Caring for Tomorrow

EFCNI White Paper on Maternal and Newborn Health and Aftercare Services

EFCNI we care.

european foundation for the care of newborn infants

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Foreword

Dr. Angelika Niebler

A healthy start at birth lays the foundation for good health throughout one's life. However, every year, 500,000 preterm infants are born in the EU – approximately one in ten babies. This means that not only does Europe have a huge influx of vulnerable newborns each year, but also the number of so-called 'ex-preterms' is steadily increasing.

As these preterm infants grow, they do so with a higher risk of learning and behavioural disabilities, cerebral palsy, sensory deficits, infections and chronic respiratory disease compared with their full term counterparts. Preterm infants are also more often affected by diabetes, cardiovascular and respiratory diseases, such as infections and asthma, all of which have an impact on their development, capacity to work in later life, and life course in general.

In many cases, these children, as well as their families, need to cope with physical, psychological, emotional and financial challenges. In addition, the costs to healthcare systems and the wider economy are huge. However, regardless of the impact on individuals and society, and despite the fact that many of these health problems and other challenges can actually be prevented, policy attention to this issue is still minimal at best. This needs to be changed - it is clear that concrete action must be taken. Early prevention measures and good maternal care should place women in the best position for a healthy pregnancy and birth. Preterm birth should not be considered a disease: preterm children have the capacity for normal development and productive, healthy lives. But it is our responsibility to ensure that this capacity is assisted and that the affected children and families are cared for through the implementation of appropriate aftercare standards.

Thus, standards and effective policies that enhance the access and quality of healthcare are urgently required to provide better health outcomes. My commitment to these principles is part of the reason why I am delighted to support this EFCNI White Paper: it highlights urgent needs, key recommendations and principles for best practice to ensure the best possible start in life for preterm infants and infants born with illnesses.

European and national policy makers should use this invaluable resource to plan, improve and deliver quality care for not only preterm infants and newborns with illnesses, but also their families and carers.

As a politician, a woman and a mother, I am concerned by this serious health issue. The European Parliament Interest Group on Maternal and Neonatal Health, of which I am proud to be one of the co-founders, seeks to increase the visibility and awareness of preterm birth and all related issues. It is my intention to make use of this Interest Group to help ensure that maternal and newborn health will become a natural part of EU and national policy agendas.

As healthy ageing across the lifespan continues to be supported vigorously as one of the most crucial ingredients towards sustainable societies, healthy ageing clearly starts at birth. Therefore, we must ask ourselves, how it is we are able to ensure this positive outcome and, for those that are born before their time, how best can society help get them to a more active status.

Dr. Angelika Niebler
Member of the European Parliament

Preface

Last year, the European Foundation for the Care of Newborn Infants (EFCNI) published an EU Benchmarking Report to help capture for policy makers the impact of prematurity across Europe. The EFCNI Benchmarking Report 'Too Little, Too Late' painted a compelling picture of the differences that exist in healthcare qualities when it comes to maternal and newborn health in Europe. Indeed, it showed that in most EU Member States, maternal and newborn health is not considered to be a public health priority, despite its obvious connection to health outcomes in adult life.

It also began a reflection process amongst parents, healthcare professionals, academics and industry partners to move from an identification of the various provisions that EU Member States have made for newborn infants, to concrete proposals for improving the standards of care in Europe.

As such, *Caring for Tomorrow, the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services* aims to highlight some of the key concerns with regard to this growing patient group. The White Paper should be used as a reference for policy makers and politicians, but also for parent organisations, healthcare professionals and other concerned stakeholders to ensure that, amongst other things, there is a greater acknowledgement of the burden of preterm birth and newborns with illnesses. Such a burden is not only shouldered by the individual children themselves, but their parents and family who raise them under difficult conditions, and also society as a whole which must help support them through into adulthood.

However, greater understanding is not an end in itself. Thus, EFCNI supports the adoption and implementation of appropriate action, particularly with regard to prevention of preterm birth and ensuring that when it does occur the appropriate measures are taken to combat the corresponding health inequalities that can result when the delivery of quality care is not possible.

Our aim is not to victimise preterm infants, or their families, but instead to address the increased incidence of preventable preterm birth. When it does take place, preterm birth should be addressed appropriately to ensure that these infants receive the best possible start in life, as should be the case with every newborn.

Therefore, EFCNI is partnering with policy makers at both national and EU level to ensure a commitment to urgent action in the fields of maternal and newborn health and aftercare services. The White Paper is not to be viewed as a set of clinical recommendations or guidelines, but instead should be used to initiate a discussion at European and national level on how to develop strategies for maternal and child health. The White Paper is designed to support equitable, high-quality specialist and neonatal services in Europe and equip policy makers with the right tools to plan, improve and deliver quality care for preterm infants and newborns with illnesses as well as for their families.

> *The health of mothers is inseparable from the health of newborns, to the point that the World Health Organization now talks in terms of "maternal-newborn health."* Clearly, one cannot have a conversation about improving the health of newborns without also considering the health of their mothers and thus, in support of the WHO's stance on these issues, EFCNI follows and endorses the need for a holistic approach.

Only by making maternal and newborn health a priority within Europe will we ensure the wellbeing of its future adult population, workforce and society. This is what we mean by 'Caring for Tomorrow', and it is with urgency that we call on Europe to act now!

Silke Mader

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Executive Summary

Well-organised, effective and targeted pre-conceptional, maternal and newborn care can make a lifelong difference to preterm infants and newborns with illnesses, as well as to their families. It is EFCNI's mission to provide research and recommendations and related resources to ensure high quality care for our most vulnerable population.

Caring for Tomorrow was designed to initiate and support discussions in the European Union and its Member States on the delivery of high-quality healthcare, starting at pre-conception and following through to aftercare. Only by making maternal and newborn health policy a priority, will the urgent health challenges of our current and future society be tackled. The body of work that went into this Paper underpins the responsibility that society has to its mothers, parents, preterm infants and infants with illnesses, to ensure that they receive the appropriate attention and care necessary to produce the best long-term outcomes for everyone.

European and national policy makers should use this White Paper to provide for the planning and investment in the necessary policies that will help to improve the delivery of quality care and services for mothers and their newborns: especially preterm infants and newborns with illnesses and their families.

Healthcare providers from different disciplines and professions, as well as parents and professional societies, were asked to provide their perspectives on the challenges and evidence-based recommendations in the field of pre-conceptional, maternal and newborn care and aftercare.

As a result of these contributions, a set of key recommendations for quality pre-conceptional, maternal and newborn care and aftercare were developed for each field.

The thirteen key recommendations made in this White Paper identify that action is needed at both European and national level in order to:

1. Recognise the issues of maternal and newborn care and aftercare as a public health priority, particularly the health of preterm infants and infants with illnesses
2. Acknowledge the potential long-term health consequences of preterm birth and newborns with illnesses that need to be tackled
3. Address health inequalities in maternal and newborn care within all EU Member States
4. Conduct national audits on maternal, newborn care and aftercare services and establish multidisciplinary task forces for developing national best practice guidelines

5. Implement national policies and guidelines for high-quality pre-conceptional, maternal and newborn care and aftercare. These policies and guidelines should include the principles highlighted in this White Paper
6. Provide equal and early access for parents to complete and accurate information, education and counselling
7. Harmonise education and training of healthcare providers
8. Provide social and financial support for parents and families
9. Develop and implement strategies for public awareness and education
10. Harmonise cross-border maternal and newborn healthcare
11. Monitor outcomes and implement audit procedures in maternal, newborn and aftercare services
12. Implement European wide standardised datasets for pregnancy and preterm birth outcomes
13. Invest in comprehensive research to tackle the challenge of preterm birth and its potential long-term consequences.

In addition to these recommendations and principles for pre-conceptional, maternal, newborn care and aftercare services, the White Paper identifies clear rights for parents and newborns that must be considered in any healthcare strategy for maternal and newborn care.

Within the heterogeneity of European healthcare standards and economic conditions, politicians, stakeholders, healthcare providers, parent representatives and strategic health authorities will need to work together to identify this White Paper's critical recommendations for implementation on a national and European level. The potential financial and societal impact of these recommendations should be discussed to understand the possible savings in direct and indirect health expenditures and other benefits such as enhanced productivity that may accrue as a result of improved, high-quality maternal, neonatal and aftercare services across all Member States.

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Supportive organisations

The following organisations support EFCNI's aim to ensure the best possible start in life through improved prevention measures, treatment and care of preterm infants and newborns with illnesses and their families as well as their long-term health through the implementation of adequate aftercare services. The below organisations therefore support EFCNI's work on *Caring for Tomorrow: the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services.*

The March of Dimes Foundation congratulates the European Foundation for the Care of Newborn Infants (EFCNI) for drawing attention to the need for quality preconception, maternal and child health care services throughout Europe in its 2011 "Caring for Tomorrow" white paper. We commend EFCNI for their ongoing efforts to bring the needs of premature infants and families into the spotlight. *March of Dimes*

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1. Introduction

The aim of the EFCNI White Paper

Caring for Tomorrow intends to initiate and contribute to discussions about the delivery of high-quality pre-conceptional, maternal and newborn care, as well as aftercare services in the European Union. Ideally, the White Paper will become a source of inspiration for politicians and stakeholders across Europe to include maternal and newborn health on political agendas. It is essential that these issues be considered as top public health priorities and that policy makers view this as a crucial prerequisite to guaranteeing the well-being of Europe's population now and into the future.

EFCNI aspires to see politicians, strategic health authorities and other stakeholders, at both European and national level, use this White Paper to begin proper reviews on how to improve existing healthcare plans for maternal and newborn health. As specific strategies are not yet in place in most countries, the White Paper should help inspire the development of European and national healthcare plans, standards of care and guidelines on pre-conceptional, maternal and newborn care, as well as aftercare services.

The White Paper should serve as a source of support to all those active in the area of pre-conceptional maternal and newborn care and aftercare services. It will help to plan, deliver and ensure access to high-quality care for parents, newborns and, in particular, preterm and newborn infants with illnesses, by:

a. Providing background, challenges, key recommendations and principles for addressing the different issues that may hinder the provision of high quality care and services. These topics were identified by parents, with the support of healthcare professionals, as being the most urgent to tackle. The various sections were then formulated by experts from the respective fields

b. Demonstrating the impact of, and challenges to, high-quality maternal and newborn health in our societies

c. Addressing the existing health disparities across Europe, especially among preterm and newborn infants with illnesses

d. Providing some of the central tenets of parents' and newborns' rights.

Within the complexity of varying healthcare systems and economic conditions throughout the European Union, we call on politicians, stakeholders, healthcare providers, parent representatives and strategic health authorities to combine forces to identify the key elements necessary for implementing these recommendations on a European and national level. We also encourage active discussion of the potential financial impact resulting from the implementation of the recommendations designed to make improved, high-quality maternal, newborn care and aftercare services a reality in all Member States.

In order to drive change at national level, each Member State is called on to develop a national charter of rights for parents and newborns based on the key recommendations and principles identified in this Paper.

The work on the EFCNI White Paper should be seen as a first important step in bringing together parents and healthcare professionals on a European level; and to combine forces, exchange ideas and work on the common goal of improving maternal and newborn health for the benefit of our children and society as a whole.

How the EFCNI White Paper was developed

- The EFCNI White Paper was initiated by EFCNI and its national parent organisations to voice their concerns in the area of maternal and newborn health, and to create a discussion document as source of inspiration and information for the elaboration of Europe's health strategies for the coming years
- An editorial board was established, comprised of representatives of parent organisations, EFCNI and healthcare providers
- Healthcare providers from different clinical disciplines and professions, professional societies, as well as parent organisations, were then asked to provide their perspectives on challenges and evidence-based recommendations in the field of pre-conceptional, maternal and newborn care and aftercare services
- A roundtable workshop was organised amongst healthcare providers from different disciplines, as well as parents' representatives and representatives from healthcare societies, to discuss key recommendations and principles
- Key recommendations and principles were extracted from the individual contributions, as well as from existing sources, such as prevailing national standards, guidelines and/or toolkits. These recommendations were then shared with all authors and roundtable participants.
- The Paper was submitted to a group of European experts in the respective fields for review

Drawing connections

The EFCNI White Paper integrates and endorses other published standards and guidelines, including the UK Toolkit for high-quality neonatal services, the position paper on neonatal care of the German Parent Organisation (Bundesverband "Das frühgeborene Kind" e.V.), the EFCNI Declaration of Rome, the Declaration of Mothers' and Newborns Rights of the Union of European Neonatal and Perinatal Societies (UENPS), Standards of Care for Women's Health in Europe – Report of a Working Party 2011 from the European Board and College of Obstetrics and Gynaecology (EBCOG), the Statement of the European Midwives Association on Intrapartum Care, the European Forum of National Nursing and Midwifery (EFNNMA) statement on strengthening nursing and midwifery workforce in the World Health Organization (WHO) Europe Region, guidelines of the American Academy of Pediatrics, the recommendations for education and training and Accreditation of the European Society of Neonatology (ESN), the Major Chronic Diseases REPORT 2007 of the European Commission's Directorate-General for Health & Consumers, the European Perinatal Health Report 2008, a EURO-PERISTAT project in collaboration with SCPE, EUROCAT & EURONEOSTAT, the Baby Charter of Bliss, the Tallinn Charter: Health Systems for Health and Wealth, of the WHO European Ministerial Conference on Health Systems, and the declaration of the 9th Council of Europe Conference of Health Ministers in Lisbon in September 2011.

How to use the EFCNI White Paper

The EFCNI White Paper provides key facts and figures, followed by key principles and recommendations, for each of the three main areas of health for mothers, infants and their families – maternal and newborn care and aftercare.

The recommendations given throughout this Paper are the result of a reflection process of parents' representatives and leading European experts. They are not intended to cover the totally of health issues of concern, give health professionals advice or provide prescriptive guidelines. Rather, they are intended to cover some of the current, essential healthcare and societal elements that require immediate action. The recommendations are meant to be used as a tool to provide guidance to the European Union and its Member States for developing and updating their policies and strategies to improve the health of mothers and babies. The main fields identified are:

a. Quality of care standards
b. Education and training for healthcare providers and research professionals
c. Funding of research to improve prevention, treatment, care and outcomes
d. Social and financial support for the families concerned
e. Public education and awareness.

In this respect, EFCNI fully endorses the recommendations and principles given by WHO Europe, including:

a. Care for pregnancy and childbirth calls for a holistic approach
b. Pregnancy and childbirth are an important personal, familial, and social experience
c. There should be no interference in the natural process of pregnancy and childbirth without a valid reason
d. Medical interventions for pregnant women, mothers and newborn babies, when indicated, need to be available, accessible, appropriate and safe.

Feedback

Recognising that there may have been new developments since the drafting of the White Paper, or that there may be a need for further explanation and clarification of some chapters, EFCNI welcomes feedback on this report. Please send any comments to the following e-mail address: info@efcni.org

1.1 Maternal and newborn health and preterm birth

A challenge for the future of the European Union

While, in most cases, having a baby is a positive experience, pregnancy and childbirth can still be the cause of suffering, ill health or even death. Every year, women and newborn babies die or suffer from severe morbidity because of complications related to childbirth – this is the case throughout the world and Europe is no exception.

Babies and children are a special case when it comes to health issues and cannot simply be treated as 'smaller adults'. They are much more vulnerable, and it is particularly important they are protected and provided with the best possible physical and social environment when brought into the world.

Healthy children are Europe's future

In the declaration at the 9th Council of Europe Conference of Health Ministers in Lisbon on 28-29 September 2011, the Ministers responsible for health in the 47 member states of the Council of Europe recognised that "*healthy children are the future of Europe and that the rights of every child to equitable access to healthcare which is appropriate, child-oriented and of good quality must be respected; The health and well-being of children are priority goals shared by all member states within the general context of human rights and the specific framework of children's rights; Investment in children's health and well-being ensures better outcomes for the entire lifespan and may reduce the burden on health and welfare systems, since a significant number of avoidable physical and socio-psychological problems in adult life have their origins in infancy and childhood; Effective and efficient child-friendly healthcare contributes to social cohesion.*"

Health inequalities exist amongst children and their families in the European Union

Maternal and newborn mortality and morbidity are indicators of existing inequalities in issues such as socio-economic status, gender rights and the place of women and children in society, as well as access to social, health and economic opportunities. In the European Union, wide differences still exist in mothers' and newborns' morbidity and mortality, as well as when it comes to access to and quality of care. These inequalities in health status and health outcomes of mothers, children and their families within a country, and amongst the EU's Member States, were acknowledged in the declaration at the 9th Council of Europe Conference of Health Ministers in Lisbon on 28-29 September 2011. Although not the focus of the White Paper, it is clear that further investigation of these issues is needed.

1.1 Maternal and newborn health and preterm birth

Maternal and newborn health policies and practices vary across Europe

Depending where in the European Union a woman becomes pregnant or a baby is born, the level of care received will vary. Indeed some care practices will fall far short of promoting and protecting the right to a healthy start in life.

Such disparities in Europe were demonstrated by the EFCNI EU Benchmarking Report "Too little, too late?" published in 2010. This report is a comparison of policies impacting newborn healthcare and support to families across 14 European Member States. The report showed that despite the growing prevalence and increasing costs, newborn and preterm infant health still ranks low on the policy agendas of EU countries:

To date, only a very small number of EU Member States have implemented targeted policies focused on newborn health and preterm infants. Out of the 14 countries covered by the Benchmarking Report, only two have developed targeted policies aimed at improving newborn health (Portugal and the UK). In most countries, the approach to newborn health policy is fragmented and uncoordinated. Newborn health, especially the huge challenge of prematurity, more often appears in the framework of other more general health and social programmes. Thus it remains a secondary priority for action. Perhaps unsurprisingly, those countries with the highest rates of prematurity in Europe are among those without a targeted national policy for newborn health and preterm infants.

One reason for this absence of developing and implementing maternal and newborn health policies might be the argument of current economic pressures and tightened public budgets. However, this is short-sighted and no excuse for ignoring the problem, which we see as preventing access to high-quality healthcare and social support for preterm infants and their families. Prevention and follow-up programmes during the first years of infancy are poorly implemented in most countries and, when they exist, are often done so in an unstructured manner. The scope of these programmes is often limited due to scarce resources and may vary significantly between hospitals and regions.

Another concrete and very important example of the variation of policies is the immense discrepancies between Eastern and Western Europe. Several countries in the European Union still fail to report on whether they are adhering to WHO guidance; therefore, official data may underestimate the full scale of the problem. There are very high socioeconomic disparities between Eastern and Western European countries, which clearly lead to further inequalities in maternal and newborn healthcare standards, as well as infant mortality and morbidity.

Eastern European countries have:

1. Limited resources that impact*:*
    a. Availability and coverage of maternal care, which is linked to demographic variables, access to qualified healthcare care, different living conditions and maternal health
    b. Different policies and limited access to prenatal ultrasound screening, which is linked to regional variations in infant mortality with congenital malformations
    c. Limitations to provide high-quality care during high-risk delivery and neonatal care, including less modern technology
    d. Reduced ability to organise systematic follow-up of high-risk newborns
    e. Poor practice of publishing good information materials to improve parent education on neonatal and infant-specific conditions
    f. Inability to register systematic perinatal and infant health data, or reporting indicators of perinatal health for assessment of quality of perinatal/neonatal care.

2. Different systems for organising the regionalisation of care – sometimes government, sometimes professional societies, sometimes not regulated at all.

3. Different educational levels and qualification standards for nurses and doctors:
    a. Rare use of evidence-based methods in neonatal care due to limited access and poor acceptance of standards
    b. Limited resources to purchase scientific journals and handbooks, to allow for high-quality research or to fund staff training
    c. Healthcare staff receive a relatively low income, reducing motivation to improve their knowledge; younger and qualified medical staff often migrate to Western Europe
    d. Limited possibilities for mother-baby attachment and family-centred care.

Maternal and newborn health is interconnected

Experience over the past decade has shown that it is possible to improve maternal and newborn health outcomes, even in the most resource-limited environments. However, no single intervention is sufficient in and of itself. Rather, maternal and newborn morbidity and mortality can be significantly reduced by using a combination of low-cost and effective interventions, which are underpinned by understanding that the health of a newborn is also linked to the health of the mother. Avoiding complications that affect the mother also improves the outcome of her newborn.

Caring for Tomorrow

1.1 Maternal and newborn health and preterm birth

In his speech to the press in April 2010, the United Nations Secretary-General Ban Ki-moon highlighted the relevance of pre-conceptional and maternal care for the health of the newborn by launching the 'Global Strategy for Women's and Children's Health'.

Also, the WHO acknowledges that "the health of mothers is inseparable from the health of newborns," and now talks in terms of "maternal-newborn" health.

Coordinated efforts are needed to engage mothers, fathers, families and communities on these topics and, thus, increase collective and individual understanding of the needs of mothers and newborn babies.

Pre-conceptional and maternal care equates to newborn health – newborn care and aftercare leads to better prevention and contributes to healthy ageing.

> *"Healthy mothers raise healthy children. Healthy children grow up stronger and better educated and help build more prosperous societies. And a health system that delivers for mothers and children will deliver for the whole community."* Secretary-General Ban Ki-moon, UNHQ , April 2010

> *"Pre-conceptional, maternal and newborn care and ageing is a continuum, which deserves all efforts for high level of human health protection "* EFCNI, November 2011

Essential services must be provided at key points in the life cycle of an individual through dynamic health systems that integrate a continuum of home, community and facility-based care. An integrated approach receives much more dividends than many separate initiatives, increasing the efficiency and cost-effectiveness of care, providing greater incentives for the society to use the available services, and offering a greater opportunity to extend and enhance coverage.

EFCNI endorses the suggestion that maternal and newborn health be understood as one in the same, and in order to ensure active and healthy ageing encourages that this dynamic be extended to the continuum of pre-conceptional to aftercare. In fact, pre-conceptional women's health, intrauterine environment or exposure to environmental factors, such as smoking or malnutrition during pregnancy, have a significant impact on the occurrence of congenital diseases and malformations; exposing the newborn to higher risks of mortality, chronic diseases and long-term morbidities, with long-lasting consequences for the individual, family and society.

Any approach aiming to improve the health of the European population must include this continuum of care, particularly when it comes to the design of future health strategy programmes from the local to the highest level, including efficient regionalisation and a multidisciplinary approach.

Urgent action on prematurity is needed

Within the field of newborn health, it is no surprise that preterm infants represent the most vulnerable group. They require much more attention from both healthcare professionals and policy makers and, as such, necessitate a much more holistic approach to tackle their care challenges, notably:

- Despite all efforts in improving prenatal care to prevent preterm birth, the number of preterm infants is increasing
- In the European Union, preterm deliveries make up 5.5-11.4% of all births
- About half a million babies are born preterm every year in the EU; preterm infants represent Europe's largest child patient group
- The introduction of neonatal intensive care in the 1960s resulted in substantial improvements in outcomes for preterm infants (those weighing less than 1,500g)
- There have been marked improvements in technology and treatment, with an increase in the number of vulnerable preterm infants surviving after neonatal care admission
- The current weight-adjusted neonatal mortality rate (NMR) for very low birth weight infants is about 50 times higher than the overall NMR, although this still varies among European countries (from 2.4 to 6.8/1000 live births)
- Preterm infants are at particular risk of suffering inequalities in health status and health outcomes because of their vulnerable condition
- Compared with their full term counterparts, preterm children are at greater risk of health, learning and behaviour problems, such as cerebral palsy, attention deficit disorders, pulmonary infections, and asthma; potentially increasing the risk for chronic obstructive airways disease, chronic heart disease, and psychiatric disease in adulthood
- This later morbidity poses significant economic costs in terms of health, education and social care; the impact on families' health must also be considered
- The risk of a disability, that permanently reduces working capacity by at least 50%, is twice as likely in moderate and late preterm survivors, and increases seven-fold in those born extremely preterm
- Prematurity is more frequent in disadvantaged populations less able to deal with the effects of later impairments and disabilities.

Therefore, the White Paper focuses on this most vulnerable population in order to tackle the challenges of preterm birth.

It's time to act, now!

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1.2 The case for change

1.2.1 From pre-conception to birth

A healthy mother and a healthy baby are naturally the hope of every family. Whilst much progress in ensuring healthier pregnancies and pregnancy outcomes has been made over the past decades, pregnancy and childbirth still involve many risks. It is commonly known that the pre-conceptional health of a woman, as well as maternal care during pregnancy, play an important role in determining the outcome for her and her baby. However, maternal and infant mortality and morbidity, birth defects, low birth weight, and preterm birth continue to be serious problems overlooked by governments in the provision of high-quality healthcare. Therefore, the large numbers of preterm infants born each year make up Europe's largest child group at risk of suffering from short and long-term morbidities, posing a serious and growing threat to the health and well-being of the future European population.

Preterm birth: An unresolved problem for pregnancy

Preterm birth, occurring when a baby is born before 37 weeks of gestation (Table 1), is the single major cause of infant mortality and morbidity in both developed and developing countries. According to data from national registers and the 2008 European Perinatal Health Report, the prevalence rate of preterm birth in the EU ranges from 5.5% (Ireland) to 11.4% (Austria), meaning about half a million babies are born prematurely in Europe every year. Existing data shows an increase in preterm births in Europe. Thus, the prevention of preterm delivery, though much sought after, has been elusive.

Table 1

Definition of preterm birth

Severity of preterm birth	Gestational weeks
Extremely preterm	Less than 28 weeks
Very preterm	28-31 weeks
Moderatly preterm	32-33 weeks
Late preterm	34-36 weeks

Table 2 summarises the main risk factors for preterm birth. While significant advances to improve the care of preterm infants have been made in recent years, there has been little progress in reducing the overall prevalence of preterm birth. In about half of all cases of preterm birth, the exact cause of the early delivery still remains unknown. Nonetheless, a number of risk factors have been identified as likely to increase the risk of preterm labour. These risk factors include lifestyle factors, medical conditions and demographic factors. A few examples of associated risks include: **multiple pregnancy** (twins, triplets or more), **preterm birth experienced in a previous pregnancy, uterine or cervical abnormalities, infections,** and **maternal age**. In industrialised countries, such as those in Europe, the proportion of women giving birth after the age of 35 years has risen considerably, increasing preterm delivery risk. **Maternal stress** is also estimated to account for about 30% of preterm births. Also, several studies show the connection between pregnancy complications and an increased risk for preterm birth, including lower birth weight or foetal neurological development and psychological factors like anxiety and depression. In addition, social disadvantages experienced by the pregnant woman may also play a role.

1.2 The case for change

1.2.1 From pre-conception to birth

Table 2

Risk factors for preterm birth

Lifestyle factors	Medical conditions	Demographic factors
Smoking	Infections (urinary tract, vaginal)	Aged under 17, or over 35
Alcohol consumption	High blood pressure	Low socioeconomic status
Drug use	Diabetes	Ethnicity
High stress level & long work hours	Clotting disorders	
Late/no prenatal care	Underweight	
Lack of social support	Obesity	
	Multiple pregnancy	
	Women having experienced preterm birth before	
	Uterine or cervical abnormalities	

Many stillbirths in high-income countries are potentially preventable

In highly developed countries, most prospective parents are unaware that stillbirth is a risk and, specifically, that particular lifestyles increase their own risk of stillbirth. Parent-based organisations and groups argue that increased public awareness of pregnancy risks will help inform the choices made by parents, alerting them to warning signs and helping them to seek health professionals' advice before it is too late.

Many stillbirths in high-income countries, such as those in Europe, are potentially preventable. Currently, women who suffer still birth tend to come from lower socioeconomic backgrounds. Thus, as a first priority, the disparity associated with disadvantaged populations requires urgent attention through improvement of living standards for women, and provision of culturally appropriate accessible antenatal care.

The absence of quality data on stillbirths is a major impediment to stillbirth education and prevention. The proportion of unexplained stillbirths that do not undergo any adequate investigation remains high in many high-income countries. Improvements in investigation and reporting practices, including agreement on definition and classification systems, are urgently needed. The implementation of perinatal mortality audit at a national level could result in important reductions in stillbirth numbers in high-income countries through improvement of quality of data and standards of maternity care.

Pre-conceptional care is a prerequisite for newborn health

The majority of congenital malformations occur between day 17 and 56 post-conception. Thus, the critical time for potential foetal organic defects starts 3 days after absence of the expected menses: a time when many women do not yet know about their pregnancy and have not sought advice and counselling.

Pre-conceptional care is comprised of interventions that aim to identify and limit the biomedical behavioural and social risks to a woman's health or pregnancy outcome through prevention and management. The approach is often to emphasise those factors that must be acted on before conception or early in pregnancy to have maximum impact, and includes care before a first pregnancy or between pregnancies (interconceptional care). While the predominant component addresses women's health, it also includes interventions directed at males, couples, families and society at a large.

Pre-conceptional care is increasingly seen as an effective way of improving the general health and wellbeing of women

The notion of pre-conceptional care has existed for a while, but has not yet been successfully implemented or recognised as a necessary tool to improve newborn health. Culturally appropriate pre-conceptional care, as an effective intervention to improve the general health and wellbeing of women throughout their reproductive years, can ensure healthy lifestyles and reduction of risks for the mother and the foetus.

Pre-conceptional care is an obligation for society to ensure that all women in childbearing age reach a status of health to promote healthy pregnancy. Pre-pregnancy care, which focuses on women with special needs, is also important for promoting social as well as physical stability and wellbeing prior to conception.

High-quality maternal care for improved pregnancy outcomes

Some of the main and most common risk factors potentially harming the unborn child can be positively influenced, and the risk be significantly reduced through good counselling and education. Such risk factors include **malnutrition, lack of folic acid supplementation, maternal diabetes, viral or bacterial infections (toxoplasmosis, rubella, varicella, CMV) and substance misuse (such as smoking, intake of alcohol and illegal drugs but also medicines), which may harm the embryo or foetus.**

An estimated 30% of all women in reproductive age use at least one medication per week that may have a negative effect on the embryo or foetus. Women with a regular intake of medications, such as those with chronic diseases, need counselling and a review of drugs and doses as part of their conceptional planning.

1.2 The case for change

1.2.1 From pre-conception to birth

Optimal nutrition is the essential basis of life and can have a profound impact for pregnant women, the developing foetus, and a newborn child. Quantitative and/or qualitative dysnutrition affects maternal health, foetal development, delivery and birth, and even the child's long-term health outcome. Indeed, it has become clear during recent years that even the global epidemics of diabetes, obesity, metabolic syndrome, and related cardiovascular diseases seem to be considerably attributable to prenatal dysnutrition which may 'programme' a certain health burden for the whole life span (perinatal programming). Even gene expressivity can become sustainably altered by dysnutrition during 'critical periods' of early development (epigenomics, nutrigenomics). Therefore, pregnancy, birth and neonatal life (i.e., the perinatal period), offer a unique chance of primary prevention for the whole lifespan.

Ideally, women of child-bearing age should be **immunised** before becoming pregnant to protect their babies against serious illnesses. For instance, rubella causes serious damage to the foetus and varicella (chickenpox) can cause congenital defects in the foetus and fatal pneumonia in the mother. Both rubella and varicella are preventable by vaccination.

Pregnant women and healthcare providers should always consider the risks and benefits of the vaccine as well as the risks of the disease before administering or receiving the vaccine. Immunisation before conception is always preferred to immunisation during pregnancy.

Smoking increases the risk of miscarriage, low birth weight, perinatal mortality and attention deficit disorder in the child. According to recent studies, the risk to the foetus is reduced to that of a non-smoker, only if the mother quits smoking at least 16 weeks prior to becoming pregnant. Still a large proportion of women smoke during pregnancy, with variations among the EU Member States (Figure 1).

Alcohol consumption can cause mental retardation, malformation, growth retardation, miscarriage, perinatal mortality and behavioural disorders in children. The effects are known to be dose related, but further research is needed. An existing recommendation is to keep alcohol consumption as low as possible and be aware of the consequences and risks, but many healthcare professionals shy away from an outright ban on the substance.

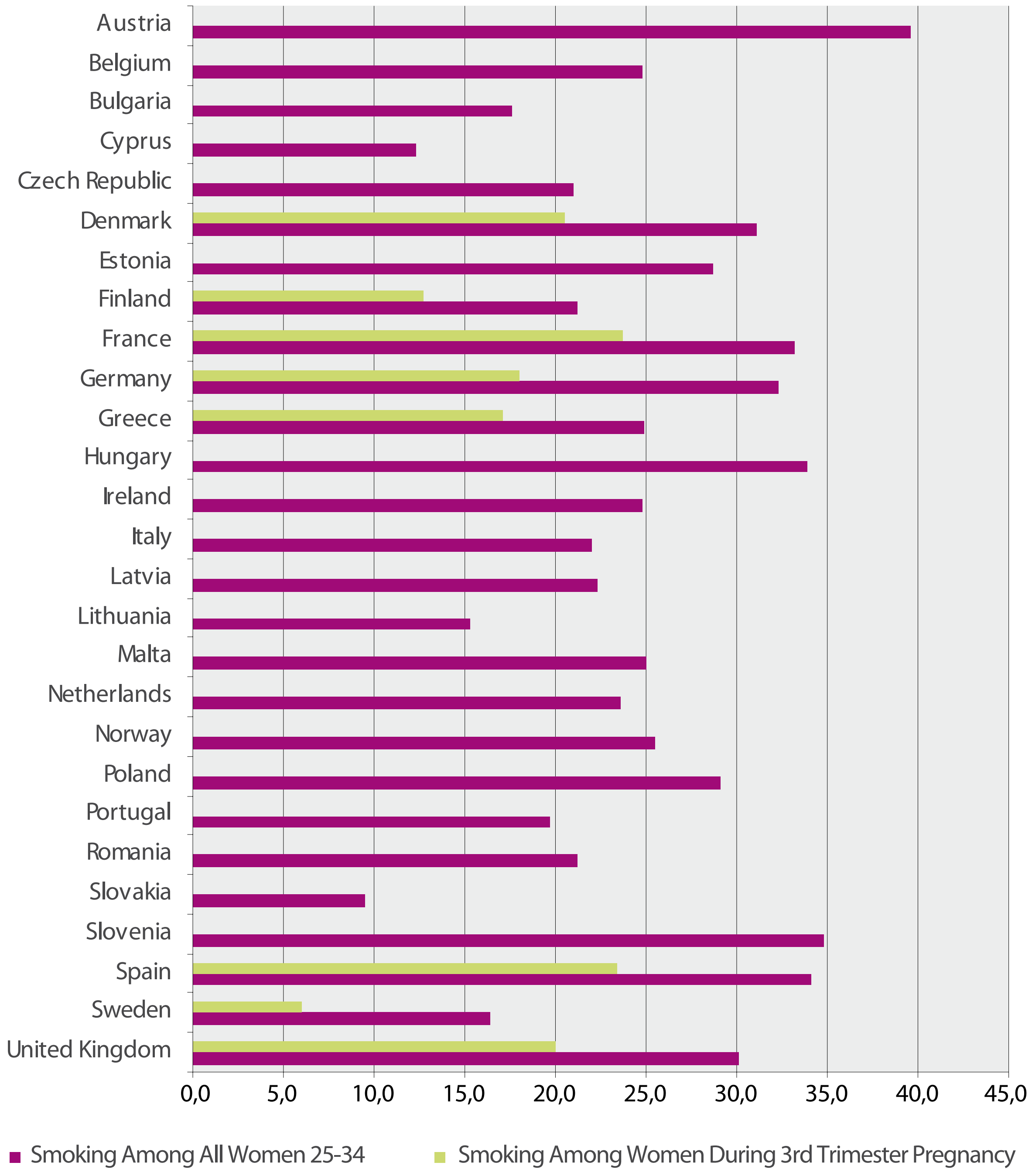
It is obvious that **illegal drugs**, even if taken occasionally, have a high impact of adverse pregnancy outcomes; illicit drug use is associated with a doubling of the stillbirth risk.

