of health-related QoL (HQoL) is also of great importance and interest in this field of research is obviously growing. HQoL has been defined as a multidimensional construct respecting physical, psychological, social and functional aspects of health and well-being. Several questionnaires have been developed to assess HQoL of adults, while the KIDSCREEN is an important instrument to assess HQoL in children and adolescents.

In general, QoL assessment in children and adolescents needs to be age-appropriate. Additionally, QoL measures for children and adolescents should address health-related concerns to identify children and adolescents who are at risk from health problems, and to determine the burden imposed by a particular disease or disability. The KIDSCREEN approach has tackled the challenges of international paediatric QoL research by providing measures that are applicable for children and adolescents as well as their parents and that can be used to monitor and evaluate HQoL in publichealth surveys, in clinical studies, and in research projects. The generic KIDSCREEN questionnaires were developed in the context of a European cross-cultural representative health survey in order to be able to compare HQoL across different countries and in order to be able to monitor the health status of children and adolescents. The KIDSCREEN group used a simultaneous approach to develop its cross-cultural instrument, which ensures the cross-cultural applicability of the KIDSCREEN measures, making them both conceptually and linguistically appropriate for use in many different countries.

The KIDSCREEN questionnaires have been used, validated and psychometrically investigated in international clinical and non-clinical studies.

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THE USEFULNESS OF QUALITY OF LIFE ASSESSMENT IN PEDIATRICS

Symone B. Detmar,
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Health-related quality of life (QOL) is a multi-dimensional construct encompassing physical, mental, social and behavioural components of well-being and function. The subject of QOL, and its relationship to health, has generated an extensive literature among adults and, more recently, interest in the concept has led to the development of QOL measures especially designed for use with children and young people. The most common application of HRQL assessment has been in clinical trials to evaluate differential changes in morbidity and the relative efficacy of medical interventions. More general rationales for assessing QOL include the identification of dysfunction secondary to illness or treatment, and patient subpopulations at risk for psychological or behavioral problems. QOL assessment can also facilitate improvements in clinical decision making, evaluation of the quality of medical care, estimation of the health care needs of a population, and an understanding of the causes and consequences of differences in health. Several examples of using quality of life assessments in pediatrics will be given. Specific attention will be given to instruments derived form the KIDSCREEN project. These instruments assess quality of life from the child's perspective in terms of their physical, mental and social well-being for use in both healthy and chronically ill children and adolescents.

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DISABILITIES AND HANDICAPS

Anne Marie Oudesluys

According to the 2011 WHO World report on disabilities about 15% of the world's population lives with some form of disability, and 2-4% experience significant difficulties in functioning. This prevalence is higher than earlier estimates from the 1970s which suggested figures around 10%. This global estimate for disability is increasing because of population ageing and the rapid spread of chronic diseases and people surving longer with these, as well as improvements in the methods used to measure disability.

The term “Disabilities” is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.

An individual may qualify as disabled if he/she has had an impairment in the past or is seen as disabled based on a personal or group standard or norm. Such impairments may include the following:

Physical disability
Any impairment which limits the physical function of limbs or fine or gross motor ability is a physical disability. Other physical disabilities include impairments which limit other facets of daily living, such as severe sleep apnea.

Sensory disability
Sensory disability is impairment of one of the senses. The term is used primarily to refer to vision and hearing impairment, but other senses can be impaired.

Cognitive disability

Cognitive disability is a broad concept that ranges from mental retardation to cognitive deficits too mild or too specific (as in specific learning disability) to qualify as mental retardation. Intellectual disabilities may appear at any age. Mental retardation is a subtype of intellectual disability, and the term intellectual disability is now preferred by many advocates in most English-speaking countries as a euphemism for mental retardation.

Developmental disability

Developmental disability is any disability that results in problems with growth and development. This term is often used as a synonym or euphemism for intellectual disability, but the term also includes many congenital medical conditions that have no mental or intellectual components, for example spina bifida.

Mental health and emotional disabilities

A mental disorder or mental illness is a psychological or behavioral pattern generally associated with subjective distress or disability that occurs in an individual, and which are not a part of normal development or culture. The recognition and understanding of mental health conditions has changed over time and across cultures, and there are still variations in the definition, assessment, and classification of mental disorders, although standard guideline criteria are widely accepted.

Invisible disability

Several chronic disorders, such as diabetes, asthma or epilepsy, would be counted as nonvisible disabilities, as opposed to disabilities which are clearly visible, such as being confined to a wheelchair.

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of environmental factors.

The rapid growth and changes that occur in first two decades of life were not sufficiently captured in the International Classification of Functioning, Disability and Health (ICF). The launch of the International Classification of Functioning, Disability and Health for Children and Youth (ICF–CY) addresses this important developmental period with greater detail. The ICF–CY confirms the importance of precise descriptions of children's health status through a methodology that has long been standard for adults. Viewing children and youth within the context of their environment and development continuum, the ICF–CY applies classification codes to hundreds of bodily functions and structures, activities and participation, and various environmental factors that restrict or allow young people to function in an array of every day activities.
Its new standardized coding system will assist clinicians, educators, researchers, administrators, policy makers and parents to document and measure the important growth, health and development characteristics of children and youth.

In agreement with disability experts, the introduction to the ICF states that a variety of conceptual models has been proposed to understand and explain disability and functioning, which it seeks to integrate. These models include the following:
the medical, social, spectrum, moral, expert/professional, tragedy /charity, legitimacy,
social adapted, economic, empowering and market models.

The ICF puts the ideas of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus ‘mainstreams’ the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including

Contextual Factors, in which environmental factors are listed ICF allows to records the impact of the environment on the person's functioning.

The American Psychological Association style guide states that, when identifying a person with an impairment, the person's name or pronoun should come first, and descriptions of the impairment/disability should be used so that the impairment is identified, but is not modifying the person. Improper examples are "a spastic" or "an autistic boy". It is more acceptable to uset the terms “a girl who is blind” or “a child with Down syndrome". It also states that a person's adaptive equipment should be described functionally as something that assists a person, not as something that limits a person, e.g., "a boy who uses a wheelchair" rather than "a boy in/confined to a wheelchair."

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http://www.who.int/classifications/icf/en/
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ICF Children and youth version English

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LONG TERM OUTCOMES OF FOSTER CARE: LESSONS FROM SWEDISH NATIONAL COHORT STUDIES

Anders Hjern, MD PhD [1]
(with Bo Vinnerljung PhD [2]*)*

Foster care in Sweden

In Sweden, three to four percent of all children are placed in foster family/residential care at least once before age 18 (Vinnerljung et al 2007). In the capital, Stockholm, one in ten receives some form of child welfare intervention (Sundell et al 2007). Half of all children who are placed in foster family care before age seven will remain in care for more than five years (Socialstyrelsen, non-published statistics). "Permanency planning", including adoption without parental consent, does not exist in Swedish legislation. For children in need of long term substitute parenting, foster family care is the only option. The great majority of child welfare interventions/services before adolescence – and even more so long term out-of-home care - are caused by parental problems or parental behavior (Vinnerljung 1996a.). "Long term care" is in practice the same as foster family care since residential care for young children is usually a temporary affair (e.g. while waiting for a foster home placement). Local child welfare authorities are responsible for care until age of age majority (18).

Until very recently the policy for Swedish foster family care consisted of providing a new home with substitute parents only. The role of social workers was to monitor the home and to re-evaluate the possibility of a return to the birth parents with regular intervals. Education and health medical care was supposed to be taken care of within the general educational and health care system.

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Health and health care for foster children

This Swedish policy for foster care has been evaluated in a series of studies during recent years. In a very recent, and yet unpublished study, the health care provided for foster children was evaluated in the child and health care records, that follow Swedish children from birth to the end of secondary school, and in the records kept by the social workers in the child welfare offices. It was found that no more than 85% of the foster children had received the recommended vaccinations compared with 95% of age and sex matched children from the same districts where their births parents lived. Screening for vision, hearing and speech delay had less often been made in the foster children. Another finding from this study was that information about health and routine health care for children in foster care was often very poorly documented by the social workers.

In a series of studies researchers have exploited the Swedish tradition of maintaining national registers with high quality data regarding health and socio-economic indicators on the entire population. Compared to majority population peers, long term foster children have been found to have five to sevenfold sex and birth year standardized overrisks for hospital because of a psychiatric disorder or a suicide attempt at age 13-17 (while in care) as well at age 19-27 (after having left care) (Vinnerljung, Hjern and Lindblad 2006). The risk of suicide death has also been found to be very high in former foster children with fourfold higher risks compared with an age and sex matched general population (Hjern, Vinnerljung and Lindblad 2004). Sweden has comparatively low rates for teenage pregnancies in international perspective, but this does not account for young girls in foster care where rates are three to fourfold compared with the general population (Vinnerljung, Franzén & Danielsson 2007).

Education and self support problems

The educational attainments at age 20-27 was examined for 30 000 former child welfare youth in eight birth cohorts of Swedish born individuals (1972-1979), comparing them to 745 000 peers who had never received child welfare interventions (Vinnerljung, Öman and Gunnarson, 2005). In the general population, 12 percent had only compulsory education at age 20-27. Among long term care alumni – regardless of their birth mother's education - the figures were over

40 percent. For youth whose career had included disrupted placements, 55 percent had basic education only. Among comparisons, 35 percent had a college level degree, compared to 7-9 percent in the long term foster care groups.

The risk for receiving public welfare at age 23-25 for over 23.000 former child welfare clients, comparing them with 576.000 majority population peers (Vinnerljung and Franzén forthcoming). Former foster children had three to four fold odds for recurring welfare or for having lived on welfare, compared to majority population peers from similar socioeconomic backgrounds.

The way forward

The bleak picture of Swedish foster care presented in these evaluation studies have caused considerable stir. These results suggest that long term foster care has at best weak compensatory power over time. - Must it be so? Taken together with previous Scandinavian reports on increased risks of future medical problems (e.g. Kristofersen 2005) and severe delinquency (Vinnerljung 1999), as well as reports on extreme mortality rates of birth parents (Franzén and Vinnerljung 2006), our results provide arguments for the US and UK policy of “permanency planning”. But today, foster care is the only way of providing Swedish children with a long term substitute family.

Given this, raising the quality of foster care is an obvious approach. In their landmark study, Kessler and colleagues (2008) have convincingly demonstrated that high quality care has a positive impact on mental and somatic health.

Several pathways toward improvements appear promising. They all involve a partnership between agencies/local authorities and foster carers, a moving away from the model of “placing out” that has been the base of foster care for many decades. Our three proposals below also outline a “minimum standard” in foster care, defined in legislation or in binding agreements between agencies, foster carers and birth families.

1. Make agencies accountable for assessing health, for health monitoring during placement, and for providing easy access to health services.
In the US, the National Association of Paediatricians (1994) and The Child Welfare League have for many years recommended that all foster children should have their somatic and mental health assessed at time of placement, or shortly thereafter. Many US foster care agencies currently have such routines (e.g. Hansen et al 2004), and in the UK children in out-of-home care receive annual medical check-ups (e.g. Hill and Watkins 2003). In Sweden, such routines do not exist. Making agencies – not foster parents – accountable for health issues should be tried and evaluated. Studies showing a high prevalence of psychiatric disorders among children and youth in foster care suggest that this may be most important in the area of mental health (e.g. Ford et al 2007).

2. Make agencies accountable for assessing children's cognitive potential, for identifying obstacles to school progress, for monitoring progress in school and for accessing/providing services aimed at promoting school achievements.
Again, the fist step is establishing routines where standardized instruments are used for assessing cognitive capacity, and for identifying obstacles for good school achievements (Evans, Scott and Schulz 2004). In a Swedish pilot project aimed at improving foster children's school achievements (n=25), three out of four children age 8-12 were initially substantially underachieving in school, compared to their tested cognitive capacity (Vinnerljung et al forthcoming). We believe school / education should be an area of priority, considering the strong links between low education and self support problems for foster care alumni (Reilly 2003; Vinnerljung and Franzén forthcoming). Our own on-going register analyses suggest that around half of the high risks for a number of negative outcomes (e.g. serious crime and substance abuse) in this group can be statistically explained by low educational attainment. In fact, one of the main conclusions of our national register studies is that poor school performance and low educational attainment seem to be
key factors in explaining – and for improving - the dismal outcomes for foster care alumni in many life areas. Agencies can and should act as champions for the educational rights of foster children and youth. According to US and Norwegian experiences, programs that

allow foster youth to remain in care several years after age of majority seem to be a simple but promising additional path to improvement (Courtney et al 2007; Clausen and Kristofersen 2008). Systematic use of mentors to support foster children's school work during time in care also seems to be worth trying and evaluating (cp.Rhodes and Dubois 2006).

3. Make agencies accountable for sex education and for provision of birth control to adolescent foster youth.

Looking at the high overrisks for teenage childbearing among foster children, it would be unethical not to try to do something about it. Improving access to mainstream services would be a first step. Meta-analyses, based mainly on US studies, suggest that effective prevention strategies employ a combination of education and provision of contraceptives (Ferrer-Wreder et al 2004). A second step may be trials where evidence based risk group interventions are adapted to the needs of foster care youth (e.g. Allen and Philliber 2001).

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CHILDREN IN STATE CARE SESSION - PROMOTING QUALITY OF LIFE FOR LOOKED AFTER CHILDREN AND YOUNG PEOPLE

D. Simkiss

Introduction

In October 2010, the National Institute for Health and Clinical Excellence in collaboration with the Social Care Institute for Excellence published guidance on promoting quality of life for looked after children and young people in England (1). This is the first time the two organisations have produced joint guidance and the report was the culmination of two years work by a Programme Development Group (PPG). I was privileged to be a member of the PDG and in this paper I describe the process, our findings and implementation.

The National Institute for Health and Clinical Excellence was established in 1999 to ensure everyone has equal access to medical treatments and high quality care from the National Health Service where ever they lived in England and Wales. It expanded to provide advice on public health interventions in 2005 and this piece of work is from the Public health Stream. The Social Care Institute for Excellence is an independent charity working with adults, families and children's social care and social work services across the UK sharing knowledge about best practice.

In 2008 the Department of Health sought advice from NICE on ‘promoting physical health and emotional wellbeing for looked after children’, though you will see from the title of this paper that the committee adopted a broader definition and addressed quality of life. The PDG first met in September 2008. It included people with experience of living in public care, social work practitioners and academics, health workers from Psychology, Psychiatry, Nursing and Paediatrics, educationalists, charitable organisations working with looked after children and health economists.

Over eighteen months the PDG met 14 times and commissioned different pieces of work to inform our decision making, these included a consultation with young people who were or had been in care, fieldwork with professionals, a practice survey and literature reviews of the evidence for; transition support services, training and support for carers and improving access to services. We also took testimony from 23 experts in important areas to looked after children and young people. All of this supporting evidence can be accessed on line (2). Personally I found the systematic review of the experiences, views and preferences of looked after children and young people on what outcomes matter to them the most powerful piece of evidence the PDG received.

Scope of the guidance

The guidance defined quality of life as physical health, and social, educational and emotional wellbeing and produced recommendations for all the influences on life as a looked after child or young person described in figure 1. The relationships between a child or young person, their carer, and professionals involved in their lives, and the continuity of these relationships, were a key discussion point in the PDG. The child's need to be loved and nurtured is fundamental to achieving long-term physical, mental and emotional wellbeing and secure attachments and a sense of permanence are fundamental. Stable education built on high aspirations is essential to promoting the quality of life for looked-after children and young people. Transition to adulthood can often be traumatic and without access to services to support this transition young people can end up unemployed, homeless or in custody, experiencing a downward spiral of rejection.

Recommendations

The guidance contains 52 recommendations, grouped by themes:

- Strategic leadership, planning and commissioning
- Audit and inspection
- Care planning, placements and case review
- Professional collaboration
- Dedicated services to promote the mental health and emotional wellbeing of children and young people in care
- Placements for children and young people – residential care, foster care and care by family and friends
- Sibling placements and contact
- Supporting babies and young children
- Health assessments, records and information
- Personal quality of life
- Diversity
- Supporting foster and residential care
- Care provided by family and friends
- Improved education for looked after children and young people
- Preparing for independence
- Training for professionals

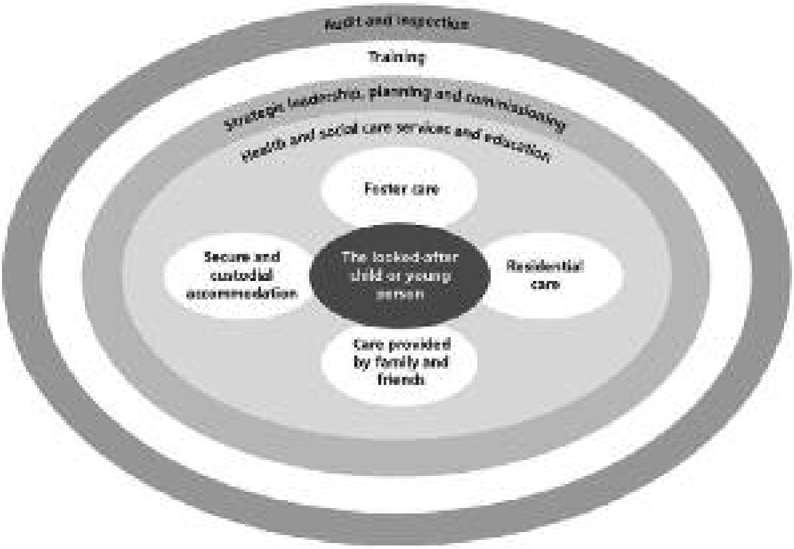

Figure 1 The influences on quality of life for looked after children and young people

Research recommendations

Our work also highlighted the need for research; it was evident from the effectiveness reviews that there were few robust, adequately controlled, studies completed to a high standard to answer basic questions such as what interventions work best, how, for whom, and over what period, and what is good value for money. The PDG recommended that robust methods for evaluating services for looked-after children and young people were developed by teams of multidisciplinary research specialists in health, social care, and economic evaluation. These should

- Explore barriers to conducting controlled studies (for example, concerns about random allocation of looked-after children and young people) and making recommendations to reduce these obstacles.
- Develop standardised, validated and reliable measures and robust tools to evaluate quality of life outcomes for use with all looked-after children and young-people from birth to 25 years, regardless of where they live.

Consider compatibility with health-related quality of life measures and the quality-adjusted life year.

- Ensure measures and methods include test–retest capability over the short, medium and long term and across the life course. Also offer robust parallel versions for completion by others including peers (that is, versions for proxy respondents), which can be translated into other languages with little or no loss of fidelity, and are designed to capture the impact of services and interventions on the quality of life of looked-after children and young people.
- indicate appropriate process and outcome measures to assess intended and unintended, short-, medium- and long-term impacts (positive and negative), enhance understanding of what outcomes are acceptable and valued by participants, and take into account the impact on particular groups.
- Give guidance on how to routinely capture robust outcome measures and aspects of wellbeing, taking account of developmental changes across the life course, and the abilities and needs of different participants.
- Explore how quantitative and qualitative methods can be combined in research to reflect the differential impact of the context, process, content and experience of those involved, as well as the impact (including the costs and health effects) of the intervention under investigation (including identification of barriers and facilitators).
- Explore whether non-randomised (observational and quasi-experimental) study designs can provide adequate evidence to evaluate services, and how to reduce sampling bias and improve the usefulness of these designs (1).

Recommendations were also made about reporting evaluations and economic evaluations.

Implementation

Since publication, NICE/SCIE have developed a portfolio of resources to complement the guidance and these are all available free online. An overview of information lists practical resources for people implementing the guidance, though it is focused on the UK (3). A slide set is available to facilitate local multi-agency partnerships as they consider what actions to take to implement the gui-

dance (4)
and there is a self assessment tool for any service, organisation or Local Strategic Partnership to determine how close their practice is to that recommended in the guidance and help prioritise
implementation activity (5). A costing report estimates the local costs and potential savings of implementation (6).

Conclusion

I have given a brief introduction to the NICE/SCIE guidance on promoting quality of life for looked after children and young people. While it is specifically written for the England and Wales context, colleagues in ESSOP may find material in the guidance and other resources that is useful in their own context. The challenge is in implementation and research to inform a revision in 2013.

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CHILDREN IN STATE CARE: SPAIN

José A. Diaz Huertas

Introduction

In recent decades, Spain has made significant progress on the issue of the child protection. The 1978 Spanish Constitution requires public authorities to protect the family in the social, economic and legal spheres, with special regard for children, as indicated in article 39.4

The Constitution recognizes and guarantees the right of the localities and regions of Spain to enjoy autonomy. This has led to the establishment of 17 Autonomous Communities that enjoy full independence in managing their own interests and have exclusive responsibility for social welfare, which includes child protection.

The first law that made provision for alternative measures to institutionalization was Law 21/87, passed in 1987.

Under this Law child protection was:

- de-judicialized so that these public authorities were now required to provide immediate protection to unprotected children. The role of social services was expanded, both in detecting a lack of protection and in taking immediate action.
- deinstitutionalized. Existing residential institutions were opened up; their children were sent to local schools and took part in local activities just like other children.

Alternative forms of family care, such as adoption and foster placement, have been developed over the last two decades. Various types of foster care are available to provide flexibility in responses to children's needs, as follows:

1. Simple foster placement, of a temporary nature because the child is expected to return to the biological family, or as an interim measure until a permanent solution is found;
2. Permanent foster placement, which occurs when required due to the age or particular circumstances of the child and family, and when requested by the relevant public authority. In this case, public authorities can ask a judge to give foster parents the powers they need to undertake their responsibilities to the full, always in accordance with the best interests of the child;
3. Pre-adoptive foster placement – the relevant public authority endorses a proposed adoption before a judge, provided that the foster parents meet the required conditions, have been selected and have consented, and that the child is suitable and ready for adoption.
   The public authority can also decide on this form of foster placement when it considers that the child needs time to adapt to the family before the proposal for adoption is presented. This period should be as short as possible and never last more than one year;
4. Open foster placements, or weekend or holiday foster placements, where children live with their alternative family during their holidays.

In Spain a year are detected at least 12,000 cases of child abuse in its various types, 30,000 children are served by the child protection services, half of them in protection centres and the other half in foster care, 800 Spanish children are adopted. All of these children have health problems and specific needs.

Quality Standards – Good Practice Criteria

In the 90´s in Spain the concept of good care to the Childhood is introduced as well as the need of establishing good practice criteria and quality standards as a means to improve the attention to Children and to prevent institutional maltreatment.

The Ministry of Social Affaires proposed a Principles and Criteria for Good Practice in Social Care to Childhood, with 36 proposals related with:

1. Family primacy.
2. Decission taking.
3. Need of a stable Integration Plan.

4. Separation.
5. The needs of the child.
6. Organizational aspects.
7. Education and support.

In 1997 the Spanish Society for Child Abuse Prevention (FAPMI) developed quality standards in residential care including the health care area and the role of doctors and other professionals.

Senate
A Senate Commission analysed the situation of the children in foster care centres in Spain, and currently they are debating a proposal of modification of the law that includes the measure that all children under 3 should be placed in foster families and never in residences.

Spanish Society for Social Paediatrics (SPS)
In 2009 the Spanish Society for Social Pediatrics (SPS) started a program sponsored by the Ministry of Health and Social Policy to determine the bio-psycho-social needs of the children in the system of child protection, elaborating guides for these children's health care, training the professionals in care of these children.

Council of Europe
The 9th Council of Europe Conference of Health Ministers will be celebrated on 29-30 September 2001 in Lisbon, Portugal, with the motto "Child Friendly Healthcare: Building a Healthy Future for and with Children".

In this meeting will be exposed the works about Child Friendly Healthcare carried out since 2009 by an Expert Committee appointed by the Council of Europe.

The Working Session III to be held on Thursday, 29 September 2011 at 16.00h will be about Fostering children's participation for child-friendly health care. Ministers of the different European countries will express their interest in this matter.

The proposed points for discussion are:

- respecting the specific problems and needs of children in health care settings as service users;
- ensuring that children are consulted, listened to and supported during decision making about their medical treatment;
- involving children in the design and delivery of health care services as well as, where appropriate, policy planning;
- making children real stakeholders – from social invisibility to social partnership;
- issues raised by the survey on children's participation.

European Commission – RICHE Project

The European Commission is developing the Research Inventory Child Health Europe (RICHE), with the target of establishing common health indicators for the European countries.

Health indicators of Child abuse and about Children in the system of child protection are being elaborated by Anders Hjern and myself -in representation of the Spanish Social Pediatrics Associationbased in the work of the Instituto Madrileño del Menor y la Familia (Child Protection Services of Madrid Region, Spain).

Conclusion

The children attended by the Protection System of the Minor have specific health needs.

The health professionals, pediatricians, nurses, need to receive training about children´s health for this population. It is necessary to establish health indicators and quality standards for their health care. We must make progress in the ways of care for these children (foster families) and in the means for giving this attention.