Also, an embryo or foetus is more susceptible to **environmental toxins** than adults; drug or chemical exposures causing 3–6 % of anomalies. Timing of the exposure determines the type and severity of the anomaly (metal, solvents, plastics, etc.), some of which women can be exposed to through their employment.

Figure 1

Rate of smoking among all women 25-34 vs. women during 3rd trimester of pregnancy

Source : Eurostat



Ethnic origin and socioeconomic status:
Health inequalities in women's health and maternal care in the European Union

However inequality is assessed, it is apparent that in high-income societies, socioeconomic status has a link with stillbirth and other adverse and longer term outcomes. The reasons for these disparities differ between countries and regions. Bryant et al described disparity in obstetric outcomes as having roots in maternal behaviours, genetics, the physical and social environments, and access to and quality of healthcare of either partner.

Currently, there are considerable disparities in access to women's health among EU Member States. Recent studies highlighted considerable variation regarding the content of guidelines and standards in antenatal care – some countries lack any guidelines at all. This is likely to produce gaps or an unnecessary, expensive and possibly harmful multiplication of tests for pregnant women, especially if care is not documented properly and the documentation is not carried by the pregnant woman herself.

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Facts and figures around pregnancy and birth

- More than five million women give birth each year in the European Union – another **two million women have failed pregnancies** (spontaneous and induced abortion, as well as ectopic pregnancies)
- Approximately **25,000 babies are stillborn** every year in the European Union
- Approximately **90,000 babies have major congenital anomalies**
- **More than 500,000 pregnancies end preterm. Thus, more than half a million babies are born prematurely in Europe** every year
- **Up to 30% of women deemed to be low risk at the start of pregnancy will develop pregnancy-related problems,** making them medium to high-risk pregnancies
- **Problems can occur in any pregnancy.** Pre-conceptional and conceptional health status, as well as the behavioural and life style factors of the mother, have a high impact on the well-being of the foetus and the newborn through till childhood and adulthood
- The main avoidable **risk factors** for pregnancy-related problems are **tobacco use, alcohol consumption, unhealthy diet, maternal weight, maternal age, stress, low socioeconomic status,** and the increased use of **Artificial Reproduction Techniques**
- There are **large differences among EU Member States in registering births, terminations of pregnancies and foetal deaths**
- Adverse pregnancy outcome is a consequence of **existing health inequalities** and **a lack of targeted policies for maternal and foetal health**
- The topics of maternal and perinatal health are currently nearly **absent from funded research programmes** of the European Union and its Member States.

1.2.2 Treatment and care of newborns

Approximately five million children are born every year in the EU, of which about 500,000 are preterm or experience complications requiring intensive care in the neonatal period. Neonatal care is highly technical and has developed rapidly over the past 30 years, resulting in improved outcomes for ill born and very preterm babies. The demand for specialist neonatal care has increased in many countries, such as the UK, where specialist neonatal care services increased by 9% between 2006 and 2008.

Alongside this increase in the numbers of babies requiring specialist care, there have been marked improvements in technology and treatment. Currently, more vulnerable babies are able to survive after being admitted to neonatal care. Indeed, intervention that reduces mortality and long-term morbidity is now available for babies born at full term after having suffered intrauterine oxygen deprivation (asphyxia). However, despite many technological advances, 28,338 babies died within the first 28 days of life (not including stillbirths) in the EU and Norway in 2005, which is equivalent to **544 deaths per week**, or **77 deaths per day** (EUROSTAT).

Neonatal mortality varies in the European Union

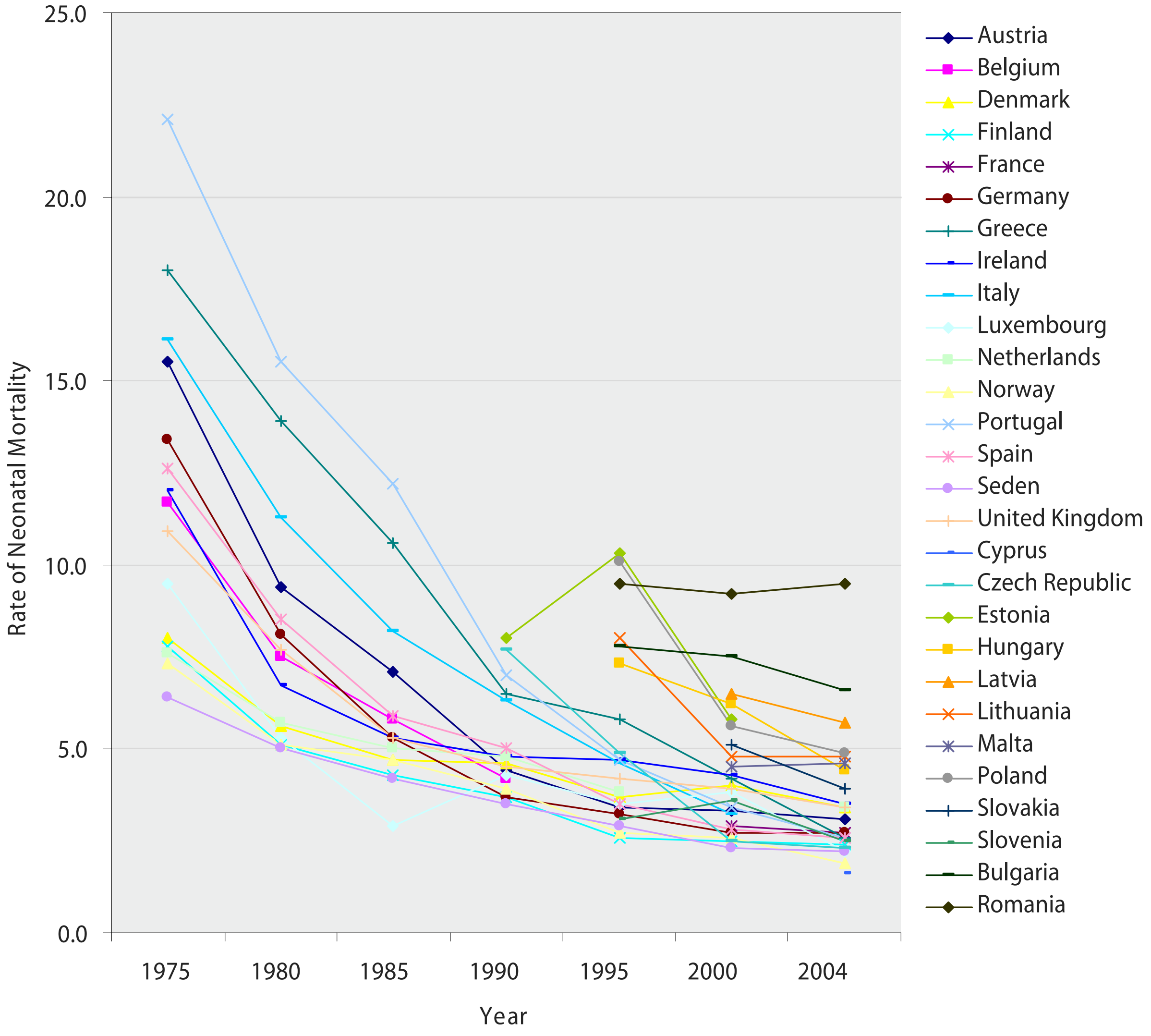
As shown in Figure 2, there has been a significant decline in the rate of neonatal mortality in the last 30 years (source EUROSTAT Population data 2004). However, these data also demonstrate a significant variation between countries in the Europe Union. On average, **neonatal death** occurs in more than one out of every hundred births in the EU, **representing 63% of the total deaths** in children under five years of age.

There are also marked differences in rates of neonatal mortality between the so-called 'new' and 'old' Europe. In 2004, among countries joining the EU prior to 2004 (the original 15 Members) and Norway, the median rate of neonatal mortality was 2.7 per 1,000 births. This median rate was much higher (4.4/1,000) among countries that joined the EU in 2004 (Czech Republic, Cyprus, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovenia, and Slovakia), and was more than three times greater (8.5/1,000) among countries that acceded in 2007 (Bulgaria and Romania).

Figure 2

Trends in neonatal mortality among EU Member States and Norway

Source: Eurostat



Increasing rate of preterm birth and survivors

Prematurity is the major cause associated with infant mortality and morbidity in both developed and developing countries. The earlier a baby is born, the less developed its organs, and the higher the risk of medical complications later in life. Existing data on the issue provides evidence of an increasing number of preterm infants across Europe in the last 10 years (except for Sweden).

1.2 The case for change

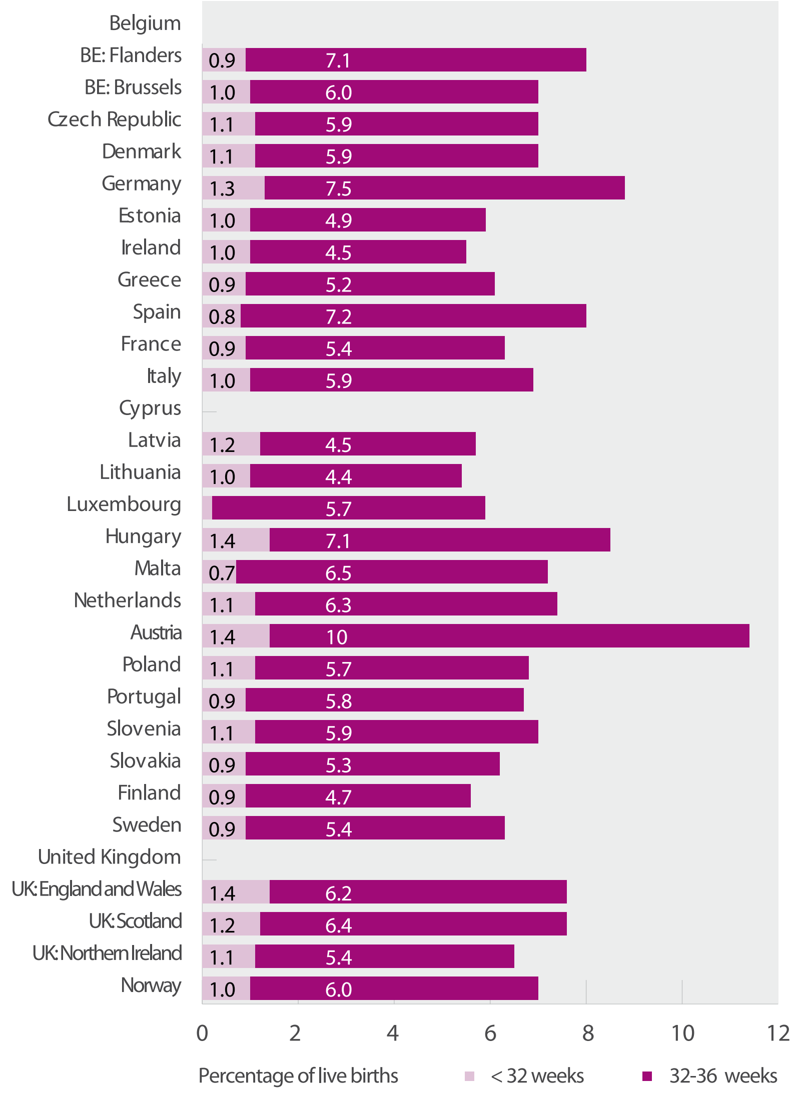
1.2.2 Treatment and care of newborns

However, prevalence varies widely in the EU, from 5.5% (Ireland, France) to 11.4% (Austria), according to data from 2004 gathered by the European Perinatal Health Report. Nonetheless, inconsistencies in data suggest that these figures are still considered to underestimate the current rate of preterm birth. In the last years, some Member States in particular have seen a considerable increase in preterm infants, such as in Portugal, where the prevalence rate has risen by almost a third, from 6.8% in 2004 to 9.0% in 2008 (Table 3). However, neonatal mortality is decreasing in most EU countries and, as more preterm infants survive, the number of babies suffering health complications increases.

Table 3

Percentage of live births with a gestational age under 32 weeks and between 32-36 weeks

Source: Euro-Peristat



These important demographic shifts mean that we must continually reappraise the capacity of neonatal services, so that we can meet parents' needs and aspirations, and produce optimal outcomes for their children.

The main contributor to neonatal morbidity and mortality

Currently, data on morbidity and mortality of preterm infants are not reported in any routine manner throughout the EU. However, such information is extremely important for evaluating perinatal health outcomes. As highlighted earlier in the paper, very preterm infants (born before 32 weeks) have the highest rates of long-term health problems, including cerebral palsy, severe learning disabilities, chronic lung disease, visual and hearing impairments, and poor growth.

However, even babies born between 33 and 37 weeks of gestation, often termed mildly or moderately preterm and late preterm (34-36 weeks) have higher neonatal morbidity than newborns born at term (Figure 3).

In addition, the neonatal and infant mortality rate increases in late preterm infants, nearly doubling with each week of prematurity (Figure 4).

Figure 3

Morbidity risk of late preterm infants

Every week of preterm birth doubles the risk of suffering from diseases and complications during the neonatal period in this group of preterm infants

Source: Shapiro Mendoza et. al. Paediatrics 2008

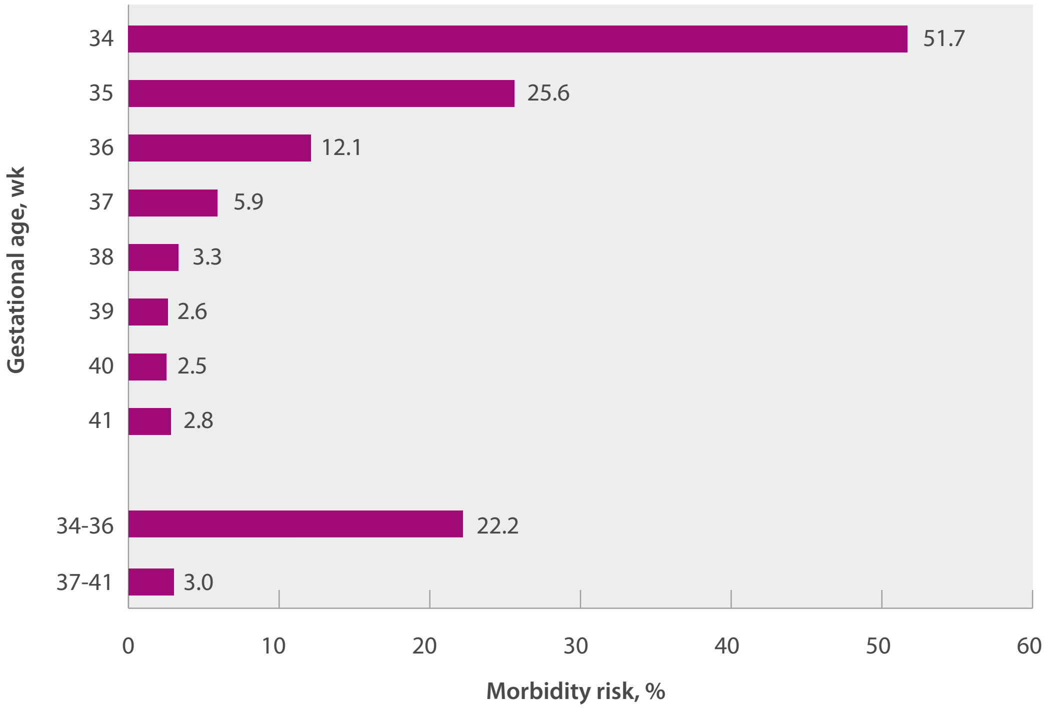
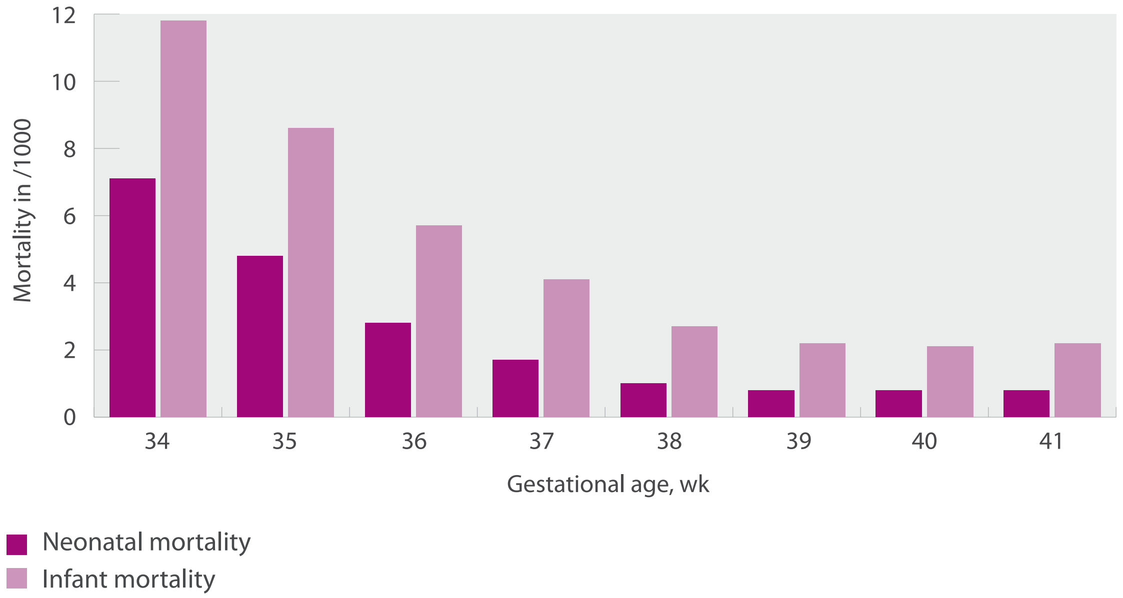


Figure 4

Neonatal mortality

Each week of prematurity doubles the risk of dying in the neonatal period and in infancy in late preterm infants

Source: Reddy et al. Pediatrics 2009



Neonatal care and prematurity

- Approximately 5 million children are born every year in the EU's 27 Member States; about 500,000 are born preterm or experience complications that require intensive care in the neonatal period
- There have been marked improvements in technology and treatment, increasing in the number of vulnerable babies who survive after being admitted for neonatal care
- Technical advances have led to an increasing demand for highly technical neonatal intensive care services
- Despite this, 28,338 babies died within the first 28 days of life (not including stillbirths) in EU and Norway in 2005; equivalent to 544 deaths per week, or 77 deaths per day
- **Neonatal mortality varies in Europe.** On average, neonatal deaths represent 63% of the total deaths in children under 5 years old. Prematurity and low birth weight are the main causes of neonatal death

- Not only very low or extremely low birth weight preterm, but also moderate and late preterm born infants are at increased risk of short and long-term morbidities
- Each week of preterm birth doubles the neonatal and infant mortality rate
- Only very few countries have **targeted national policies for maternal, foetal or neonatal health**
- In the European Union, the field of newborn health and the challenges of preterm birth has no priority and is not on the top agendas; e.g. EU and national funded research programmes
- Neonatal health sets up the lifecourse, influencing health, impairment and wealth
- Morbidity can be avoided with good care and appropriate intervention
- Research will identify key causal pathways and prevention to later disadvantage and disability
- Economically enhancing the quality of life for EU citizens will address key inequalities and disadvantages, and will enhance productivity.

1.2.3 Preterm birth and long-term consequences

Compared with their full term counterparts, children born preterm are at greater risk of a range of health, learning and behaviour problems, which are more frequent the more preterm the birth.
These problems are most prevalent in the following areas:

- Neonatal brain injury leading to cerebral palsy – increases in frequency from 2-3 per 1000 at full term to **200 per 1000** at 24-25 weeks of gestation; cerebral palsy leads to major motor deficits and a range of associated functional impairments, with important implications for care, education and social support as the child grows
- Altered brain development - leading to learning and cognitive problems and major implications for educational support, or special educational needs as a child grows, increase from 6-7% at 36 weeks to **over 50% of children** at 24-25 weeks
- Altered brain development - frequently manifest as behavioural deficits, such as inattention and symptoms of anxiety or autism. Such problems may reach diagnostic criteria in **1 in 4 of the most premature**, translating into an excess of psychiatric morbidity as adults
- Neonatal lung disease - long-term consequences for children requiring prolonged supplemental oxygen or born preterm; these include need for hospitalisation e.g. due to infection over the first 1-2 years for respiratory illness and increased use of pulmonary medications. Also, lung function is reduced as teenagers and the **risk of chronic obstructive airway disease** in middle age may be increased
- Cardiovascular risk factors - more common in preterm children and often linked to lung function, whilst the risk of **hypertension and chronic heart disease** increases in adult life.

Many infant deaths, chronic disabilities and health conditions could be prevented through improved neonatal prevention, treatment and care.

1.2 The case for change

1.2.3 Preterm birth and long-term consequences

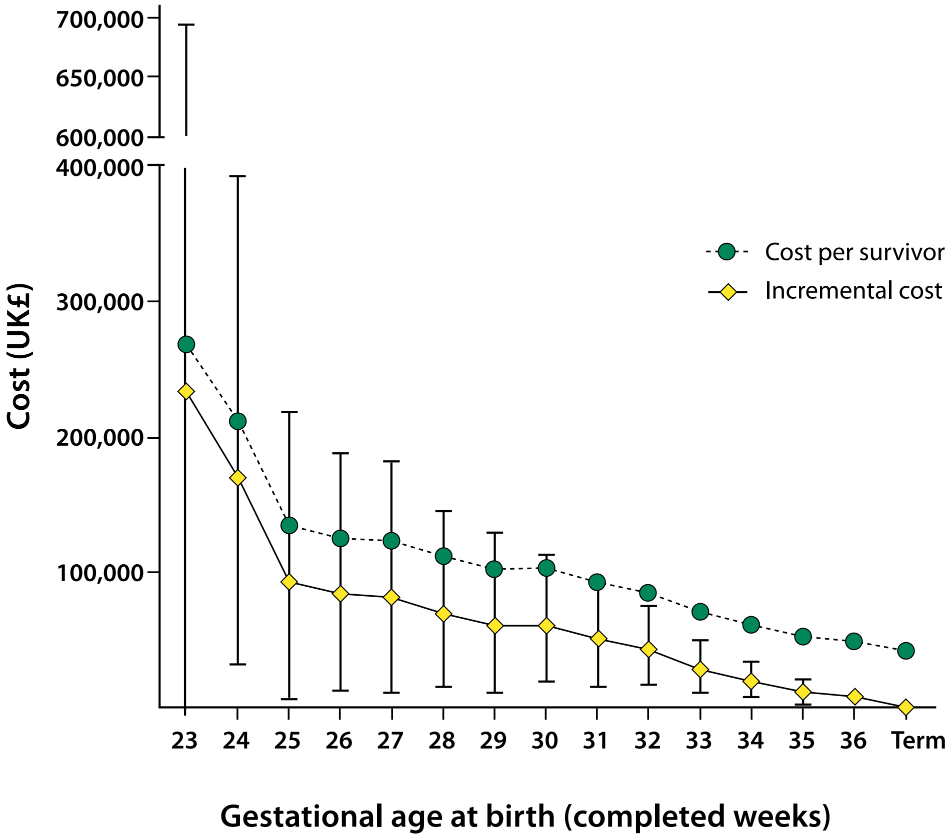
Long-term morbidity of preterm infants poses a serious financial burden to families, healthcare systems and societies

Preterm birth involves significant incremental economic costs during the neonatal period, comprising the majority of childhood costs, which increase the more preterm the birth coupled with the associated need for intensive care activity (Figure 5). Although incremental educational, health and family costs are modest in childhood, they are not negligible and are more of a financial burden on those disadvantaged families, who are also more likely to have children with impairments. In addition, the more severe the disabilities, the greater the associated economic, social and family costs.

Figure 5

Absolute and incremental costs over childhood per survivor

Source: Neil Marlow, Lindsay J. Mangham et al. Pediatrics 2009



Indeed, one striking example of the societal costs of preterm birth is the incidence of cerebral palsy, with an incidence of 2.3 in every 10,000 newborns. The lifetime costs of this illness are estimated at a minimum of €750,000 per child, totalling more than €7 billion per year. In the USA, the annual cost estimate for preterm birth based on 2005 figures is USD 26.2 billion.

Another example of the societal costs is the weakening of Europe's workforce. Members of society born preterm who have not received proper care are more likely to have lessened abilities as workers, resulting in a significant population missing as full participants in the European employment market. Up to 10% of preterm infants suffer from medical disability that will affect their working capacity by more than 50%. Considered in the long-term, preterm births equate to 20,000 children per year, each of whom risk being unable to fully contribute to the workforce.

Preterm birth and low birth weight also have a high impact on parental workplace performance. Many mothers of preterm infants who intended to return to work after the birth either postpone doing so, reduce their hours, or leave the workforce altogether to care for their child. This is usually associated with a reduction in family income of up to 32%.

Parents of infants with neurosensory and cognitive disability often require support from social services during the immediate period following the infant's discharge from the neonatal unit. In later life, developmental services, including day care programmes, case management and counselling, respite care and residential care, may also be required to supplement health and educational services.

In addition, some of the intangible costs include the emotional and physical energy required to care for the preterm infant and the consequent parental isolation and restricted social contact.

In view of the increasing number of preterm infants in Europe, the above findings are an alarming sign of the immediate need for action, especially when considering the ambitious priorities of the Europe 2020 strategy:

1. Reducing the share of early school leavers to less than 10%
2. Raising the 30-34 year old population completing tertiary education to at least 40%
3. Reducing the poverty and social exclusion of 20 million people
4. Raising the employment rate of the population aged 20-64 to at least 75%.

Decision makers should be aware of the substantial long-term economic impact of preterm birth. Furthermore, they should be sensitive to the financial constraints faced by parents on low incomes at a critical time in the parent-child relationship.

1.2.4 Aftercare services and follow-up: a focus on prevention

Parenting shapes the early years: parent mental health and family function, including sibling relationships, are crucial to enable optimal development for a preterm infant. Preterm birth and neonatal illness may affect the natural development of parenting and impose anxiety on parents, which will disturb the natural development of a family's relationships. These anxieties are most acute around the time of transition from the neonatal unit to home, especially as some of the preterm infants then suffer adverse long-term outcomes; including increased rates of ill health and neuroimpairment, and a range of other problems, such as with growth and development. As such, children requiring neonatal intensive care are an easily identifiable high-risk group.

However, during the newborn period, it is not always possible to identify whether preterm infants will develop health or educational problems later in life. While some morbidities are identifiable in infancy, such as respiratory or feeding problems, others will only be identified at school age; e.g. psychiatric or learning difficulties. Likewise, the total impact of preterm birth on the children and their parents is often only known in adulthood. Parents live through considerable uncertainty regarding the health and educational outcome of their children.

Due to the high personal and societal costs associated with preterm birth, minimising any financial impact and burden to parents should be the key goal of aftercare services.

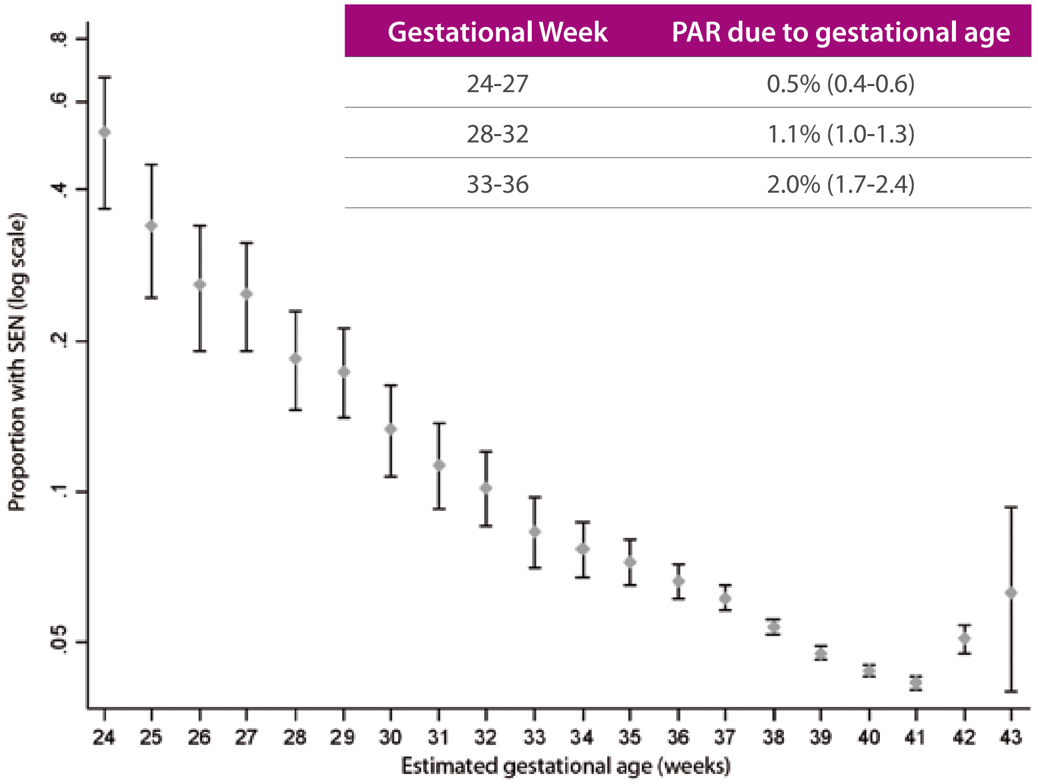
Aftercare services and follow-up is currently lacking in different areas, including:

- **Planning for discharge** needs to take place early in the neonatal course to promote parental-infant interaction ('bonding') and breast-feeding, to optimise both neonatal course and outcome, and to promote parental confidence and independence. Most babies do not need intensive multidisciplinary follow-up, but community care systems should be aware of the risk for later neuro-cognitive and pulmonary outcomes associated even with a relatively uncomplicated neonatal unit admission
- **Formal follow-up and aftercare services are needed for children at highest risk of impairments** that develop as a consequence of their perinatal course or preterm birth, or are identifiable in the neonatal period. Most follow-up guidance comes from infant-based criteria, such as very preterm birth (<32 weeks of gestation) having a 10% likelihood of a serious impairment risk and higher risk of educational special needs, as well as a case of neonatal encephalopathy (such as that following birth asphyxia), where there is a 30-40% risk of serious impairment and special needs and identified congenital conditions (infection, abnormality)
- **Population attributable risk** – although most follow-up procedures concentrate on those identified above, it is nonetheless important to recognise that seven to ten times more children are born moderately preterm or near term, or with perinatal complications (5-10% of all children) and it is likewise essential that this population be well cared for after discharge and into childhood and adult life. Overall, this group has a larger impact on population health than the 1% of high-risk children (see panel below). Furthermore, intervention studies suggest that those infants born at moderate to near term are most likely to benefit from early intervention. A major challenge is the identification of infants at risk for later neuro-cognitive and pulmonary outcomes in this group of moderate and late preterm born infants.

Figure 6

Prevalence of special educational need by gestation at delivery

Source: MacKaye et al PLOS Medicine 2010



Gestational Week	PAR due to gestational age
24-27	0.5% (0.4-0.6)
28-32	1.1% (1.0-1.3)
33-36	2.0% (1.7-2.4)

- **We find follow-up care to be necessary in order to:**

  1. Identify evolving impairments in the developing child
  2. Support parental care and decision making concerning the introduction of mixed feeds, immunisation, transitions to education, and to provide reassurance concerning developmental trajectories
  3. Provide outcome information to facilitate benchmarking of neonatal services, which should be collated on a population rather than a hospital basis to avoid biases in reporting.

- **The developmental domains of interest** are physical health, early behavioural regulation (such as feeding or sleeping), neuro-motor development, cardiovascular and respiratory development, cognition and learning, mental health and the social relationships of the child. Social integration, participation, quality and satisfaction of life should be the ultimate goals, independent of disability.

- **Follow-up in infancy** is aimed at health surveillance, usually within the first two years after birth, and detection of major impairments – developmental delay, cerebral palsy, sensorineural problems (blindness and deafness) pulmonary sensitivity for infections, asthma – provide the major outcomes for which early medical intervention is important and comprise the major benchmarking outcomes. Although often provided by the neonatal service, it is critical that there are clear care pathways for children who need support from neurodisability services and other paediatric inputs (for example respiratory medicine)
- **Later health and psychological surveillance** is important as the bulk of impairments (i.e. behaviour, cognition, learning and neurosensory function, reduced pulmonary function) are not reliably detectable until school age, but seriously impair quality of life. However, neonatal follow-up services are rarely equipped, or have the expertise and resources, to provide surveillance in these multiple and often quite delicate areas. Two potential approaches require evaluation so that early interventional strategies can be established to minimise the disability:
    1. Development of inexpensive and accurate screening tools to alert health and educational services
    2. A system of continuing professional development to raise awareness of the importance of preterm birth and perinatal risk in the development of these impairments.

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Preterm birth: long-term consequences and their implications for aftercare services and follow-up

Compared with children born at full term, children born preterm are at risk of a range of health, learning and behavioural problems, which are more likely the more preterm the birth. These problems are most prevalent in the following areas:

1. Neonatal brain injury, which can lead to cerebral palsy
2. Altered brain development, leading to learning and cognitive problems associated with have major implications for educational support or special educational needs
3. Neonatal lung disease, associated with long-term consequences for children requiring prolonged supplemental oxygen or who are born preterm; these include the need for hospitalisation for respiratory illness over the first 1-2 years, and increased use of pulmonary medications – lung function is reduced during teenage years and the **risk of COPD** in middle age may be increased
4. Cardiovascular risk factors, which are more common in ex-preterm children and linked to lung function.

- Later morbidity poses significant economic costs to both families and society as a whole in terms of health, education and social care
- The risk of a disability permanently reducing working capacity by 50% is twice as frequent in moderate and late preterm survivors compared with full term births, and increased 7-fold in extremely preterm survivors
- Prematurity and the sequelae of preterm birth are more frequent in disadvantaged populations who are less able to deal with the effects of later impairments and disabilities
- Parenting shapes the early years, and admission for neonatal care may disturb the normal process of attachment and generate anxieties about vulnerabilities that influence rearing practice: the quality of family support, preparation for coming home and post discharge support is critical in minimising these effects
- Case management, structured aftercare programmes, parental support and preventive strategies are cost effective and can improve outcomes.

2.1 Key recommendations and principles: pre-conceptional and maternal care

1. **Make maternal and perinatal care a European and national policy priority**
   Maternal and perinatal care must have the highest priority in healthcare policy in order to ensure a healthy start in life for Europe's babies; an essential precondition for healthy and active ageing. All Member States should acknowledge the potential long-term consequences of a significant population born preterm, or with illnesses, and provide adequate resources to maternity care to support the health of pregnant women.

2. **Address health inequalities amongst and within EU Member States**
   The European Union and its Member States should address health inequalities between Member States and within the countries themselves in order to ensure equitable, comprehensive, high-quality and patient-centred care in the pre-conceptional, maternal and perinatal setting. Clearly, an additionally important element in this is determined at delivery; in particular, the interconnection between preterm delivery and social inequalities. Concerted and coordinated action is required to improve and harmonise the care of women and their unborn children in Europe.

3. **Conduct national audits on maternal and perinatal care and establish a task force for developing national best practice guidelines**
   Each Member State should establish a national audit report on maternal and perinatal care as well as on preterm delivery. Based on the results, an interdisciplinary national task force, including parents and experts in obstetrics and gynaecology as well as neonatology and paediatrics, should develop national roadmaps and strategies for prevention of preterm delivery and best possible pre-conceptional, maternal and perinatal care.

4. **Implement national policies and guidelines for high quality pre-conceptional, maternal and perinatal care and implementation of audit procedures**
   It is strongly recommended that each Member State ensures that up to date national policies are in place for the care of women at pre-conception, during pregnancy, labour and post-delivery phases. In addition, national policies should be in line with recommendations, such as those made by the European Board and College of Obstetrics and Gynaecology (EBCOG) in '*Standards of Care for Women's Health in Europe*'. To achieve high-quality pre-conceptional and prenatal care, networks and their constituent services must achieve a range of quality of care indicators. EFCNI has identified several such indicators and strongly endorses the following principles:

   - *Equal and early access to high-quality pre-conceptional care*
     All Member States should have strategies in place to provide a system of pre-conceptional care and family planning, with equal and early access for women and their partners. All women of reproductive age are empowered to be as healthy as possible to enable pregnancy in optimal health

   - *Equal and early access to high-quality screening services and antenatal diagnostic testing*
     All Member States should have strategies/national guidelines in place to minimise pregnancy risks and provide interventions and behavioural counselling for identified 'at risk' pregnancies. Women identified as high risk for a preterm delivery should be followed in specialised preterm delivery programmes

   - *Prevent rather than cure*
     The aim of a structured preterm delivery prevention programme is to avoid the necessity of treatment. Thus, a well designed disease prevention programme and health promotion is considered a key component towards effective prevention, early diagnosis and adequate care of women showing signs that might lead to preterm delivery

   - *Clearly defined care and referral pathways*
     All Member States should have an effective system with clearly defined care and referral pathways in place, so that mothers and foetuses that are 'at risk', particularly for preterm births, are identified and transferred to the appropriate specialised peri- and neonatal centres and/or are seen at a combined consultation with the appropriate professionals. All Member States should establish up to date transparent clinical governance frameworks, risk management policies and documented care plans for each birth setting, as well as staffing levels and multidisciplinary competencies on labour wards complying with the complexity of the clinical work load

   - *Audit procedures*
     Improvements and benchmark performance of individual peri- and neonatal centres against nationally agreed standards should be monitored and analysed. Audit findings need to be addressed and each Member State should ensure there is central monitoring of preterm delivery rates using a harmonised European dataset.

5. **Enhance activities to reduce the number of stillbirths**
   Stillbirth should be recognised as no less significant than any other death. Information on stillbirth, as well as the aim of reducing its rate, should be included in all relevant maternal and neonatal health initiatives, care plans, health reports and healthcare research projects. All Member States should have strategies and policies in place to eliminate all preventable stillbirths and close equity gaps. These policies should be based on recommendations made by professional organisations and parent groups.

6. **Provide equal and early access to comprehensive information, education and counselling for expecting parents**
   All prospective parents should receive equal and early access to up to date, evidence-based education, full information and counselling/advice on pre-conceptional and maternal issues, sexual and reproductive health, healthy pregnancy, delivery, newborn care and early parenthood. They should be provided with comprehensive and accurate information on available techniques and procedures of prenatal diagnosis and therapies, including risks. Based on this information, expecting parents should be given freedom of choice and included in the decision-making process to select the diagnostic and/or therapy of choice.

2. EFCNI vision for improved care

2.1 Key recommendations and principles: pre-conceptional and maternal care

7. **Harmonise education and training of healthcare providers**
   - Education and training of healthcare providers should be harmonised among the EU Member States to meet minimum standards for training in their respective area
   - Regular, specific, continuing professional education and training should be an obligation for all healthcare professionals providing pre-conceptional, maternity and perinatal care, including obstetric emergencies and how to communicate information in an effective and sensitive manner to (prospective) parents. Providing regular multidisciplinary training for clinical staff is highly recommended
   - Training programmes should follow recommended standards of the according professional societies (e.g. European Board and College of Obstetrics and Gynaecology, and the European Midwives Association)
   - It is of high importance to increase the awareness of all healthcare professional providers in contact with women of reproductive age when it comes to underlying risks during pregnancy and consequences. Also increased awareness of on-going care is important for chronic conditions, intervention for identified risk factors, and safe use of medication during pregnancy.

8. **Develop and implement strategies for public awareness and education**
   Society at large needs to be constantly updated on healthy pregnancy and possible (preventable) risk factors, starting with school-aged young people.

9. **Protect pregnant women and their foetuses**
   All Member States should protect pregnant women and their foetuses to ensure individual safe and healthy pregnancy and birth by providing the right public, professional and legal framework. This should ensure that all citizens, especially the young generation, are informed about their reproductive health and rights. Becoming pregnant during ones career should be regarded as a woman's contribution to society. Thus, neither the employer nor the working pregnant woman should be negatively impacted by pregnancy.
   - Assist pregnant women and families in difficult situations (such as in cases of low income, unemployment, domestic violence, or single parenthood) to ensure healthy pregnancy and birth
   - Working environments should be individually adapted according to the needs of becoming a mother. Time off for doctors visits during working hours should be granted to pregnant women. Pregnant women should also be informed of their rights and duties when at their work place
   - In case of high-risk pregnancies, women should be allowed earlier pregnancy-leave without risking any financial disadvantages
   - Continuity of work must be guaranteed to all pregnant women following delivery
   - Expecting mothers should be protected from potentially harmful environmental, behavioural and lifestyle risk factors, such as smoking and second hand smoke or alcohol drinking, as long as safety has not been demonstrated
   - Providing safe medication for pregnant women and extension and strengthening of the teratology information services (TIS) network in Europe.

10. **Harmonise cross-border maternal healthcare**
    - All Member States should have strategies in place and be able to implement a legal framework for cross-border healthcare, enabling pregnant women to choose their own provider and place of birth, including beyond their national borders
    - Therefore, all Member States urgently need to agree on a common system for documenting antenatal care (maternity records) and approve a common dataset for national reproductive health registers for developing EU-wide outcome indicators
    - It is recommended that a European standardised dataset collected in the EU Member States be established, and that data collection of centralised European registry for epidemiological and quality outcomes data also take place. To enable comparative analysis, such a registry should be founded on the basis of common definitions and measurement criteria.

11. **Invest in more research**
    All Member States should provide adequate research funding to ensure that financial support is available, enabling evidence-based best interventions for follow-up studies on developmental mechanisms and on intervention trials with international networks. Research for *preterm delivery prevention and treatment* services should be included in European and national funded research programmes.

2.2 Key recommendations and principles: treatment and care of newborns

1. **Prioritise neonatal healthcare on policy agendas of EU Member States**
   Even when resources are limited, each Member State should prioritise maternal and newborn health; the health and wellbeing of future adult European Union citizens is of the utmost importance.
2. **Conduct national audit on neonatal care and establish a task force for developing national best practice guidelines for neonatal care**
   Each Member State should establish a national audit of newborn care. Based on the results, a national task force consisting of parents and an interdisciplinary group of experts should develop national roadmaps and strategies for delivering best possible neonatal care for every newborn EU citizen.
3. **Implement national policies and guidelines as well as audit procedures for high-quality neonatal care**
   Each Member State must establish, implement and audit national policies to deliver the best possible, and highest quality neonatal care to produce optimal outcomes for mother and baby. This strategy should focus primarily on the provision of trained medical personnel and modern medical equipment, evidence-based treatment and care methods, infrastructure and logistical cooperation, neonatal audit and quality control. Family-centred and developmentally adapted neonatal care, including parent involvement in their child's care, should be essential overarching elements of the guidance.

   EFCNI has identified and strongly endorses the following principles, which cover the major areas of activity within the neonatal hospital care pathway and should be read with other professional standards:

   a. *Clearly defined care and referral pathways and infrastructure*
      All Member States should have an effective system with clearly defined neonatal care and referral pathways to provide safe and effective transfers of newborn babies needing special care to the appropriate specialised unit (centre)

   b. *Care of the baby and family experience*
      Neonatal hospital units should adopt a family-centred philosophy to alleviate parental and family stress and anxiety, and to promote parenting roles in the hospital. This principle puts the physical, psychological and social needs of both the baby and his/her family at the core of all care given. Ultimately, family-centred care may enhance attachment and result in improved long-term outcomes for both; education of parents, psychological support and developing parental competence are essential components of this activity. Dedicated family space and neonatal family-centred infrastructure is an important prerequesite to effectively integrate the parents in caregiving with permanent proximity to their baby

   c. *Clinical standards and quality*
      Neonatal care techniques should come from evidence-based medicine and best available clinical standards. Each neonatal unit should have written guidelines for the most common diagnoses and treatment procedures for babies

   d. *Professional competence, education and training*
      Members of the multidisciplinary neonatal team should be adequately educated and trained to the level of competence necessary to enable the delivery of high-quality care. Certificates can be used for demonstrating that individual staff members have adequate training for certain procedures

   e. *Audit procedures*
      Improvements and benchmark performance of individual units against nationally agreed standards need to be monitored and analysed. Audit findings must be addressed and acted upon.

4. **Harmonise clinical guidelines**
   Policies and practices in place for the treatment and long-term care of preterm infants vary considerably across Europe, with a substantial impact on the quality of care, health and social outcomes. In order to address these disparities, the EU would benefit from a set of basic and independent evidence-based professional guidelines for the care and treatment of newborn infants. The European neonatal and perinatal societies should collaborate to establish common guidelines on scientific evidence, long-term experience or consensus of opinion, and recommendations to harmonise medical treatment in Europe.
5. **Increase efforts to develop approved, safe and effective medicines for newborns**
   The EU and its Member States should increase and support efforts to develop safe medications for newborns.
6. **Harmonise education and training of healthcare providers**
   In the majority of EU Member States, there is a shortage of trained neonatal healthcare and research professionals (specialised nurses and doctors, as well as scientists) to meet the needs of care for preterm birth. One option is to support the establishment of European postgraduate training programmes, which include local, onsite training programmes for neonatal units and hospitals, national and European postgraduate courses and seminars, and the exchange of neonatal trainees between certified European educational centres of excellence; as suggested in the training syllabus provided by the European Society of Neonatology (ESN). The Neonatal Curriculum also specifies key components for training centre accreditation by the ESN. It is strongly recommended that structures and capacities are funded; e.g. on-site visits for accrediting European Neonatal Training Centres.
7. **Implement European-wide standardised datasets**
   Reliable epidemiology and quality outcomes data are necessary to develop meaningful, evidence-based health policies at EU level, and to support complementary efforts at the national level. While there have been attempts to create independent European networks (e.g. EuroNeoNet) with the aim of improving data collection, such initiatives remain limited, require improved coordination as well as more sustainable, long-term funding, and necessitate a broader scope in order to make a real impact on the quality of care. A first step for the EU would be to establish a European standardised dataset, collected in the EU Member States, and data collection centralised in the European Neonatal Registry to support epidemiological studies and quality improvement intiatives. Such a registry should be founded on the basis of common definitions and measurement criteria in order to allow for comparative analysis.

8. **Invest in more research**
   The European Union and its Member States should invest more in research in the field of neonatal health by implementing research in maternal and newborn health in upcoming research programmes, e.g. 'Horizon 2020'. Research should be funded to bring together a 'network of networks', designed to maximise follow-up and research experience at the EU level and streamline follow-up guidelines across the EU landscape. Research areas should also include:
   a. Quality of life research (adults born preterm)
   b. Family-centred care and psychological parental support
   c. Individualised medicine in preterm and full term newborn infants
   d. Gastrointestinal immaturity
   e. Lung development, asthma and prevention of chronic pulmonary disease
   f. Disease process, diagnosis and prevention of cerebral palsy and developmental brain injury
   g. Determinants of mental health among preterm infants and development of neuroprotective strategies
   h. Disease mechanisms of retinopathy and post-chiasmal vision deficits
   i. Impact of environmental factors on pre- and postnatal child development.

2.3 Key recommendations and principles: aftercare services and follow-up

1. **Acknowledge the potential long-term consequences of preterm birth and newborns with illnesses**
   All Member States should acknowledge the potential long-term consequences of improving preterm survival, and provide adequate resources to support the health of these children beyond hospitalisation.

2. **Address health and social inequalities**
   All Member States should address the interconnections between prematurity, chronic diseases as well as health and social inequalities. By addressing health and social inequalities, and improving access to support and aftercare, particularly for disadvantaged populations, poor health outcomes following preterm birth may be minimised.

3. **Conduct national audit on follow-up and aftercare and establish taskforces for developing best practices**
   Each Member State should establish a national strategy for aftercare and publish audits of the penetration and coverage of such care. This may be best accomplished by establishing a national task force, including experts across all involved disciplines as well as parents representatives, to develop a national roadmap and strategy for best possible aftercare.

4. **Implement national policies and guidelines as well as audit procedures for high-quality aftercare services**
   To achieve high-quality aftercare, EFCNI has identified and strongly endorses the following principles, which cover the major areas of activity within the aftercare pathway and should be read with other professional standards:
   a. *Aftercare and follow-up of infants at risk*
   Children born preterm identified as high-risk, or newborns with complications requiring special care, should be provided with specialised aftercare programmes
   b. *Prevent rather than cure*
   The aim of a structured aftercare programme is to avoid the necessity for treatment. The follow-up is a key component towards effective prevention, early diagnosis and adequate care of linked chronic diseases
   c. *Structured discharge management*
   Every hospital should have an individual discharge planning policy for each very preterm or at-risk baby and their family. Discharge planning is best when started early in the hospital course, with the goal of ensuring successful transition to home care
   d. *Clearly defined aftercare, referral pathways and infrastructure*
   Aftercare should be coordinated to reduce additional burden on families, and should be performed by experienced trained healthcare providers to avoid parental uncertainty and doubts. Aftercare services should ensure appropriate expert treatment and provide equity of access to care of the highest standard for optimal outcomes. Case management to coordinate aftercare services is strongly recommended
   e. *Minimal components of aftercare services*
   An aftercare service should include minimum components, such as:
      - Standardised follow-up to at least 2 years of age for all high-risk groups, particularly preterm infants. Appropriately trained assessors should screen for growth, health problems, and cognitive, developmental, neurological and sensory impairments, and behaviour problems
      - Access for families to advice and support during this period
      - Planned transfer to appropriate multi-disciplinary services for on-going surveillance through to school age.

f. *Family support*
   Aftercare services should provide support to the whole family in a family-centred aftercare approach. Parental confidence should be developed through appropriate education and direction, leading to better support of the vulnerable child

g. *Continuity*
   The follow-up of at-risk infants to school age is necessary to identify restrictive and disabling conditions, ranging from health problems and social problems with peers, to specific learning problems (e.g. in mathematics) and behavioural disorders. Key to this aim is education concerning the issues resulting from preterm birth for staff interacting with children

h. *Audit procedures*
   Aftercare services should be monitored and analysed. Each Member State should ensure that there is central monitoring of outcomes (mortality, neurodevelopmental and cognitive disability and cerebral palsy rates, as defined by consensus) for each neonatal service or group of services. Where possible, such reports should be population-based to facilitate monitoring, and conducted by assessors not involved in neonatal care. Audit findings must be addressed and acted on.

5. **Support parents and families**
   All Member States should develop parental materials specifically for preterm infants for inclusion in existing national baby health records (e.g. yellow book in Germany or red book in UK), to develop consistency in terms of interventions; such as immunisations, follow-up visits and specific weaning advice. In addition, Member States should improve the financial and social support for families with preterm infants and newborns with morbidities, and provide the possibility for prolonged maternity/paternity leave for parents of affected children.

6. **Implement continuous professional education and training**
   All Member States should develop and implement continuous training and educational programmes on the consequences of preterm birth. Such education should focus on children and their families, and all healthcare professionals involved in aftercare for preterm children and their families; e.g. paediatricians, obstetricians, therapists, day-care staff, social workers and teachers.

7. **Monitor outcomes**
   It is recommended that a European harmonised dataset is established for use in all the EU Member States. Data collection should also be centralised through a European registry for epidemiological and quality outcomes. Such a registry should be founded on the basis of common definitions and measurement criteria, enabling comparative analysis. The appointment of a multidisciplinary European steering committee is recommended.

8. **Provide adequate research funds**
   Several identified interventions (e.g. physiotherapy to prevent disability in cerebral palsy) are of proven benefit. Other developmental or educational interventions are of less certain value; the European Union should recognise such an evidence gap and focus efforts on supporting research into identifying effective and evidence-based strategies to ameliorate these very important long-term consequences and enhance the societal contribution of adults born preterm.

3. Parents and newborn rights

1. **The right to receive equal and early access to education**
   All (expecting) parents have the right to receive equal and early access to evidence-based adequate education. This must include comprehensive and adequate information and counselling/advice on pre-conceptional and maternal issues, sexual and reproductive health, healthy lifestyles, healthy pregnancy, delivery, newborn care and early parenthood.

2. **The right to evidence-based high-quality treatment and care**
   All (expecting) parents and newborns have the right to evidence-based, high-quality treatment and care as a basis for active and healthy ageing. This includes equipment, use of medication, as well as education and training of healthcare providers.

3. **The right to remain as a family unit**
   All families have the right to be considered as a unit. Each member, and the family as a whole, has to be approached with dignity, respecting their social, cultural, developmental, emotional and clinical needs as well as their rights to privacy.

4. **The right to comprehensive and accurate information**
   All parents have the right to be provided with comprehensive and accurate information on available techniques and procedures of diagnosis and therapies, including risks in their own wording and language. Based on this information, parents have to be included in the decision-making process to perform a chosen diagnostic and/or therapy service.

5. **The right to be actively involved in child care**
   All parents have the right to receive appropriate education and be actively involved in their baby's care giving in an effective and sensitive manner.

6. **The right to complain**
   All parents have the right to voice complaints and recommend changes without fear of negatively affecting or influencing a change in the quality of care of their child.

7. **The right to support**
   All (expecting) parents and children born at risk have the right to psychological, social, and financial support and, if required, individual culturally-appropriate bereavement support.

8. **The right to pregnancy-, maternity/paternity- and parental leave**
   All parents are entitled to pregnancy -, maternity/paternity- and parental leave. Families of preterm infants, with multiple births and infants with illnesses should be entitled to extended leave periods.

3. Parents and newborn rights

9. **The right to family-centred care**
   All parents and newborns have the right to family-centred care and to stay together while the child receives healthcare.
10. **The right to allow close family members contact with the newborn**
    All parents have the right to allow close family members (i.e. grandparents, siblings or close friends) to have contact with the newborn.
11. **The right to receive information about services and help groups**
    All parents have the right to receive adequate information about the existence and services of parents help groups and national parents and patients organisations.
12. **The right to appropriate transfer and discharge procedures**
    All parents and newborns have a right to appropriate and individual transfer and discharge procedures.
13. **The right to receive specialised aftercare services**
    All parents and newborns at high-risk have the right to receive evidence-based and experience-based, coordinated, specialised and appropriate follow-up and aftercare services.
14. **The right to lifelong inclusion**
    All newborns with adverse neurologial and motoric outcome have the right to lifelong integration and/or inclusion as well as psychological, social and financial support.

A

Towards Healthy Birth

From pre-conception to birth

Appendix A

Contents Appendix A

Towards healthy birth – from pre-conception to birth

Appendix A

1. Introduction

1. Introduction

Background

At the beginning of the 20th century, maternal and child deaths and illnesses associated with childbirth began to decrease, thanks to improved standards of living, the development of maternal and newborn health services and technological advances in obstetrical and neonatal care. However, despite the improvements made in recent decades, and although all European healthcare systems aim at promoting healthy pregnancy and safe childbirth, pregnant women and their babies are still at risk during the perinatal period, which covers pregnancy, delivery, and post-partum.

As an example, babies born preterm are more likely to die than those born at term. They are also more likely to have neurological and developmental disorders that carry long-term consequences for their quality of life, their families, and for health and social services. The same is true for babies born with severe congenital anomalies, and many of them have important medical, social, and educational needs. The incidence of stillbirths has not decreased by the same extent as neonatal deaths, and the causes remain largely unknown. Maternal deaths are rare but tragic events in high-income countries, particularly because a significant proportion of these deaths are associated with substandard care.

It is increasingly understood that a healthy pregnancy and infancy reduces the risk of common adult illnesses particularly chronic diseases, such as hypertension and diabetes. This **life-course approach to our health begins at conception and even before** and suggests that better management of the major morbidities associated with pregnancy, such as intrauterine growth restriction or preterm birth, may lead to better health outcomes.

Challenges

Large inequalities in relation to perinatal health exist between and within the European countries; poverty and low social status are associated with poor pregnancy outcomes. These inequalities have long-term consequences on the individual, the family and society.

Continuing medical innovations create new risks and raise ethical issues. Artificial reproductive techniques make it possible for more and more couples to conceive, while at the same time increasing the number of multiple births associated with preterm birth and other adverse pregnancy outcomes.

Improved antenatal screening techniques raise a number of difficult issues, such as when to terminate a pregnancy. A key challenge for the care of pregnant women and newborns is to use and benefit from new medical technology without the associated overmedicalisation of pregnancy and childbirth; resulting in additional diagnostic tests after false positive screening tests, unnecessary caesarean deliveries and their higher risk of maternal morbidity, and higher levels of parental anxiety.

Data about deliveries, births, mothers and newborn babies are collected extensively to monitor the health and care of mothers and babies during pregnancy, delivery and the post-partum period. However, there is no common approach in Europe. A key challenge is the identification of meaningful, valid indicators used across different healthcare systems. While many of the current indicators are useful at a national level, they cannot be transposed for comparisons between Member States. Reducing the rate of maternal and newborn mortality and morbidity depends largely on all mothers and all children having **access to quality healthcare** from pre-conception over pregnancy through childbirth, the neonatal period and childhood.

Recommendations

- Low cost, feasible, and effective intervention strategies should include:
  - Improved family planning
  - Obstetric care at delivery
  - Prenatal services.
- Programmes targeting maternal and perinatal health should be holistic in their approach, take into account demographic, ecological and economic factors, and should include the promotion of good health, rather than avoiding mortality.
- European countries can learn from each other by:
  - Sharing information as well as their experiences in healthcare provision
  - Establishing interdisciplinary networks to improve the quality of healthcare
  - Agreeing on standards for education and training of healthcare providers.
- To enable international comparisons, standard definitions in the field of maternal and perinatal health should be developed. Moreover, a list of causes of foetal, infant, and maternal deaths should be developed.
- More operational research is required on various aspects of maternal and perinatal health; in particular, the cost-effectiveness of different service components.

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2. The importance of pre-conceptional care

Background

The term 'pre-conception' refers to the period leading up to a pregnancy; i.e. from the decision to have a baby to becoming pregnant (conceiving). The goal of pre-conceptional care is to reduce perinatal mortality and morbidity. Pre-conceptual counselling is based on the medical theory that all women of child-bearing years should be pre-screened for health and risk potentials *before* attempting to become pregnant. This would allow women to reduce health risks within her control; screening tools have been developed to this effect. In addition, comprehensive check-lists and assessments have been developed for women planning to become pregnant.

The pre-conceptional counselling assessment and screening is intended to assess the health of a child-bearing woman, while at the same time identifying:

- Existing or emerging illness or disease that may have previously been undetected
- Existing risks for the woman who may become pregnant
- Existing risks that may affect a foetus if the woman becomes pregnant.

Challenges

There is a lack of national standards of practice, or a comprehensive agenda, to ensure that all women of child-bearing age receive appropriate services that will enable them to achieve optimal health before pregnancy. This is perhaps due to the fact that many pregnancies in Europe are still unplanned, with recent data from France showing that up to 33% of pregnancies are unintended.

Additionally, most women do not know, realise or understand the benefits of visiting their physician before trying to become pregnant and still take for granted the biological aspects of becoming pregnant, nor do they consider the value of pre-screening.

While most women who want and anticipate having a baby are naturally inclined to assume that their baby will be healthy, many women do not know how their own medical history could put their developing foetus at risk. Likewise, they may not understand that pregnancy carries a certain number of risks as well. When family history and pregnancy risks are considered together, it may result in the identification of potential problems.

Finally, a lack of health insurance policy may pose a barrier to pre-conception counselling and assessment.

Recommendations

- All healthcare providers interacting with women of childbearing age should understand the potential benefits of pre-conceptional counselling and approach the assessment in a thorough manner during routine health checks.
- Women who are considering pregnancy should see their physician before stopping their current birth control.
- Policy makers should ensure that the public at large (especially younger generations) is well informed about their reproductive health and rights.
- Pre-conceptional care should be provided in the most cost effective way, as an integral part of primary care services during routine health checks. It may be introduced during routine health screening, through patient education literature, and in group health promotion classes, as well as by means of information and screening activities linked to schools, workplaces, and the community.
- A woman should visit her physician as soon as she is contemplating having a child, preferably around 3 to 6 months before attempting to conceive.
- National strategies, policies and awareness for pre-conceptional care in society need to be developed and implemented. Development of such policies should take place in national task forces, with close cooperation across cross-divisional professional societies and patient organisations.
- More and better research data supporting pre-conception care is needed.

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3. Main maternal risk factors for adverse pregnancy outcome

Background

The consequences of preterm labour and delivery have a bearing on neonatal mortality, morbidity and lifelong neurological problems. One of the most important goals of maternal/antenatal care is the identification of women who are at high risk for adverse pregnancy outcomes, especially as regards preterm labour and delivery.

During prenatal visits, identification and early diagnosis, combined with focused care of threatening preterm delivery, can positively impact foetal/neonatal outcomes. Until now, the focus was on treatment of preterm labour and obstetrical care during a preterm delivery; however, prevention should become the main aim of antenatal care as a matter of urgency.

Challenges

It is well established that medicine must be evidence-based. This means that the best available evidence gained from a scientific method (empirical studies, scientific research) of medical decision-making has to be applied. Studies addressing risk factors for preterm labour and evidence-based procedures for early diagnosis of preterm labour do exist. Factors such as **infections** (genital, urinary tract, toxoplasmosis or CMV), **unhealthy diets / malnutrition, smoking (including passive smoking)**, **use of illegal drugs, alcohol, multiple births, maternal age, low socio-economic conditions, stress at work and/or home, or life changing events** all contribute to higher risk.

- **Bacterial infection** that spreads to the uterus and amniotic fluid may trigger inflammation, which could result in preterm labour or preterm rupture of membranes. Goldenberg et al. reported that up to 80% of women who deliver before 30 weeks of gestation have evidence of bacterial infection.
- **Local as well as systemic inflammation** should be regarded as a factor in preterm birth. Attempts to prevent preterm birth by simply treating infections or by trying to restore altered vaginal microbiota via antibiotic therapy have failed, even though screening programmes for early signs of altered microflora were employed. Recent work highlights that probiotic food supplementation, anti-inflammatory diet and the anti-inflammatory potency of progesterone may be useful approaches to counteract inflammation in the woman´s reproductive tract. Unfortunately, compelling evidence is still missing.
- **Optimal nutrition** is vital for health in general, but crucial to pregnant women, the developing foetus, and the newborn child. Quantitative and/or qualitative dysnutrition affects maternal health, foetal development, delivery and birth, and even health outcomes throughout life.
- The important impact of maternal-foetal nutrition during pregnancy has rarely been considered until now. However, it became clear during recent years that diabetes, obesity, metabolic syndrome, and related cardiovascular diseases can be attributed to prenatal dysnutrition which may ‘programme’ health throughout life (‘perinatal programming’). Even gene expressivity can become sustainably altered by dysnutrition during ‘critical periods’ of early development (epigenomics, nutrigenomics). Therefore, pregnancy, birth and neonatal life - the perinatal period - offer a unique opportunity to contribute to primary prevention throughout the lifespan.
- **Overnutrition, overweight, and diabetes** are among the primary current health challenges resulting in increased morbidity and mortality world-wide. Accordingly, in Europe, about one third of pregnant women are overweight and probably more than one in ten pregnant women suffer from diabetes during pregnancy (gestational diabetes). This is often unrecognised and untreated as no universal screening is practised. However, maternal overnutrition, overweight and gestational diabetes lead to overfeeding of the developing foetus. This can favour the development of macrosomia, which strongly increases peripartal and perinatal risk of morbidity and mortality. Moreover, epidemiological, clinical and basic research results clearly show long-term (lifelong) increased disposition for diabetes, obesity, and cardiovascular complications in perinatally overfed children. This ‘epigenetic’ risk seems to contribute to the general ‘diabesity’ epidemic. Nonetheless, as opposed to genetic disposition, this can be prevented.
- **Supplements are the subject of broad popular reflection**. The need for vitamins, trace elements, etc. is adequately covered by a balanced diet during pregnancy, but an increase in the demand for folic acid and iodine can be seen, which has its roots in population-wide prophylactic supplementation in pregnant women. Whether and to what extend this applies to Fe, Mg, Zn, vitamins (A, C, B1, 2, 12, Niacin) and LC-PUFA is a matter of intensive debate. Evidence-based recommendations are still lacking, though urgently needed. Supplementation of specifically folic acid as well as fortification of staple food with folic acid should be strongly recommended and be accessible to all women of childbearing age.
- **Foods, alcohol and tobacco use** are highly relevant during pregnancy, as they may lead to health problems. Overconsumption is one of the current major challenges in public health. While pregnant women should be careful with high caloric snacks and coffee (max. 2 cups per day), alcoholic drinks and tobacco should be an absolute taboo. The negative effects of alcohol and smoking on pregnancy, foetal development, risk of preterm birth, birth complications, malformations, and long-term health problems in the offspring are evident.
- **Multiple gestation and abnormal placental implantation,** including placenta previa, are amongst the highest risks for preterm labour and delivery. These risk factors can be the result of reproductive medicine and correlate with a higher rate of preterm deliveries. **Increasing age of women at childbirth** is one of the most noticeable trends in our modern society, leading to an increased risk of prematurity. In Germany, for example, the average age of women at the time of their first birth was 24 years in the 70’s: current statistics reveal this has increased to 30 years. The odds of unassisted pregnancy decrease dramatically with increases in maternal age, from around 25% at 25 years of maternal age to around 15% at 30 and about 7% at 35 and, significantly, fewer than 5% at 40 years of age.

Recommendations

- Risk identification and behavioural counselling of women have to be a normal part of pre-conceptional and maternal/antenatal care.