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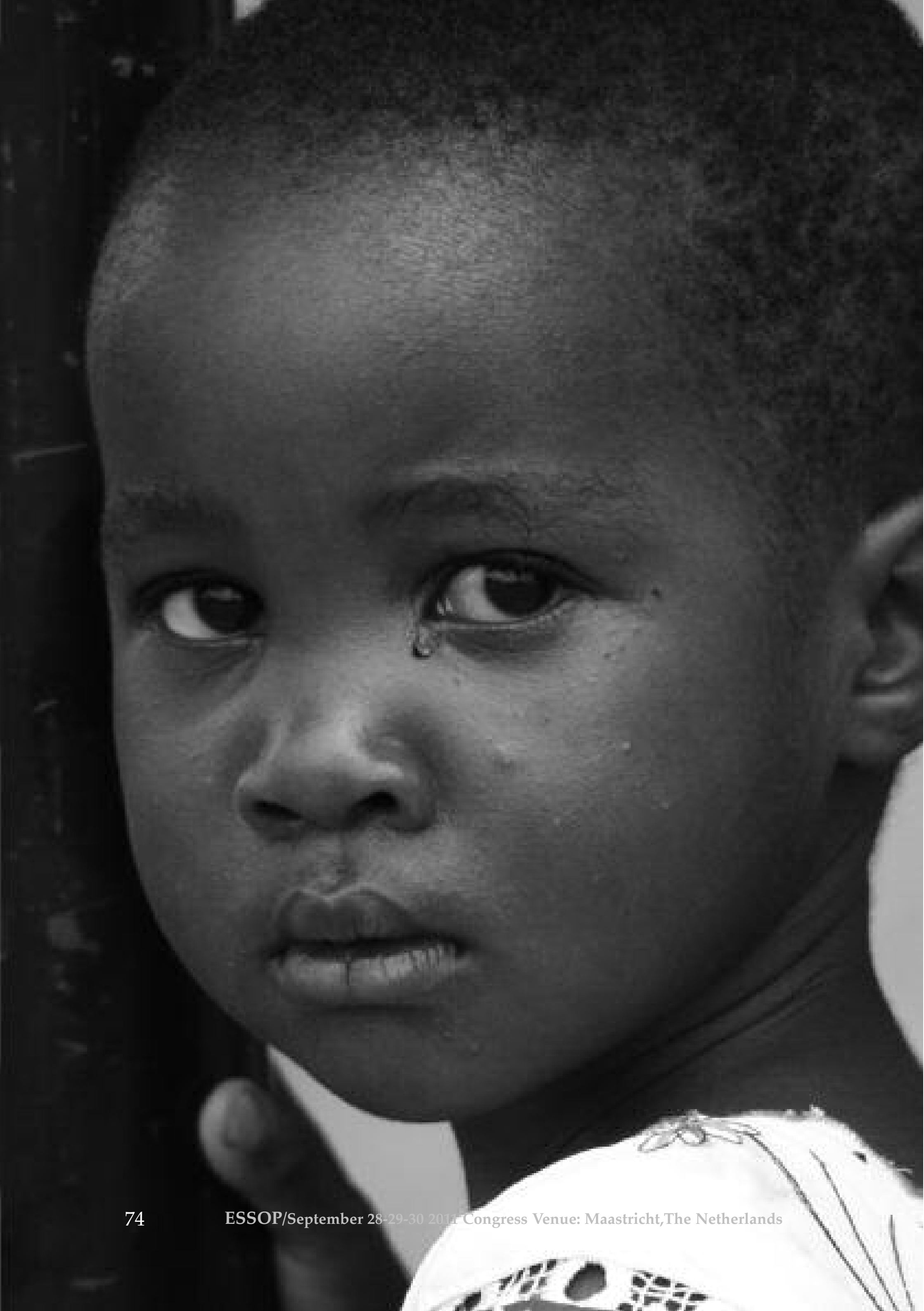
SHOPS

ESSOP/Partnerships in Prevention, Cure and Care



CHILDREN, SEX AND INTERNET
Behaviour, risks and consequences

Rachel Levi and Noor Landsmeer

Summary

In this workshop we will take a jump into the digital world that young people live in, a great deal of their time. We will talk about their online reality: what does the internet mean to young people? How does their online identity effect their online (health) behaviour? What are the risks and problems that they are facing online? What kind of understanding about their online world should every professional working with children have? Those and other questions will come across in this workshop.

The first part of the workshop will focus on young people and their online behaviour and victimization. The second part will focus on online sex offenders, grooming children. This summary is built up in the same way.

Part 1. Online behaviour and victimization

Young people and Internet

More than 90% of Dutch households were connected to internet in 2009 (Eurostat 2009). Only a handful of children don't have access to internet at home (de Rooij et al, 2008). 93% of the 6-18 year olds use internet (De Haan, 2010) and more than 90% use it daily (Eurostat, 2009). Research shows that young people spend 13-15 hours per week on the internet (IVO, 2009). Even 26% of toddlers in the age of 2-3 use the internet at least once a week (Sikkema, 2009). The internet offers a lot of great opportunities for young people. They have access to an enormous amount of information and fun stuff, like music, games, chats and social networks.

More than 80% of Dutch children between 9 and 16 years old are active on a Social Network Site. Friendships that started online, are valued just as highly as friendships that started in real life. Research amongst young people points out that speaking online sometimes brings them actually closer to a friend, that speaking in real life, because there are less feelings of shame. The quality of friendships improves with the addition of online contact amongst friends.

This lack of shame, and the way people build and gain trust online, can cause trouble for children.

Sex and internet

Also in the sexual development of youngsters internet has a big influence. Youngsters their curiosity about sex on internet. They can find all the information they need, without guidance.
There is not much parents can do about this. Media have become part of children's upbringing.
It is important to accept and understand this.

Research from Rutgers Nisso Groep (2005) points out that 62% of boys and 34% of girls (age 12-25) have searched on the internet for information about sex in the past half year. Internet is the main source for information about sex. Youngsters value the information they find online highly. 15% of the youngsters used the internet to have cybersex.

Youngsters also use the internet to experiment with their identity (Rutgers Nisso Groep, 2009).
There is a difference between their online and offline identity. 74% of the girls agrees that "most girls my age use social networking sites to make themselves look cooler than they really are."
41% admitted that this was also the case for their own online identity. Especially girls with a lower self-esteem 'pimped' their online profile into sexy (22%) and crazy (35%).

Dangers on internet

Internet is a big source for information and can be exciting for youngsters in many ways. Also the internet is a new and easy way to get in touch with people. However, there are some traps and dangers on the internet as well.
Most youngsters deal with their online problems quite well, but sometimes situations can develop into abuse with great impact. In this paragraph we discuss different types of online abuse.

Insult or slander

One type of online abuse is insult, or slander. For example when innocent pictures from a youngster are abused to produce videos of pictures with insulting comments or accusations. The goal is to affect a youngsters reputation and good name. An example of such slandering is the spread of video's in which specific girls are accused of being sluts, with their picture, name and phone number depicted. The impact of insulting messages spread on the internet can be enormous. It could be seen as a form of online bullying or . Insult is punishable.

Grooming

Child grooming refers to an act of deliberately establishing an emotional connection with a child to prepare the child for child abuse. Grooming can be done offline and online. Since the use of internet, grooming of children occurs more often online. Because internet provides the possibility to stay anonymous it's easy to lie to a child about real identity and age, and pretend to be a child as well, in order to gain trust. Goal of the adult, is to prepare the child (for example through chat rooms) for face-to-face meetings, with the intention to commit a sexual offence against that child. In the second part of this summary more information will be given on the offenders who use internet as a source for their grooming activities.

Webcam abuse

Webcam abuse occurs in different forms. Adults engaging in conversations with youngsters online can use their webcam for "mature" things without the consent of the youngster. This can be quite shocking.

Another form of webcam abuse occurs when experimental behaviour of youngsters is abused.

Youngsters who experiment with getting naked in front of the webcam, engaging in sexual behaviour, can be recorded without them knowing this. This material is then abused to blackmail the person depicted in the images. The victims are pressured and intimidated to divert their boundaries and go further and further with their sexual experiment, because otherwise the recording will be spread on internet. Even when such a recording does not exist, youngsters can be victim of blackmailing.

Just the threat or the possibility that someone might have slandering images, can cause youngsters to get in big trouble. Not only adults abuse the webcam for blackmailing in this way, it also happens amongst youngsters.

Another worrying situation is that webcams can be hacked. The webcam is turned on, without the user knowing anything about this. If the computer is in a youngsters bed-room and has an internet connection it is easy to obtain unwanted images.

Sexting

Sexting is sending sexually explicit messages via cell phone or instant messenger. Youngsters sext to show off, to entice someone, to show interest in someone, or to prove commitment. The risk of sexting is that photos and videos sent privately can easily be shared with others. Once a photo is sent, you lose control of that image, and it is impossible to take it back. The person receiving it can forward the image, copy it, post it online, or share it with anyone.

Problems happen when relationships end, and someone is left in possession of highly compromising materials. This can cause great damage to a person's reputation. There are also serious legal consequences. What most youngsters don't realise is that sharing sexual or naked photos of minors, even when it's pictures of themselves and even when they are only sharing with other minors, is illegal. Sexting can and has led to prosecution for child pornography.

Helpline for youngsters

In 2007 the Dutch Hotline combating Child Pornography on the Internet established the website Helpwanted.nl for youngsters. This website is made for young people (12-18 years old) to report online sexual abuse. Furthermore, teenagers, parents and caregivers can find information about the safe use of Internet on the website.

In 2010 the Hotline received 327 reports through www.helpwanted.nl. Most were about sexual abuse by means of webcam. Reports on online bullying have increased in the past year. The remaining reports are about violation of portrait rights, hacking, images of child sexual abuse on websites and peer-to-peer networks or (shocking) adult pornography.

In the workshop, some of the cases reported at Helpwanted.nl will be given as examples. The cases will show the impact of online abuse on youngsters and the need for (online) guidance.

Part 2. Online sex offenders, grooming children
In the second part of the workshop Nike Peters will reveal some of the conclusions from her master thesis: To catch a predator – about online grooming.

The results are based on cases from online sex offenders in a few different countries. They give some insight in the motivation of online sex offenders, the reasons behind their behaviour and the methods that offenders use to groom children. In this workshop you will learn more about how online sex offenders operate. Furthermore, the research gives you more information about the social-demographic characteristics of the offenders. It provides us with a 'profile' of 'who does it'.

Note: The report is not public at the time of writing this summary. This is the reason that there is no in depth information provided above, such as figures and statistics.

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The Dutch Hotline is an independent private foundation. Main objective is to contribute to the reduction of the distribution of child abuse images via the internet. With the ever increasing traffic on the internet Police, Ministry of Security and Justice and the Hotline have concluded that online child abuse has increased as well. Since the start of the Hotline the number of reports has increased enormously. In the past 10 years the Hotline has processed over 40.000 reports. The Dutch Hotline finds it important to raise awareness amongst Internet users about the fact that images of sexually abused children are on the Internet. Furthermore should they come across any of such images users are encouraged to report this at the Dutch Hotline or the police. In this way Internet users can contribute to the tracking down of distributors of images of sexually abused children, sexually abusers of children and they hence to the bringing to safety of the victims. The Dutch Hotline also educates Internet users about responsible use of the Internet. Through the website www.surfsafe.nl the Dutch Hotline wishes to raise awareness amongst children and parents about the risks of the Internet. The website www.helpwanted.nl is aimed at youngsters and contains a clear reporting form, information about safe Internet usage and there is the possibility to chat with one of the employees of Meldpunt.

PINKY

RESEARCH ON AND WITH CHILDREN: EPIDEMIOLOGICAL AND ETHICAL ISSUES

Stuart Logan

Participants in this workshop will have an opportunity to discuss the particular ethical issues raised by research involving children. They will also address the practical and ethical effects of involving families more deeply in all aspects of the research process.

To discuss some of the ethical aspects of medical research involving children, first the main ethical dilemma and the existing guidelines will be introduced. The focus then will be on the researcher's ethical obligation to enhance the direct medical benefits to the participants where possible, and to minimize, on the other hand, the research risks and burdens. The participants will be asked to explore the various ways in which this obligation can be met, with a focus on the possible role of patients and their families: how can researchers learn from their knowledge and experiences?

There is general agreement that involving families in the research process is important for both ethical and practical reasons but less certainty about how best this can be accomplished. In this part of the session participants will be encouraged to consider both some of the advantages and the potential pitfalls of family involvement. In addition, there will be the opportunity to discuss a number of practical issues and challenges including:

- How to involve families and get the ‘right’ people
- How to involve children
- Barriers to involvement
- Managing expectations and conflicting perspectives
- Supporting participants

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ACCESS TO INVESTIGATIONAL MEDICINAL PRODUCTS FOR MINORS IN EUROPE: ETHICAL AND REGULATORY ISSUES IN NEGOTIATING CHILDREN'S ACCESS TO INVESTIGATIONAL MEDICINES

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ABSTRACT

Patients who search for a better treatment, an increased quality of life, or even a chance to preserve life itself may claim to have an interest in accessing investigational medicinal products (IMP), particularly when no validated treatment for their disease or condition exists. For many, awaiting the uncertain and time-consuming process of converting an IMP into an approved drug may not appear a realistic option, as prognoses may be grim and a dramatic outcome may seem hard to avert. Gaining access to an IMP, however, often proves to be a difficult enterprise with a highly uncertain outcome. In addition, the process of seeking access to IMP is surrounded by various ethical issues that will be explored in this article.

This paper explores the ethical concerns in two potential tracks of seeking access to IMP for minors: on an individual basis, or collectively, as a patient organisation.

In this discourse, several unique ethical and regulatory concerns related to the direct negotiation of access to IMP for minor patients are identified, with a focus on product safety, the recruitment of research subjects, the unnoticed entry of market mechanisms in the recruitment of research subjects, and the sidelining of third parties in the recruitment process. The paper concludes with a concise reflection on the way forward.

The quest for access to investigational drugs is particularly relevant to paediatric practice, in which a significant share of the drugs prescribed has never been tested in children or labelled for use in the paediatric population.