3. Main maternal risk factors for adverse pregnancy outcome

- Any pre-conceptional care should consider avoiding or limiting multiple pregnancies in assisted reproductive programmes, as well as avoiding repeated uterine treatment (e.g. uterine curettage). This includes being well informed about prognosis of the foetus and ethical aspects.
- EU Member States should consider setting up a task force to develop and ensure unified protocols and standards of care for assisted conception treatment. There is strong evidence to suggest that single embryo transfer during assisted reproductive treatment cycles has significant advantages.
- Implementation of social policies that support maternity at an optimal maternal age in order to avoid pregnancy risks or need for assisted reproduction techniques should be encouraged.
- Policy makers should adopt social policies that help to reduce occupational risks and improve prenatal care (e.g. time off for prenatal visits, shift work at nights, paid pregnancy leave, etc.).
- Member States should ensure equal and affordable access to high-quality, safe prenatal care, monitoring and counselling.
- Awareness on the scale of the problem of preterm birth needs to be raised. Information campaigns, e.g. favouring smoking cessation before and during pregnancy, should be put in place on a national and European-wide basis.
- Clinical practice and public health measures for healthy lifestyles should be strongly promoted, implemented and practised in a politically responsible way, to reduce long-term health burden, including:
    - **Avoiding** being **overweight** (BMI>25) before conception, increased weight gain (according to IOM guidelines) **and overnutrition** ('do not eat for two'; maximum of +200 kcal/d in 2nd and 3rd trimester in women with pre-conceptional BMI<25; sea fish 2 times/week) during pregnancy
    - **Ensuring adequate** (moderate and regular) **physical activity** during pregnancy
    - **Diagnosing and adequately treating all forms of glucose intolerance** in pregnant women, on the basis of a universal diabetes screening in all pregnant women (according to IADPSG guidelines)
    - **Avoiding neonatal overnutrition**, especially by providing exclusive breast feeding during the first four to six months of life, are scientifically founded, appropriate, cost-effective, but so far underestimated measures of perinatal primary prevention to the benefit of pregnant women and their offspring
    - **Strict avoidance of alcohol and tobacco** should be recommended and promoted for pregnant women by public health services and educational programmes and measures, starting in young girls who enter reproductive age
    - Population-wide **prophylactic supplementation in all pregnant women** should be realised with folic acid (400 µg/d, 4 weeks prior to and 8 weeks after conception) and iodine (200 µg/d, throughout pregnancy).

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4. Interventions to reduce morbidity and mortality of preterm birth – early detection of women with pregnancy risk factors

Background

Preterm birth (before 37 weeks of gestational age) is the leading cause of perinatal morbidity and mortality in developed countries. Early detection of preterm labour is difficult because initial symptoms and signs are often mild and may occur in normal pregnancies. Thus, many healthy women will report symptoms during routine prenatal visits, whereas others destined for preterm birth may dismiss the early warning signs as being normal occurences in pregnancy.

Primary strategies for cancer and vascular disease have begun to show benefit after decades of effort. Thus, greater perseverance is likely to be needed for preterm birth, as the magnitude of the problem is underestimated by the public.

Challenges

So far, all efforts to reduce the incidence of preterm birth have been ineffective. Potential interventions, such as universal screening of cervical length in the whole population, have been proposed recently as a cost-effective strategy to select women at risk of preterm birth who may benefit from progesterone treatment. However, performing an ultrasound on the entire pregnant population may lead to an overload of health systems and difficulties managing false-positive women. Only one study of cost-effectiveness has been performed in this area; studies using foetal fibronectin have not been published.

Recommendations

- Strategies designed to reduce preterm birth rates should be carried out at three levels:
  - Primary interventions that aim to reduce the risk of the whole population
  - Secondary interventions, aimed at eliminating or reducing the present risk
  - Tertiary interventions that aim to reduce the impact of prematurity.
- While primary interventions should be planned as part of primary or basic obstetric care (low risk women), secondary and tertiary interventions (high risk women) should be carried out by a sub-specialised obstetric team.
- Interventions for primary and secondary prevention of preterm birth should be based on clear patho-physiological concepts and accompanied by, or implemented in, well-designed interventional clinical trials, along with information campaigns.
- For the purpose of developing clear patho-physiological concepts, factors that prevent the initiation of labour in healthy pregnancies should be explored in more detail.
- When establishing well-designed interventional clinical trials, low risk pregnancies should also be included, since nearly half of preterm births occur in women without current identifiable risk factors. Interventions as part of routine prenatal care are more likely to be acceptable to pregnant women.
- Risk identification and education regarding the signs and symptoms of preterm labour should be a routine part of maternal care. Healthcare providers should be able to advise and appropriately triage patients at risk for preterm labour.
- During maternal/antenatal care, evidence-based risk factor scores and procedures for early diagnosis of preterm labour and delivery should be used and laid down in national and local guidelines.
- Women with a risk history (e.g. spontaneous preterm delivery, cone biopsy or uterine malformation) should be followed and assessed by specialised obstetric teams. However, methods of genetic predisposition have yet to be determined.
- Women with multiple pregnancies or with a short cervical length should be followed and assessed by specialised obstetric teams.

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5. Challenges of dealing with 'at risk' pregnancies

Background

The risk status of any pregnancy can change at any point throughout the antenatal period, as well as during labour. It has now been established that up to 30% of women considered low risk at the start of pregnancy will develop pregnancy-related problems, and are to be viewed as medium to high risk.

Therefore, it is vital that pregnant women have up to date plans of care and risk status, and are assessed throughout pregnancy at every clinical contact.

The European Peristat report clearly demonstrates that the immigrant population, especially those from economically poor countries and those who do not speak the host country's language, are at a higher risk of developing complications during pregnancy and are at a higher risk of maternal morbidity and mortality. It should also be recognised that psychological morbidity in the perinatal period has a significant impact on the woman and her family. Unidentified or inadequately treated mental illness during pregnancy and following birth can have serious consequences. Therefore, it is important to have a targeted approach to the care of individual women, which would allow interagency support systems to be put in place to meet individual needs.

Challenges

Current difficulties exist when it comes to identifying pre-existing risk factors to ensure optimum pregnancy management by the relevant multi-professional teams in the most appropriate environment.

Expectant mothers require information about the effects of the condition on their unborn child, as well as on themselves. The development of an obstetric early warning system will also assist with the timely diagnosis of critical illness, help ensure prompt referral to other specialists, and promote the speedy transfer of women to high dependency and intensive care units.

Recommendations

- Each maternity unit should have a clinician specialised in developing and monitoring antenatal care guidelines, and to ensure that care providers adhere to these guidelines by regularly auditing the outcome of low risk pregnancies.
- All professionals involved in the care of women immediately after childbirth should be able to distinguish normal emotional and psychological changes from significant mental health problems.
- All maternity care providers should have local guidelines and care pathways for the management and identification of women developing common conditions. Such guidelines should reflect national recommendations adapted to suit local needs and resources.
- There should be clear referral care pathways so that women are referred to high risk pregnancy clinics as and when required.
- A fast track care pathway should be in place within regional/national maternity networks for early referral to a specialist team for assessment. These care pathways should cater for routine and emergency situations in high risk pregnancies.
- Perinatal networks should ensure that robust communication plans are in place between all professionals and the expectant mothers.
- Local protocols should be in place to carefully assess and support the needs of the immigrant population.
- Joint working arrangements should be in place between maternity services and local services responsible for dealing with domestic abuse. Information about these services should be made available to all pregnant women.
- EU Member States should ensure that service providers in their respective countries are working towards implementation of standards of care described in the 'Standards of Care for Women's Health in Europe' (2011) published by the European Board and College of Obstetrics & Gynaecology.
- Information should be available in a variety of ways and using multiple media. At the very least, patient leaflets should be available, in the languages required by the local population.
- In the case of less frequently encountered conditions, women should be directed to recognised support groups and recommended on-line information. Women with complex medical conditions must be offered assessment by a specialist.
- Interpreting services should be provided for women where the local language is not their first language. Relatives should not act as interpreters. Arrangements should be in place for interpretation services in the community, especially in emergency or acute conditions.

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Towards healthy birth – from pre-conception to birth
Appendix A

6. Maternity care

6. Maternity care

Background

Although the vast majority of pregnancies proceed without complications and result in a healthy newborn, others may be more complex because of antenatal or intrapartum conditions. Good labour care makes women's transition to parenthood easier and has an impact on the long-term wellbeing both of herself and her baby.

Intrapartum hypoxia, regardless of aetiology, can cause long-term physical and mental disability. Although the majority of foetal neurological injuries predate labour, the intrapartum period is a time of risk for asphyxia and asphyxia-related morbidity and mortality. The extent to which intrapartum asphyxia can be prevented by improved care is controversial, but several investigators and malpractice claims analysis suggest that a significant proportion can be prevented.

Challenges

Labour is a dynamic process which requires all healthcare providers to be aware that even an apparently low risk pregnancy can develop intrapartum complications, which could escalate the pregnancy to high risk.

Currently, there is a lack of comparable European datasets which makes identifying risks difficult. The Euro-Peristat Report (2008) has correctly identified that a dearth of data collected by different countries regarding maternal morbidity during labour exists. This does not allow a meaningful comparison between different EU Member States for the quality of obstetric care. For example, the rate of maternal morbidity ratios for eclampsia varied between 0.2/1000 women to 3.8/1000 women in the EU Member States.

Maternity care would be improved, were clinical governance to be embedded into a quality framework (for each health organisation). By adhering to principles of clinical governance, quality care can be provided and regularly monitored.

Recommendations

- Maternity care should be underpinned by seven pillars of clinical governance:
  - The care unit should have adequate capacity to provide antenatal, intrapartum and postnatal care
  - The care unit should be able to provide the required services in a timely and friendly manner. There should be a round-the-clock (24-hour) on-site consultant presence if the unit is clinically very busy or deals with complex obstetric cases
  - Evidence-based guidelines should be used to provide the best individualised care by multi professional teams within the constraints of the resources and facilities available
  - Healthcare providers should be up to date with their continuing professional developments
  - There should be mechanisms in place for clinical audits leading to care improvement
  - Risk incidence should be regularly monitored to identify modifiable risk factors and reduce risk to mothers and babies
  - Complaints received from women and staff should be treated seriously to improve services within individual units.
- The EU should ensure that the training programmes for all healthcare professionals (specialist obstetricians, neonatologists, anaesthetists, midwives, obstetric nurses, and allied professionals) are harmonised. This will not only ensure safe delivery of care in the respective countries, but also facilitate free movement of appropriately-trained professionals across EU Member States.

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7. Women's right to a healthy birth

Background

All women should receive full and quality information to enable a choice regarding the preferred place and type of birth. This requires an equal partnership between the woman and her health professionals and lays the foundation for interactive decision making along her care pathway. The majority of women enter labour without complications and it is the duty of health professionals to support and help to maintain normality throughout labour. Midwives should be primary caregivers for these women. However, there are women who require an interdisciplinary team of professionals as they have extra needs and higher risks.

Challenges

In many European countries, women still do not have the choice of where to give birth. This may reflect the belief that birth environment does not impact on outcomes, which are mostly regarded as dependent on the level of clinical care available.

This creates difficulties because birth is more than a clinical episode for women and their families and standards of care should reflect this. Early assessment of a woman's current status of pregnancy and health when entering labour allows for interactive decision making on the woman's need for midwife-led care or wider health team engagement.

Currently, different health systems impact directly on practice and act against multi-disciplinary working and development of policies. Every woman's individual needs should be respected, and she should be empowered to control her own care by receiving unbiased information during labour. Effective strategies are needed to increase women's and health professionals' belief in women's ability to give birth.

Likewise, the increasing rates of caesarean births and wide variation across Europe cannot be explained by differences in women's physiology; rather, they indicate a clinical or system failure variation. There is no evidence that increased caesarean sections have improved perinatal outcomes.

One way of addressing these growing challenges is by boosting continuity of care during labour, which is proven to reduce the need for non-midwifery interventions. Of course, in emergency situations, women should still be kept informed and their birth partner may play a pivotal role. Due to time restraints and clinical practices, this may not be given priority, but good antenatal care prepares women for healthy labour.

Recommendations

- Women-centred care will ensure that individual women remain in control, and that their privacy and ability to make decisions is supported. All women, regardless of whether their pregnancies are high or low risk, should be treated with respect and should be in control of, and involved in, what is happening during labour.
- Guidelines, practice standards and care pathways should be put in place and developed by multi-disciplinary teams including women and based on evidence, where possible.
- A positive birth environment is important for women and impacts on outcomes. Maternity systems should provide full and quality information and choice. All birth environments should be improved.

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8. Medicines during pregnancy

Background

Approximately 30% of all women of reproductive age use drugs at least once per week, excluding oral contraceptives. Some of these prescribed or over the counter drugs may have harmful unwanted effects on the pregnant woman, her foetus or during lactation. The use of certain medications can lead to infertility in women or men.

The most frequently used drugs are pain killers, followed by medication to treat skin diseases or thyroid disorders, allergies or colds.

Challenges

Even if the situation of medicine use during pregnancy has improved substantially since the thalidomide scandal, there is still an increasing need to provide healthcare professionals and patients with updated individualised risk information to enable sound clinical decision making. For the majority of medicines, clinical experience is still insufficient in terms of their safety in pregnancy. It is often unclear how to interpret the available scientific data.

Randomised controlled clinical studies usually exclude pregnant women and focus on therapeutic efficiency rather than on prenatal adverse drug effects. Therefore, for the majority of drugs used by women of reproductive age, there are insufficient human data to accurately assess the prenatal risk and safety. Drug risk classifications in many countries tend to convey a message of high risk, making healthcare professionals and consumers less confident when deciding on specific drug prescription choice or estimating the risk of a past drug exposure during pregnancy.

Of high importance is the correct treatment and administration of medicines to women affected by chronic illnesses when they decide to become pregnant. Also worth noting, chronic diseases are more frequent in women of an older age. This has become increasingly important as women in industrialised countries are delaying their first pregnancy until 35 years of age and older.

Recommendations

- Women of reproductive age should be educated, informed and advised on the risks of medicine use during pregnancy and lactation.
- Awareness raising of healthcare professionals should take place, in order to provide tailored advice to those professionals in contact with women of reproductive age. The importance of this topic and of surveillance should be highlighted, ensuring that pregnant women or those wishing to conceive are treated conservatively and only with medications where the risks and side effects are known. If possible, new drugs should be avoided whenever well-established medications are effective and tolerated by the mother and the foetus.
- Extending and strengthening the teratology information services (TIS) network should be supported, as its primary goal is to provide healthcare professionals and pregnant women with information on safety and risks of drugs in pregnancy. As many TIS are poorly funded, advocacy is necessary and contact with health policy decision makers and administration should take place, highlighting the high return in terms of health outcomes and cost savings provided by TIS as reference institutions in clinical teratology.
- A system of data reporting, documentation and evaluation in collaboration with the TIS network should be established.
- More research for further information on drug utilisation patterns during pregnancy in different countries should be conducted.

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9. Prenatal steroids

Background

A Cochrane Review of 21 studies showed that treatment of women at risk of preterm birth with a single course of antenatal corticosteroids reduced the risk of neonatal death by 31%, respiratory distress syndrome by 44%, and intraventricular haemorrhage by 46%. The use of antenatal corticosteroids is also associated with a reduction in necrotising enterocolitis, respiratory support, intensive care admissions and systemic infections in the first 48 hours of life compared with no treatment or placebo.

The authors of the Cochrane Review, the American Congress of Obstetricians and Gynaecologists (ACOG) Committee opinion (2008) and the Royal College of Obstetricians and Gynaecologists (2010), conclude that despite the paucity of data at earlier gestation, the reduction in outcomes (other than RDS at 26 weeks of gestation) would suggest that there is some benefit in corticosteroid prophylaxis at earlier gestations between 24-26 weeks.

Challenges

The challenge for EU Member States is to develop universal guidelines on the use of steroids when there are signs of preterm labour risk.

Recommendations

- There should be universal recommendations and policies across all EU Member States on the use of antenatal corticosteroids for the intrauterine treatment of preterm babies.
- Furthermore, mechanisms should be in place to monitor the level of adherence to these guidelines, and to prevent the use of multiple antenatal steroids where no safety data are available.

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10. Education, training and intervention for expecting parents (mothers)

Background

The aim of antenatal/parent education is to transfer knowledge to women regarding the behaviours needed to keep themselves healthy during pregnancy; promoting post-natal self-care, increasing confidence and enabling better decision making regarding birth. In addition, it should equip parents with the skills and social context of parenting. This is the period when women are receptive to advice and new information.

Not only do midwives have a care partnership with the women, they also often have opportunities to engage with the immediate family, opening avenues for broader health promotion. The education can focus on nutrition, hygiene, smoking and other substance misuse, as well as on how to prepare for birth (e.g. methods for relaxation and coping with pain) and information on newborn care.

There is evidence about maternal emotional states on foetal and infant physiological and behavioural functioning; further studies are forthcoming. In modern society, practices ensuring the cascading of birth information from generation to generation are no longer in place. Midwives are aware that the information sources sought are not only family and friends; new technology has brought a high level of unchecked information within the reach of women and their families.

In ideal circumstances, health promotion activities should start during pre-conceptual care when a woman is considering a pregnancy, aiming for optimum health at its start. To set the building blocks for a healthier pregnancy and road to normal birth, early antenatal contact must be the minimum aim to start antenatal education and assess individual needs.

Current practice in some European countries, such as the UK or Sweden, has shown that women with specific social determinants linked to poor pregnancy outcomes (e.g. teenagers, substance misuses, asylum seekers) have benefitted from targeted midwifery care. This group of women is often less willing or able to access healthcare. The direct links that midwifery teams can make with these women in the local communities and outside the hospital environment will support prevention, help reduce risks and provide an appropriate care plan for individual women to share and own.

Challenges

The EU Directive 2005/36/EC Article 42 clearly states that "*the provision of programmes of parenthood preparation and complete preparation for childbirth including advice on hygiene and nutrition, is one of the professional activities of a midwife*." However, it is a challenge for midwives to provide this expert activity within EU countries that do not have health systems allowing midwives to practice within the antenatal period.

There is some debate relating to what is understood by parent craft/ antenatal education. It can be defined as a series of group or individual sessions that cover specific topics focusing on labour and birth, usually one session earlier in the pregnancy and one in the third trimester. These sessions also address breastfeeding and care of the newborn and are outlined below:

Group sessions

- Group sessions have a dual role in acting as a social trigger between pregnant women, especially in isolated urban communities. They support the development of networks and increase confidence by sharing experience and knowledge. Therefore, benefits do not only relate to transfer of knowledge; they also relate to acknowledging the mental health aspects of pregnancy and its impact on post-natal health.
- Having group-based, interactive, culture-specific classes for certain population groups (e.g. teenagers) are seen as effective. Issues like health promotion and preparation are reportedly more successful when working with groups. Women and partners want information and believe that techniques such as relaxation and pain management are important to them; this is true for all social classes.
- The challenge is equality of access for pregnant women. Whatever the preferred or optimum method of delivery of education-oriented interventions, policies must ensure the importance and value of antenatal education and parenting preparation is recognised and embedded into maternity care and health systems as standard, and free of charge.

Individual sessions

- Education and preparation for parenthood is part of a midwife's practice; midwives acknowledge the individual changes women experience throughout the pregnancy, in social, emotional and physical terms. This support can only be provided by regular antenatal contacts and checkups that allow for exchange of information, tailored to the woman's individual needs, and which does not only focus on bio-medical parameters. As mentioned earlier, midwives are best placed to provide this role, which is underpinned by their training and combines bio-medical, social and health promotion skills.
- Women across Europe should have equal opportunities in relation to obtaining complete information, choice in place of birth, and type of birth. Increasing caesarean section rates are a universal concern, with an associated long-term health impact on both the woman and baby. Challenging questions remain regarding provision of information over choices in relation to birth if more restrictive frameworks of maternity care exist, and whether these support evidence-based practice.

Recommendations

- Health systems should support equal access to antenatal education and parent craft for all women, within agreed standards, regarding making childbirth more 'human' and enabling choice.
- The approach to care of pregnancy and birth should be holistic, acknowledging the need for information and advice of women and their families, which impact on their wider health determinants.
- There is a need for early access to the most appropriate health professionals to start on-going antenatal education, which should be flexible and appropriate.

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11. Education, training and interventions in the pre-conceptional phase and during pregnancy to reduce the incidence of preterm birth (based on the German model)

Background

Preterm birth, defined as childbirth before 259 days of gestation (<37 weeks), is the major challenge faced in obstetrics and gynaecology worldwide. Despite many improvements in diagnosis and treatment, over recent decades the rates of preterm birth have increased in most industrialised countries, with the incidence in Austria and Germany reaching some 10%. Preterm birth not only causes harm for newborns and their families, morbidity may also be increased across an individual's lifetime. Therefore, preterm birth is also very expensive.

Based on 2005 figures, the annual cost estimate for preterm birth in the USA is USD 26.2 billion. According to a recent study, the costs of pregnancy, delivery and the first two days of life of a newborn in Germany amount to EUR 12,800 for preterm births, compared with EUR 2,300 for normal deliveries.

Challenges

Over recent decades, projects and programmes aiming to reduce preterm birth have been established in some countries. Assessments of these interventions reveal conflicting results with respect to their effectiveness and efficiency. This is unsurprising given the strategies, settings, framework of obstetric care and target populations were often very different. In Germany, the programme BabyCare was established in 2000 and is evaluated annually; it shows a reduction in preterm birth of at least 25% compared with general perinatal statistics when controlled for age, education, parity and multiple pregnancies.

Although a relevant reduction in the incidence of preterm birth can be achieved through the BabyCare programme, further risk factors leading to preterm birth remain present in our population even after intervention. Thus, in order to improve its effectiveness, the prevention of preterm birth may also need addressing at the pre-conceptional phase. What further reductions in the incidence of preterm birth can be achieved with a health promotion strategy for this pre-conceptual stage?

To meet this need, in 2007 the programme planBaby was created. Logically, the risk and protective factors of preterm birth are the same whenever the time of intervention. However, many risk factors can be targeted more easily and more effectively before pregnancy. For example, this applies to stopping smoking, weight reduction, immunisation and, in the case of chronic disease, switching medications to those with no toxic effects on the embryo or, at least, having the lowest toxicity.

In contrast to such interventions in pregnant women, the interest in and acceptance of such a programme is likely to be low, at least at the outset. Nonetheless, this and similar programmes and instruments may serve as a model for the development of further national and international interventions.

Further epidemiological research is urgently needed. This applies in relation to the statistical evidence on risk factors often discussed, such as parodontitis, as well as to risk factors currently only suspected as relevant, such as Vitamin D deficiency. In addition, the unresolved question of the effects of multiple risk factors on preterm birth deserves particular attention.

Recommendations

- In addition to interventions targeting pregnant women, a pre-conceptual programme for couples planning to have children is highly recommended. The period for intervention is much longer and there are no contra-indications in relation to the reduction of the risk factors.
- There is also little difference with respect to the substance of the interventions and the methods used. The challenging question, however, is how such a programme can be integrated into gynaecological care or, better still, elsewhere in the healthcare system. In Germany, at least, other routes may have greater potential, as family planning is rarely a matter for gynaecologists. In addition, the evaluation of such a programme will face certain challenges. Nevertheless, a programme aimed at would-be parents appears necessary, especially as the target for the lowest rate of preterm birth, some 5% in Germany, remains distant.

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12. Education and training of healthcare professionals

Background

In a world of medicine that evolves more and more rapidly, sufficient quality of education in the arts and crafts of obstetrics and gynaecology and quality control are essential; not only for the progress and commitment of obstetricians and gynaecologists, but also for nurses, midwives and other healthcare professionals dealing with women in reproductive age.

In addition to a focused policy on education, training and research, the importance of education and training has been raised in numerous reviews in the context of quality and risk. Principal among these is the *Report of the Commission on Patient Safety and Quality Assurance (2008)*, which highlights the importance of education, training and research in ensuring a safe, high-quality healthcare system.

Challenges

There are great variations in training for obstetrics, gynaecology or midwifery within the European Union. However, if training programmes could be more universal and quality control mechanisms more flexible, the objective of high-quality care standards throughout Europe is achievable.

It is uncertain what type of obstetricians and gynaecologists will be needed over the next 30 years. Both the active, as well as the new generations, need to receive high-quality postgraduate training and lifelong education in order to ensure high-quality services in Europe. This is especially important as European integration allows for the free movement of persons, resulting in increases in cross-border healthcare. Therefore, a separate set of standards to facilitate a universal quality of training is needed.

In all European countries, midwives are permitted to undertake the full range of activities, according to EU Directive 2005/36/EC on the recognition of professional qualifications of the midwife. However, in some countries, midwives are not the primary health professionals involved in birth. Where activities of midwives are limited, student midwives' experience of midwifery is also limited. This means that they are prevented from achieving the necessary competencies to support labour and birth. The safety of pregnant women may be jeopardised when midwives with limited antenatal care experience register in host countries where midwives fulfil activities according to the Directive 2005/36/EC.

Recommendations

- Agreement on content and quality of training in all countries in Europe, as well as on criteria to which specialist training centres should conform, and universal training programmes to achieve specialist status.
- European-wide standards for the training of specialists in maternal and perinatal care should be developed and audited in close cooperation with recommendations from the professional societies, e.g. the European Board & College of Obstetrics and Gynaecology or the European Midwives Association.

- The knowledge and skills of obstetricians and gynaecologists, nurses and midwives should be maintained and updated.
- A system to assess and recognise the quality of training and practice should be put in place.
- The exchange of specialist trainees between training centres throughout Europe should be facilitated, especially involving Eastern European countries.
- The title of nurses and midwives should be protected to ensure reliable data for workforce planning policies, patient safety, proper registration and professional mobility.
- Research or research education should be included as an important component in training.

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13. Reducing stillbirth rates in Europe

Background

In high-income countries, there is an expectation that every pregnancy will end with the birth of a healthy baby; public perception is that stillbirths are a thing of the past. However, stillbirths are not rare events, with approximately 25,000 babies stillborn every year in the EU. The effect on parents is devastating and long-term: to these parents the death of their baby before birth is no less a death than is the death of any other child. Families are often left with intense grief and damaging psychological and social problems for many years.

Challenges

Although no cause is known for some 30% of stillbirths, this outcome is largely associated with failure to perform appropriate investigations. Only 5% of stillbirths are classified as unexplained despite full assessment (including autopsy and placental investigations).

Many stillbirths in high-income countries can be prevented. The disparities associated with disadvantaged populations require urgent attention: living standards for women need to be improved and provision of culturally appropriate and accessible antenatal care needs to be ensured. A greater awareness of risk factors for stillbirth is needed at healthcare provider, community and policy levels.

The absence of quality data on stillbirths is a major impediment to prevention. In many high-income countries the proportion of unexplained stillbirths that do not receive adequate investigation remains high. Improvements in investigation and reporting practices, including consensus of definition and classification systems, are urgently needed. At a national level, the implementation of perinatal mortality audits in high-income countries could result in important reductions in stillbirths through improvement of quality of data and standards of maternity care.

However, substantial proportions of stillbirths lack an obvious maternal risk factor and are thought most likely to portray an incompletely understood abnormality of placental function, which might or might not be associated with impaired growth. Future research should focus on screening and interventions to reduce antepartum stillbirth and stillbirth associated with extremely preterm birth and infection.

Identification of ways to reduce maternal incidence of overweight and obesity is also a priority for high-income countries. Effective research collaborations are needed to carry out the often large-scale research needed to address stillbirth in high-income countries.

Affected mothers are often subjected to stigma and marginalisation in communities that blame her stillbirth on her own sins or destiny. Around the globe, most stillborn babies are disposed of without any recognition, such as being named, held, dressed, or given a funeral, and are often seen as taboo objects. Efforts are needed to provide education to lessen the stigma associated with stillbirth and provide bereavement support.

Even in high-resource settings where psychological support might be available, one in five mothers is affected by long-term depression, anxiety, or post-traumatic stress disorder after a stillbirth. Fathers are also affected by negative psychosocial consequences.

Parents have the greatest stake in the wellbeing of their baby, so they must be part of the drive to reduce stillbirth. Parents and health professionals working collaboratively (in such models as the International Stillbirth Alliance) have a powerful part to play in bringing stillbirth to the public attention and should push for the prioritisation of stillbirth in research and maternity services.

Recommendations

- Future improvements in prevention of stillbirth should target specific causes, risk factors, and vulnerable groups.
- Social disparities in stillbirth rates by ethnic origin and women from disadvantaged backgrounds should be addressed and acted on.
- Perinatal mortality audits should be put in place at a national level.
- Women should be empowered to formulate plans to reduce stillbirth.
- Stillborn babies are to be treated like human beings and parents allowed time to grieve.
- All parents should be offered the option of a high-quality autopsy examination after a stillbirth.
- Parents should be offered bereavement and psychological support, and associated stigma should be reduced.
- Efforts are needed to raise awareness and improve education for maternity care providers, and to improve accuracy of surveillance data.
- A universal classification system for stillbirth should be created.
- Routine data collection for stillbirths; collation and dissemination of accurate stillbirth rates, including data on causes of death, should be carried out.
- Significant research gaps should be addressed.

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14. Influence of working conditions and low socioeconomic status on pregnancy outcome

Background

The role of women in society has changed dramatically in recent decades. Today's women are more likely than their mothers to pursue formal education, work outside the home, marry later, and delay having children. The decision to work during pregnancy reflects a large variety of factors, such as education, social support and health status, which are independently linked to the risk of preterm birth.

The impact of low socioeconomic status on infant and maternal health is well documented in research and reports from service providers, including low birth weight and other complications prior to and following delivery. The use of hospital days for treatment of pregnancy-related complications is nearly four times greater for women in the lower vs. the highest income group.

Challenges

A broad range of studies demonstrate that certain working conditions, particularly physically strenuous or fatiguing work, increase the risk of preterm birth. Identifying employment-related risk factors for preterm birth is of particular importance, as such risks are modifiable through policies granting work leaves or altering working conditions during pregnancy.

Women with high risk pregnancies are more likely to both stop work and deliver before term; therefore, testing the impact of pregnancy leave policies on preterm birth at individual level is difficult. Comparing risk levels between groups of countries is one approach that can be used to explore these issues.

Results obtained from a large European case-control study in the mid-90s show a moderate excess risk of preterm birth for pregnant women employed as manual workers/physically demanding work, night work and for those working long hours (40-42 hours a week or more), standing for long periods (over 6 hours per day), and reporting dissatisfaction with their job.

Further factors, such as poverty, discrimination, stress, violence or lack of support at home or lack of social support/social and healthcare policies, play a mediating role in determining the impact of exposure to employment-related risks. Low socioeconomic groups, and women with specific social determinants linked to poor pregnancy outcomes, are often less willing or able to access healthcare and do not feel comfortable with hospital and clinic-centred care.

Recommendations

- Each Member State should put in place social policies granting women paid leave in pregnancy, and limiting exposure to onerous working conditions during pregnancy.
- National policies should be in place granting pregnant women time off for prenatal visits.
- Pregnant women should be protected from physically demanding work, night shifts, long working hours, and positions requiring multiple hours on their feet.
- Awareness should be raised amongst healthcare professionals; individual assessment of risk by the antenatal caregiver should be possible.
- Work leave policies, and the impact on women exposed to high risk employment conditions, should be considered in future analyses.
- National policies should be put in place to guarantee all women equal access to pre-conceptional and maternal care through culturally and socially sensitive programmes.
- Personal and structural barriers to maternal care should be addressed to increase health checks and quality of service.
- Midwives should be trained; midwifery care should be provided to women with specific social determinants, through a trustworthy, acceptable person or team outside the hospital environment.
- Social and financial support and networks should be provided to women's families in need.

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15. European-wide minimum standards for antenatal care

Background

The Treaty of the European Union forms the basis for a dedicated common public health strategy of the EU. Article 219 specifies that the Member States of the EU are to coordinate their health policies and programmes with the cooperation of the European Commission, to ensure a high level of health protection and to prevent widespread and severe illnesses. In 1999, Article 152 of the Treaty of Amsterdam enlarged the healthcare duties of the EU. Specifically, in Article 152 §1 of the Treaty of Amsterdam, it is clearly stated that EU action shall complement national health policies to improve public health, prevent human illness and diseases and to obviate sources of danger to human health. Cooperation among the Member States was highlighted as important for the health sector, although the organisation and delivery of health services remain the responsibility of the Member States.

A prerequisite of the European integration process is the right to free movement of persons, services, capital and goods. Therefore, patient mobility and its implications for patient safety become increasingly important.

Challenges

Patient mobility and its implications for patient safety are becoming increasingly important due to the European integration process and the right to free movement of persons, services, capital and goods.

There is great heterogeneity with regard to the content of guidelines on antenatal care in the EU Member States; several Member States do not have national guidelines. This is likely to result in healthcare gaps or the unnecessary, expensive and possibly harmful multiplication of tests for pregnant women; especially if care is not documented properly and if the documentation is not physically carried by the pregnant woman herself.

Towards healthy birth – from pre-conception to birth

Appendix A

15. European-wide minimum standards for antenatal care

16. Harmonised Reproductive Health Datasets - Improving data for monitoring, evaluation and research for mothers and babies in Europe

Neither European legislation, nor budgets, are factors prohibiting the development of a common European set of guidelines addressing antenatal care, as less wealthy Member States currently recommend more tests per pregnancy than the wealthier ones.

Recommendations

- EU-wide guidelines on the minimum requirements for antenatal care in uncomplicated pregnancies based on the existing national guidelines should be developed, which would:
  - Result in lower costs for the less wealthy Member States, whilst ensuring higher safety for pregnant women and their infants
  - Not necessarily imply an unwanted harmonisation of health systems
  - Allow for a specific method for developing a genuine European guideline.
- A common system for documenting antenatal care should be introduced, such as the German or Austrian maternity records, which are carried by the pregnant women themselves.

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16. Harmonised Reproductive Health Datasets - Improving data for monitoring, evaluation and research for mothers and babies in Europe

Background

Data are at the core of any health improvement, and providing accurate descriptions of the current health status in our communities is essential for healthcare and public health services planning, for research and development of new knowledge on causes, and to ensure that the burden of diseases is registered and made visible to society.

Invisible health issues cannot be prioritised, and important outcomes in reproductive health, such as stillbirth and neonatal mortality, are examples of issues left invisible and unprioritised globally until recently. Data on health outcomes and healthcare provision are essential to monitor the implementation of new health initiatives, as well as to evaluate their effect for enabling further improvements and accountability towards society.

In the field of maternal and child health, birth registries have been the most significant source of data. In general, population-based health registries have a number of qualities enabling public health surveillance and advice to the public and governments. This includes the possibilities for long-term follow-up, longitudinal surveillance, and the ability to observe social and regional inequalities in health when data are collected unselected and unbiased from the entire population. For research, there are further quality advantages available with data collected routinely and prospectively in a cost effective manner, including large population numbers, multiple outcomes and exposures, and a broad approach to health sciences when combined with population-based biobanks.

Challenges

Many European countries have a long tradition for operating birth registries, developed at different times, in different legal contexts, with different medical focus areas, and with research and public health surveillance as their main purpose.

However, they collect different data. Currently, there are more than a dozen definitions used to identify the death of a baby (perinatal mortality), including babies dying before, during or after the first week of delivery. Some countries exclude induced terminations of pregnancy, while other countries do not, and still more countries simply lack definitions for perinatal mortality.

Sadly, none of the European countries appears to have definitions that fully comply with the definitions of the WHO's International Classification of Diseases that all member countries of the UN World Health Assembly have (in principle) recognised. Data on perinatal and reproductive health include aspects of health in pregnancy and birth/delivery for a mother and her baby, as well as life as a newborn for the baby and the 6-week puerperium after birth for the mother; biologically, these are intimately connected. Optimal quality data need to be captured as an entity: pregnancy, birth, neonatal and post-partum life need to be addressed in reproductive health registries.

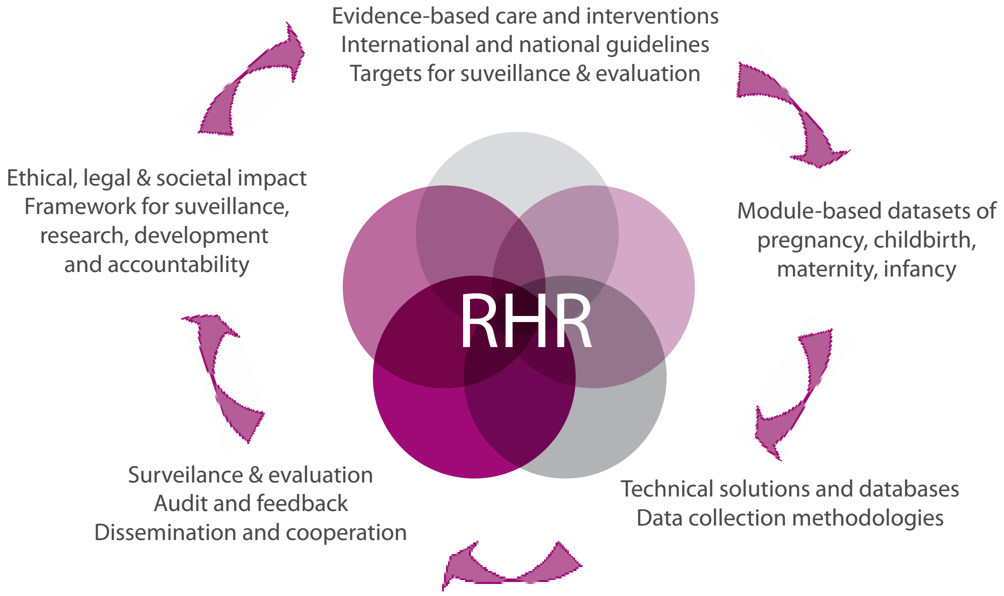
However, a birth registry is only part of the story. As an example, if there are no data on the number of pregnancies entering basic antenatal care, the denominator to address stillbirths and maternal mortality will be flawed (by underreporting), as will our understanding of quality in basic antenatal care.

16. Harmonised Reproductive Health Datasets - Improving data for monitoring, evaluation and research for mothers and babies in Europe

In Europe, there are few, if any, examples of true reproductive health registries. Rather, a variety of sources are used, including civil registration based on birth and death certificates, medical birth registries, hospital discharge systems, congenital anomaly registers, confidential enquiries and audits, perinatal surveys and aggregated data collection systems.

Harmonisation of data is key to bolster international collaboration and common efforts. There have been significant European efforts to harmonise data and data sharing for large population-based cohorts and biobanks, such as ENGAGE, P3G and PHOEBE. In addition, there have been initiatives to harmonise existing perinatal health data, such as EURO-Peristat, REPROSTAT, EUROCAT, ECHIM. Yet, the current status demonstrates that further, broader initiatives are needed (figure 7).

Figure 7 Harmonised Reproductive Health Registries



With a focus on defining which entities/conditions/diseases/outcomes to include on a register, the existing initiatives do not approach the harmonisation of ethical and legal aspects required for improved data sharing and collaboration; such as harmonisation legislation concerning which data can be shared and how consents (if any) are worded.

Systematic efforts by a number of agencies and inter-agency consortia have produced evidence-based guidelines outlining what must be included in perinatal care. However, data collection and reporting has not been harmonised with the guidelines to enable the monitoring and reporting of these interventions and evidence-based care. Furthermore, technological solutions and dataset formats are not harmonised to optimise data sharing. Finally, the translational tools enabling interpretation of data for public health improvements (reflecting how societies should prioritise actions to gain from registries) have not been harmonised. Thus, a new European platform to enhance collaboration could provide significant scientific and public health improvements.

Recommendations

- Common definitions in relation to perinatal databases should be created.
- Ethical and legal aspects should be harmonised to enable more data sharing and collaboration; e.g. harmonisation of legislation determining data sharing and consent wording (if required).
- Data collection and reporting should be harmonised to enable the monitoring and reporting of interventions and evidence-based care.
- Technological solutions and dataset formats should be harmonised to optimise data sharing.
- A new European platform to enhance collaboration and provide significant scientific and public health improvements should be created.

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17. Research for pre-conceptional and healthy pregnancies

Background

The understanding of basic mechanisms in healthy and complicated pregnancies is still limited. The predominant problems during pregnancy are related to clinical conditions usually classified as common complex diseases. The largest disease burden relates to pre-eclampsia, intrauterine growth restriction, preterm delivery, perinatal asphyxia and intrauterine foetal death. All these conditions have a complex genetic and environmental origin. In obstetrics, complex diseases are even more problematic as both the maternal and foetal components can influence the impact and contribution of the different genomes, which are all different in the varying pregnancy conditions.

Translational research may offer a solution. The term 'translational research' normally relates to a clinical bedside problem identified by the physicians, which is then taken into the wet or dry laboratory to find possible solutions. The potential solutions are then tested and implemented in clinical practice.

During the last decade, additional interest in obstetrics and perinatal medicine has been generated by Barker's hypothesis of the foetal origin of adult disease.

Challenges

Translational research is extremely expensive and developed over a long time. To disentangle the basic problems of complex diseases and translate the solution to clinical practice requires long-term financial support to dedicated research groups.

The complexity of disease understanding, from both a biological and a clinical point of view, has led to a deepened sub-specialisation and professionalisation of biological and technical researchers, as well as among clinicians. This complexity has generated different, new obstacles in translational medicine, such as a monolingual culture and need of professional matchmaking. However, the obstetric community has created examples of positive translational research environments; e.g. PREBIC (Preterm Birth International Collaborative), where researchers with different professions generate new translational projects in different workshops.

Recommendations

- Major research programmes should be launched to understand the basic mechanisms of both normal and complicated pregnancies and deliveries.
- A major birth cohort should be created, recruiting women/couples before the conception.
- A forum for translational research should be developed, with the inclusion of scientist with varied research expertise.

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1. Introduction: Principles of newborn care: towards evidence-based neonatal medicine

1. Introduction: Principles of newborn care: towards evidence-based neonatal medicine

The rights of newborns

Neonatology is the branch of medicine concerned with the care and development of newborn infants. It is a relatively new paediatric subspecialty and, until the 1970's, units that cared for the special needs of newborns were mainly located within obstetrical departments. In the early 1980's, Neonatal Intensive Care Units (NICUs) gradually evolved within children's hospitals. Technological advances, especially in the field of neonatal ventilation and thermal care (incubators), triggered this development. Neonatology became a board-approved paediatric subspecialty in most European countries in the 1980s and, from the late 1990's onwards, neonatology also gained academic status and rapidly developed into a key area of interest within paediatric research. Alongside the development of neonatology as a standalone discipline, preterm infants have become the focus of practitioners and researchers, as prematurity accounts for more than half of perinatal mortality.

As the discipline matured, neonatology moved on from an 'eminence-based' field (one which relies on the individual experiences of experts) to being a truly 'evidence-based' discipline; i.e. one grounded in scientific observational and intervention studies, including randomised trials and translational laboratory research. As such, many of the initial medical interventions and care procedures were never scientifically investigated, despite being widely practised for decades. One such example is that of an infant's breathing, whereby oxygen was routinely given to newborns judged to adapt too slowly to extra-uterine life. Today, thanks to well-designed studies, neonatologists understand that slow adaption of oxygen saturation in the delivery room is a normal phenomenon and that (non-critical) delivery of excess oxygen does more harm than good. The future challenge will be to establish additional guidelines based on scientific data, rather than practices based on personal beliefs.

In Appendix B, key experts and parents have summarised the important principles of neonatal care, including major challenges for improvements of neonatal care in Europe.

When discussing the development of better standards of neonatal care, there are a multitude of issues to consider and within this text, EFCNI was not able to address all aspects of the complexity of neonatal care. However, the intention was to cover some of the more pressing concerns and both EFCNI and the editors and authors hope that it provides adequate resources, with any further issues covered at a later stage.

The following recommendations focus on strategies for providing equal access to high-quality care for newborn infants in Europe, including education and quality control. They should not be considered as clinical guidelines.

We strongly recommend that national audits and taskforces that are responsible for, or at least involved in, developing national newborn care programmes take the recommendations into thorough consideration and adopt and/or modify them according to the national needs, conditions and economic considerations.

Principles of neonatal care

All children, including newborn children, are entitled to human rights as defined by the UN Convention on the Rights of the Child; a legally binding document that a majority of countries world-wide have adopted. The four, core principles of the Convention are: non-discrimination; the best interest of the child; the right to life, survival and development; and respect for the views of the child. Some parts of the Convention are of special importance for newborn children, and especially sick or preterm children/infants; i.e. paragraphs 5, 6, 9, 23 and 24, which (in brief) recognise parents as caregivers (5), recognise that all children have the right to life and development (6), insist that children should not be separated from their parents (9), note that a child with a handicap has a right to a full life (23), and that every child has the right to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation (24).

Several attempts have been made to insist on principles of newborn care and the rights of newborn infants. EFCNI strongly endorses the global principles of essential newborn care by UNICEF. From a national perspective, the principles of good newborn care supported by the Bliss Baby Charter Standards serve as a good basis for these rights. Additionally, the declaration of newborn rights stated by the Union of European Neonatal and Perinatal Societies 2010 in Barcelona helps further identify that, at birth, the newborn infant is dependent on some essential elements of care in order to survive and needs to be assisted in this regard. Even more so, a baby that is born preterm or with an illness is entirely dependent on immediate high-quality care in order to increase the chance of healthy survival.

Nonetheless, despite the number of texts that seek to identify their specific needs, the care of preterm or newborn infants born with illnesses in Europe does not always adhere to these important principles and recommendations. However, the reason for a lack of standardised care and commitment to national and international standards vary. In this document, we have listed some important factors that could improve and develop family-centred neonatal care, including short and long-term outcomes for the individual infant.

Table 1: Principles of essential newborn care (UNICEF)

Air	Resuscitate and maintain an airway
Warmth	Keep the newborn warm and avoid unnecessary hypothermia or cold stress
Food	Encourage early breast feeding; feed high-risk newborns more frequently
Hygiene	Maintain hygiene during delivery and cord cutting; treat infections promptly
Love	Ensure the newborn infant stays close to its mother and that mothers have open access to their newborn infant if he or she requires special care

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Table 2: Principles of newborn care (adopted from Bliss, UK 2005)

1. Every baby should be treated as an individual and with dignity, respecting their social, developmental and emotional needs, as well as their clinical needs. This includes respecting the baby and family's right to privacy, time to make attachments and referring to the baby by name.
2. Neonatal care decisions are based on the baby's best interest, with parents actively involved in their baby's care.
3. Decisions on the baby's best interest are based on evidence and best practice, and are informed by parents who are encouraged and supported in the decision-making process, and actively participate in providing comfort and emotional support to their baby.
4. Babies receive the nationally recommended level of specialist care in the nearest specialist unit to the baby's family home.
5. Parents are informed, guided and supported, so they understand their baby's care processes and feel confident in caring for them. Information provided to parents should cover clinical conditions, tests and treatment, as well as practical issues such as breastfeeding, financial support, transferring between units and local facilities.
6. Breast milk expression and breastfeeding are actively promoted, and mothers receive practical support to achieve successful lactation. Relevant health professionals are equipped with appropriate knowledge and skills to facilitate and support lactation following a preterm birth.
7. Discharge planning is facilitated and coordinated from initial admission to discharge date, to ensure both the baby and their family receive the appropriate care and access to resources.
8. Units encourage parents to be involved in plans and processes for continuous service improvement, and outcomes of care are benchmarked against local and national standards.

Table 3: Newborns' Rights (adopted from UENPS 2010)

1. The universal declaration of human rights refers to all stages of life. All human beings are born free and with the same dignity and rights.
2. The dignity of the newborn, as the human being he/she is, is a transcendent value. Newborns must be protected in accordance with the Convention of the Rights of the Child.
3. Every newborn has the right to life. This right must be respected by all people and governments without discriminating on the grounds of race, sex, economy, geographical place of birth, religion, presence of disability or any other. States should take the necessary measures to protect children from discrimination.
4. Every newborn has the right for its life not to be put at risk due to cultural, political or religious reasons. Nobody has the right to carry out any action whereby the newborn's health is put at risk or his/her physical integrity is affected, be it in the short or in the long-term. Under no circumstances may any mutilation be justified; circumcision is allowed, provided that necessary analgesia is given.
5. Every newborn has the right to a correct identification, filiation and a nationality. The state must guarantee this right to the same extent as for any other person at any age in life.
6. Every newborn has the right to receive sanitary, affective and social care, which will allow him/her to undergo optimal physical, mental, spiritual, moral and social development later in life. The Society is responsible for the compliance of all requisites so that this right is respected. No medical act should be carried out without the informed consent of the parents, given the lack of autonomy of the newborn, and only emergency situations are excluded from this at which the physician is forced to act in defence of the child's best interests and there is no possibility of any intervention by the parents or guardian. There must be equity of attention and absolute rejection of all forms of discrimination, irrespective of economic or social class.
7. Every newborn has the right to correct nutrition, which guarantees his/her growth. Maternal lactation must be encouraged and facilitated. When it is not possible for the mother to breast feed, be it for personal, physical or psychological reasons pertaining to the mother, correct artificial lactation must be facilitated.
8. All newborns have the right to correct medical care. Children have the right to enjoy the highest degree of health and to have access to medical, rehabilitation and preventive services. The states must take all necessary measures aimed at abolishing traditional practices, which are detrimental to the health of the child. Governments must take care of both pre and post natal healthcare.
9. A pregnant woman carrying a foetus with anomalies, which are incompatible with life has the right to continue with the pregnancy or to choose to terminate pregnancy within the legal limits of each individual country if they so wish. If the foetus should actually be born, futile therapeutic measures should not be applied to the newly born, but palliative care is to be performed to avoid pain.
10. It should not be attempted to keep alive any newborn whose immaturity is greater than the lowest limit of viability. This right should consider the real local possibilities and survival rates of the place where the baby is born. In all cases, the parents will have to be informed before the birth whenever possible.
11. Every newborn has the right to take advantage of the measures of each country regarding social protection and safety. This right refers as much to measures of protection and care in health as to the legal field.
12. Every newborn has the right to be preserved from pain. Good analgesic drugs and treatments are available; provoking pain has to be considered malpractice.
13. The newborn may not be separated from its parents against their will. In cases in which there is evidence of abuse, and these circumstances indicate that the life of the newborn is at risk, the appropriate legislative and administrative measures shall be taken in order to guarantee the child's protection, even if this means separating the child from its parents. This norm will be applicable during the newborn's stay in hospital.

14. In case of adoption, every newborn has the right to be adopted with maximum guarantees. In states where adoption is recognised, the interest of the child must always prevail and all necessary guarantees that adoption is admissible and that all authorisations from the empowered authorities have been obtained must be guaranteed. Under no circumstances shall the sale of organs be justified.
15. All newborns and pregnant women have the right to protection in countries where armed conflict is present. In these situations, maternal lactation must be promoted and protected.
16. The newborn is a person with specific rights which it cannot demand itself due to its physical and mental immaturity. These rights impose a series of obligations and responsibilities on society, which the legislative and executive institutions of all countries must enforce.

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2. Neonatal Unit, infrastructure and levels of care

Background

Infants receive care in the Neonatal Intensive Care Unit (NICU) during an extraordinary period of brain growth and development. In the third trimester of pregnancy and the first few months after term delivery, a baby's brain is establishing synaptic connections at a rate far higher than at any other time in life, primarily in the sensory centres for touch, movement, pain, taste, smell, auditory and visual development. This creation of sensory function in the brain then serves as the foundation for all subsequent learning about the outside world.

In utero and after a healthy full-term delivery, sensory development occurs in extended and intimate contact with the mother and other caregivers, with few noxious stimuli (e.g., pain, frequent loud noises, bright lights, etc.), but the NICU environment may be quite different. To some extent discomfort, separation from parents and exposure to noise and bright lights is unavoidable for critically ill infants. Yet for many infants, these unnatural and noxious stimuli are much more common than necessary, as many existing NICUs were designed prior to an appreciation of these sensory needs of the infant. It is now clear that providing infants with individual rooms where their family can stay with them whenever desired, leads to shorter lengths of stay and improved medical outcomes and is favoured by families and caregivers alike although it should also be noted that some families prefer to have their babies in open rooms with other babies to avoid the feeling of isolation.

The sensory environment of the NICU is also an important consideration for families and caregivers. Extensive literature has documented the adverse effects of excessive noise, glaring lights, and limited access to daylight and views of nature in many different settings where adults work and live. Job performance and mental and physical health are strongly linked to the sensory environment, so design of the NICU should reflect the latest evidence available for the needs of the adults who spend extended periods in the NICU, as well as for the babies.

Infection is a major cause of mortality and morbidity in premature infants. Historically, attempts to reduce this risk focused on limiting access to infants by family members, but studies done in the early years of family-centred care demonstrated that the vast majority of neonatal infections were nosocomial in origin. The built environment is also a potential source of many toxins, to which premature infants may be especially sensitive. Good NICU design is a key aspect of efforts to control both exposure to nosocomial organisms and toxins, whilst still fostering family participation in the care of their infant.

Challenges

Historically, NICUs have occupied very small, cramped spaces. Upgrading a NICU to current evidence-based standards often requires 5-10 times more space than currently assigned. As such, the culture of the medical team in the NICU has been built on close proximity to one another and the babies. Providing a NICU that is more spacious, quiet, and private requires a major change in caregiving, communication patterns, and social structures.

The culture of the medical team in the NICU has also been built on limited access to babies by families and friends due to a hierarchical medical model, as well as concerns about contagious illnesses, stress to the babies, and disruption of vital and sensitive monitoring and treatment devices.

2. Neonatal Unit, infrastructure and levels of care

The nature of intensive care does not always allow for an optimal sensory environment for either the baby or the caregiving adults. Cultural diversity in the community leads to differing family needs with respect to privacy, socialisation, and many other aspects of care, so a NICU must be designed with enough flexibility to meet those needs.

Recommendations

- The NICU should be designed with sufficient space and facilities so that any parent who wishes to stay with their infant may do so with comfort and the degree of privacy they desire.
- If not present in the patient room, there should be additional space for families to eat, shower, store personal belongings, learn more about their baby's care, and receive lactation support.
- Each patient care area should be designed with sufficient space at the bedside for all typical equipment appropriate to the level of care, as well as space for parents to provide skin-to-skin care without endangering vital IV and respiratory tubing, monitoring wires, and other critical care devices that may be in use.
- Each headwall area supplying vital gases, outlets, and equipment mounts should be a consistent design from one bedside to another, so that critical items can be easily found and utilised.
- All patient care areas in the NICU should be designed to minimise noise, with an hourly Leq goal on the dBA scale of no greater than 45 dB in unoccupied space, and no greater than 55 dBA when occupied.
- Infants should be protected from direct light at all times. After 28 weeks, exposure to a cycled day-night lighting scheme is appropriate, but daytime lighting must still be indirect.
- Most spaces occupied by adults in the NICU outside of the patient room should have either direct or 'borrowed' access to daylight and views of nature. In addition, all work spaces should have adequate and appropriate ambient and task lighting.
- When the NICU is in a maternity hospital, it should be in close proximity and have controlled access to the delivery area. When the NICU is in a children's hospital, it should have controlled access to the transport area.
- The NICU should be designed with controlled entry/egress to minimise the risk of infant abduction.
- All materials used in the NICU should be free of substances known to be teratogenic, mutagenic, carcinogenic, or otherwise harmful to human health. These materials should be easily cleanable with non-toxic materials.
- Hygiene stations (handwashing sinks and/or waterless cleanser dispensers) should be easily accessible to all patient care beds.
- Comfortable, attractive lounge areas should be provided that are separate from, but in close proximity to, the patient care area for both families and caregivers, so that they can return to the patient care area relaxed and refreshed.
- Standards for design, construction, and operation of NICU facilities should be developed and adopted for use within EU Member States.

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3.1 Neonatal resuscitation

Background

About 10% of all babies (corresponding to 500,000 European babies each year) need some help transitioning from a placental circulation to establishing adequate independent breathing. Fewer infants, around 2-3%, may need resuscitation. Usually, this will involve ventilating the baby for a few minutes to aerate the lungs and oxygenate the blood, heart, and brain while waiting for the baby to start breathing on its own. A few very ill babies - less than 1% - may need more extensive resuscitation, including cardiac compressions and the administration of drugs. In general, preterm infants are at increased risk of needing neonatal resuscitation after birth, and a majority of extremely preterm infants need ventilatory management after birth, including treatment with continuous positive airway pressure (CPAP) and endotracheal intubation.

During the last decade, there has been an increase in international guidelines for resuscitation, which are acknowledged as important evidence-based documents for the acute management of infants that have been deprived of oxygen at birth. A major change occurred in 2010, when the recommendations altered from starting resuscitation with 100% oxygen to recommending that the process take place with room-air. There has been quite good progress with a number of countries having adopted recommendations for neonatal resuscitation based on the international guidelines, but national guidelines are still missing in many countries.

Babies can only be resuscitated if the staff in attendance are trained in neonatal resuscitation and have experience in the procedure. Continuous team training is necessary for maintaining high standards of neonatal resuscitation in hospitals across Europe. Although many centres have adopted guidelines and run training programmes, several studies have shown that neonatal resuscitation is very often not provided according to the recommended guidelines. Video recordings of neonatal resuscitation situations demonstrate that departure from the guidelines does occur during administration, often due to leader and team member conduct, inappropriate preparation, communication, and coordination. Overly aggressive stimulation is found to be quite common, as is poor ventilation and suctioning techniques, and slow intubation.

Suboptimal resuscitation techniques increase the risks for adverse infant outcomes. This is particularly worrying, as most infants who need resuscitation at birth also need extra attention and care afterwards due to increased risks for developing conditions such as hypoglycaemia, encephalopathy, and respiratory disturbances. Moderate hypothermia is currently the best intervention treatment available for term asphyxiated babies, and an increasing number of countries have created national guidelines for this treatment. However, research in this issue is still needed as, aside from treatment with hypothermia, there are no evidence-based guidelines for the care of high-risk infants after neonatal resuscitation has taken place.

Challenges

The main challenge in neonatal resuscitation is to ensure that every hospital that cares for newborn infants has the necessary equipment and personnel for the care of sick infants from the moment of birth; personnel need to have undergone the appropriate training and have the right skills. Many European infants are born in hospitals where adequate resuscitation cannot be provided, and consequently these infants are put at increased risk when an emergency situation occurs.

The equipment should be very close to the place where babies are born, so that it can be used immediately. It should be checked daily by appropriately-trained personnel to ensure that it is working correctly. There should be several sets of equipment available for resuscitation of twins and situations where two or more babies are born around the same time.

The equipment should be on a mobile trolley that can be taken into the delivery room. It must be at a height that is convenient for all staff and have a safe platform where the baby can be placed, a radiant heat source, a supply of oxygen and air and a blender to mix them, a resuscitation 'bag' or T-piece device for ventilation and CPAP, a laryngoscope of appropriate size, and different sized endotracheal tubes for intubation and ventilation. Suction equipment for clearing the nose and mouth are also required.

The staff caring for newborn infants must be trained in neonatal resuscitation. This should involve knowledge on how to assess a newborn infant for its condition at birth in order to determine whether resuscitation is required. The staff must all be trained in using all the equipment, particularly how to perform effective mask ventilation.

Recommendations

- All EU Member States should create national standards and guidelines for resuscitation and the general care of infants requiring resuscitation.
- Every hospital should adhere to evidence-based guidelines for neonatal resuscitation protocols.
- Every hospital delivering babies should have appropriate equipment to transport sick or ventilated newborn infants to a nursery, where the required treatment can be administered by experienced staff.
- Every hospital should be accredited for resuscitating newborn infants. Without proper accreditation, there would be reason to assess whether a given hospital should be allowed to continue operating as a birthing centre, as even low risk births may require resuscitation. As such, hospitals should be regularly assessed to ensure that the appropriate equipment is available and functioning to the highest standard.
- It is essential that at least one member of staff trained and accredited in neonatal resuscitation is available at all times, whose principle duty is to resuscitate babies.

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3.2 Respiratory care

Background

The survival and long-term outcome of very preterm infants is highly dependent on their lung development at the time of delivery and, thus, on the respiratory management they receive during the neonatal period. Many preterm infants need respiratory support immediately after birth due to respiratory distress syndrome, which is caused by deficient surfactant production by the immature lung. The most preterm infants may need continuous respiratory support for a number of weeks, and sometimes months. Respiratory support can be given as continuous positive airway pressure (CPAP) by a nasal mask, whereby the infant is able to manage spontaneous breathing supported by a positive end-expiratory pressure, which stabilises lung function. Mechanical ventilation is commonly needed, at which point the baby is ventilated through an endotracheal tube passed via the nose or mouth through the larynx and into the trachea.

Improvements in respiratory support, including the early administration of exogenous surfactant, have dramatically decreased mortality rates in preterm infants. However, the prevalence of chronic lung disease for preterms, particularly bronchopulmonary dysplasia (BPD), has not decreased. This chronic condition, which is associated with a long-term need for respiratory support, including a need for additional oxygen, involves an increased risk of suboptimal neurodevelopment. These dangers are related not only to the immaturity of the respiratory system, but also to the quality of the respiratory support that the baby receives. Survival rates and incidence of BPD vary between care centres, demonstrating that differences in the quality of care and the respiratory support applied have a major impact on the health outcomes of preterm infants.

Although the most preterm infants are at the highest risk for developing severe pulmonary conditions, also moderately preterm infants and full-term infants may develop life-threatening (albeit curable) respiratory problems requiring immediate recognition and treatment. Consequently, these infants may also need advanced respiratory support for conditions such as respiratory distress syndrome, meconium aspiration syndrome, persistent pulmonary hypertension, congenital or acquired pneumonia, and congenital malformations such as diaphragmatic hernia.

Only well-trained, highly specialised teams should provide neonatal mechanical ventilation to ensure a decreased risk of preterm lung damage; due to the combined effect of the oxygen and the high pressures or lung volumes used. Recently, it has been demonstrated that new strategies using non-invasive methods to support the respiratory functioning of preterm infants can decrease the risk of lung damage, but much work is still needed on this area.

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Appendix B

3. Medical standards

3.2 Respiratory care

Challenges

The main challenge in respiratory care is to provide high-quality respiratory support with CPAP and mechanical ventilation, when indicated, to all newborn infants with respiratory insufficiency. Along these lines, standards are needed for neonatal care within the EU so that all institutions where babies are delivered can provide adequate respiratory support. As explained, respiratory support may be required for all newborn babies immediately after birth and during the very first hours after delivery, when the fragile lungs are adapting to the extra-uterine environment and access to this treatment needs to be guaranteed.

Better methods for respiratory support of newborn infants also need to be developed, including non-invasive respiratory support and various modes of mechanical ventilation. Special modes of ventilation should be researched, as high frequency ventilation can be a lifesaving rescue therapy in some instances.

Treatment with exogenous surfactant should be made available throughout the EU to all infants with severe RDS, since the life-saving surfactant medication is very expensive and as a result, access varies.

High-risk infants needing advanced respiratory support should be treated or transferred to centres where well-trained teams are immediately available at all times. And to enable better preparation for such cases, there should be an early identification of pregnant women with common and serious pregnancy complications, such as infections or preeclampsia, in order to reduce the risk of very preterm birth and to optimise the care of the preterm infant after delivery.

Those pregnant women identified as at risk of very preterm delivery should, in appropriate cases, receive antenatal steroids to reduce the risk of RDS and decrease infant mortality rates. Also, there should be systems in place for ensuring efficient and safe antenatal transfers of pregnant women at high risk for preterm delivery to centres where highly specialised neonatal teams are immediately available at all times.

Recommendations

- Within the EU Member States, national strategies and standards of care for newborn infants with respiratory insufficiency should be created.
- Within the EU Member States, when medically indicated, exogenous surfactant should be available to preterm infants with severe RDS.
- Within the EU Member States, antenatal and perinatal maternal care should be available to all women and organised so that threatening preterm delivery can be diagnosed and prevented.
- When possible and when it is safe for the mother, pregnant women with threatening very preterm delivery should be transferred to centres where optimal initial management and adequate ventilatory support can be provided around the clock to the very preterm infant.
- Volume-guaranteed ventilation should be considered as primary ventilation mode.
- A European perinatal quality register should be created and include data on respiratory management and outcome of newborn babies within the EU Member States.

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3.3 Thermoregulation

Background

Maintenance of normal body temperature is of fundamental importance for the management and outcome of the newborn infant, especially in the period immediately after delivery when resuscitation may be required. The environment into which the baby is born may be inappropriately cold (as lower temperatures are more comfortable for the labouring woman and for the attending maternity staff), or draughty, and the personnel in immediate attendance may not be fully aware of the importance of maintaining a normal temperature in the newborn.

In extremely preterm infants, a body temperature below 35°C on admission to the NICU is directly associated with adverse outcome, and the increase in mortality association with low-temperature is highly significant. In this context, the use of simple plastic occlusion coverings, in the form of plastic bags or sheets, are highly beneficial. Yet, in practice, the use of these methods still varies.

Following delivery and the stabilisation of the preterm infant, body temperature is best maintained in incubators, where temperature and humidity can be accurately controlled. High humidity may be used to minimise heat and fluid loss, although the optimal regime for altering humidity as postnatal age increases remains uncertain. Temperature control is also important in moderately preterm infants and sick full-term infants, since hypothermia increases oxygen and calorie requirements, and may contribute to adverse outcomes.

At present, there is only one major indication for hypothermia in newborn infants, and this is term or near-term infants suffering from a severe perinatal asphyctic insult. In these infants, several large randomised controlled trials have shown that a lower body temperature is neuroprotective, and associated with better neurological outcome, when controlled moderate hypothermia is applied soon after birth and during the first three days of life. However, the accurate and continuous measuring of body temperature in infants passively cooled during resuscitation or during transport to a special NICU for hypothermia treatment is often not sufficiently recognised.

Challenges

Concerning thermoregulation, the main challenge is to ensure that all healthcare professionals who are present at deliveries are aware of the importance of maintaining normal body temperature in newborn infants of all gestational ages, and of the mechanisms and methods for obtaining this target. In addition to ensuring professional preparedness, it is also important to ensure that the environment into which a baby is born is appropriate for maintenance of normal body temperature.

This requires a greater understanding of the importance of 'normothermia', including the recognition that temperatures above the normally acceptable range may be as undesirable as temperatures below the normal.

There should be an increase in the use of temperature monitoring in the immediate postnatal period when there is a risk of hypothermia developing. Likewise, healthcare professionals should ensure that the equipment available at the time of resuscitation of high-risk infants is of a suitable standard to maintain normal body temperature.

There is also a lack of clear understanding of the importance of humidification for on-going management of very preterm infants. This knowledge needs to be developed with a review of the regimes used for altering humidification as postnatal age increases. In addition, a clear understanding of the importance of rectal temperature monitoring during therapeutic hypothermia should be encouraged. And professionals should ensure that passive cooling is started as soon as phyctic infants fulfil agreed criteria, based on the likely need for initiation of controlled therapeutic hypothermia.

Recommendations

- Education stressing the importance of temperature control should be a mandatory part of training programmes for all personnel that may attend the delivery of an infant. Such training is addressed in accredited resuscitation courses that now exist, e.g. Newborn Life Support in the UK, but is not uniformly accepted or taught in all countries.
- Standardised resuscitation programmes, which are regarded as mandatory training for specialist staff and emphasise the importance of temperature control, should be used to help raise and maintain standards.
- A core set of standards should be developed for the environment and equipment required to maintain infant normothermia at the time of delivery. This would facilitate the ability of individual units to assess their performance and identify deficits, where appropriate.
- A core set of principles is needed for the approach to maintenance of normal body temperature. This would include recommendations for the use of temperature monitoring, the type of temperature probe used, the appropriate ambient temperature, the use of occlusive plastic wrappings and any other essential core principles. Again, this would allow for the assessment of individual units against agreed standards.
- Standards for recommended ambient-air humidity in newborn infants of different gestational ages should be established. Available research should be reviewed and standards proposed, where possible. If a review shows the current research to be insufficient for the creation of clearly defined recommendations on the use of humidity, further research should be commissioned.
- There should be a mandatory audit of the time of first temperature recording and the temperature attained for any unit providing care for newborn infants.