Patients who search for a better treatment, an increased quality of life, or even a chance to preserve life itself may claim to have an interest in accessing investigational medicinal products (IMP), particularly when no validated treatment for their disease or condition exists.[1] For many, awaiting the uncertain and time-consuming process of converting an IMP into an approved drug may not appear a realistic option, as prognoses may be grim and a dramatic outcome may seem hard to avert. Therefore, patients have been actively seeking access to IMP ever since the AIDS crisis in the 1980s.[2] Gaining access to an IMP, however, often proves to be a difficult enterprise with a highly uncertain outcome.

In general, there are two ways to obtain access to an IMP, of which participation in a clinical trial is the most obvious. Unfortunately, many patients will be denied access to clinical trials as they fail to comply with the eligibility criteria or because the sample of research subjects is limited in number, time, or location. Alternatively, terminally ill patients can be granted access to IMP exceptionally under different types of compassionate use programmes, several of which exist in the USA, the EU and Canada. For patients failing to access IMP through participation in a clinical trial or under a compassionate use programme, there appears to be no systematic opportunity, not to mention a generally recognised right to access IMP, as is for example suggested in the paradigmatic case Abigail Alliance v von Eschenbach.[3 4]

The quest for access to investigational drugs is particularly relevant to paediatric practice, in which a significant share of the drugs prescribed has never been tested in children or labelled for use in the paediatric population.[5-7] As a result, the line between using IMP and prescribing medicines offlabel may at times be very thin, and therefore in paediatrics, IMP may be appear appealing as any non-validated treatment prescribed off-label. However, as off-label prescriptions are part of therapeutic practice and using IMP is part of drug development processes, there is a profound difference between prescribing treatments off-label and opening up the access to IMP. As a result, strategies to open up access to IMP for children create unique and profound ethical and legal issues. As creating access to IMP is clearly perceived as an interest of some paediatric patients, these issues need to be addressed urgently.

In this paper, we explore the ethical concerns in two potential tracks of seeking access to IMP for minors: on individual basis, or collectively, as a patient organisation. In our discourse, we identify several unique ethical and regulatory concerns related to the direct negotiation of access to IMP for minor patients, with a focus on product safety, the recruitment of research subjects, the unnoticed entry of market mechanisms in the recruitment of research subjects and the sidelining of third parties in the recruitment process.

INDIVIDUAL PATIENTS SEEKING ACCESS TO IMP: AN ILLUSTRATORY CASE

Sandra Massart, a Belgian girl aged 7 years with from metachromatic leukodystrophy, is rapidly declining in the absence of a validated treatment for her disease. Her parents devoted themselves indefatigably to provide her with Metazym, an IMP developed by the Danish firm Zymenex.

Sandra could not obtain Metazym through participation in a clinical trial becausedexceeding the upper age limit of 60 monthsd-she did not comply with the eligibility criteria of the running trial. Therefore, the parents searched for an alternative way to obtain Metazym and claim to have negotiated that Zymenex would provide Sandra with Metazym under the named patient programme on payment of approximately €45 000 per month, or €1 000 000 for 2 years of administration. Because the Belgian public health insurance rejected the parents' request to refund Metazym, an extensive media campaign was set up to raise the necessary funds. This campaign peaked when Belgium's largest commercial channel reported on Sandra's cruel fate during Christmas day's prime time newscast. In the following days, public indignation was nurtured and in no time the necessary funds were raised.

However, in sheer contrast to the rapid and easy fundraising, the family did not succeed in gaining access to Metazym. Shire, the British firm that had acquired Metazym by the time funds were raised, stated that they were unable to provide the family with Metazym, due to supply constraints.8 Even when production restrictions are not applicable, litigation fears and public relations concerns may constitute a hurdle to the provision of an IMP at the request of an individual patient.[1 2]

Recently, Shire announced that they were stopping the trials of Metazym because of the low efficacy.

Obviously, this complex case raises many more ethical issues than that of access to IMP alone. However, in this paper, we will limit the scope of the ethical assessment of this case to the issue of access to IMP.

NEGOTIATING ACCESS COLLECTIVELY: THE COLLECTIVE CLAIMOF PATIENT POPULATIONS

The case of Sandra Massart clearly illustrates the interest in accessing IMP that may be attributed to individual patients.

Similar to this individual interest in accessing IMP of individual patients, a collective interest in accessing IMP can be claimed by patients with the same disease. As a consequence, it is worthwhile to extend the scope of ethical reflection on the direct negotiation of access to IMP from the individual level to a group level. As patient organisations serve the collective interests of patients at such a group level, it is worthwhile to explore their potential role in negotiating the access to IMP collectively.

Theoretically, patient organisations are well placed to discuss and negotiate the access to IMP for the collective of their members. Not only do they increasingly present themselves as partners of the pharmaceutical industry in drug development,[9] their role in the field of clinical research also well exceeds that of individual research subjects,[10] providing them with a wide repertory of assets that may appeal to the producers of IMP. First, patient organisations are a major source of information to their members, and may raise enthusiasm as well as suspicion about clinical trials among them. Second, patient organisations may actively contribute to the success of clinical trials by facilitating the recruitment of research subjects, which is often difficult for paediatric clinical trials. In addition, patient organisations are well placed to create patient registries, which are of great importance to clinical research. Third, patient organisations may be willing to provide financial support to clinical research, which enables them to press on the research agenda and direct clinical research towards the experienced needs of the patients they represent. In addition, to a certain extent, acting as a research funder grants patient organisations a say in the design of clinical trials, including the eligibility criteria for trial participation. Holding these assets, patient organisations enjoy a privileged position in the negotiation of access to IMP, particularly with regard to IMP provided to research subjects in clinical trials.

ETHICAL AND REGULATORY CONCERNS

The negotiation of access to IMP, either by individuals or patient organisations, generates various ethical and regulatory issues that need to be addressed. In particular product safety, the recruitment of a sufficient number of research subjects, the unnoticed entry of market mechanisms in the recruitment of research subjects, and the sidelining of third parties involved in the recruitment process deserve specific attention in this respect.

Product safety Obviously, the therapeutic nature of an IMP is contingent until its safety and efficacy have been tested, appropriate dosages and administration forms have been determined, and adverse effects have been identified. Therefore, the control of product safety of medicinal products is a time-consuming process,11 and hastening access to these productswill expose patients to considerable risks, as serious toxicities are often only detected in late stage drug development.

12 13 Nonetheless, the benefits of using IMP may appear plentiful to patients, and the odds are that for many patients the risks and therapeutic contingency of IMPwill easily be overruled by their presumed benefits, particularlywhen no validated drugs exist, and time is pressing because patients deteriorate rapidly.[11]

However, in paediatric clinical research, product safety is of special importance as minors, in contrast to their adult counterparts, are most often considered incapable of taking full responsibility for voluntary risk taking. This renders it unethical to expose minors to research risks unnecessarily, not only in the sense that minors should not be exposed to unnecessary research risks, but also in the sense that no more minors than necessary should be exposed to research risks, regardless of their severity or acceptability. In this regard, based on the ethical principle of nonmaleficence,[14] many ethical codes and legal regulations require that clinical trials of IMP are only conducted in as few minor subjects as necessary to obtain relevant research results. Therefore, opening up the access to IMP to more patients than required to gather relevant data raises serious ethical concerns, also when access is facilitated outside the setting of clinical trials.

The requirement to limit the number of subjects in clinical trials to a minimum, however, does not automatically rule out the compassionate use of IMP when patients enter a case beyond aid and no more therapeutic options are available.

However, here, vulnerable parents who may be willing to spend fortunes on ill-founded hopes and despair should be protected against the drawbacks of an unregulated market. As medicinal products are subjected to strict licensing and marketing requirements for very sound reasons, any commercial supply of productsdmost often at an excessively high costdappears ethically questionable. Therefore, we suggest that the provision of IMP for compassionate use should never be organised as a free market or by direct negotiation between the beneficiary and the producer. Quite the reverse, society should take the important responsibility of protecting all who have outreached the scope of therapeutic options against the devastating consequences that ill-founded hopes and despair may have. As IMP are to be situated at the frontline of medical innovation, one must question whether it is acceptable to send minors to the front, acknowledging that the majority of IMP will not make it to validated drugs,[11] and the use of IMP is likely to expose more minors than necessary to considerable research risks.

The recruitment of a sufficient number of minor research subjects

The conduct of clinical studies in a sufficient number of eligible research subjects is indispensible to develop safe and efficacious 792 J Med Ethics 2010;36:791e794. doi:10.1136/jme.2010.036442 Law, ethics and medicine Downloaded from jme.bmj.com on November 26, 2010 - Published by group.bmj.com drugs.[2,13] However, opportunities to access IMP outside of clinical trials are likely to interfere gravely with the already difficult recruitment of minor research subjects.[1,15] In particular, the many patients who seek to avoid random assignment will seek access to IMP outside of clinical trials, and may even try to render themselves ineligible for trial participation.[1]

Apart from these recruitment difficulties, permitting companies to provide unapproved IMP against payment contrasts sharply with the extensive efforts to encourage the pharmaceutical industry to invest in complex and expensive clinical trials,[2] including the provision of considerable incentives to compensate the poor profitability of paediatric drug development.[16,17] Preserving recruitment from market mechanisms Ever since the involvement of human subjects in clinical research has become the subject of extensive ethical guidance and legal regulation, considerable efforts have been made to preclude market rationales from becoming involved in the recruitment of minor research subjects. For example, in Europe, the provision of payments or other incentives to researchers, minors, and/or their parents has been regarded with great suspicion because of the bias and conflicts of interests such incentives may generate.

However, when patients negotiate their access to IMP outside of clinical trial participation, market rationales tend to enter unnoticed.

For example, obtaining IMP outside of clinical trials comes at a price, which can be excessively high.[1] Also when patient organisations negotiate their members' access to IMP within clinical trials, market rationales tend to become involved. The fact that the owners of IMP have something of great interest to the members of the patient organisation and that patient organisation owns several assets of interest to the producers of IMP provides all the ingredients for market-driven exchanges. The unnoticed entrance of market mechanisms in paediatric clinical research cannot be reconciled with the ethical premises and legal requirements that have been governing paediatric research for decades now. Therefore, care should be taken that market rationales do not erode the voluntariness and altruism that traditionally underpin research participation. Keeping third parties involved Third parties, such as competent authorities, regulatory bodies, ethics committees and physicians who operate independently from the sponsor play an essential role in the design and conduct of clinical trials. However, the direct negotiation of access to IMP between patients and companies willing to provide IMP to them tends to bypass the timely involvement of such third parties, releasing this form of experimental drug use from substantive scientific and ethical assessment. While it is obvious that competent authorities, regulatory bodies and ethics committees will always have entry points in the development and supply of IMP, the involvement of physicians operating independently of the sponsor (eg, hospital physicians agreeing to cooperate with a clinical trial and to recruit among their patients) tends to fade away when access to IMP is negotiated directly between patients and sponsors.

Nonetheless, such physicians have several important opportunities to implement ethical standards in practice.

First, being committed to the treatment of their patients, physicians are well placed to assess whether an IMP, administered either within or outside a clinical trial, suits an individual patient against the background of the medical history, the current condition and the prognosis of the patient concerned. In consequence, physicians are well placed to inform their patients about all relevant aspects of using an IMP, which is likely to counter misplaced enthusiasm about IMP, similar to therapeutic misconceptions in clinical research.[18] Second, the relationship of trust that physicians have established with their patients over time appears to be an excellent situation in which to discuss the use of an IMP. Third, operating independently from the sponsor, physicians can easily refuse to recruit subjects among their patients when they judge that a study protocol is ethically unacceptable or does not serve the interests of their patients, even when the protocol has been approved by an ethics committee and the competent authority.[19] In this way physicians personally provide an additional ethical assessment of study protocols.

CONCLUSION AND DISCUSSION

It is encouraging that new innovations in clinical research are considered to be of interest to minor patients, that hope in future scientific developments is cherished, that enthusiasm about new IMP is raised, and that minor subjects find themselves prepared to participate in clinical trials. Enthusiasm and hope, however, should not push the desire for health innovation beyond the ethical and regulatory safeguards that have been integrated into the procedures of clinical trials and alternatively in systems of compassionate use. However, in a setting in which a relatively large share of the drugs used have not been tested for safety and efficacy, such as paediatric health care, patients who seek a better treatment, an increased quality of life, or even a chance to preserve life itself may claim to have an interest in accessing IMP, and actively seek access to IMP, either individually, or collectively as a patient organisation. In this article, four serious ethical concerns in the quest for access to IMP have been explored: (1) product safety; (2) the recruitment of research subjects; (3) the unnoticed entry of market mechanisms into the recruitment of research subjects; and (4) the sidelining of third parties in the recruitment process. These ethical concerns indicate that broadening the access to IMP is a very precarious enterprise that appears hard to align with existing ethical and regulatory frameworks. In addition, it is strongly to be discouraged that vulnerable parents are tempted to spend large amounts of money on ill-founded hopes and despair. On the other hand, access to IMP can be provided legitimately, as is currently done within clinical trials and compassionate use programmes. However, these ways of providing IMP have a number of constraints that are open to discussion. First, both clinical trials and compassionate use programmes have no truly systematic way of determining which patients can be provided with IMP. This may appear manifestly unjust to the parents of children whose lives are at stake, and is therefore very likely to be hard to accept. Against this background, families may actively seek access to IMP, even outside of clinical trials and compassionate use programmes, and backed by massive support from the media and the public at large, as the case of Sandra Massart indicated. Second, any determination of who is eligible for clinical trial participation is a result of scientific or policy choices, which are open to discussion and change. Therefore, notwithstanding the profound ethical concerns described in this article, patients, individually or collectively, may feel they have strong reasons actively to seek access to IMP.

Responding to the phenomenon of the direct negotiation of access to IMP adequately, however, is a complex challenge. A mere prohibition of access to IMP outside clinical trials and compassionate use programmes is not sufficient in this respect, because the direct negotiation of access to IMP between patients and drug developers may also affect access within clinical trials J Med Ethics 2010;36:791e794. doi:10.1136/jme.2010.036442 793 Law, ethics and medicine Downloaded from jme.bmj.com on November 26, 2010 - Published by group.bmj.com or compassionate use programmes. Three additional concerns are in need of ethical attention. First, firm and realistic understanding about what is to be expected from healthcare and drug development should be nurtured in all actors involved. No matter how tragic the situation or how strong and emotional appeal to a last resort, it should always be recognised that IMP are no panacea. Opening up access to IMP will not discharge patients in need from irreversible, and at times cruel and fatal disease.

Also, the fact that time may work against cure will not be resolved by opening up access to IMP (unless maybe in an extremely exceptional case).

The recognition that disease can come as an inevitable tragedy is not to result in scepticism towards drug development but merely serves to show that the disadvantages of rushing a process as complex, contingent and risky as drug development are likely to outweigh the benefits. Against this background, one should be vigilant about what claims to health care we support as clinicians, patient organisations and society at large (including popular media, as the case of the family Massart clearly illustrates). Second, ethical and regulatory guidance should enter the drug development process as early as possible, preventing direct partnerships between patients or patient organisations and drug developers from taking place in an underregulated environment. In contrast to the provision of IMP in clinical trials or compassionate use programmes, partnership between patient organisations and drug developers as such is not specifically regulated or guided. This does not imply that such partnerships are to be avoided, but raises concerns about how ethical and regulatory issues are to be addressed, for example when such partnerships result in agreements that shape the research agenda or the design of future clinical trials. In particular, concerns related to the unnoticed entry of market mechanisms should be detected and addressed as soon as possible. Therefore, a timely involvement of third parties in the partnership between patient organisations and drug developers, including experts in treatment, ethics and law is strongly recommended. Third, it is both prudent and responsible to rely on important efforts to supply safe and efficacious drugs for the young that are currently being made. In the European Union and elsewhere, important efforts have been made to encourage and reward the development of safe and efficacious drugs for minors. Against this background, one must be particularly vigilant that recruitment for clinical trials is not hampered by efforts to facilitate or extend access to IMP. Although time consuming, the quest for better treatments and increased quality of life should obviously focus no regular processes of drug development in controlled clinical trials.

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MEDICALLY UNEXPLAINED SYMPTOMS; UNEXPLAINED? INTEGRATED APPROACH FOR SEVERE INVALIDATING MEDICALLY UNEXPLAINED SYMPTOMS (MUS)

Andrieke C. Knottnerus, Bert H. Derkx
and Ellen Kohnhorst

Medically unexplained symptoms (MUS) often occur, also in children. These are complaints that cannot be explained by a somatic disease in the traditional way. In children abdominal pain, headache, fatigue and complaints of pain in joints and/or muscles are the most common functional somatic complaints.(1) The incidence of recurrent abdominal pain (at least once a month during three following months without an organic cause) is 8-25% for children aged between 9 and 12 years old.(2) MUS are in literature also known as e.g. somatic unexplained symptoms, physically unexplained symptoms or functional somatic complaints. By using the term unexplained the impression is made that it is not possible to declare these symptoms. Actually there is more and more known about the neurobiological background of these symptoms. (3;4) Besides that, the term unexplained can give the patient the feeling that the doctors are in doubt about the existence of the complaints. Stone et al concluded after research that functional complaints is the best accepted term by patients (5). All these reasons together lead to the choice of these authors to use the term 'functional'; meaning that there is nothing wrong with the organ itself, but it doesn't function the way it should. In most of the children the complaints disappear spontaneously or after visiting the general practitioner, medical specialist, physiotherapist, psychologist or an alternative therapist. Part of the children and their family get stocked in the complaints and their consequences. In these children, presenting with therapy resistant functional somatic complaints, there is often more than one complaint (6). This increases the impact on the life's of the patient and family, enlarges the confusion and the anxiety about having one or more severe diseases followed by the quest for medical diagnosis. The idea that complaints originate in either body or mind makes these functional complaints hard to understand for the patients and their family, but also for the doctors and other therapists working with these patients. After ruling out all the medical causes, the complaints have to be psychological; an idea that often insults the patient and the parents, because this makes them feel their doctor thinks it is all in their mind. So there must be psychological problems or they are making things up. This can lead to a disturbed doctor-patient relation and non-compliance in treatment. (7)

The Psy-Med Unit (PMU), Emma's Children Hospital, Academic Medical Centre Amsterdam, a tertiary referral centre for children with invalidating functional somatic complaints, presents a new approach for these complaints; an approach out of the vision that body and mind are one. The purpose of the PMU is to help the patients and their families minimize the complaints and return to the life they lived before the complaints started.
The patients are seen by a paediatrician and a psychiatrist/psychotherapist together from intake on. The patients are between 6 and 18 years old, have therapy resistant complaints for longer than 3 months which have an invalidating influence on the patient's life and their family life. This is seen by at least 2 of the following: school absenteeism (at least one day a week), giving up of hobbies and less social contact with peers till social desolation. The approach starts with a two hours lasting intake by pediatrician and
psychiatrist/psychotherapist seeing the patient and family together. At the beginning of the intake it is explained by the following examples to patient and family that body and mind belong together.
'When you have physical complaints it can make you angry or sad. When you are scared you can experience physical reactions; heart beating, abdominal pain etc.. So, physical complaints/symptoms can lead to emotions and vice versa. (8) The place where this all is arranged, are your brains. You cannot experience pain without your brains; physical signals are processed there and signals return to your body from there. But they also go to your emotional centres. So there is a continuous cooperation between body and mind.
That's the reason why we sit here all together.'
The patient and their family are asked to tell their entire story even

though all their history is known from the earlier caregivers. This will include all the consequences of the complaints, the fears and thoughts about the complaints, the way the family deals with the complaints, what diminishes and what aggravates the complaints. A thorough physical examination is done. Emphasized is that the complaints are real even though a specific somatic cause hasn't been found. This all is part of validation of the complaints. On the other hand it is mentioned that there are methods to help them without knowing the specific somatic cause.

The combination of complaints is very confusing for patients and family, as mentioned before. All the complaints together are explained in an individual declaration model based on the patient's individual and family situation, including the interaction between the body and mind. Neurobiologic models are used for this explanation, eg stress model, pain sensitization model and somato sensory filter hypothesis. The stress system switches on when a stress stimulus occurs. This could be everything; from someone who scares you till a pain experience or disease (emotional and physical). Maybe even more important, the stress system has to switch off when 'the danger' is over. When this failed deregulation of this system happens. Many functional somatic syndromes can at least partly be declared by an over- or under-activation of the stress system. After a period of over-activation the system can pass into under- activation. (9) A continuous activation of the stress system can give complaints of tiredness, nausea, dizziness, heart beating, transpiration ea. Another model often used is the somato sensory filter hypothesis. (10). This hypothesis is based on the fact that by an increased activity of the limbic system less somato sensory signals are caught away, more symtoms/complaints are experienced. Stress in all ways causes an increased activity of the limbic system. So this hypothesis is related to the stress model. The last hypothesis regularly used is the pain sensitization model. (11) This hypothesis presumes that after extreme or long lasting pain the pain perception continues after the tissue damage has recovered. The body gets more and more sensitive for pain and the threshold for pain experience is lowering. This model is also linked to the stress model, because every experience of pain causes a stimulus of the stress model in the hypothalamus. The limbic system is excessively active in chronic pain, suggesting psychological factors being important in chronic pain. (2;12) This also brings the three models in relation.

In composing the individual explanation models every time there is chosen which model fits most to this patient and their family or more than one model is used. Out of the individual declaration model an individual treatment plan is assembled. Treatment elements could be par example graded exercise, rehabilitation, cognitive behavioral therapy. Which element is chosen depends on what kind of patient in what kind of phase in treatment. Learning

mentalisation is another important component of the treatment including learning to listen to the borders of your body and the change from only experiencing complaints to reflection on the complaints. Depression and anxiety are very common in this population. (13;14) The question is if this could be seen as a different disease or are the complaints the physical expression of the depression/anxiety. There must be attention for trauma's in history. Research suggests that early trauma's increase the sensibility for stress later in life.(15) Chronic traumatising results in a continuous activated stress system and could be related to functional syndromes as described by Van Houdenhove. (16) It is impossible to treat these patients without being informed about their parents/family. Modelling is the process the child learns from their parents how to deal with physical symptoms. Children of mothers with IBS show significant more abdominal pain but also other complaints than children in a control group. (17) Negative attribution; parents who are directly connecting the complaints to a severe disease, often occurs in MUS. It is important asking directly about the attribution of the complaints during the intake. Having worried parents seems to influence the seriousness of the experienced complaints. (17) Walker et al have shown in an experiment that attention for the pain by the parents attributed to the persistence of the pain.(18) Knowing the psychiatric history of the parents is also very important; a parent with a psychiatric disorder experiences the complaints of his child differently. On the other hand genetic components could play a role. (19)

The purpose of this workshop is that you learn about the pathogenesis of the functional complaints and how to use this knowledge in practice. Using the declaration models in contact with your patients is practised during this workshop by roll models after a theoretical explanation.

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AN ATTACHMENT AND MENTALIZING APPROACH
TO THE TREATMENT OF
PATIENTS WITH FUNCTIONAL SOMATIC DISORDERS

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Patients with chronic pain and fatigue constitute a considerable proportion of patients seen in routine clinical practice. Yet, chronic pain and fatigue conditions are very complex disorders, not only from the perspective of causation, but also from a treatment perspective. Although the precise nature of these conditions remains unclear, research increasingly suggests that complex interactions among biological and psychological factors are involved both in the causation and maintenance of these disorders [1-4]. Hence, rather than considering these disorders as somatoform or medically unexplained syndromes, it seems more appropriate to conceptualize these disorders in terms of functional somatic disorders. A further complicating factor is that these conditions are notably heterogeneous with respect to etiology [5, 6], which renders it highly unlikely that a “one size fits all approach” is effective in the treatment of these conditions [2, 7]. Although several psychosocial treatments, and most notably Cognitive Behavioral Therapy and Graded Exercise Treatment, lead to improvements in core symptoms [8-11], treatment strategies have in many respects lagged behind insights into the nature of these disorders [2, 4, 7]. This may explain in part the relatively limited effects of current evidence based treatments. There is therefore an urgent need to develop more effective treatments, that are more solidly rooted in extant knowledge of the causation these disorders [2, 7, 12].

In this workshop, we introduce the rationale and basic treatment principles of Dynamic Interpersonal Therapy for patients with functional somatic symptoms (DIT-FSS), a novel treatment approach that is currently being developed and evaluated. DIT-FSS is rooted in attachment and mentalization-based approaches to FSS and primarily addresses the relationship between functional somatic symptoms and interpersonal functioning. DIT-FSS focuses primarily on impairments in mentalization (the ability to understand both the self and others in terms of mental states) that negatively influence interpersonal relationships and feelings with regard to the self, that in turn maintain and exacerbate symptoms. DIT-FSS entails an active approach addressing impairments in mentalization with regard to both others and the self (with a special focus on embodied mentalization), and how these impairments are related to attachment experiences, but also to current symptoms and circumstances. Indeed, although in some patients impairments in mentalization are related to disrupted attachment relationships in the past, they can also result from or can be reinforced by chronic pain and fatigue and negative responses from (significant) others, including health professionals. Basic interventions and techniques used in DIT-FSS will be illustrated by means of a discussion of clinical vignettes.