- The importance of temperature monitoring during postnatal care needs to be recognised, particularly at times when temperature may drop (during invasive procedures for example), and an appropriate strategy should be devised for maintaining normothermia at this time.
- Agree guidelines for the conditions under which passive cooling should be initiated and for the mechanisms by which this is attained. Guidelines should include recommendations for the type of temperature probe used and the site at which temperature is monitored.

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3.4 Neurology of the newborn: Preterm brain haemorrhage

Background

Very preterm infants are at increased risk of developing both cognitive and neuro-motor handicaps in childhood due to brain haemorrhages and white matter injury incurred in the neonatal period. A germinal matrix haemorrhage (GMH) is a brain haemorrhage occurring mainly in preterm infants. The germinal matrix is a structure from which neural cells migrate to the cerebral cortex and is most prominent between 24 and 34 weeks of gestation, while almost completely regresses by full-term. The GMH often ruptures into the lateral ventricle and is then referred to as an intraventricular haemorrhage (IVH). Progression from a small GMH-IVH to a parenchymal haemorrhage can occur and is most likely related to impaired venous drainage of the medullary veins in the white matter with obstruction at the site of the germinal matrix.

The incidence of GMH–IVH is directly related to the maturity of the infant, and the risk increases with decreasing gestational age. GMH-IVH occurs in around 20% of live born infants of less than 1500 grams. More than two-thirds of preterm infants that develop brain haemorrhages suffer from IVH. Extensive IVH and/or venous infarction (intraparenchymal lesion or IPL) occur in about one case in three to four, and are associated with a high-risk for cerebral palsy. There is a well-known inverse relation between the prevalence of GMH-IVH and gestational age: at a gestational age of 25 weeks the prevalence is about 30%, at 32 weeks it is around 5%.

The mechanisms leading to the development of GMH-IVH are only partially known and include respiratory distress syndrome, development of pneumothorax, circulatory instability, and an immature coagulation system. Breech delivery is thought to increase the risk for GMH-IVH and a caesarean section is often performed when the foetus is known and the preterm delivery can be planned. The increased use of antenatal corticosteroids to prevent respiratory distress syndrome in preterm infants has played a major role in the reduction in the prevalence of GMH-IVH. There is some evidence that delayed cord clamping can increase the infant's blood volume after delivery and may also stabilise the circulation after birth and reduce the prevalence of GMH-IVH; otherwise, there are currently no evidence-based interventions available for preventing GMH-IVH in preterm infants.

Challenges

A key challenge in the neurology of preterm infants is to reduce the prevalence of severe haemorrhages. Although a reduction is seen in the overall prevalence in GMH-IVH, the prevalence of a severe haemorrhage (large IVH and/or parenchymal haemorrhage) has not decreased during the last decade. As these infants are particularly at risk of developing post haemorrhagic ventricular dilatation (PHVD) and subsequent hydrocephalus, it is especially important to reduce the prevalence of severe haemorrhages in this at risk population.

Additionally, PHVD needs to be treated in a uniform method across Europe. Using sequential cranial ultrasound (cUS), PHVD can be recognised, enabling timely intervention and also prevention of severe PHVD. This earlier intervention may help reduce additional damage on the periventricular white matter and improve neurodevelopmental outcomes. Intervention differs across the neonatal centres in Europe, as demonstrated by results of a recent questionnaire.

Recommendations

- Mothers at risk of preterm delivery should be ensured antenatal transfer to specialised centres and to administer antenatal steroids, when appropriate.
- Standards for sequential cUS investigations should be created in order to diagnose GMH-IVH and PHVD.
- There is a need to centralise care for infants who develop PHVD and develop a uniform treatment policy for PHVD in Europe.
- Standards should be created for performing early cerebral MRI in very preterm infants, at least at term equivalent age, but preferably also earlier (around 30 weeks' postmenstrual age) in order to reliably assess associated white matter injury.
- Standards for adequate follow-up into childhood and preferably into adolescence should be created.

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3.5 Neurology of the newborn: Neurological monitoring

Background

Neonatal encephalopathy (NE) is a condition that affects brain function in newborn infants. It is a relatively common problem in the neonatal period, with perinatal asphyxia being the most common preceding event. NE may also develop in infants with other severe conditions, such as sepsis and meningitis, respiratory and cardiac problems, hypoglycaemia, and metabolic diseases. NE develops in at least 1 to 2 of every 1000 live term births and can be seen in preterm as well as full-term infants, but most data in the literature concerning NE are with regard to full-term infants.

Seizures can be the most common symptoms of NE during the first 12-24 hours after birth, but clinical recognition of neonatal seizures is very unreliable as it is often difficult to distinguish from normal immature movements. In addition, a majority of neonatal seizures are subclinical, and may only be possible to diagnose with electroencephalogram (EEG). Consequently, clinical recognition in and of itself will lead to both underestimation and overestimation of seizures, with a high risk for both too little and too much administration of antiepileptic medications. While the heart rate, respiratory rate, saturation and blood pressure are continuously monitored in most of the infants admitted to NICU, routinely monitoring electrical brain activity, which has a potential of early detection of neonatal seizures and deterioration in brain function, does not often take place. While the use of continuous video-EEG monitoring would be the best way to accomplish this, it is unavailable in most NICUs. However, continuous monitoring with (2 channel) amplitude integrated EEG (aEEG) and near infrared spectroscopy (NIRS) is available and being increasingly used in many centres. While the first technique monitors electrical activity and detects neonatal seizures, the second can measure changes in regional cerebral oxygenation and also enables the assessment of oxygen extraction.

Challenges

There should be an increase in awareness amongst healthcare professionals that neonatal monitoring should not be restricted to the parameters dealing with the functioning of the heart and the lung, but also include the brain. This is especially important as 60-80% of neonatal seizures are subclinical, which means that electrographic seizures occur without any clinical symptoms; this is common following administration of an anti-epileptic drug, referred to as 'uncoupling'.

Treatment of neonatal seizures is often difficult and new drugs are required. Randomised controlled trials are urgently needed to improve our knowledge about how to treat neonatal seizures more successfully.

Recommendations

- All newborn infants with NE should undergo continuous (a)EEG monitoring, preferably combined with NIRS.
- There should be centralised care for infants who develop neonatal seizures and better regimes to treat neonatal seizures are needed.
- Continuous (a)EEG monitoring during administration of anti-epileptic drugs should take place to assess their effects. This is especially important in view of the 'uncoupling' phenomenon.
- Multicentre, randomised and controlled trials should take place with new anti-epileptic drugs, ensuring that long-term follow-up and neonatal MRI are available for all these infants.

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3.6 Retinopathy of Prematurity (ROP)

Background

Retinopathy of Prematurity (ROP) is an illness of the preterm retina. ROP is a major cause of blindness worldwide and causes blindness in 50,000 children each year. The two major risk factors identified are prematurity and hyperoxia.

The pathogenesis of ROP includes two phases. In Phase I, hyperoxia leads to the cessation of vessel growth. It is thought that this mechanism is mediated by a hyperoxic inhibition of VEGF (vascular endothelial growth factor). The second phase typically develops 5-6 weeks after birth and is precipitated by an increased metabolic demand in the growing eye and retina with a lack of vascular supply. This creates a relative hypoxia, triggering an increase in VEGF leading to uncontrolled vessel growth that may extend into the vitreous body. The Phase II, ROP is divided into 5 stages, where 1 and 2 are associated with moderate vision disturbances, and 4 and 5 lead to severe visual impairment and blindness. Typically treatment is begun during stage 3 and in some cases even during stage 2. The treatment of choice is laser therapy, although anti-VEGF treatment is currently being investigated.

In addition to VEGF, several other factors are related to ROP development, such as the insulin-like growth factor (IGF); IGF increases towards Phase II and is likely needed at a certain level to precipitate the VEGF increase in this phase. Erythropoietin (Epo) is also high in Phase II, and experimental anti-Epo therapy has shown a reduction in ROP. Dietary omega 3 fatty acids have also been shown to help prevent ROP.

A low oxygen saturation approach may reduce severe ROP by approximately 50%, although existing data indicate this may increase mortality. Therefore, at present, there is no consensus over the optimal oxygen saturation in these children.

Challenges

Although laser treatment of infants at risk for severe ROP decreases retinal detachment and reduces blindness by approximately 25%, non-blinding ocular morbidity is not reduced and highlights the need for preventive efforts. Preventing ROP includes challenges such as the prevention of extreme prematurity, avoidance of hyperoxia and oxygen fluctuations the first weeks after birth, and increased dietary content of omega 3 fatty acids for the pregnant mother and the child.

It is important to identify the optimal oxygen saturation targets in these children. A saturation that is too high (e.g. >94%), significantly increases ROP. A low saturation (e.g. 85-89%), significantly increases mortality. Some data may indicate that saturation should be kept low during Phase I of ROP and higher during Phase II in order to normalise VEGF; however, clinical studies are needed before any further assessment can be made.

The interplay between VEGF and other factors, such as insulin-like growth factor and erythropoietin, is not fully understood. It would be desirable to develop diagnostic blood tests to determine when ROP moves from Phase I to Phase II.

Additionally, the indications for anti-VEGF therapy for ROP must be clarified. The role of other factors, such as those mentioned above, must be investigated. And finally, systematic follow-up of babies at risk by trained ophthalmologists is needed.

Recommendations

- All preterm infants receiving oxygen treatment should have continuous monitoring of oxygen saturation, respiration and heart rate to reduce risk of ocular abnormalities.EU Member States need to ensure that all children at risk for developing ROP are systematically followed-up by well-trained ophthalmologists.
- Research is needed regarding:
  - optimal levels of oxygen saturation
  - biomarkers of ROP
  - use of anti-VEGF therapy for preventing Phase II ROP.
- In addition, other factors should be tested (Anti-Epo treatment, omega 3 fatty acids, etc.).
- All healthcare professionals involved in the care of babies at risk of ROP must understand the basic pathogenetic mechanisms behind the disease.
- EU Member States must assess the incidences and risk factors for developing ROP.

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3.7 Nutrition of preterm and term infants

Background

During pregnancy, the foetus receives well-adapted nutrition for growth and development from its mother via the placenta and umbilical cord. After birth, the healthy full-term baby will start breastfeeding, providing the newborn infant with the best nutrition.

In contrast, providing optimal nutrition to preterm infants during weeks and months of extrauterine life is a challenge. During the first days and weeks of life, very preterm infants are unable to tolerate full enteral feeds and normally require support with intravenous nutrition. Due to the very preterm infant's initial fragility, early weight loss and postnatal growth retardation is common even when both enteral and parenteral nutrition is provided. Consequently, malnutrition is common during critical stages of development, leading to long-lasting negative effects on growth and neurodevelopment, lasting at least through school age, and possibly also into adulthood. In addition, malnutrition during pregnancy and the first weeks and months of life increases an infant's risks for high blood pressure, high cholesterol levels and diabetes later in life.

Although breast milk is the best nutrition for very preterm infants, it may need fortification (e.g. protein, fat), the amount estimated on an individual basis. There is now international consensus about the recommended amounts of fortification that preterm infants need, although the optimal dosage of many nutrients is still unknown.

Challenges

A key challenge regarding nutrition is to prevent postnatal growth failure in preterm infants during the first weeks of life by providing adequate parenteral and enteral nutrition. This means providing adequate quality of nutrition (preferably fortified breast milk or otherwise high quality preterm formula) for preterm infants admitted to all NICUs in Europe. As such, mothers of sick or preterm infants should be encouraged and supported to continue to express breast milk for their infants during weeks and months of neonatal care.

Throughout this process, the quality of enteral and parenteral nutrition should be continuously monitored and resources should be devoted to the creation of evidence-based recommendations for the optimal dosage of many nutrients.

Recommendations

- All EU Member States should encourage the use of breast milk in NICUs, either the baby's own mother's milk or contributions made by donor breast milk banks.
- European regulations for the use of donor breast milk should be established.
- Research funding is needed for a better understanding and improved use of breast milk as well as for appropriate/ improved infant formula.
- Standardised enteral feeding protocols should be developed.
- Quality indicators, including growth (weight, length, head circumference) should be recorded during the first two weeks, at 2 months and at term-corrected age.
- National follow-up programmes for preterm infants are needed to at least school age, and preferably to adulthood, in order to monitor nutrition concerns.

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3.8 Neonatal jaundice

Background

Neonatal jaundice refers to the yellow colouring of the skin and the sclerae that appears commonly in newborn babies during the first week of life caused by increased bilirubin levels in the blood stream. Bilirubin is a breakdown product from haemoglobin in the red blood cells. Newborn infants have high levels of foetal haemoglobin, which has a rapid turnover. Due to immature liver function, bilirubin serum concentrations rise after birth in a transient and predictable fashion. Preterm babies and babies with very high haemoglobin or increased breakdown of haemoglobin, such as in haemolytic diseases, are at increased risk for developing high bilirubin concentrations.

While low levels of bilirubin (which is a potent antioxidant) may even be beneficial for the newborn infant, high bilirubin concentrations are toxic for the brain and may cause permanent brain damage, i.e. kernicterus, associated with development of severe cerebral palsy and hearing deficits. The prevalence of toxic neonatal hyperbilirubinemia due to Rhesus immunisation has declined dramatically following the introduction of maternal blood group tests during pregnancy, and cases observed today usually represent failed neonatal outpatient care. The importance of early detection and treatment of hyperbilirubinemia has been acknowledged in several countries, and evidence-based national guidelines for the prevention and management of severe hyperbilirubinemia are available; e.g. United Kingdom (NICE guidelines), Sweden, and USA (American Academy of Pediatrics).

Challenges

Toxic neonatal hyperbilirubinemia is a disease leading to severe handicap and can lead to a life-long burden (kernicterus) on the affected individuals and their families. Despite the ease of bilirubin measurement and the availability of cheap and effective treatment (phototherapy, rarely exchange transfusion), kernicterus continues to occur.

While 12% of all newborn babies undergo some treatment for hyperbilirubinemia, toxic hyperbilirubinemia (serum bilirubin concentrations >30 mg/dl [510 µmol/l]) is observed in 1% of these babies (0.001% of newborns), of which 10% will end up with permanent brain damage (0.0001% of newborns). Given the availability of easy diagnosis and treatment, these cases should be 100% preventable.

The challenge ahead lies in the identification of organisational loopholes, the creation of sustained but unagitated public awareness, and the mutual collaboration of various professionals (midwives, hospitals, primary care physicians) involved in the outpatient care of term and late-preterm newborn infants.

Recommendations

- All EU Member States should create national guidelines for prevention and management of hyperbilirubinemia in newborn infants.
- Increased awareness of European parents over the risks associated with high bilirubin levels is needed, including which symptoms they should acknowledge, and what action should be taken.
- A European kernicterus registry should be set up, with neonatal jaundice with toxic hyperbilirubinemia (serum bilirubin concentrations >30 mg/dl [510 µmol/l]) a reportable condition.
- Each case of kernicterus needs to be scrutinised for the attributes of human and system failures (e.g. to recognise jaundice, to perform bilirubin measurements, or to institute prompt treatment).
- Based on these analyses, specific education programmes for healthcare providers (doctors, midwives) should be created and implemented. Parents of the country or region where the case of toxic hyperbilirubinemia has occurred are also important to inform.
- Data across Europe should be compared and lessons created from countries and regions with very low rates of toxic hyperbilirubinemia for those with increased rates.

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4. Healthcare-associated infections

Background

Healthcare-associated infections (HAIs) are among the most important patient safety threats faced by hospitalised neonates. In particular, very low birth weight infants have an increased risk of HAIs; which affects around 40% of these infants. In preterm infants, HAI doubles mortality rates and also results in significant increases in morbidity and long-term sequelae in survivors. Moreover, HAI of neonates is associated with prolonged hospitalisation, and the additional healthcare costs for affected infants have been estimated to be more than 10,000 USD per patient.

Increasing attention to the consequences of HAI by healthcare professionals, patients, families, and accrediting organisations, has raised the issue of preventing these infections, so that it is now a top priority for healthcare providers and hospitals. Several institutions have published the results of multi-faceted interventions ('prevention bundles') to reduce HAIs, revealing that approximately 30% of all HAIs in NICU patients are preventable. One example underlining the importance of this patient safety issue is the recently published evidence-based recommendations for the prevention of HAI in high risk neonates by the German Commission on Hospital Hygiene and Infection Control (Robert Koch-Institute, Berlin).

Challenges

Although risk factors for HAI in neonates are well known, their prevention requires defined structural, technical and organisational procedures, as well as careful handling of staff-related issues. There is a need for an extensive HAI surveillance system. Surveillance data also have to be analysed by trained hygiene professionals, and findings addressed rapidly.

Although infection prevention strategies have been in place for decades, changes in patient risk factors and the availability of prospective intervention studies demand novel approaches to preventing HAIs. Indeed, due to the high density of antimicrobial use, resistance to first line antimicrobials is emerging as a real threat to neonates who experience late onset infections during the clinical course of neonatal intensive care.

Outbreaks due to nosocomial transmission of viral and (multidrug resistant) bacterial pathogens are a growing problem in NICUs. Associated factors are:

- higher resistance levels because of uncritical use of antimicrobials
- spreading of germs due to insufficient hand hygiene practice in healthcare professionals (including the attending physicians), contamination of medical devices or environmental surfaces, and overcrowding of rooms
- unnoticed infections as a result of understaffing, with less attention on each individual neonate.

To face the challenges of NICU care, a customised multifaceted concept of infection prevention is necessary.

Neonatal Care
Appendix B

4. Healthcare-associated infections
5. Using approved medicines for newborn infants

Recommendations

- Distances between delivery room, operating theatre and NICU (according to recommendations by the AAP and Gemeinsamer Bundesausschuss, Germany) should be as short as possible.
- Distance between incubators should be a minimum of 2 meters (according to AAP recommendations 2002).
- A reasonable amount of isolation rooms with connected upstream changing rooms should be available for 10-30% of rooms, according to the standards for standard-care paediatric wards. These rooms have to be suitable for the prevention of aerogenic transmission.
- There should be a mandatory separation of units for laboratory analysis and asservation of potentially infectious material.
- Mandatory separation of rooms is needed for drug preparation, equipped with clean bench and fridge for drugs.
- Mandatory separation of rooms is required for preparation of baby formula and storage of breast milk.
- NICUs (optionally all facility rooms) should be air-conditioned. Incubators have to be equipped with air filters as a barrier to airborne infections.
- All rooms should be equipped with hand washing basins, paper towels and dispenser for disinfection solution. Hand disinfection solution dispensers next to every incubator are mandatory; one stethoscope for every patient should be provided; mandatory wearing of gowns during patient contact; technical equipment and control elements have to be suitable for disinfectants.
- Staffing should be planned according to official recommendations: nursing staff/bed 1:1-1:3.
- There should be at least one hygiene professional responsible for the NICU.
- Standardised infection control regulations in every NICU are recommended.
- Sterilisation of incubators should be done by trained staff only.
- Continuous evaluation of water quality in the NICU should take place and be surveyed by hygiene professionals.
- Continuing hygiene education should take place at least once a year for the whole NICU staff (nurses, doctors, others).
- Hygiene instructions for visitors and parents have to be implemented in routine care.
- Awareness and tolerance towards human errors and a responsible and open handling of critical situations should be integrated into the daily work schedule.

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5. Using approved medicines for newborn infants

Background

Many commercially available medicines are only licensed for use in adults and, for many, the available formulations are unsuitable for paediatric use. This situation leads to the unlicensed or off-label use of medicines in neonates, infants and children. There are several reasons for this highly unsatisfactory situation. Firstly, paediatric patients represent only a small market as regards absolute numbers, but also relatively because most infants and children are healthy. Secondly, worries over unforeseen adverse effects and long-term toxicity make clinical studies in paediatric populations more difficult to perform. Hence, from a commercial perspective, it may not be profitable to invest in paediatric drug research. Finally, there are ethical problems that act as barriers for conducting clinical studies with medicines for children.

As a result, paediatric drug trials have been relatively scarce and often include only a limited number of patients. However, in recent years, the public discussion about medicines for children and the health of children in developed countries, as well as in the developing world, has reached unprecedented intensity. One main driver has been the introduction of the EU paediatric regulation, in force since January 2007, which has directed the pharmaceutical industry to include children into the drug development process. Additionally, the launch of the WHO campaign 'make medicines child size' is drawing attention to the health of children in the developing world. Further drivers include the increased collaboration between the regulatory authorities of the USA, EU, Japan and other countries and regions in their effort to combine forces to promote better medicines for children.

Challenges

Clearly, adverse events in early infancy might have life-long consequences or may not show up until many years later, which makes research in this field very challenging. Currently, there is a lack of child-friendly age-appropriate formulations which makes using approved medicines for newborn infants difficult. As growth and development continually change the disposition and effect of medicines in neonates, infants, children and adolescents, further problems persist.

Also ethical issues, such as informed consent/assent from parents, for participation of their babies in pharmaceutical studies, complicate the development of medicines. And solutions to these problems are difficult to find because of the lack of teams consisting of investigators, clinicians, nurses, parents, pharmacologists, statisticians, etc. that could optimise the design and conduct of clinical trials in paediatric and newborn patients according to good clinical practice (GCP).

There is a need for the development of appropriate microanalytical assays and for well-trained research nurses, etc. Also, researchers must realise that the small numbers of individuals with a specific disease make multicentre trials necessary.

Recommendations

- Drugs approved for use in newborns should be used in preference to those that are not.
- Research and development of paediatric and neonatal drugs should be prioritised, including training of new clinical investigators and multidisciplinary teams; provision of resources to conduct clinical trials.
- There is a need for increased information exchange between countries of existing child-friendly age-appropriate formulations.
- Research on drugs should be facilitated by creating acceptance guidelines for local committees of ethical approvals by central committees for multicentre trials.
- Long-term follow-up of study participants should involve patients if they reach an appropriate age.
- Parents and parent organisations should be involved and informed.
- The development of clinical research centres for pharmaceutical research needs to be encouraged, independent from industry sponsorship, in order to support scientifically justified applications and studies, GCP procedures, and ethical approvals.

6. Pain and stress

Background

Newborn infants requiring intensive care are subjected to a large number of painful, although necessary, procedures. Newborn infants depend on others to recognise, assess and treat pain and discomfort. The situation for the preterm infant is usually worse than for the sick full-term infant, since preterm infants often need to stay in the NICU for many weeks and sometimes months.

The NICU environment is fundamentally different when compared to the intrauterine environment, and frequent sensory and sometime noxious stimulation can be disruptive; e.g. blood sampling, diaper changes, changes of feeding tubes. In addition, noise (voices, alarms) and round the clock lighting may be very distressing for the infant. Although there is an increased awareness, pain and stress symptoms are still often underestimated.

Challenges

The challenge in reducing neonatal pain and stress starts with prevention in a global perspective:

- The NICU environment should be designed to avoid unnecessary acoustic, visual, tactile or vestibular noxious stimuli for the baby
- The necessity of each procedure or intervention should be questioned
- Parents should be present when newborn infants are exposed to distressing procedures.

In order to recognise pain and stress, appropriate assessment is required: systematic pain detection needs guidelines and tools utilised by skilled and trained staff. Then once perceived, pain and stress should receive proper treatment including:

- The NICU design should be comfortable and quiet, and designed for permanent access to families to help support the baby
- According to the baby's condition, pharmacological and/or non-pharmacological strategies should be proposed. Breastfeeding, oral sucrose, non-nutritive sucking, swaddling, facilitated tucking and Kangaroo Mother Care (KMC) are very effective
- Pharmacological treatment should be used according to current published guidelines and appropriate pain scales.

Recommendations

- When potentially painful procedures need to be performed as part of the medical care, all newborn infants treated in NICUs should be assessed with validated pain scales and receive adequate pain treatment.
- All newborn infants treated in NICUs should regularly be assessed for on-going, continuous pain with appropriate and validated pain scales and receive adequate pain treatment when indicated.
- Hospital staff working in NICUs should have knowledge about causes of neonatal pain and how pain is assessed and treated, and should receive repeated education to increase the awareness of neonatal pain, including methods for preventing, identifying and treating neonatal pain and discomfort.
- Structural environmental strategies, appropriate assessment tools, and treatment approaches have to be implemented in a family-centred care perspective.

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7. Family centred developmentally supportive care

Background

The fundamental difference between preterm infants and all other patient groups is that the preterm brain is in a very active stage of development. Although genetically geared, brain development is to a large extent influenced by sensory stimulation, which makes infants exceptionally receptive but also vulnerable, especially when born preterm. Consequently, the sensory environment may influence both short-term morbidity and long-term development in these infants.

In order to adjust the medical care according to the appropriate developmental stage of the individual infant's brain maturation, some caregiving models have evolved that focus on enhancing the competence of the caregivers (parents and medical staff) to better meet the babies' needs and to make the environment more appropriate for the individual infant. These models reduce the length of hospital stay and short-term morbidity, as well as improve long-term development.

The physical environment is important, and standards for design of NICUs should be used. Providing facilities for parents to stay with their infants in the nurseries, and avoiding parent-infant separation, is not just in accordance with the United Nation Convention on the Rights of the Child (paragraphs 7 and 9) but has also been shown to reduce morbidity and duration of hospital stay. However, families need support not only during the hospital stay, but also after; post-discharge intervention programmes report improved long-term cognitive and behavioural outcomes of preterm infants.

Challenges

In order to increase the uptake of family centred developmentally supportive care, an increase knowledge of, and implementation of, evidence-based care procedures in European NICUs is needed. This includes practical aspects, such as positioning of the infant, minimal handling, enhancing infant's sleep organisation, infant massage, kangaroo care, supporting breastfeeding and pain relief.

It is also essential that knowledge about infant development is increased among neonatal staff. Likewise there should be a greater number of developmentally educated professionals in neonatology, which traditionally has not taken behavioural science and caregiving issues into consideration. This situation could be helped by increasing the number of training facilities for advanced caregiving models, as well as providing economic means to introduce and implement such methods.

Throughout the world, the majority of NICUs were designed according to adult standards and not for a patient population whose brain development could be negatively influenced by bright lighting and high sound/noise levels. Furthermore, a majority of NICUs do not provide the possibility for parents to stay with their infant which is problematic for a variety of different reasons.

Also of concern is the fact that very few hospitals provide couplet care (i.e. medical care for both the mother and infant in the same unit and room) when needed, in order to avoid mother-infant separation. Close collaboration between obstetrics and neonatology is required.

7. Family centred developmentally supportive care

Additionally there exists a current shortage of:

- Paramedical disciplinary professionals; e.g., physical therapist, occupational therapists, speech and language therapists, lactation consultants, social workers, psychologists, etc.
- Resources for research in developmental care
- Post discharge early intervention programmes and aftercare support for the development of the child
- Adequate financial and judicial support for families in neonatal care or with chronically ill infants.

Recommendations

At the hospital level, it is important to:

- Ensure competence in family-centred developmentally supportive care: train developmental care professionals
- Ensure multidisciplinary competence: employ physical therapists, occupational therapists, speech and language therapists, lactation consultants, social workers, psychologists, etc.
- Provide Couplet Care – ensure collaboration between obstetrics and neonatology
- Renew or rebuild NICUs according to current design standards.

At the community level, further action is needed to:

- Train personnel and implement early intervention programmes
- Provide post-discharge programmes, including medical care, developmental consultations and follow-up.

At Governmental/EU-level, policy makers should:

- Support national and international parents' organisations
- Support existing training programmes and conferences for family-centred developmentally supportive care and early intervention programmes to increase the number of trained instructors for the training of developmental professionals
- Support hospital systems to acquire developmental professionals by training grants
- Support research projects in family-centred developmentally supportive care
- Pass laws enabling reimbursement of families with children in hospitals; help families to temporarily quit working without losing employment during the times when children are ill.

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8. Parental empowerment

Background

The situation of parents of preterm and severely ill full-term infants is characterised by several distinct features that may affect their role as the infant's primary caregiver, both in a physical and emotional sense. For the preterm infant, pregnancy is interrupted at a point when parents are not fully prepared to become parents, and the fragility of the preterm infant, and the immaturity of the infant's behavioural cues may also influence infant-parental interaction. For infants treated in NICUs, the parent-child-attachment process cannot take place in a natural manner because of the need for medical treatment. Further problems arise from the special situation of the NICU, which may be experienced as a strange and frightening environment with technical equipment and frequent alarms, worries for the infant's medical condition, dependence on the medical team, and the parents' feeling of an inability to protect their baby, etc. Hospital routines may also create limitations for 24-hour access to the baby.

All these factors contribute to difficulties in starting a normal parent-child relationship. Family needs, e.g. care for siblings, work, travel and economic conditions, may also create difficulties for the parents in caring for their sick or preterm baby in the hospital. Parental empowerment can be aided by several measures aimed at supporting the establishment of the parental role in the hospital. Such measures include unlimited access to the baby, and provision of psychological support. This support should encourage the endogenous abilities of the parents, support acute psychological crises reactions in response to the infant's birth, and promote the best possible neurodevelopmental outcome of preterm infants by optimising child-parent interaction. This requires well educated neonatal staff able to demonstrate empathy and show respect for the family's cultural, religious and social preferences and needs.

Challenges

In all instances, the parents should be acknowledged as the infant's primary caregiver. This view may sometimes be challenging both for the neonatal staff, since they are the medical experts, but also for the parents who are unlikely to have received the necessary support to empower their new role as parents. Likewise, during the infant's hospital stay, the parents should be able to stay with the child in the NICU to enhance infant-parental attachment, and parents should be encouraged and educated by the neonatal staff how to develop their competencies in order to deliver quality care to their child.

The 24-hour access for parents is often limited by the care policy of the NICU, the distance between the NICU and the parents' place of residence, and available support by the parents' social and family network. It is a challenge to invent creative, working solutions for parents that cannot stay with their baby permanently. Virtual visits can to some extent help to compensate the lack of real visits. By using a webcam (situated at the bed of the infant), parents have the opportunity of additional real-time visual contact with their child.

Parents should be empowered in their parental role in the hospital and all staff in the neonatal unit should be made aware of the difficulties parents encounter when they have a newborn infant needing hospital care by showing positive engagement and empathy towards parents during busy and stressful times. Special support teams, who are integrated in the regular neonatal care, are needed for psychological, educational, and social support for the families, and should encourage families to engage their social networks to assist them. Also, siblings should be welcome in the neonatal unit, if the infant's medical condition permits it.

Recommendations

- Each EU Member State should acknowledge the difficult psychological, social and economic burden that families of very preterm infants encounter during weeks and months of hospital care, and take actions to alleviate these burdens.
- Each NICU should have a psychosocial support team consisting of psychologists, social workers, pedagogues, nurses, and neonatologists. The team must work in accordance with a scientific understanding, with the aim of supporting the family and improving the interaction between child and parents.
- Each NICU should allow parental access as freely and as much as possible, preferably around the clock. If parental access is impossible for some reason (e.g. the parents live too far from the hospital), other close relatives or friends can help the family, as requested by the parents. Telephone contact with the NICU should be available around the clock, and parental internet based support and information systems should be offered.
- With the help of the neonatal staff, acknowledged parent organisations working from outside the NICU should establish parental support groups at each NICU. This kind of support from parent to parent is different than the support from the neonatal staff; the main goal is to give new parents hope and support-sharing experiences.

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9. Communication with parents

Background

Parents whose babies are admitted to a neonatal unit face a very challenging situation, in contrast to their expectations for normal postnatal care of the newborn baby. Their early experience of parenthood is often characterised by stress and uncertainty. Studies have shown that one of the main causes of parental stress in the neonatal unit is the change in the parenting role, with limited participation in decision-making and care of their baby.

Parents have a strong need for information about their baby's condition and treatment. The type of information that parents receive, and how they receive it, is very important. Research shows that interventions to improve the communication between parents and neonatal health professionals can have a significant impact on parents' confidence, their parenting behaviour, and the wellbeing of the family in general. A clear, consistent, and empathic professional communication is important at all times during the neonatal journey, but especially during periods of transition (e.g. admission to the unit, transfer between units, leaving the unit to take the baby home), which parents find particularly stressful.

Challenges

It is important that neonatal staff are made aware of the diverse communication needs of a wide range of families (i.e. differences in first languages, and in cultural and socio-economic backgrounds). Also there should be an understanding that parents' communications needs may fluctuate according to their baby's condition.

By increasing the sensitivity of neonatal staff to some of the issues that these parents are faced with, it will help the professionals understand the parents' position and feelings and thus help them fully appreciate that communication is a two-way process which includes parents sharing their feelings, wishes and observations.

Increasing the staff's sensitivity will ensure that they provide good communication with parents even if units are understaffed.

Sometimes staff may assume a spoken conversation is enough, and not ensure this is backed up with written information (due to stress parents may find it hard to retain information if only given verbally); or, conversely, may assume face-to-face communication is not required and leaflets are sufficient. Situations such as these need to be carefully monitored. Also, healthcare professionals should ensure that fathers are included in communication as often as mothers.

Recommendations

- Ensure that all neonatal staff, including nurses and doctors, have adequate knowledge and training on how to communicate with parents who may be in acute psychological crisis.
- Ensure that information given to parents is consistent (conflicting messages can undermine their confidence).
- Neonatal staff, and doctors in particular, should ensure that they use appropriate language with parents; it is good practice to check back with parents that any explanations are understood.
- Parents should be encouraged to ask questions and discuss concerns (this is key to supporting their wellbeing and avoiding miscommunication); thus, ensuring that communication is a two-way process.
- Face-to-face communication should occur regularly, particularly around key transitions (e.g. transfer to another unit).
- Written information should be used to back up what is shared face-to-face.
- Translation services should be made available for key consultations, and written information provided in relevant languages.
- Mothers who are still on the postnatal ward, and therefore separated from their baby, need to receive appropriate communication about their baby's progress on the neonatal unit as soon as possible.