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USING OUR CURRENT UNDERSTANDING OF PRESCHOOL CHILDREN AT RISK OF ADHD TO SUPPORT EARLY IDENTIFICATION AND INTERVENTION

Petra Hurks and Emma Van Daalen

Abstract:

Attention-deficit/hyperactivity disorder (ADHD; APA, 1994) is characterized by the core behavioral symptoms of inattention, hyperactivity, and impulsivity. It is a developmental disorder that affects approximately 1–5% of children worldwide (Barkley, 1998; Birnbaum, Kessler, et al., 2005). Kroes et al. (2001) estimated the prevalence rate of ADHD within a population of Dutch school-aged children at 3.8%. This indicates that over 100,000 Dutch children and adolescents are currently suffering from the symptoms of ADHD. The impact of ADHD is believed to be profound, not only in terms of the child's well-being, but also for his or her direct family as well as for our society in general. In literature, ADHD has often been associated with e.g., poor school or work performance, poor relationships with family and friends, low self-esteem, substance abuse, accident proneness (e.g., automobile collisions, poisoning, and fractures), and an increased percentage of comorbid syndromes (ie, disorders that co-occur with ADHD), such as depression and behavioral disorders. The problems seem to continue as the child gets older, at least to some extent. Various outcome studies have followedup children with ADHD into adolescence and found varying rates of persistence (43–72 percent), high rates of co-morbid behavioural disorders (such as Conduct Disorder or Oppositional Defiant Disorder), and increased rates of substance abuse - most frequently with alcohol, tobacco, or marijuana, rather, than cocaine or opiates and other street drugs (Steinhausen, 2009; Biederman et al., 2000; Rasmussen & Gillberg, 2000). Therefore, despite a rather simple clinical definition, ADHD has many facets because of frequent comorbid disorders and their varying impact on psychosocial functioning (Steinhausen, 2009).

Not surprisingly, individuals with ADHD utilize a greater than average share of healthcare, mental health, social, and special education services. For instance, Haakkert-Van Roijen et al. (2007) found that the mean direct medical costs per Dutch ADHD patient (and his or her mother) per year were $3902, compared to $467 for the group of children with no behaviour problems. For the US, societal costs seem to be comparable. Birnbaum et al. (2005) estimated the total cost associated with ADHD in the US in 2000 at $31.6 billion, including the care for children and adults with ADHD ($16.3 billion) as well as for their families ($15.3 billion). However, being treated, annual costs of persons with ADHD seem to decrease significantly, i.e., $19.8 billion for those untreated versus $11.8 billion for those treated. These data stresses the importance of (reliably) classifying and (successfully) treating individuals with ADHD, preferably at an early age. In her lecture, Petra Hurks will focus on the current state of affairs in terms of (early) identification and intervention of children with increased levels of impulsive behavior, inattention, and/or overactiveness. Note: The speaker discusses these topics primarily within a neuropsychological (and/or neuroscience) framework.

Why is this neuropsychological framework of particular importance? Neuropsychology is a branch of psychology and neurology that aims to understand how specific psychological processes (e.g., memory, language, motor behaviour, and affect) relate to the structure and function of the brain. Thereby, studies examining the neuropsychology of ADHD provide an opportunity to understand the relationship between underlying biological processes and behavioural or psychological symptoms of ADHD. Indeed, although the exact cause (or causes) of ADHD is (are) not fully mapped, there is consensus that ADHD is caused by a highly complex interplay of environmental factors (e.g., parenting style, motivation) as well as neurobiological factors (including genetics, brain structure and their influence on neuropsychology). For one, neurophysiological and/or neuroimaging evidence is pointing towards an involvement of the frontal-striatal circuits in ADHD (Barkley, 1998; Oades, 1998; Sagvolden & Sergeant, 1998; Dibbets et al, 2010; 2011). Also, from a neuropsychological perspective, ADHD is associated with deficits

in well-defined neurocognitive domains, including sustained attention, working memory, planning, self-regulation and time management (Barkley, 1998; Pennington & Ozonoff, 1996; Hurks & Hendriksen, 2011; Gonzalez-Garrido et al., 2008).
Finally, although many treatment strategies that have been used for this condition, including various psychotropic medications, megavitamin and orthomolecular therapies, dietary management, sensory-integration therapy, chiropractic manipulations, meditation or relaxation training, traditional play therapy, and faith healing (Bussing, Zima, Gary, & Garvan, 2002; Chan, Rappaport, & Kemper, 2003; Concannon & Yang, 2005), efficacy has been demonstrated only for parent training (e.g., counseling and behavior management), teacher training (e.g., educational and behavior management), cognitive behavior therapy, and stimulant medication (Dryer, Kiernan, & Tyson, 2011). This supports the relevance of studying brain-behavior relationships in ADHD.

The vast majority of this research is based on school-aged children between 7 and 12 years of age, even though ADHD has an onset prior to age 7 years by current definition (APA, 1994). This is unfortunate, as e.g., Mahone et al. (2011) found that, by the age of 4 years, as many as 40% of these children have sufficient problems with attention to be of concern to parents and preschool teachers. In line of this, 59 to 86% of preschoolers are referred to psychiatry clinics for ADHD-related problems (Wilens et al., 2002). Additionally, several authors (e.g., Bussing, Masson, Bell, Porter, and Garvan, 2010; Sagvolden & Sergeant, 1998; Taylor, Chadwick, Heptinstall, & Danckaerts, 1996; Weiss & Trokenberg Hechtman, 1993; Kalff et al., 2002; Kalff et al., 2005) found that subthreshold ADHD in early childhood is associated with later academic failure and grade retention. Early identification and treatment of children presenting with attention problems in the preschool years may minimize the harmful impact of ADHD (Sonuga-Barke & Halperin, 2010; Wilens et al., 2002). Thereby, studies including children < 7years old increases our knowledge in terms of e.g., developmental cognitive trajectories, neurobiological course, early markers, diagnostic methods, but also treatment options. Petra Hurks will provide an overview of the available research regarding these topics and discuss its relevance as well as its limitations.

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COMPARISON OF EARLY CHILD HEALTH AND DEVELOPMENT SERVICES OF CANADA AND THE NETHERLANDS

Meta van den Heuvel

Key words: child health services, child development, social medicine

Abstract:

Early childhood is a key time in the physical, cognitive, and social development of children. It is also a key time when public health, the health care system, and social services can impact on the life trajectory of a child. Although investment in early child development (ECD) programs benefits individual children, the potential to "lift all children up" exists on a population scale. In this study, we compare the early child health and development services of Canada and the Netherlands. Both countries are signatories to the United Nations' Convention on the Rights of the Child, and have invested extensively in ECD programs. Both countries also offer free health insurance for all children. However in both countries the services offered are complex and fragmented across various levels of government and neither country has a comprehensive system to measure outcomes of programs and services.

Objective: The purpose of this comparison is to highlight similarities and differences between both countries that could better inform ECD policies which can help to decrease the inequality gap between children.

Methods: We compared 7 indicators which are associated with positive child health and development outcomes. These included: 1) prenatal care, 2) maternal leave, 3) care at time of delivery, 4) breast-feeding, 5) child health care, 6) early childhood education and child care services (ECEC), and 7) early school programs. These indicators were chosen as they provide information across the span of early childhood from the prenatal period to preschool.

Results: The child health care programs tend to be more organized in the Netherlands than in Canada, and the Dutch child health system overall scores better according to internationally used key health indicators. In comparing Canadian ECEC services with Dutch ones very little information was found on the access, quality and long-term effects of ECEC services available in both countries.

Discussion: There is an emerging need for measuring the quality and effects of all ECD programs offered in both countries. Further efforts should focus on improving developmental outcomes for children universally through evidence-based, systematic programs and policies, and continued measurement of key indicators to ensure success is measurable.

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EXCLUDED GROUPS TO HEALTH SERVICES IN MONKEY BAY, MALAWI AND GLOBAL PARTNERSHIP

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Introduction: One important tendency in evaluation and monitoring of development assistance is to evaluate large themes while less importance is given to projects and programme evaluations. The focus should be on the Millennium Development Goals (MDGs) and the local socio-economic context. Since the year 2000, the Icelandic International Development Agency (Iceida) has supported the health services in the Monkey Bay area in Mangochi district in Malawi. In the area, health services are delivered by two governmental run health facilities and three health facilities run by CHAM (Christian Health Association of Malawi).

Objectives: Identify population groups that are excluded from health services in the area.

Methods: The study was conducted in April 2009. Interviews were held with over 140 individuals, including health professionals and community members, and conducted with the help of a translator from the local language of Chichewa to English, as needed. The interviews were based on open-ended questions that related to the health service delivery and seeking of health care. In addition, quantitative information on attendance to the out-patient departments was collected and analysed.

Results: Access of poor people to services was identified as curtailed in areas served by privately run CHAM facilities that apply user-fees in contrast to governmental run services where the services are free of charge. Thus, government run health facilities were asked for in areas under the responsibility of CHAM. Some argued governmental health centres had to follow governmental rules, while private clinics did whatever they liked to earn money: “It is their business.” One respondent argued there is a social bias in the whole system: “Someone who lacks money is dead.” Functional transport vehicles were considered crucial to minimize exclusion to health services.

Conclusion: Increased attendance figures and general satisfaction with the governmental health services in the Monkey Bay area, with Iceida support, should not disguise the fact that some groups may for various reasons be excluded from attending. In line with the MDG 8, global partnership is crucial if the MDGs are to be achieved, in particular those that address prevention, cure and care of mothers and their young children.

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PREVENTION OF RECURRENT RESPIRATORY TRACT INFECTIONS IN DOWN SYNDROME: WHAT COULD POTENTIALLY BE GAINED?

Helma van Gameren-Oosterom

KEY WORDS Down syndrome, recurrent respiratory tract infections, development, health related quality of life, behavioural problems

Abstract*:

Background and aims – Recurrent respiratory tract infections (RRTI) are frequently seen in children with Down Syndrome (DS). Both parents and clinicians believe that RRTI have a large impact on these children. Therefore, we addressed the potential effect of improved preventive care for RRTI in children with DS on developmental status, behavioural problems and health related quality of life (HRQoL).

Methods – During a 3-year period, all members of the Dutch DS Foundation with an 8-year-old child with DS were asked to fill in the Child Behavior CheckList and TNO-AZL Children's Quality of Life Parent Form. Also, a psychological assistant administrated the McCarthy Scales of Children's Abilities. Based on parental report, the children were divided into increased RRTI (RRTI+) and no increased RRTI (RRTI-). Linear regression analyses were performed to assess the effect of RRTI on the outcomes, correcting for the influence of confounders (i.e. presence of siblings, socioeconomic status, childcare attendance, being breastfed (>1 month), gender and comorbidity).

Results – The influence of RRTI was significant for most outcome measures, corrected for the influence of confounders. Compared to RRTI- children (n=176; missing data n=12), RRTI+ children (n=149, 46%) showed lower mean developmental age (3.67 vs. 4.08 years), more behavioral problems and lower scores on most HRQoL scales (p-values<.05).

Conclusions – Our study shows that RRTI have a significant impact in 8-year-old DS children: it causes relatively more delayed development, more behavioural problems, and lower HRQoL. Since RRTI are potentially preventable, further studies should focus on its causes and results of more aggressive treatment of RRTI in children with DS, such as improved care by a Ear-Nose-Throat-(ENT)-specialist, knowledge on causative pathogens, extent of immunodeficiency, prophylactic antibiotics, and additional immunizations.

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NTRODUCING CULTURAL COMPETENCE TRAINING INTO PAEDIATRIC PUBLIC HEALTH SERVICES

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Objectives: The ESSOP position statement on Migrant Children in the European Union, 2008, highlighted the need of training for paediatricians in advocacy and specific communication skills. Is it possible to develop and introduce decentralised training courses supporting cultural competence in paediatric public health services?

Methods: A three-level curriculum on intercultural communication has been introduced into the programme of the Academy of Public Health for Schleswig-Holstein, Bremen, Hamburg, Lower Saxony, North Rhine-Westphalia (NRW) and Hesse. An additional focus on a regional in house component on level 1 in the services in NRW has been financially supported by the local government. The trainings were free of charge, in small groups of 10-15 participants and conducted in cooperation with AD, an experienced ethnologist/empirical cultural scientist. For quality reasons and comparability of the evaluations all courses on level 1 were held by one person and other lecturers introduced on levels 2 and 3.

Results: Based on the original concept as well adaptations according to the continuous evaluations the curriculum on level has been further developed and finalized during the project. Based on needs assessments performed in the basic courses, it was possible to base the curriculum on level 2 on a "bottom- up" approach, which has also been applied on the next level.
The acceptance has been confirmed by the courses/participants in 2008-2011: Level 1: n=71/n=929, level 2 n=21/n=272, level 3 n=3 / n=58. In 2010, all mean results of all courses evaluated rendered <3.0 for any item included on scales from 1 (excellent) to 6 (very

poor). >95% of the participants of level 1 courses (n=323) indicated that further training on migrant child health is important or very important, 30% indicated that an amount of 60 hours or more would be appropriate.

Conclusion: Easily accessible training on cultural competence should be offered systematically to paediatric teams in (child) public health institutions.

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CHILDREN OF TEENAGE MOTHERS : DELAYED PSYCHOMOTOR AND LANGUAGE DEVELOPMENT

Florence Noirhomme-Renard

Keywords: Child development ; maternal age; teenage mothers

Introduction and objectives

Our goal was to investigate the development of pre-school children of teenage mothers and compare to adult mothers.

Methods

We analysed data from the BDMS, child health database from the belgian french-speaking community. We focused specifically on child development and accident occurrence. The study population involved children registred for well-child visits at ages 18 (n=30486) and 30 (n=13247) months old (cumulated data from 2006 to 2009). Psychomotor development was assessed at 18 months based on speach and motor items, and at 30 months based on 3 motor items (percentage of children without delay); occurrence of domestic accidents was assessed at 18 months (at least one event); language development was assessed at 30 months (percentage of children without delay). Data were compared in regard to the maternal age at delivery (<20 years, 20-35 years and >35 years).

Results

Compared to the 2 groups of adult mothers (20-35 years and >35 years), statistically significant differences were found:

- **At 18 months**,
  - The psychomotor development is higher in children of teenage mothers: 93,9% vs 92,3% and 90,5% (p<0,001)
  - The occurrence of domestic accidents is higher in children of teenage mothers: 14,5% vs 11,0% and 9,8% (p<0,001)

- **At 30 months**,
  - The psychomotor development is lower in children of teenage mothers: 58,3% vs 67,2% and 64,9% (p=0,005)
    The language development is lower in children of teenage mothers: 45,9% vs 50,8% and 49,2% (p<0,001)

Conclusion

Maternal age is an important determinant of child development. Children of teenage mothers are exposed at increased risk of accident. Young parents should be given priority in prevention programmes.

Data source: BDMS : Banque de Données Médico-Sociales de l'ONE, « Bilans de santé à 18 et 30 mois », Données 2006-2009.

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EFFECTS OF CHANGING POLICY ON SCREENING AND DETECTION OF CHILD ABUSE IN EMERGENCY DEPARTMENTS

Eveline Louwers

Keywords: Child abuse, emergency department, screening, implementation, intervention

Objective:
This is a prospective intervention cohort study to assess the time trends of the screen rate and detection rate of suspected child abuse at seven emergency departments in the Netherlands for 23 months to understand the effects of screening and changes in national and local policy.

Methods:
All children aged 0-18 years who visited the emergency departments from February 2008 to December 2009 were included. We developed a new screening checklist ('Escape form') and implemented it in four hospitals and we implemented training in four hospitals comprising a three hour during interactive workshop in interview techniques.

Results:
We included 104 028 children aged ≤ 18 years visiting one of the seven emergency departments. Implementation of the 'Escape form', training for emergency department nurses and making screening legally required by the Health Care Inspectorate resulted in an increase of the screen rate from 20% in February 2008 up to 67% in December 2009. The detection rate of suspected child abuse was 0·2% (243). The pooled odds ratio for detection of suspected child abuse in screened children in the seven hospitals was 4·88 (95%CI 3·58 - 6·68). The detection rate in the children who were screened for child abuse was significantly higher compared to the children not screened for child abuse (0·5% versus 0·1%, $p < 0{\cdot}001$).

Conclusions

The results of our study support that screening for child abuse in emergency departments is effective to increase the detection rate of suspected child abuse at emergency departments. Screening for child abuse increased after implementation of a checklist of warning signs for child abuse, training for emergency department nurses and legal requirement of screening.

Conflicts of interest:

All authors declare there are no conflicts of interest.

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BEHAVIOURS OF HEALTH SCIENCES FACULTY STUDENTS IN THE ROAD OF DEVELOPING HEALTHY LIFE STYLE

Selda Bülbül

Keywords: health promotion, healthy lifestyle behaviors, university students

Objectives: To establish a healthy community, health services should be directed on protection and development of healthy life styles. First step in reaching this goal, is to give the importance of this concept to the students in the field of health as they are expected to be the models of the society. The aim of this study was to determine the health promoting lifestyle behaviors of students who would be working in health care services in future.
Methodology: The study group was consisted of 130 students studying in the Kırıkkale University Faculty of Health Sciences. Data were collected by using the Health Promoting Lifestyle Properties (SGYB) Scale. It is a foursome Likert-type Scale consisted of 52 items and 6 sub-dimensions such as; self-realization, health responsibility, exercise, nutrition, interpersonal support, and coping with stress. Minimum and maximum scores of the scale are 52 and 208 points. High points are related with health promoting lifestyle behaviors.

Results: Among all, 27.7% of the students were from Nursing, 39.2% from Health Management, 16.2% from Physical Medicine and Rehabilitation, and 16.9% from Child Development departments. Students' average age is 19.81 years and 70% were females, 83.8% chose this profession willingly, 56.2% lived in a city before the university, 3.1% has a mother and 22% has a father with university degree and, 68.5 % were from middle socio-economic level. The mean SGYB Scale score was 126.03 ± 17.61. The sub-scale scores were; self-realization subscale 26.12 ± 4.91, health responsibility subscale 20.73 ± 4.15, 16.61 ± 4.22 subscale of exercise, nutrition subscale 20.13 ± 3.75, 25.85 ± 3.82 and the subscale interpersonal support subscale of coping with stress was found to be 19.80 ± 3.51. Total score and sub-scale scores were higher among female students, and students whose mothers had a university degree.

Conclusion: The health promoting lifestyle behaviors of the students were found to be moderate. This can be accepted as a reflection of the Turkish society. Therefore, special effort should be given to these students as they will be the roll-models of the community in very near future.

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SOCIAL DISADVANTAGE AND CHILDHOOD LIMITING LONGTERM ILLNESS/DISABILITY: CAUSE OR CONSEQUENCE?

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Background: There is a well established association in the literature between social disadvantage and childhood limiting longterm illness/disability (LLTI/D). Explanations for this association vary but it has been suggested in some publications that social disadvantage is both cause and consequence of childhood LLTI/D. In an extensive literature search, we have identified evidence that family income, at least in the USA and the UK, is reduced as a consequence of having a child with LLTI/D but have not found any empirical data supporting a causal role for social disadvantage in childhood LLTI/D.

Objective: This presentation will report the findings of a study addressing the temporal relationship of social disadvantage and the onset of childhood LLTI/D in a large UK census-based longitudinal study, the Office of National Statistics Longitudinal Study (ONSLS) and discuss the contribution of these findings to resolving the issue of social disadvantage as cause, as well as consequence, of childhood LLTI/D.

Methods: Children born between the 1981 and 1991 UK censuses who became ONSLS members and were present at the 2001 census were identified. Data were extracted on those children who didn't have LLTI/D in 1991 but did in 2001 (index)and those with no LLTI/D on either occasion (comparison). A social disadvantage index (SDI) comprising low household social class, rented housing and no car ownership was constructed for 1991. Logistic regression models were fitted on LLTI/D with the SDI as the independent variable of interest adjusted for age, gender, lone parenthood, and ethnicity.

Results: 60,000+ children became ONSLS members between 1981 and 1991 and were present at the 1991 and 2001 censuses. 52,438 in the index and comparison groups had complete data. In bivariate analysis, social disadvantage, age, gender and lone parenthood but not ethnicity were significantly associated with the onset of LLTI/D in the index group. After adjustment for confounding, the SDI showed a finely graded association with onset of LLTI/D in the index group (most disadvantaged OR2.12(1.77,2.54); disadvantaged in two domains OR1.45(1.20,1.75); disadvantaged in one domain OR1.14(0.94,1.40)).

Discussion: Our findings support the possible role of social disadvantage in the aetiology of childhood LLTI/D. The presentation will discuss the limitations of the study and additional research that will be needed to confirm the causal role of social disadvantage.

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POSTERS

THE FIRST CHILDREN'S RIGHTS CONGRESS IN TURKEY: CHILDREN'S RIGHTS FOR CHILDREN'S REPUBLIC

Serpil Ugur Baysal, Selda Bülbül and Guzide Kurt

Keywords: children's rights, Turkey, strategy

Background: Signing the United Nations Convention on the Rights of the Child (CRC) in 1990, ratifying CRC in 1994 are milestones to meeting the needs of Turkey, where more than 40 percent of the population is 18 or younger. In the past decade, human rights advocates, educators, health care professionals and social workers in Turkey have secured important gains in the realm of children's rights. This is true particularly with regard to child welfare concerns. Resources to investigate child welfare issues are still insufficient.

The First Children's Rights Congress was organized in February 25-27, 2010 in Istanbul as a part of National Strategy for the implementation of child rights.

The Mission: (Thinking of all children in one child): The mission was to ensure that all parties responsible for children's rights policies and practices are examined by the child impact analysis within the scope of children's best interest; to constitute Turkey's Children's Rights Strategy and Action Plan; to determine all issues regarding children incorporating Turkey's Policy on Children based on children's rights culture.

The Vision: (The Dream): The Meeting was organized with an aim to realize a vision of Turkey where problems are addressed through working with and for children and children will live a childhood with a culture of child rights.

Methods: During a 15-month-period, written opinions were obtained from 7000 children, 2865 aduts, non governmental organizations (NGOs), local administrations, universities and institutions, following with workshops, targeted groups discussions including 345

area specialists' contribution, and discussions with children and adult delegates during the three day Meeting.

Main Outcome: As a consequence of multiprofessional cooperation between authorities and experts, a preliminary study on Turkey's First Children's Rights Strategy 2012–2016 was completed. 20 different publications on children's rights and culture of Turkey aimed to children and adults were the accompaniments.

Conclusions: Six steps are needed for the implementation: The adaptation according to the needs of the children; the determination of the time frame; the organization of a nation wide action plan; the determination of the shareholders; to establish an emergency strategic action plan; ensuring the participation of NGOs for supervision and evaluation.

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CARE AND NUTRITIONAL STATUS IN CHILDREN WITH CEREBRAL PALSY

Selda Bülbül

Keywords: Cerebral Palsy, care, nutritional status, anaemia

Objectives:

Inadequate care causes malnutrition and increased incidence of nutritional anaemia that would negatively affect the life quality in patients with Cerebral palsy. This cross-sectional casecontrol study aimed to determine the characteristics of CP patients, their nutritional status in relation with their care.

Methods:

A total of 106 [76 boys, 30 girls] CP children and 104 [64 boys, 40 girls] healthy children with a mean age of 9, 09 ± 4, 72 and 7, 85 ± 4, 95 years were enrolled the study. CP patients who were attending to private education institutions and Kırıkkale University and state hospitals were included. Control group was consisted of children without any sign of a neurologic disease, infection, chronic disorder and/or inherited disease affecting the nutritional status. Every child who accepted to attend the study was carefully examined nutritional status and anaemia after a questionnaire was filled by the parents.

Results:

Our findings revealed that natal factors such as; prematurity, low birth weight, asphyxia were significantly higher in CP group. Most of them were (43%) tetraparesic and epilepsy was the most common additional problem. Among all, 95, 3% were cared by the mothers, 33% could eat without help, and 31% never brush the teeth, only 4, 7% have bathed every day.

CP patients had significantly lower z scores for weight for age, weight for height and BMI when compared to the control group.

According to weight for age and height for age measures 42,5% and 56,6% of the CP children were under the 3. percentile. Anaemia was determined in %21,7 of the CP group (iron deficiency 15%, B12 deficiency 5,7%, folic acid deficiency 6%).

Conclusion:

In conclusion, malnutrition and nutritional anaemia were higher among CP children. Caregivers of these patients need to be supported and supervised periodically. If nutritional deficiency and anaemia would recognized early, it could allow physicians to help these patients and their parents in raising the life quality of both patients and their parents.

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ADDITIONAL HEALTH PROBLEMS AND FUNCTIONAL STATUS IN CHILDREN WITH CEREBRAL PALSY

Selda Bülbül

Keywords: cerebral palsy, children, functional status, health problems

Objectives: Cerebral Palsy (CP) is the most common cause of physical disability affecting function and development in children. Although, locomotor dysfunction is one of the most obvious problem, these children often have several associated problems such as mental retardation, seizures and oromotor function disorders. The aim of this study was to investigate the additional health problems and functional status in children with CP.

Methodology: Fiftyseven children with CP who were treated in a special education and rehabilitation center in Ankara, in 2010 was the study group of this cross-sectional study. The mean age was 62.9±21.2 months. Socio-demographic characteristics, type of CP, severity of impairment and functional status were assessed. Pediatric Evaluation of Disability Inventory=PEDI) was used to assess the functional status. Scoring is made according to skills in activities, and the degree of personal assistance or environmental modification.

Results: Among all, 89.5% children were classified as spastic CP. The mean number of additional health problems was 3.5±2.9 where some of them had additional health problems as much as 12. The most common additional health problems were dental (30%), speech (22%) and visual (21%) problems. The mean scores of self-care, mobility, and social function subscales of PEDI functional skills domain were 38.4±19.9, 26.9±18.0, and 36.8±19.7 respectively. Negative moderately correlations were found among all sub-scales of functional skills domain and the number of additional health problems ($p<0.01$).

Conclusion: Children with CP, have several associated health problems that affect their functional status negatively. To reduce the primary and secondary health problems, qualified multidisciplinary treatment and rehabilitation services are needed. The purpose of these services is to help them reaching the highest functional level. Therefore, every child should be evaluated of the functional status before planning a rehabilitation programme. With high functional level, community integration of a CP child would be easier as he/she can perform the basic functional activities safely, on time and independently.