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10. Maternity and paternity leave

Background

Maternity and paternity leave has, over the past years, come to be understood as a mechanism of social policy with an impact on gender equality at work, gender equality at home, child development and health, parent health, fertility, and participation of women in the labour market.

For parents of preterm infants or infants born with illnesses there is even another, much more important point to maternity or paternity leave: Maternity leave starts when the baby is born, it does not recognise the difficulty and often enough complete distress of parents whose leave begins long before they can take their baby home from hospital.
In many cases of preterm birth, mothers have to return to work whilst their babies still are in neonatal care. This problem is, of course, much more common for fathers. Many will choose to return to work while their baby – and possibly their partner – are still in hospital so that they can save their precious weeks of paternity leave until the family is at home together.
As such, extended maternity leave and also paternity leave for parents of preterm infants or infants born with illnesses is one of the main concerns and requests of parents groups. In countries where changes successfully took place (e.g. France), reality shows that its application still remains difficult despite the changes in law, and despite trying to raise awareness with the authorities concerned.

Therefore, it is important that policy makers have a multi-disciplinary view of the benefits of these mechanisms, so they understand that maternity and paternity leave is not a burden to business, but can be contributors to efficiency under the right circumstances.

Challenges

In the present economic climate, it is certain that national governments may decide to cut public support to a variety of social policy areas and, thus, efforts to raise the European standard for maternity and paternity leave might not be considered as favourably as they would previously even more so, when it comes to extended leaves for parents with preterm infants or infants born with illnesses.

As mentioned, standards for the length of leave, to which parent the leave is awarded, the compensation rate during the leave, and whether this mechanism is funded publically or privately, vary across the Member States. Not surprisingly, Scandinavian countries have some of the highest compensation and longest leave periods, while other Member States offer interesting options to extend the length of a mother's leave should she a) have twins (i.e. Belgium, France), b) be having her second, third or more child (France) and c) have a baby born premature (Belgium, Germany). Certain Member States, such as Cyprus, also make special arrangements for adoptive parents.

Some of these decisions are based on research, others a result of strong campaigns from parent groups and other advocates to improve the system, and still others find their basis in cultural understandings of a mother's role in childbirth and rearing. A strong body of research exists that is able to connect 'social investment' as public benefits; however, it is important to ensure that policy makers also focus on the current well-being of children, and not just the future economic prospects of children and their parents.

However, still not enough attention is given to the personal dimension of this problem, as the specifics of each family's situation make it very difficult to develop a 'one size fits all' approach when it comes to leave periods for families with preterm babies. Many parents of preterm born children still have to experience the absurdity of outdated laws and/or administrative rules in their local community – even if national law proves they are right. Often enough, they are confronted with personnel that is not aware or trained enough to deal with the severity of the situation these parents are in and miss the necessary sensitivity. Parents of children born below 32 gestational weeks also experience particular difficulties in locating community care facilities willing to take on vulnerable infants, which means that some mothers are forced to provide their infants with care in the home for longer than would normally be the case or to hire a nanny. Both solutions mean additional costs added to the anyway high financial burden of the family.

Recommendations

- True equality of opportunity and effective support to cope with the new family situation would be given to families of preterm and ill born babies if maternity leave started to count from the day of discharge of the child and paternity leave could be extended.
- Increasing awareness of society at a large for the problems families, especially parents, are facing when affected by preterm birth, or bereaved parents would lead to more understanding and sensitivity when it comes to dealing with administrative issues.
- Outdated laws and inadequate regulation are some of the reasons for unfavourable developments. Aside from the employment practices which clearly dictate the length of leave periods, changes will also have to be made to the judicial and administrative systems which interact with these other players to ensure that parents of preterm or ill born babies or bereaved parents get appropriate treatment, in a sensitive and culturally appropriate manner under the current system.
- Day-care facilities for parents of preterm infants born below 32 weeks of gestation or of ill born infants need to become affordable and practicable alternatives if parents are not in a position to extend their leave from work.

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11. Discharge management

Background

The process of taking a child home and becoming the sole caregivers after a long period of neonatal intensive care, including extensive periods of intense monitoring of vital functions, may be immensely challenging for parents. These concerns stem from a range of worries regarding their infant's health, which has been heavily medicalised within the hospital. Some common concerns involve fears over unknown aspects of how they will develop through childhood, anxieties about providing 24-hour care, and the lack of immediately available advice.

The process of discharge is complex and all neonatal services need to develop robust policies to ensure that when a family is discharged, going home is a happy time, and that parents have the skills and confidence needed to move forward with caring for their infant. Planning for discharge should start with admission by building the foundations of a close parent-infant relationship, assistance to help with breast feeding, and confidence in the caring team. This care continues after discharge into the follow-up clinic. For some high-risk infants, home monitoring with a device that is able to monitor, alarm and store events, trends and full disclosure data of respiration, heart rate and oxygen saturation is recommended.

The medical and psychological support required after discharge changes over time. Initially, families often need advice about feeding and support for some routine procedures, such as sleeping habits and immunisation policies, although some high-risk infants will require close medical attention throughout this period; e.g. preterm infants who must have home therapy with oxygen due to chronic lung disease. Later on, growth and neurodevelopment usually become more important and, thus, parents also need to be prepared for this change.

Challenges

Efforts should be made to continuously plan for home discharge throughout inpatient care, in appropriate steps according to the medical situation of the baby. This requires supporting the parental role before discharge by providing adequate facilities for breast feeding support, privacy and skin-to-skin care. Healthcare professionals need to adequately meet and respond to parental anxieties about health and on-going health needs, such as immunisation, feeding or special needs. Also, efforts should be made to refine, as much as possible, prognosis regarding long-term disability risks.

When it comes to equipping parents with skills, prior to discharge they should be trained for the unexpected, including resuscitation advice and training. Also, outreach teams should be provided to support the transition to home and follow-up clinic support, including developmental and neurological assessment. Throughout this process there should also be the possibility of receiving support from other professionals – therapists, clinical services (hearing, vision).

Recommendations

- All hospitals should have a comprehensive policy for preparation for discharge and follow up care as part of a family-focused strategy. The policy should be audited, monitored and reported, with parents of babies receiving specialist neonatal care encouraged and supported to be involved in planning and providing care for their baby. Regular parent-clinical staff communication should occur throughout the care pathway.
- Support starting and continuing breastfeeding for mothers of babies receiving specialist neonatal care should exist, including being supported to express milk.
- There should be facilities for 'rooming in' by parents as preparation for discharge.
- Training in resuscitation and strategies for seeking help should be discussed with parents.
- Babies receiving specialist neonatal care should have their health and social care plans coordinated to help ensure a safe and effective transition from hospital to community care: a discharge planning meeting should bring together the inpatient and community support teams to ensure smooth handover and transition to home.
- Central support for the use of respiratory syncytial virus infection (RSV) prophylaxis for at risk groups is advisable.
- Health outcomes should be monitored in babies receiving specialist neonatal care: routine follow-up clinic appointments should facilitate developmental awareness of parents in addition to monitoring health and screening for disability.
- Where disability is suspected, such as cerebral palsy or developmental delay, appropriate referral to community support services as early as possible is essential.

- As a minimum follow-up to 2 years after term-equivalent age is recommended, although given the high prevalence of special needs, support at school should be particularly considered for the extremely preterm group (<27 weeks).
- Hospitals should report the prevalence of key outcomes, such as cerebral palsy, neurosensory problems and developmental delay, in key groups (as a minimum, babies <31 weeks of gestation at birth) using standard definitions for reporting; these should be available publicly.
- National and local recommendations for home monitoring should be in place and may include children who showed signs of an apparent life-threatening events, patients with cardio-respiratory problems, preterm babies undergoing oxygen therapy, patients receiving artificial respiration treatment, neonates with tracheostomy, or children who have had a significant number of apnoeic events prior to being discharged from hospital.

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12. Palliative care

Background

Supportive end-of-life care, sometimes called palliative or 'comfort' care, is a key strategy in situations where a baby is likely to die or for whom a decision has been made not to intervene. Decisions about continuing intensive care are based on the best evidence available about the baby's prognosis and involve the parents, their families and advisers, and the clinical team providing care.

Although unique conditions arise in each situation, there are continuities between cases and principles on which such care should be based. Palliative care is in essence an extension of normal care, focused on providing support and comfort for the baby and the family. Such care is, of necessity, provided by multidisciplinary teams and key aspects of palliative care relate to the planning and coordination of care.

Challenges

Planning for palliative care should commence when it is clear the prognosis is limited, not as an afterthought after major decisions have been made; as part of this process, parents need privacy and time to come to terms with the situation. Developing a plan for palliative care involves a wide range of professionals and aspects of the care package; the immediate care team need consideration and communication to avoid problems.

Often the neonatal unit or delivery room setting provides an inadequate environment for principles underlying the performance of palliative care. This makes things difficult for parents, who need close one-to-one support through the initial phases of end-of-life decisions, including immediate access to support throughout the palliative care process.

Unfortunately, community palliative care teams and hospice facilities are rarely used to deal with small babies and may not have appropriate resources or facilities.

Recommendations

- All hospitals should have a comprehensive policy for providing palliative care packages with an agreed care pathway, detailing the arrangements and communication required for coordinating such care.
- This policy should cover three main situations:
  - Where palliative care is agreed antenatally because of a life-threatening condition where treatment is either not possible or not deemed appropriate
  - Where a decision is made after birth not to offer active care to an extremely preterm baby because of limited prognosis, or a baby with a life-threatening condition where treatment is either not possible or deemed inappropriate
  - Where a decision to switch to palliative care is made in the face of established neonatal complications with very poor outcomes

- Clear pathways for supporting parents' decisions and situations where disagreement occurs with the clinical team should be established as part of the pathway.
- Family arrangements are critical and support for the family in terms of initial accommodation and financial support may be necessary.
- Communication with the family by the palliative care team is critical and should be undertaken by experienced staff.
- Parents may need psychological support through the process and the policy should be to collect appropriate mementoes for them; e.g. photographs, identity bracelets, foot and hand prints, and locks of hair.
- Parents may receive much support and comfort from their spiritual advisers, who should be involved if requested.
- Each baby has the right to a post-mortem and parents should be offered the opportunity for follow-up support after their baby has died; an important part of the palliative care pathway.

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13. Ethical decisions on the border of viability

Background

Extremely preterm birth raises a number of ethical dilemmas centred on how far medical interventions should continue to advance. Increasing survival rates of extremely preterm infants are accompanied by relatively high rates of neuro-developmental difficulties. Public and medical attitudes, and sometimes laws, vary considerably between countries and perinatal centres, from the absolute respect for life to the tolerance of active euthanasia. Indications for stopping or limiting life support, as well as definitions of what can be accepted as palliative care, can differ greatly. Involvement of parents in decision-making also varies.

Challenges

The need for decision-making is recurrent during the prenatal and postnatal course of extreme preterm birth, in nearly all individual cases, especially in the quickly changing context of the obstetrics clinic, delivery room stabilisation and postnatal intensive care.

Medical prognostic tools and investigations, although in progress, still do not provide sufficiently accurate information on long-term expectable outcomes, particularly for extreme preterm birth. Some information, such as the detection of periventricular leucomalacia, a major factor of poor outcome, can be obtained only with a delay, at a time when the patient is no longer dependent on life support.

Additionally, simplified conducts on a general limit of intervention are often proposed based on the adoption of an arbitrary threshold of gestational age or birth weight. They allow the standardisation of practices, but are in contradiction both with the fundamental principles of bioethics and the individual rights of patients who are born alive. In this context the limit for intensive care is usually set according to a statistical approach, based on outcomes obtained in observational, population-based or perinatal centre-based cohorts of preterm infants.

Studies have shown that neonates (as well as elderly patients) are considered differently when an end-of-life

life decision has to be made. The withdrawal or withholding of life-support therapy or curative care is more frequently considered during the neonatal stage, than for adults in similar situations.

Recommendations

- Ethical principles and evidence-based research should be the grounds on which medical decisions are made. This implies that decisions be individualised, on the basis of each individual patient's condition, evaluated comprehensively with a careful examination of all medical risk or favourable factors, and of the human context. The decision should not be purely statistically based, within an *a priori* policy applied to an arbitrarily (although scientifically defined) category of patients.
- Parents should be allowed to take part in the decision-making process, although the final responsibility should be medical. Even the 'grey zones' of gestational age should not be considered simply an area for which parents have the sole ability to decide. The interest of the infant must be considered first and individually, in cooperation between doctors, nursing staff and parents. If a conflict of interest is raised, in exceptional situations, a judiciary intervention should be considered.
- In all situations where intensive or curative care is no longer considered optimal, structured palliative care should be applied.
- Continuing education of medical and paramedical staff and further research are needed in this field.

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14. Education and training of neonatal professionals

Background

Neonatology is a highly specialised medical discipline requiring theoretical and practical skills, not only of the involved staff on an individual basis, but also the multidisciplinary team. The competences of doctors, nurses, social workers, psychologists and many more specialists work in concert to provide the best care for the infant and their family, and to ensure optimal outcomes.

Traditionally, and in most European countries, neonatology is a subspecialty of paediatrics. Doctors specialising in neonatology are first trained to become paediatricians. Thereafter, a three-year education dedicated to neonatology ensues. To help the national societies harmonise this training throughout Europe, a Curriculum and Assessment Plan has been developed and ratified by the European Board of Paediatrics. The Curriculum specifies necessary theoretical, practical and social competencies. In Europe, the main responsibility for this training lies within the individual Member State. Recently, the European Society for Neonatology (ESN) published a survey demonstrating differences in how the training programmes of the EU Member States adhere to the Curriculum. In addition, several organisations offer teaching courses in neonatology. Recently, and supported by the DaVinci Programme, an on-line series of teaching courses has been launched, the NOTE (Neonatal On-line Training in Europe).

As a medical discipline, neonatology is rapidly developing and it is important that professionals receive adequate continuous professional development (CPD) to improve the quality of care and long-term outcomes for sick newborn infants. Neonatal research continuously provides new insights in pathophysiology of diseases and various neonatal conditions, in their clinical manifestations or in different therapeutic approaches, such as improved ventilatory, nutritional and neuroprotective strategies. All these demand implementation of proper training and education to ensure skills are maintained.

To achieve the best outcome, team-training in neonatal emergencies, procedures and transport is necessary. Full-scale simulations of these stressful situations have proven very useful. These simulations should include not only neonatal medical trainees or staff, but also other professionals that could be faced with neonatal emergencies; i.e. nurses and midwives, obstetricians, anaesthesiologists, paediatric intensivists, transport-staff, etc. Multidisciplinary debriefing is essential to analyse what was performed well and what could have been done better.

Similarly, having access to up-to-date sources, such as consensus-based guidelines and courses provided by experts in the field where discussion is encouraged, constitute other important tools for neonatal training. Nurses play an important role in neonatal care. Concern for the extremely premature child requires special skills of the nurses. Not only highly technical operations and the science of the developmental care are important but also empathy for the parents who are in vulnerable condition.

Challenges

There is need to harmonise neonatal training of doctors throughout Europe. Likewise, by improving the quality and increasing the appreciation of neonatal nursing, the care received by patients and their families will also improve. To encourage the uptake of higher standards, more resources should be given to encourage multi-disciplinary-based learning and training for the neonatal team. Likewise, further measures should be taken to

increase the recruitment and retention of neonatal nurses and doctors.

Recommendations

- There should be continuous intergration of professional development (CPD) in all neonatal services and the neonatal staff should be allowed to repeatedly up-date and retain their competencies.
- Interactive web-tools for self-learning should be developed and, when appropriate, maintain use of these programmes.
- More full-scale simulation centres need to be developed.
- Dedicated training programmes for neonatal nurses should be developed.

15. Accreditation of neonatal training facilities

Background

In the European Union, the responsibility for training in neonatology lies with the individual Member State. In order to obtain theoretical and practical competencies, training must take place in settings that provide competent teachers, adequate exposure to all types of patients, and possibilities of learning and practicing new skills. Also, the training facilities must have close collaboration with other medical specialities, such as obstetrics, intensive care, laboratory services, paediatric subspecialties, cardiac and neurosurgery. Access and support from child psychiatry, social workers and parental support organisations helps the neonatologist learn how to best support the new family.

The Neonatal Curriculum specifies key components for a training centre to become accredited by the European Society for Neonatology (ESN). At the moment, there are no on-site visits planned for this accreditation. Instead, a self-report is available on the website of the European Society of Paediatric Research/European Society for Neonatology.

Challenges

Currently, it is difficult to secure common competencies, skills and knowledge of neonatologists throughout Europe. This situation would be improved through the facilitation of exchanges of experiences to enhance collaboration and networking throughout Europe.

Recommendations

- The development of regional and national networks for perinatal care should be supported.
- Neonatal trainees should be supported to do (part of) their training in another European country.
- Funding for on-site visits for accrediting European Neonatal Training Centres is needed.

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16. Database, benchmarking, and quality improvement

Background

Being born 'too soon, too small' has the possibility of compromising the chances of healthy survival and full integration in future society. Such high-risk infants will require prolonged, complex and expensive care in NICUs, provided by well-trained health personnel. And yet, standards of care do not exist at a European level, resulting in a wide variety in the quality of care between hospitals, regions and countries. Moreover, comparable standardised data of short- and long-term outcomes, and homogeneous and effective quality improvement initiatives, are not available at a European level.

Several neonatal networks involved in benchmarking exist in Europe at regional (e.g. Basque country and Navarre, Lazio, and Lombardia) and national levels (e.g. Belgium, Italy, Portugal, Spain, and Sweden), but there is only one neonatal network at the European level, the EuroNeoNet. Financed by the European Commission's Directorate for Health and Consumer Protection EuroNeoStat I and II projects, this network collects voluntary standardised data on preterm infants of a gestational age of less than 32 weeks, from 167 neonatal units from 14 EU Member States plus Norway, Turkey, Switzerland and Russia. The EuroNeoNet Perinatal Database contains information from a total of 26,894 infants born from 2006 to 2011. A registry is kept, and yearly reports for benchmarking are made available to participating units. Additionally, the network promotes patient safety, by the collection of adverse event data, and is implementing quality improvement initiatives on prevention of hospital-acquired infection.

The lack of standards of care for preterm infants causes a wide variability in mortality and morbidity rates between neonatal units, regions and countries. As an example, data from EuroNeoNet show that the average predischarge mortality rate was 13.3%, with a wide inter-unit variation from 2.2% to 37.4%. Likewise, the overall rate of chronic lung disease in preterm infants was 16.6%, but varied from 1% to 60.3%.

Quality improvement initiatives are being developed and implemented across Europe, but at individual units, local networks and in an independent, non-standardised manner. Thus, interventions applied, indicators used and results reported are not harmonised and make comparison difficult.

Challenges

There are many challenges to overcome in harmonising and improving the quality of care provided to all preterm infants born in Europe. Ideally, the outcome for every infant should be similar to that achieved in the best performing centres, regardless of the place of birth or where the care is received.

Furthermore, to permit comparisons of outcomes for benchmarking and assess the effects of any quality-improvement interventions, a harmonised data collection system and a permanent registry must be provided and appropriately funded at EU-level. This information system should have a set of standardised, well-defined indicators for prenatal risk and protective factors, neonatal interventions and complications, as well as neonatal and post-neonatal survival to assess not only perinatal and neonatal care, but also the long-term neurodevelopmental status at follow-up in infancy and early childhood.

Good clinical practices and effective preventive strategies used in some countries must be disseminated and implemented where they do not already exist. Specifically, incident-reporting systems and interventions to measure and prevent hospital-acquired infections should be implemented to improve patient safety.

Recommendations

- Health authorities of EU Member States must realise that the level of care provided to preterm infants impacts strongly on neonatal and post-neonatal mortality, as well as on health and neuro-developmental performance later in childhood. Moreover, prematurity posses a significant financial impact on health systems and causes acute and long-term stress for infants, their families and society as a whole.
- Significant efforts and resources should be allocated by national, regional and local health institutions to not only support neonatal units but also to promote and standardise training of neonatal medical and nursing personnel, and develop a harmonised classification system of the levels of care that can be provided by neonatal units; improving care to high-risk infants.
- A European registry for data collection of short- and long-term consequences of prematurity must be funded and established in a permanent manner. The registry must provide all European neonatal units with a harmonised set of standardised well-defined indicators to assess the quality of care provided and to permit standardised comparisons for regions and countries.
- The health institutions of EU Member States should propose to the WHO the inclusion of very low birth weight-specific and very low gestational age-specific mortality rates into the set of indicators measuring maternal and child health worldwide.
- Specific calls to support outcome-related research on prematurity, its causes, prevention and long-term consequences, and to implement quality-improvement strategies, should be funded by the EU through the Research Framework Programmes and the appropriate authorities.

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17. Research

Background

During the last decades, one key aspect of neonatal research has focused on understanding and improving lung function and the haemodynamics of sick infants, which has resulted in a dramatic increase in survival rates of preterm and sick full-term neonates. The scientific attention is currently shifting towards interventions that may contribute to improved long-term outcomes and better quality of survival, and includes methods for providing optimal nutrition and neuroprotection.

A large scale research involving and integrating SMEs and companies in order to provide innovative biomarkers and therapies to be delivered to patients at risk in a timely manner should be developed. Due to the socioeconomic impact of prematurity and its potentially preventable long-term consequences, prevention strategies have to be implemented, which will require reliable biomarkers and which will allow to save money (no long term handicap) and maintain the working young adults to support the retired and ageing ones.

Challenges

A strategy for providing family-centred care, which looks at the needs of the infant and the entire family, is becoming increasingly important. This more holistic approach involves experts outside the traditional medical field, e.g. psychologists and social workers. Future research should allow us to better individualise standards in care and determine the individual need of each infant; e.g. concerning technical support. Moreover, the adverse effects on infant development from pain, stress, noise, and excess light in the neonatal unit need increased attention. Methods aimed at reducing noxious effects from the treatment and the intensive-care environment, including 'minimal handling' and 'developmental care', need further evaluation in carefully designed scientific studies. However, most importantly, there is an urgent need to learn more about prevention, especially factors triggering preterm birth, as prevention of prematurity is clearly a better option than treatment.

Drugs and treatments especially created for the needs of newborn infants should be developed and tested in this age group. An example of the importance of developing drugs for newborns is surfactant, administered to preterm infants with respiratory distress, which was the first drug designed specifically for the needs of newborns and has helped thousands of preterm infants to thrive. However, full-term infants and their problems (e.g. infections, asphyxia and malformations) should not be forgotten in the development of guidelines/neonatal pathways. Neonatal care demands organisation in perinatal centres as a multidisciplinary approach including, for example, prenatal diagnostics, obstetrics, genetics, paediatric surgery and other disciplines.

Recommendations

EFCNI and its scientific advisory board have identified the following key aspects that need to be addressed in future national and European research funding:

- **Involving Europe's SMEs to find solutions**
  A large scale research involving and integrating SMEs and companies in order to provide innovative biomarkers and therapies to be delivered to patients at risk in a timely manner should be developed.
- **Determinants of preterm delivery, its prevention and maternal health**
  Prevention of preterm delivery remains the best option. However, the underlying mechanisms of spontaneous preterm delivery remain largely unknown. Preventing ascending infection, e.g. by enhancing the physiological vaginal bacterial milieu, might be one possible route for prevention. Also, early biomarkers and identification of genetic and environmental risk factors are needed, and pathomechanistic research could allow the definition of new targets for preventing preterm delivery.
- **Address the lack of comparable European data**
  Reliable data on the prevalence and cost of preterm birth is difficult to compare due to different reporting mechanisms and methodologies, lack of data collection both across Europe, and even within the individual countries.
- **Network of networks**
  In Europe, multiple national networks have been created to study the long-term development of preterm infants. Research should be funded that aims to bring together a 'network of networks', designed to maximise follow-up and research experience at the EU level, and streamline follow-up guidelines across the EU.
- **Towards individualised medicine in preterm and full-term newborn infants**
  Current experimental and clinical studies do not consider the individual phenotype of the developing organism. One example is enzymes responsible for drug metabolisms are developmentally regulated and dependent on genetic factors. In addition, prenatal, perinatal and postnatal factors, such as inflammation, might already have impacted foetal metabolism, altering the response to treatment and intervention. Future preventive, diagnostic and therapeutic approaches should be based on the individual phenotype to increase, for example, efficacy and safety of drug treatment or postnatal interventions (oxygen supply, nutrition).
- **Research on gastrointestinal immaturity**
  In extremely low birth weight infants, immaturity of the gastrointestinal tract and associated complications (including necrotizing enterocolitis and spontaneous perforation) contribute significantly to neonatal mortality and morbidity. Experimental and clinical studies should be fostered to prevent and help provide early diagnosis of gastrointestinal complications.
- **Lung development, asthma and prevention of chronic pulmonary disease**
  All preterm infants, not only those with neonatal pulmonary disease, appear to be at increased risk for chronic airway disease/asthma. Experimental and clinical studies should be developed that attempt to elucidate the determinants of long-term pulmonary disease among children born preterm.

17. Research

- **Disease process, diagnosis and prevention of cerebral palsy and developmental brain injury**
  Recent research indicates that, following preterm birth, some brain damage mechanisms (e.g. inflammation) appear to exert systemic effects after initial insults. Projects should be developed to study the hypothesis that some disease processes among individuals born preterm continue after the new born period. In addition, research evaluating diagnostic and therapeutic approaches is required.
- **Determinants of mental health among preterm infants and development of neuroprotective strategies**
  Emotional problems and attention deficit problems are very frequent amongst children born preterm. Yet, both issues are highly relevant for academic achievement and later integration into work; autism is more common among children born preterm. Previous studies have found associations between antenatal infection and mental disorders, such as autism and schizophrenia. Experimental and clinical studies should be designed to explore the spectrum of determinants of mental health among individuals born preterm including, but also above and beyond, antenatal infection. Experimental mechanistic and clinical/epidemiological research focusing on biomarkers should be given special attention. The study of brain function and neuronal networks is additionally important in understanding how prematurity or early insult affects the brain and its function.
- **Disease mechanisms of retinopathy and post-chiasmal vision deficits**
  Both retinopathy of prematurity (ROP) and post-chiasmal central nervous system abnormalities play an important role in long-term visual health of preterm children. Research is needed to determine the respective roles for ROP and central processing abnormalities in visual abnormalities among preterm individuals.
- Impact of environmental factors on pre- and postnatal child development
  - *Nutrition:* Postnatal nutrition plays a key role in the survival and neurodevelopmental outcome of very preterm infants. Early enteral nutrition is, therefore, especially important. One of the key areas of research is, for example, the optimal protein intake of very preterm infants: as there are indications that brain growth and later life cognitive function are directly related to protein intake during the neonatal period in preterm infants, further clinical studies to clarify the remaining open questions are needed.
  - Another promising insight that merits further study is the positive effect of probiotics on the prevention of Necrotising Enterocolitis (NEC). The optimal timing, doses, and duration of treatment with probiotics, as well as the best probiotics for use in preterm infants, remain to be defined. Dietary optimisation constitutes an effective and low-cost opportunity to improve the mental development of small preterm infants. Thus, research 'pays' for both the small patient and society at large.
  - *Allergies:* Over the past several decades, the incidence of atopic diseases, such as asthma, atopic dermatitis, and food allergies, has increased dramatically. It is recognised that early childhood events, including diet, are likely to be important in the development of both childhood and adult diseases. Although atopic diseases have a clear genetic basis, environmental factors, including early infant nutrition, may have an important influence on their development and, thus, present an opportunity to prevent or delay the onset of the disease. At present, inadequate study design and/or a paucity of data limit the ability to draw firm conclusions about certain aspects of atopic disease prevention through dietary interventions. More studies (e.g. pregnancy and lactation-avoidance diets, timing of introduction of specific complementary foods) would be needed to clarify whether there is a positive or negative effect on atopic disease outcomes.
  - *Vaccination:* Preterm infants are at greater risk of increased morbidity from vaccine-preventable diseases. Advances in the care of preterm infants have substantially increased survival rates, thereby adding challenges in the selection and optimisation of appropriate immunisation regimens for infants with immature or impaired cellular and humoural immune systems. More information on the immunogenicity, durability, and safety of routinely-recommended childhood vaccines is required for preterm infants.
  - *Drugs:* Most drugs used in the preterm or even full-term newborn infants are not properly investigated with respect to their efficacy and safety. Since the physiology of the developmental organism in the preterm and full-term born infant is not comparable to the physiology in adults, there is an urgent need to evaluate drug efficacy and safety in this most vulnerable group of patients.
  - *Environmental factors interfering with normal organ (lung/brain development):* It is considered that environmental factors, such as oxygen supply, mode of care and pain, interfere with normal organ development. Future research is necessary to understand the impact of environmental conditions on development in order to optimise therapy and prevention, particularly for the lung and brain.
- Quality of life research (adults born preterm)
  Most quality of life research focuses on children with certain diseases, such as cerebral palsy. These projects should be designed to elucidate the quality of adult life of individuals born preterm; studies should not only compare individuals born preterm with individuals born full-term. Previous research of preterm children has focused on parent reports of their children's quality of life, whereas recent reports in small samples indicate that preterm children themselves consider their quality of life higher than reported by their parents. Follow-up into adulthood is necessary to determine the quality of life, as reported by the prematurely born young adults themselves, compared with reports by parents or significant others.
- Research on family-centred care and psychological parental support
  The preterm infant, or newborn infant with illnesses, is in the centre of their family. Current data imply that parental education and competence has a significant impact on the outcome of patients. Increasing parental competence by family-centred care and psychological support, starting at the prenatal stage, is hypothesised to increase parental bonding, reduce the time of primary hospitalisation, reduce the rate of child abuse and divorce, and increase the rate of acceptance of secondary prevention programmes (e.g. vaccination). Clinical studies should be developed to test this hypothesis.

C

Aftercare services and follow-up

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Aftercare services and follow-up

Appendix C

1. Introduction

1. Introduction

Approximately 5 million children are born every year in the EU's 27 Member States; about 10% are born preterm or experience complications that require intensive care in the neonatal period. It is important to note that parenting shapes the life course, and parental mental health and a family's functioning, including sibling relationships, are crucial to enable optimal development after discharge. Preterm birth and neonatal illness may disturb the natural development of parenting and impose anxiety concerning later development on parents, which will disturb the natural development of family relationships. These anxieties are most acute around the time of transition from the neonatal unit to home.

Survivors, who required intensive care in the neonatal period, have an increased risk of adverse long-term outcomes, including increased rates of pulmonary diseases and neuroimpairment, and a range of other problems, such as with growth and development. Aftercare services of these critically ill newborns and preterm infants is challenged by the identification and predication of patients suffering from neurodevelopmental adverse outcome and chronic diseases at an early stage. Not all children who will develop health or educational problems are identifiable in the newborn period. While some morbidities are identifiable in infancy, such as respiratory or feeding problems, others (such as psychiatric or learning difficulties) will only be known at school age; the total impact of at risk birth on the children and their parents are often only known in adulthood. Thus, parents live through considerable uncertainty regarding the health and educational outcome of their children.

Experts and parents were asked to summarise, in detail, the aspects that should be addressed in the context of neonatal outcomes that challenge the quality of life of the child and the family.

EFCNI, editors and authors are aware that it was not possible to cover all important factors in detail in the White Paper. All aspects of the complexity of aftercare services and follow-up would need to be addressed separately. The following recommendations should not be seen as clinical guidelines.

However, we strongly recommend that national audits and taskforces develop national aftercare programmes that take the recommendations into strong consideration and adopt/modify them according to the national needs, conditions and economic situation.

Major challenges in the area of aftercare services and follow-up include:

- Planning for discharge needs to take place early in the neonatal course to promote parental-infant interaction ('bonding') and breastfeeding, to optimise both neonatal course and outcome, and to promote parental confidence and independence. Most babies require community care systems with health professionals aware of the risk for later neuro-cognitive outcomes associated even with a relatively uncomplicated neonatal unit admission

- Formal multidisciplinary follow-up is needed for children at highest risk of impairments that develop as a consequence of their perinatal course or preterm birth, or are identifiable in the neonatal period. Most follow-up guidance is based on infant-based criteria, such as very preterm birth (<32 weeks of gestation, 10-25% risk of serious impairment, higher risk of educational special needs), neonatal encephalopathy (such as that following birth asphyxia: 30-40% with serious impairment and special needs), and identified congenital conditions (infection, abnormality)
- Population attributable risk – although follow-up concentrates on those identified above, being an efficient use of resources given the prevalence of impairment, seven to ten times more children are born moderately preterm or near term or with perinatal complications (5-10% of all children). Overall, this group has a larger impact on population health than the 1% of high-risk children (see panel right). Furthermore, intervention studies suggest that those born at moderate-to-near term are most likely to benefit from early intervention
- Follow-up is necessary to:
  - Identify evolving impairments in the developing child
  - Support parental care and decision-making concerning introduction of mixed feeds, immunisation, transitions to education, and to provide reassurance concerning developmental trajectories
  - Provide outcome information to facilitate benchmarking of neonatal services, which should be collated on a population rather than a hospital basis to avoid biases in reporting.
- The developmental domains of interest are physical health, early behavioural regulation (such as feeding or sleeping), neuro-motor development, cardiovascular and respiratory development, cognition and learning, mental health, and social relationships of the child. Social integration, participation, quality and satisfaction of life should be the ultimate goals, independent of disability
- Follow-up in infancy is aimed at health surveillance, usually within the first two years after birth, and detection of major impairments, including developmental delay, cerebral palsy, and sensorineural problems (blindness and deafness); these provide the major outcomes for which early medical intervention is important and comprise the major benchmarking outcomes. Although often provided by the neonatal service, it is critical that there are clear care pathways for children who need support from neurodisability services and other paediatric input (for example respiratory medicine)
- Later health and psychological surveillance is important as the bulk of impairments – of behaviour, cognition, learning and neurosensory function – are not reliably detectable until school age, but seriously impair life chances. However, neonatal follow-up services are rarely equipped, or have the expertise and resources, to provide surveillance in these multiple and often subtle areas. Two potential approaches require evaluation: the development of inexpensive and accurate screening tools to alert health and educational services; a system of continuing professional development to raise awareness of the importance of preterm birth and perinatal risk in the ontogeny of these impairments, so that early intervention strategies can be developed to minimise the disability
- The impact on society: preterm birth confers significant incremental economic costs in the neonatal period and comprise the majority of childhood costs, rising with decreasing gestation as intensive care activity becomes more necessary (see panel right). Although incremental educational, health and family costs are modest in childhood, they are not negligible, and fall more frequently on disadvantaged families, who more frequently have children with impairments. Children with the most severe disabilities also attract high economic, social and family costs. Minimising this impact is the key goal of aftercare.