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FACTORS AFFECTING THE SATISFACTION LEVELS OF PATIENTS APPLYING TO A NEWLY ESTABLISHED UNIVERSITY HOSPITAL AND THE PEDIATRICS CLINIC

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Keywords: satisfaction, quality, hospital

Objective: The present study was planned to determine satisfaction levels of patients applying to a newly established university hospital and the pediatrics clinic and polyclinics of this hospital, and the factors affecting the satisfaction levels, to make suggestions on things to be done to improve the quality of patient services.

Methods: Totally, 493 people (58.6% male; 41.4% female) with a mean age of 36.34±7.150 years participated in the study. Of the group, 63.5% applied to the investigated hospital, and overall, 54% stated that they were very satisfied/satisfied with the hospital. The reasons for not applying to the hospital were; crowdedness of the polyclinics (21.2%), difficulty in transportation (14.6%), and long waiting time in the line (10.6%).

Result: The most frequently referred unit in the hospital was the polyclinic of the department of pediatrics (27.1%), and 58.7% of the appliers stated that they were very satisfied/satisfied, 76.4% found the explanations of the physician comprehensible, 58.5% stated that they were very satisfied/satisfied with the physician's attention, 81.3% stated that the physician examined sufficiently, 74.3% felt comfortable by the physician, and 76.4% found the polyclinics clean.

At least one child of 46.9% of the participants received inpatient treatment at the clinic of department of pediatrics. Of these participants, 89.2% stated that they were very satisfied/satisfied with the attitudes of the physicians at the clinic, and 82.4% were with the nurses, 12.5% found the physicians impolite, and 31.9% stated that the physicians and the nurses attended inadequately. The reasons for dissatisfaction were rather related to general operation of the hospital (cleanness of toilets, general sanitation, lack of hot water,

lack of running water, safety concerns, unavailability of medications).

Conclusion: According to the results of the present study, which is a self-assessment, satisfaction with the services of the hospital and pediatric clinic and polyclinics was found to be low. Several deficiencies were detected in the pediatrics clinics, and reformative efforts were made to improve the inadequacies reducing the patient satisfaction and to meet patient demands and needs. Keeping efficiency of human factor in health care services, staff of the pediatrics department received a series of training on patient-physician relations.

Keywords: satisfaction, quality, hospital

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PREVALENCE OF DISCIPLINARY MEASURES FOR CHILDREN IN ICELAND

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Introduction: Accounts give evidence that Icelandic children have throughout history experienced hardship and heavy labour. Qualitative interviews with Icelandic adults of different generations expose that physical violence in families was an accepted norm until 1970s. Such experience increases the risk for adolescents to suffer from symptoms of depression, anxiety, anger and low self-esteem. Yet, there is no information on the prevalence of different disciplinary practices of children in Iceland.

Objective: Estimate the prevalence of different disciplinary measures for children used by Icelandic parents.

Methods: From a random sample of 1500 adults (18 years and older) in the population register in Iceland, 963 (65%) responded to questions related to their experience of disciplinary measures as practiced by their parents. The survey was conducted in October and November 2010 through telephone contact by trained interviewers.

Results: In total 810 (84%) reported they had enjoyed good upbringing. Some reported negative experiences of parental upbringing practices: 133 (14%) had been laughed at or belittled; 163 (16%) had been threatened and thereof 41 (4%) often; 92 (10%) had been rejected and thereof 37 (4%) often; 273 (28%) had experiences of different forms of time-out; 308 (32%) had been scared up once or more often; 120 (13%) had been shaken at least several times; and 280 (30%) had been spanked at least once, and thereof 22 (3%) who reported frequent spanking.

Of those who had such experiences, 134/418 (32%) responded that it had always been a legitimate measure taken by their parents and 123 (29%) never.

Conclusion: The preliminary results are the first on the prevalence of different disciplinary practices for children in Iceland, as reported when adults. These indicate that some Icelandic children experience a wide variety of measures that may have negative consequences for their later health, development, and wellbeing. Parents need to be made aware of the negative impact harsh disciplinary practices may have on children´s health and wellbeing, and later adult health. It is important to find ways to strengthen primary prevention so children do not experience physical and psychological violence that can risk their long-term wellbeing.

CONSULTATION TEAM FOR HIGH RISK PREGNANCIES: PREVENTION OF (INTRA-UTERINE) CHILD MALTREATMENT

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Introduction: Child abuse is commonly defined as the physical, sexual, emotional maltreatment or neglect of a child. Although not explicitly mentioned in this definition, maltreatment or neglect may also affect an unborn child. There are certain factors that can signal possible risks to the well-being of the unborn child and if these are identified at an early stage of the pregnancy, action may be taken to mitigate the health and safety risks to the child and its mother. This type of intervention can only be achieved through a multidisciplinary approach.

Methods: In 2009 Maastricht University Medical Center (MUMC+) established a special multidisciplinary consultation team to discuss the situation of pregnant women in which threats to the well-being of the unborn child are identified.. Within this team, several representatives from different organizations, which provide care for pregnant women and newborns, come together to discuss the at risk-cases on a monthly basis. The team includes professionals from various medical departments such as the Medical Social Work, Neonatology, Gynecology/ Obstetrics, Psychiatry and hospital Legal Service. Aside from the internal experts, the team also reaches out to professionals employed by the Advice and Report Centre on Child Abuse; the Child Preventive Health Care Organization; the Maternity Care and the regional Organization for Midwives. Due to the different, but overlapping, roles of these organizations during the pregnancy, communication between these groups is crucial in order to form a complete picture of the risks faced by the unborn child. Based on the insights from these different professionals, a comprehensive plan is composed in order to provide optimal care. Each plan is customized to the case at hand and may vary from a referral to the Department of Mental Health Care or a specialized social worker, to reporting the case to the Advice and Report Centre on Child Abuse. The paramount goal is to realize a safe and secure environment for the child and its mother, during and after pregnancy.

Results and conclusion: In 2010 a total of 34 women were discussed within the consultation team. The measures taken to realize a safe environment were various and individually fixed. In 50% of the cases it was possible to realize support on a voluntary basis, the other cases were reported to the Advice and Report Centre on Child Abuse. Characteristics of these cases will be shown in an overview.

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ELSPAC AS AN EXAMPLE OF A LONGITUDINAL EPIDEMIOLOGICAL STUDY ON CHILDREN AND ADOLESCENTS

Lubomír Kukla

Keywords: ELSPAC, epidemiological study, children, adolescents

ELSPAC is a prospective longitudinal study conducted in several European countries. The study follows a selected sample of children and their families from the pregnancy of the mother, through delivery, puerperium, infancy and adolescence until 19 years of the child's age. The aim is to identify factors which influence healthy development of the children positively and negatively. The study was initiated by the WHO European Office in Copenhagen. International coordinator of the project was initially Prof. Jean Golding from the Institute of Child Health University in Bristol, Great Britain (until the end of February 2007). Current international coordinator is Assoc. Prof. Lubomír Kukla, from Brno, Czech Republic. Countries participating on the project are following: Great Britain, Isle of Man, Czech Republic, Slovakia, Russia, Ukraine, partly Croatia and Estonia; in the early stages of the study also Spain and Greece. ELSPAC is the first study which starts already during pregnancy of the mothers and follows the development of their children through childhood and adolescence. Both parents of the children are involved in the project nearly equally. We are interested in personalities, behaviour, attitudes, and health status of the parents. ELSPAC is an international project with the same methodology and data collection procedures in all participating countries; therefore it allows comparisons of the results among different countries.The aim of the project is to detect biological, psychological, and social factors as well as factors of external environment associated with survival and health of the foetus, infant and a child. Obtained results can be compared with the data collected in other participating countries. The study also focuses on bio-psycho-social determinants of the child's development from conception until the end of school age, while taking into consideration a life style of the family, environment, care, or relationships among family members as well as personalities of the mother and the father. Furthermore, we are aiming to find the links between bio-psycho-social determinants as well as origin and development of health disorders of a foetus, newborn and a child.

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PERINATAL DEPRESSION IN ADOLESCENT MOTHERS : A PUBLIC HEALTH CONCERN

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Keywords: Perinatal depression; adolescent mothers; risk factors; prevention

Introduction and objectives

Each year in Belgium, about 4% of all children are born by teenage mothers. Due to the high frequency and co-occurrence of vulnerabilities, teenage mothers are at higher risk of perinatal depression than adults mothers.

We performed a review of the literature investigating the epidemiology of adolescents mothers'depression, compared these data to adult mothers and listed associated factors, to develop a more preventive approach and specific follow-up.

Methods

The review is based on Pubmed and Sciencedirect research combining "adolescent" or "teenage" and "depression" as keywords.

Results

Seventeen international studies were included, evaluating both prenatal (6 studies) and postnatal (14 studies) depression with 3 different scales (CES-D, BDI, EPDS). Depression rate in adolescents mothers varies from 26 to 63% in the third trimester of pregnancy and from 26 to 61% in the first 3 months postpartum, with differences depending of studies designs, screening instruments and cutt-offs. Depression rate declines with time, but still persists with a prevalence ranging from 21 to 32% at 4-5 years after delivery. Depression rate in adolescent mothers are globally twice higher than in adult mothers, both in prenatal and postnatal periods. Characteristics associated with adolescent mothers depression include socio-demographic factors (less education, low income), psychosocial factors (confidence, self-esteem), poor or inadequate social support and negative life events (violence exposure, history of abuse).

Conclusion

Perinatal depression in adolescent mothers is very high and can contribute negatively to child-mother interaction. It should be a priority to screen depression early during pregnancy and to offer appropriate support services during the first years of motherhood. Moreover, it could be of high interest to assess maternofoetal attachment during pregnancy using validated instruments combined with depression scales.

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INTERDISCIPLINARY HOSPITAL-BASED CHILD BUSE AND NEGLECT TEAM IN AN ACADEMICAL CENTRE; OVERVIEW OF INTERVENTIONS

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Sonja Brilleslijper-Kater and Rian Teeuw

Keywords: Child abuse, Pediatrics, Emergency department, Interdisciplinary partnerships

Introduction

Child abuse and neglect (CAN) is a health problem affecting approximately 3% of all children in the Netherlands. A place where CAN can be detected is the medical system. It is known that hospitals do not recognise CAN very well. A multidisciplinary CAN Team (TKM) can give hospital staff advice in how to deal with a suspicion of CAN. Besides practical advice, it can provide training on symptoms and signs of CAN and give emotional and juridical support. In our hospital a multidisciplinary TKM has been active since 2004. Objective of this paper is to describe which forms of CAN are seen in our hospital and which types of measures were taken.

Methods

Data of all patients discussed in TKM in 2010 were collected. Data were obtained from IMS, the intranet based reporting system, an excel file with all patient data, minutes taken during the monthly TKM meetings and patients medical records. Analyses were performed with PASW Statistics 18.

Results

A total of 185 cases of suspected CAN were reported to the TKM in 2010, 90 (56%) girls, 70 (44%) boys. 109 reports (59%) were substantiated, 23 (12%) no definitive conclusion could be reached and in 53 cases (29%) CAN could be disregarded. 74(40% of all suspicions involved physical abuse, 55 (30%) emotional abuse, 43 (23%) physical neglect, 29 (16%) sexual abuse, 18 (10%) witness of domestic violence, 7 (4%) prenatal abuse and 3 (2%) paediatric condition falsification. Of the cases in which CAN was substantiated, in 7% of the cases a guardian was appointed and 31% of the children were placed outside their homes.

Discussion
Results show that CAN is a significant health problem in our hospital. The measures that were taken suggest the TKM deals with the more severe forms of CAN in particular. This indicates health care personnel either does not recognise the more subtle forms of CAN, or they do not report these cases to the TKM. This means there is room for training on recognising these forms of abuse.

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ABUSIVE HEAD TRUMA : REPORT OF 3 CASES

Gonca Yilmaz, Nilgün Caylan and Candemir Karacan

One form of abusive head trauma (AHT) is perpetrated when an abuser violently shakes an infant or a young child, creating a whiplash motion and rotational acceleration/deceleration forces resulting in injuries to various intracranial structures, historically called shaken baby Syndrome (SBS). Shaking may or may not be associated with subsequent impact, hence, shaken impact syndrome, another form of AHT. Lately, American Academy of Pediatrics published a position paper stating that although the terminology "Shaken Baby Syndrome" may and should be used in prevention-focused projects and research efforts, diagnostic terminology should be replaced with "Abusive Head Trauma" since shaking is not a mechanism in all inflicted intracranial injuries.

Incidence of AHT is based on limited studies and hospital records. The incidence is believed to be much higher than reported because milder forms of AHT may not be associated with severe symptoms, thus may not require a hospital visit (3). Extrapolation of the data from the few epidemiological studies revealed that SBS incidence may be as high as 15–30 per 100 000 children under the age of one year . The estimation of fatality from this type of injury is 15-17% in affected children and morbidity in the form of serious neurological consequences may affect more than half of the survivors.

Professional awareness of AHT is still poor in Turkey, leading to rare diagnosis at hospital settings. As a result, interdisciplinary management involving medical, child protective and legal professionals is even poorer almost non-existent.

A series of three cases of AHT that were admitted to the hospital with different constellation of clinical symptoms is presented in this paper. This series is the first reported from Turkey, to our knowledge.

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