Aftercare services and follow-up

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1. Introduction

These challenges should be tackled by the following recommendations, summarised in this appendix

- Each Member State should ensure their neonatal services have coordinated aftercare programmes to provide support for families of children born preterm or at neonatal risk, and to identify babies with evolving impairments; there should be established referral systems to multi-disciplinary expert care for those so identified.
- Each Member State should ensure there is central monitoring of outcomes (mortality, neurodevelopmental and cognitive disability and cerebral palsy rates as defined by consensus) for each neonatal service or group of services; where possible, such reports should be population-based to facilitate monitoring and conducted by assessors not involved in neonatal care.
- Every hospital should have an individual discharge planning policy for each very preterm or at-risk baby and their family, this should include:
  - Support to establish and continue breast feeding
  - Health advice and entry into the national immunisation programme
  - RSV prophylaxis, if indicated
  - Planned support for the family after discharge in the community
  - A linked up service between hospital and community
  - Arrangement for standard follow-up.
- Aftercare services should include the following minimum components:
  - Standardised follow-up, to at least 2 years of age, by assessors not involved in neonatal care for all high risk groups
  - Follow-up of moderately preterm children using screening measures and referral if scoring in the disability range
  - Access for families to advice and support during this period
  - Planned transfer to appropriate multi-disciplinary services for on-going surveillance through to school age
  - Screening for growth, health problems, and cognitive, developmental, neurological, and sensory impairments, and behaviour problems, by appropriately trained assessors
  - Implementation of continuous training and education on the consequences of preterm birth for children and their families should be provided for all healthcare professionals involved with aftercare for preterm children and their families, such as paediatricians, obstetricians, psychologists, therapists, day-care staff, and teachers.
- To ensure evidence-based best interventions, research funds should be available for follow-up research on developmental mechanisms and intervention trials with international networks. Future initiatives to prevent preterm birth and improve the support for, and outcome of, preterm babies and their families should be supported in each Member State – examples include:
  a. Development of materials for parents to be included in existing national baby health records (e.g. the 'yellow book' in Germany or 'red book' in UK) to develop consistency in terms of interventions, such as immunisations, follow-up visits, advice about schooling and specific weaning advice
  b. Improvements in the financial and social support for families with preterm infants and infants with risks
  c. Education in school about fertility and the risks of delaying childbirth, and associated reproductive treatment for preterm birth and associated problems.

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2. Management of Care after discharge

Background

Parenting an infant born preterm is stressful and a different experience from parenting infants born at full-term. However, in both situations, the quality of parental interactions is predictive of later infant development, highlighting the importance of supporting the families of preterm infants. Successful interventions with families of physically fragile infants have focused on fostering the mother–infant relationship through the provision of support (including peer support), information about infant developmental needs, and through increased mother–infant contact. Programmes, such as the Mother-Infant-Interaction Programme (MITP), have the aim of promoting parenting by focusing on helping parents to recognise infant cues and achieve conditions for optimal social interaction. They have been shown to reduce parenting stress in both fathers and mothers.

Challenges

Having a baby born too soon is a significant trauma and mothers of preterm infants are at increased risk of depression and anxiety. Several studies have found that mothers of preterm infants score particularly highly in terms of parenting stress, which can lead to dysfunctional interactions between the parent and child. Another barrier to effective interactions is low parental confidence. Preterm infants are often perceived as too fragile for play or too sleepy to be responsive partners. Play and social development are areas often neglected by health professionals when preparing parents for the transition from neonatal care to home. Advice typically focuses on medical care, resuscitation skills and feeding, serving to reinforce perceptions that the infant is vulnerable and increases the likelihood that infants will experience a limited and protected environment following discharge.

The stereotyping of preterm infants as vulnerable has been shown to be pervasive and has a negative impact on the quality of parental interactions. Parents often perceive that health professionals in the community lack specific expertise and experience in the care of preterm infants, which further undermines parental confidence. Lack of experience can also lead health professionals to reinforce stereotypes, for example by commenting on the infant's size. The involvement of fathers has been shown to be important, but little research has yet explored the impact of prematurity on father-infant interactions. Fathers more often engage in physical play and their contribution to the development of infants' physical skills may be particularly important since many very preterm infants have at least mild motor delay, which can be compounded by limitations in physical experience such as the opportunity for play in the prone position. Prematurity is a common complication of a multiple birth and caring for multiples presents additional challenges, with increased risk of parental depression.

Recommendations

- Care in the neonatal unit needs to consider parents' emotional needs and should aim to reduce distress through the provision of information, support for effective coping and facilitation of infant contact.
- Transition planning for infant discharge from neonatal care is crucial and should seek to build and support parental confidence.
- An important goal of transition care should be to reduce the negative effects of stereotyping by emphasising infant potential and the importance of early experience for preterm infants.
- Training for community health professionals should equip them to deal with the informational and support needs of parents of preterm infants, to recognise clinical levels of anxiety and depression, and to identify families at particular risk.
- Web–based resources for parents of preterm infants have important advantages, in that they can provide information in an engaging, interactive and accessible format using a variety of media, including film.
- There is a need for evidence-based, sustainable interventions delivered in the home for families of preterm infants that also meet the needs of neglected groups, such as fathers, grandparents and families with multiple births.

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3. Sudden Infant Death Syndrome (SIDS)

Background

Sudden Infant Death Syndrome (SIDS) is defined as the sudden death of an infant under the age of one year that is unexpected and unexplained after a thorough post-mortem examination, including a complete autopsy, investigation of the scene of death and review of the medical history. This tragic event is one of the leading causes of infant mortality between the first month and the first year of life. Over recent years, the mortality rate for SIDS has dropped more than 50% thanks to public campaigns aimed at reducing risk factors. Even though preterm and full-term infants share the same risk factors, SIDS occurs approximately three to six times more frequently in the former; therefore, it is important to target the specific risks for these infants.

Challenges

Preterm infants are usually placed prone (lying on their stomachs) during hospitalisation because this position improves the chest wall stability, allowing for increased oxygenation and a lower incidence of apnoeas. At the same time, the prone sleeping position is also the major risk factor for SIDS; however, the peak of incidence for SIDS is between the second and fourth month of life in full-term infants and four to six weeks later in preterm infants. Therefore, preterm infants may be placed prone during their hospitalisation because they are not within the age bracket at risk of SIDS and, moreover, they are generally monitored.

Instead, a targeted intervention by neonatal practitioners is required before discharge from hospital in order to educate the parents to place their infant in the correct (supine) sleeping position at home. Data from recent studies show that this crucial information may be lacking in the NICUs; therefore, preterm infants may be exposed to an increased risk of SIDS after being discharged.

As preterm infants may spend some weeks in the NICU, this provides many opportunities to provide evidence-based advice to prevent SIDS. Modelling of the appropriate infant care practices in the hospital is crucial to ensuring these practices are continued when the baby is discharged home. Documented home monitoring is recommended after being discharged from hospital if there is any risk of persistent bradycardia, apnoea or desaturation, which are potentially life-threatening or harmful for the integrity of Central Nervous System. This electronic surveillance may be discontinued if the monitor does not detect any cardiorespiratory events beyond the 43rd week of post-gestational age, when the risk of life-threatening episodes in preterm infants becomes equal to that of the general population.

Recommendations

- Infants born prematurely should be placed in a supine position during sleep as soon as the medical condition allows. The infant should sleep supine for a minimum of 1-2 weeks before being discharged from hospital, in order to educate the parents to adopt the correct sleeping position at home.
- The safest place for a baby to sleep is in the same room with a parent or caregiver, but on a separate sleeping surface.
- Infants must be placed to sleep in a crib or bassinet with a firm mattress that fits the base of the cot without gaps.
- Sleeping surfaces, such as cushions, sofas, chairs, or waterbeds are unsafe.
- Pillows, quilts, comforters, sheepskins, stuffed toys, bumper pads, plastic sheets, plastic bags, strings, cords and ropes must be kept out of the baby's sleeping environment.
- Parents and caregivers must maintain the home free of cigarette smoke; this includes the baby's sleeping area and any car used to transport the baby.
- Mothers should breastfeed their infants exclusively for the first 4-6 months. Breastfeeding (with the addition of solids) for longer, if mutually desired by mother and child.
- Using a pacifier (sometimes referred to as dummy or comforter) while sleeping also reduces the risk of SIDS. Because there may be some disadvantages in the use of pacifiers, some professionals recommend that they should not be discouraged but not specifically recommended.
- Whenever cardiorespiratory instability occurs, documented home monitoring is recommended. This electronic surveillance should be performed with monitors allowing for simultaneous recording of heart rate, respiration via thoracic impedance measurement and pulse oximetry.

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4. Case Management and early support for preterm infants and their families

Background

Preterm infants face many risks during their development. Mental developmental problems and schooling problems can occur, including behavioural disorders or psychological difficulties. Reduced self-regulatory abilities of the child and the following problems in child-parent interactions can contribute to these risks.

Challenges

To reduce these risks, it is necessary to provide early support to parents regarding their parenting and caretaking skills, to assist in adaptive child-parent interaction and promote secure attachment. A range of early intervention programmes have been tested, with early interventions that start in the special care unit and continue after discharge home showing the best results in reducing risk and providing protection for the premature child and its family.

Recommendations

- Establishing and implementing case management
  A practical, effective and efficient method to provide support from the neonatal unit into the home is called Case Management. This method is carried out in a step-by-step fashion. First, during the Intake, a case management nurse contacts the family at least one week before discharge and rates if the family needs their support. If they do, the second step involves assessment of the infant's and family's conditions and of support networks at home. The third step involves planning the kind of support needed by the family and child.
- Case management should be initiated during the hospital stay.
- Major efforts should be undertaken to empower the parents to take their baby home as soon as possible, to be secure in the care, and to be able to integrate the new family member into their life at home.
- Interventions should also contain information about possible care suppliers, the establishment of a network of suppliers near home, the support of coping abilities, the motivation to cope with caring responsibilities, information about the condition of the child, and the reduction of anxieties.
- According to the family's needs, a psychologist or social worker should be consulted.
- Home visits are strongly recommended, because individual problems and challenges can be identified and confronted directly.

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5. Parents: education and information

Background

Parents whose babies are admitted to a NICU are likely to face a very challenging situation; in contrast to what they were expecting. Their early experience of parenthood is often characterised by stress and uncertainty. Studies have shown that one of the chief causes of stress is the alteration in the parenting role (with limited participation in making decisions and caring for their baby).

Research shows that interventions to improve the provision of information for parents and to increase involvement in their babies' care can increase parents' confidence, and have a positive impact on their parenting behaviour and the wellbeing of the family. Such interventions include the provision of clear information about their baby's condition, and education about the baby's developmental needs and behavioural cues.

There is promising evidence that meeting parents' information needs, and encouraging their involvement in their baby's care, is both of benefit to babies and welcomed by parents; promoting positive parent-child interaction and wellbeing. It can reduce the length of stay of preterm babies in the neonatal unit, the need for re-hospitalisation, and long-term morbidity.

Challenges

If units are under-staffed, staff will focus on the clinical needs of the baby and not the needs of the family. There can be the perception that time spent on supporting the parents' needs is a 'luxury'; whereas, in the long-term, it is likely to free up staff time.

Indeed, there is general lack of knowledge and understanding about parents' information and support needs, as family-centred care (FCC) is not necessarily part of health professionals training. This problem is not helped by the lack of knowledge and understanding about and resources for implementing existing parent education programmes.

Specialist staff with the knowledge and skills to directly support parents are needed to help embed the FCC approach into the culture of the unit. Additionally, more resources are needed to produce information for parents, in the range of languages and formats, in order to support families from a range of cultural and socio-economic backgrounds. And lastly, there is a real need to ensure that support is targeted not only at the mother, but equally at fathers and siblings.

Recommendations

- Parents should have access to relevant information, as and when they need it, available in different formats (verbal, written, web-based).
- Parents should be introduced to the health professionals caring for their baby on the unit, and an introductory leaflet about the unit itself should be provided (including the technology used for stabilising and monitoring their baby, and the facilities provided for parents).
- Consistent information and active support to parents is needed about how they can care for their baby from the point of admission (including inputs on expressing breast milk, positive touch & skin-to-skin, involvement in daily cares).
- Formal and informal education sessions for parents should be facilitated (e.g. on developmental needs, behavioural cues, infant massage).

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Aftercare services and follow-up

Appendix C

6. Parental stress
7. Feeding difficulties

6. Parental stress

Background

The preterm birth of an infant, and the intensive care in a NICU which follows, causes psychological distress and can have a traumatising effect on parents. The situation of preterm birth may lead to recollections of their own attachment biography, and former psychological problems, such as anxiety and depression. A large proportion of mothers have symptoms of trauma long after hospital discharge, and describe painful memories of the postnatal period. Maternal anxiety is greater when infants are smaller, in terms of birth weight, and younger in gestational age. Parental education, marital status and quality, country of origin, and social support are associated with anxiety. For both mothers and fathers, anxiety and infant medical risk are related to parental behaviour. Among mother–preterm infant dyads, two specific patterns of interaction are identified that could play either a protective (cooperative pattern) or a risk precipitating (controlling pattern) role on developmental and behavioural outcome. The inappropriately controlling pattern is often a result of anxiety, depression, and traumatisation in the process to becoming parents; it is much more prevalent among preterm than term dyads, and related to a less favourable infant outcome. Early individualised family-based interventions during neonatal hospitalisation and transition to home have been shown to reduce maternal stress and depression, increase maternal self-esteem, and improve positive early parent–preterm infant interactions.

Challenges

Currently, parental confidence needs to be boosted. This could be helped through additional support to parents during hospital stay as well as after discharge. This support needs to consider emotional or social needs, as well as other needs. Additionally, efforts need to be made to support a healthy parent–infant relationship, not only in the NICU, but also in the first months of the infant's life. Interventions programmes should be developed with these aims in mind. And indeed, aftercare pathways should be designed to support parents during the first time as a family outside the NICU.

Recommendations

- Programmes are needed to support parents developing a sense of coherence (be competent, able to cope, give preterm parenting a sense as early as possible) during NICU stay.
- Psychological programmes should support parents with serious psychological problems, such as trauma, anxiety, and depression.
- Peer-to-peer-support, such as the buddy concept, as a programme for mothers of very preterm infants in NICU and in aftercare is needed.
- An interdisciplinary team of specialists, in addition to NICU medical or nursing staff, which supports the staff and parents should be in place.
- The presence of an interdisciplinary team of specialists and structured parental support should be implemented as quality indicator of best neonatal and aftercare practices in neonatal units.

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7. Feeding difficulties

Background

Feeding difficulties and a feeding disorder for preterm infants can compromise catch-up growth; thus, feeding and nutrition is central for catch-up growth, cognitive and motor development. The risk for feeding disorder is high, with a rate of 40% with feeding difficulties or feeding disorder in the first year of life. Factors that place preterm infants at risk for feeding disorder include oral motor coordination problems resulting from prematurity and inexperience; medical conditions, such as Chronic Lung Disease, Heart conditions or Gastroesopheagal Reflux Disease; and psychological issues, such as traumatisation, limited self-regulation capacity or problematic infant-parent relationship. Feeding disorder does not only result in disturbed eating routines, but can also necessitate long-term artificial feeding via tube.

If a feeding disorder is present, the likelihood that it remains throughout childhood is high. Eating and feeding are likely to become a struggle for parents and their child during the future years. Untreated feeding disorders are a high risk factor for the emotional development of the child, a burden for the parents, and are costly for the health system. It is a risk factor for emotional and cognitive development, caused by the high-risk for permanent malnourishment and an unhealthy relationship to food and eating. Feeding disorders are a burden because of the struggle to eat at each mealtime, with long lasting effects on parental wellbeing. In addition, there is a high associated cost factor for the health system due to the high percentage of children fed via feeding tube.

7. Feeding difficulties

The first symptoms of feeding difficulties are often described in the NICU stay; but may also develop in the first year of life where no symptoms are visible during NICU treatment. Therefore, prevention of feeding disorders from NICU until school age is a challenge that must be addressed, and requires continuous support to prevent the development of long-term disadvantages.

Challenges

There is a need for establishing continuous oral stimulation treatment from birth to NICU discharge in order to help support early oral feeding via parents and breast feeding during NICU treatment. Mothers should receive continuous support in the feeding situations in case of feeding difficulties and, when necessary, an adaptive feeding regime at discharge of premature infants should exist as a part of discharge management.

Indeed, it is important that feeding becomes a central part of aftercare management. Such a regime would be helped by establishing interdisciplinary early intervention teams to prevent maladaptive feeding development (waiting time shorter than 1 month). Also, immediate crisis intervention should be available in the case of food refusal.

Some risks may by avoided by training early intervention teams in medical, functional and psychological conditions that would increase the risk for feeding disorder which in the long-run will help prevent long-term feeding tube dependency in premature infants.

Recommendations

- Oral feeding by the parents should be introduced as early as possible in the NICU, supported by a nurse or speech or language pathologist.
- Breast-feeding should be introduced as early as possible.
- Feeding difficulties in the first months are a high-risk factor for feeding disorder and tube dependency. It is necessary to establish feeding-focused early intervention services to monitor the feeding development and prevent maladaptive feeding patterns.
- Early intervention services must be interdisciplinary to address all possible risk constellations, which result in feeding disorder and tube dependency.
- A home-based intervention service is preferred to parental and infant stress from intensive treatment and increased nosocomial infection risk for high-risk infants.
- Early intensive treatment for children with feeding disorders is needed to prevent tube dependency.
- In children with feeding tube dependency, a tube weaning treatment should be conducted as soon as the medical disorder resulting in tube feeding is resolved.
- Interdisciplinary treatment and training groups should be established to support parents and medical teams to prevent feeding disorder and feeding tube dependency.

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Aftercare services and follow-up

Appendix C

8. Behavioural and emotional problems
9. Cognitive problems

8. Behavioural and emotional problems

Background

Children born very preterm are at significantly higher risk for behavioural and emotional problems compared with children born at full-term. The major problems are difficulties such as attention, anxiety and social problems; e.g. building relationships with their peers. Extremely and very preterm children have a 3- to 4-fold increased risk of psychiatric disorders, compared with children born full-term. The most frequent diagnoses are Attention Deficit Hyperactivity Disorders (particularly of the inattentive subtype), emotional disorders (particularly anxiety disorders), and Autism Spectrum Disorders.

Challenges

Psychiatric disorders have an adverse impact upon a child's integration and performance at school. The preterm behavioural profile indicates that these children tend to be inattentive, shy and withdrawn, and are less likely to be disruptive in the classroom. On the other hand, they are more likely to have learning problems and need for special help. As such, they may fail to come to the teacher's attention as requiring support, and special educational needs may go undetected. Learning difficulties may then become exacerbated throughout schooling.

The increased prevalence of psychiatric disorders is known. However, there are also a significant proportion of preterm children that have behavioural and emotional symptoms that fall below the diagnostic threshold. These children have subtle difficulties that go undetected, yet have an adverse impact on everyday functioning.

Recent research has shown that babies born late and moderate preterm (32-36 weeks) are at increased risk for behavioural sequelae. Although the prevalence of problems is lower than very preterm survivors, the population-attributable risk for this large group is likely to present a greater public health burden.

Whilst early intervention is beneficial, identification of children at greatest risk remains challenging. There is a paucity of infant behavioural measures, and children are rarely followed-up after 2 years; when screening has improved diagnostic accuracy. Early signs of behavioural problems may be missed during the preschool years.

Recommendations

- Routine behavioural screening, and appropriate psychiatric referral following preterm or after at risk birth, should be incorporated in routine neonatal follow-up. Ideally, this should extend beyond the current 2-year model to include screening throughout the preschool period.
- Routine behavioural screening should be carried out at school entry for very preterm children to identify difficulties and aid educational planning and management.
- The predictive validity of infant behavioural screening tools for predicting life course outcome should be investigated further in preterm and at risk populations.

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9. Cognitive problems

Background

All preterm children are at increased risk for developmental problems, in most domains of development. There is a gradient effect with children born earlier showing, on average, a greater risk for cognitive problems. Most severe effects on overall cognitive problems are found in children born extremely preterm (<26 weeks' gestation) with intelligence quotients (IQ) some 20 points lower than full-term controls; learning problems are up to 50 times more likely, with up to 62% requiring special educational support in school. Overall deficits in IQ of around 10 points between VP/VLBW children and full-term children are documented. These findings are very similar across different countries and severe cognitive disabilities can be identified in the first 2 years of life.

9. Cognitive Problems

There is a relationship between decreasing gestational age (GA) and increasing risk of academic underachievement, with moderate prematurity (32-36 weeks' GA) resulting in mild cognitive deficits, learning problems, and special educational needs; whereas, in children born very (<32 weeks' GA) or extremely preterm (<26 weeks' GA), every lost week of gestation has a highly increased adverse impact (Table 1) With every week of gestation lost resulting in a decrease of IQ-score of 0.3 to 0.5 points. Moderately preterm children require two to three times more special education.

Apart from difficulties in general cognitive functions, preterm children have more problems in executive functions that include planning, attention and working memory. They also have difficulties in language, reading comprehension, and spelling, and particular deficits in numerical reasoning skills and mathematics/arithmetic have been found. It appears that, with increasing prematurity, the brain is less able to integrate different pieces of information simultaneously, indicating resource limitations in processing and communication between brain areas.

Table 1: **Percentages of achievement problems according to gestational age at birth** (data of various studies)

	>36 weeks GA	32–36 weeks GA	<32 weeks GA	<26 weeks GA
Special schools (%)	2 – 3	3 - 8	18	13 - 31
Special educational needs (%)	7 – 14	8 - 25	20 - 45	45 - 62
Mathematics deficiencies (%)	2 – 12	2 – 31		26 - 69
Reading/language deficiencies (%)	5 – 9	6 - 34	24 - 34	22 - 64
Attention problems (%)	1 – 13		16 - 21	12
General cognitive impairment (%)	2 -14	19	22 - 26	29 - 66
Below average attainment (%)	5 – 8	12	48	50 - 78
Grade retention	8	19	30	19 - 43

Challenges

With the increasing survival of preterm children, a larger number of children with significant cognitive problems are discharged into the community. Cognitive problems (in particular, deficits in executive functions, the ability to manipulate numbers and visual spatial integration) are predictive of school success and, thus, life chances. Inability to master these tasks is frustrating for these children. A major challenge is to provide appropriate interventions and support for these children, and to recognise that this is not due to laziness but to underlying problems in processing complex information.

Parents of preterm children expect developmental catch-up before school entry. However, cognitive difficulties are relatively stable from 2 years onwards and differences between preterm and full-term children either remain or increase with age.

Problems often become more apparent during primary school because of the larger demands on differential abilities. For example, attention is important for learning in the classroom, but preterm children often suffer from attention problems and slow processing speed. Furthermore, a recent meta-analysis concluded that parenting interventions did not benefit preterm children into school age. Most interventions are modelled on programmes originally designed for socially disadvantaged children who have the capacity to catch up if they are provided with high-quality learning opportunities. However, very or extremely preterm born children may lack developmental plasticity to take advantage of learning opportunities, and their deficits may thus persist throughout schooling.

Recommendations

- Mandatory follow-up for all preterm and those born at risk are required in the first 2 years to identify severe cognitive disabilities.
- Regular developmental follow-up during the preschool years can help identify preterm children who may profit from special support to develop their full academic potential.
- Teachers and special need coordinators require adequate training in understanding the special constellation of cognitive problems of preterm children to provide appropriate intervention.
- More research is required about the underlying mechanisms of preterm children's neuropsychological development and to develop interventions delivered via the parents, teachers or directly to the children (e.g. computer programs) to enhance their working memory and simultaneous information processing.

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10. Long-term quality of life in preterm infants

Background

A substantial proportion of preterm infants are disadvantaged in physical and psychosocial areas of development during childhood and adolescence. Cultural differences in development and health utility have also been reported. Despite of the effects of preterm birth on physical health, most preterm born teenagers report a good health-related quality of life. One of the largest national cohort studies of adolescents who were born preterm, the Dutch POPS cohort study, has found that these adolescents show less risk-taking behaviour but had more difficulties in establishing social contacts and starting up a career at 19 years of age. Follow-up into adulthood will show whether the outcomes found until 19 years of age have an effect on societal participation, the development of adult onset diseases, and having children and a family of their own at later stages of life.

Challenges

Many cohorts of preterm children have been followed up throughout the world. However, to date there has been a lack of sharing and pooling of data, which is essential in understanding the consequences of preterm birth.

Additionally, prevention of preterm birth has proved to be a difficult issue, since we know little of determinants that may be targeted, except for infection prevention, smoking and alcohol drinking cessation or advanced maternal age. In particular, western European societal developments have led to a growing number of women postponing conception to their late thirties; thus, leading to increased demand for fertility treatment and (hence) preterm birth. Governmental programmes to counteract this trend are lacking.

Also, little is known about societal participation of preterm children and also about long-term medical and societal cost. Such information is vital as input for developing interventions and guidelines for children with a high risk of adverse physical or social outcomes. Physicians, teachers and parents often do not communicate effectively about what is best to be done in various stages of the development of preterm children and this situation needs to change.

Recommendations

- A worldwide network of long-term follow-up research into preterm children is needed.
- Promising medical and social interventions aimed at reducing preterm birth rates should be identified.
- Women should be encouraged to have their babies in their twenties. Career opportunities should be created to facilitate this.
- Long-term follow-up research into societal participation of adolescents born preterm should take place. The results can be used to develop interventions for teenagers born preterm to support them in their course of life towards adulthood; for example, by assigning job or life coaches.
- Research into cost-effectiveness of long-term medical and social treatment of preterm children should be encouraged.
- Guidelines for treatment and counselling by neonatologists, paediatricians, general physicians, well baby clinics and teachers should be developed.

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11. Chronic airway diseases in preterm infants: preventing bronchiolitis

Background

Prematurity is associated with long-term sequelae, including eye disease, abnormal psychomotoric development, epilepsy and chronic lung disease. In particular, chronic lung disease has a high incidence among preterm infants. Among very preterm infants (gestational age <32 weeks), the incidence of chronic lung disease may be as high as 80%. In late preterm infants with gestational age >32 weeks (85-90% of all preterm infants), the incidence of chronic respiratory symptoms is >25%, although the precise incidence has not exactly been established. Lung function of late preterms is poor with no signs of catch up during early childhood. Viral lower respiratory tract infection (bronchiolitis) is the most important modifier of infant lung function in preterm infants. Among respiratory viruses, respiratory syncytial viral (RSV) is the virus of greatest consequence, with high morbidity during the acute infection, but also long-term negative implications up to school age and beyond.

RSV bronchiolitis is the most frequent cause of hospitalisation in the first year of life among prematurely born children. Hospitalisation for RSV bronchiolitis occurs in 10-28% of children with very low birth weight and bronchopulmonary dysplasia, and in 5-10% of late preterm children with gestational age >32 weeks. RSV bronchiolitis is a serious disease, often necessitating life-saving mechanical ventilation. In addition, it strongly adds to the risk and burden of chronic lung disease in preterm infants. Moreover, it is independently associated with reduced health-related quality of life over a large number of domains.

The most effective strategy to prevent chronic lung disease or prevent progression of disease, and improve health-related quality of life in preterm infants, is to prevent viral bronchiolitis. Although the risk of bronchiolitis is associated with viral exposure by siblings attending day care, no evidence exists that reducing exposure is an effective measure to prevent bronchiolitis. In addition, there is no vaccine for bronchiolitis. RSV infection may be prevented by administration of RSV-specific monoclonal antibodies. This form of prophylaxis is now generally used in infants with severe prematurity, but not in late preterms, despite well-established efficacy.

Challenges

To achieve highest impact, efforts should be targeted at the large population of late preterm infants. Although RSV prophylaxis has shown to be effective in preventing RSV infection in late preterm infants, it is not generally used in most European countries due to high costs. However, cost-effectiveness of providing immunoprophylaxis to a subgroup of late preterm infants at highest risk for RSV bronchiolitis, based on individualised risk prediction, may be acceptable. Prediction models have been developed to identify late preterms with the highest risk of bronchiolitis.

There is no active RSV vaccine. A formaline-inactived RSV vaccine trial in the 1960s was disastrous, because vaccinated children had augmented disease, including death, upon natural exposure to the virus. There is no treatment of RSV bronchiolitis. The burden of RSV bronchiolitis in late preterm children has major consequences for the parents, the healthcare system and society. To make prophylaxis more acceptable for this special population, prediction rules have been developed to target expensive prophylaxis to the children with the highest risk of RSV bronchiolitis among late preterm children. Using such prediction tools, total costs of RSV prophylaxis are reduced and cost-effectiveness is improved.

Recommendations

- In order to improve long-term respiratory outcome and health-related quality of life of all preterm infants, efforts should be aimed at preventing harmful viral lower respiratory infections during the first year of life, in particular RSV infection.
- RSV bronchiolitis may be prevented by non-medical and medical strategies:
  - Reducing cigarette smoke exposure
  - Reducing viral exposure by delayed day care visits in children without siblings
  - Parental education may prevent the occurrence of RSV bronchiolitis. The burden of disease may be prevented by increasing awareness of the disease in parents and caregivers of preterm infants; in particular, by educating them on measures to prevent infection.
- In the absence of a safe and effective vaccine, the only proven preventive measure is the use of antibody-

mediated RSV prophylaxis. Because of high costs of RSV prophylaxis, this intervention should be targeted at children at highest risk of infection.

- Individual prediction models, which may need to be adapted to individual countries, should be used for targeted (individualised) prevention and are feasible at acceptable cost-effectiveness.
- Monthly injection of virus-specific antibody can also prevent RSV bronchiolitis in all preterm children with 55-80% efficacy.

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12. Follow-up programme

Background

Survivors of preterm birth have higher rates of adverse long-term health outcomes than those born at full-term; the prevalence of ill-health rises with diminishing maturity at birth, but remains high even in those born closer to term, so-called 'moderate preterm' children (32-36 weeks' gestation), who outnumber those <32 weeks by 10-to-1.

The requirement for long-term follow-up depends on the perspective; if it is to provide clinical care for a child and family, then assessments may need to be more frequent, but less detailed; if it is to audit outcomes of perinatal care, or for other types of research, such as to determine outcomes from perinatal randomised controlled trials, assessments might be less frequent, but more detailed.

Challenges

If audit or research is the goal, the major challenge is to identify the research question(s) being addressed. This should follow the PICOT (Patients, Interventions, Comparisons, Outcomes, at what Time) structure, which will facilitate the number and type of subjects required, what outcomes need to be assessed, and at what ages they take place.

Ensuring adequate funding for longitudinal studies is always a challenge. Clinical care providers argue they do not have resources to provide long-term follow-up beyond their perinatal/neonatal hospitals; however, research funding agencies argue that long-term follow-up is an audit function and should be funded through clinical resources. All research funding is highly competitive, and many well designed and important studies, including longitudinal follow-up studies, cannot attract research funding.

Health administrators must appreciate the long-term consequences of acute perinatal care and provide adequate resources to support the health of preterm children beyond the primary hospitalisation. Indeed, it is vital to ensure that all patients requiring follow-up actually receive it. In a clinical setting, the child who does not attend an appointment may not necessarily be pursued vigorously to ensure they return in the near future. In a research setting, those who require multiple appointments or other strategies to obtain data, such as visits to schools or to home, have substantially higher rates of adverse outcomes, particularly higher rates of cognitive impairment. If follow-up is incomplete, the rates of adverse outcomes will be seriously under-estimated.

Often, not enough time or resources are provided to allow for analysing and reporting of results. Accumulation of data alone should not be considered an endpoint of any study.

Recommendations

- Research questions should be formulated according to the PICOT structure.
- Adequate funding should be obtained to complete the following:
  - Locate the families and ensure they attend; this often requires dedicated staff who support the family from the nursery and beyond, know how to find families, and how to encourage them to attend assessments
  - Ensure adequate resources to complete the assessments, including post-acquisition of data, such as from MR scans, or other high-technology assessments that require detailed analyses
  - Ensure adequate resources and time dedicated to analysing and reporting results of follow-up assessments. These results need to be highlighted to healthcare providers, who may change their clinical care as a consequence
  - Provide feedback to families and the subjects (where appropriate) as to the implications of the results of the assessments. Offer to facilitate further assessments and discussion of results with others, such as healthcare providers or educators, who may need to know the results.

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13. Education and information for parents, kindergarten staff, teachers, therapists

Background

Very preterm children are at a highly increased risk for a range of cognitive deficits (visual spatial, maths problems), attention problems and emotional and social problems. Often these difficulties occur together and, thus, very preterm but also moderately preterm children are at an increased risk of school achievement problems and require increased educational support, including special education. Special educational provisions and chronic psychiatric problems are very costly on an annual basis and far outstrip costs for physical health problems in preterm children. Thus, the needs of these children are often complex learning difficulties. Success in school and visual spatial processing and numeracy are highly predictive of career choices and life success.

Challenges

A major challenge for parents, children and teachers is to make informed decisions about the best possible educational pathway for preterm children or those at neonatal risk. The pattern or phenotype of problems is often different than those found in children with learning problems in the general population. For example, very preterm children show characteristic problems in attention but no increased hyperactivity or impulsivity, indicating a different origin of problems but also different approaches to pharmacological and educational intervention.

Parents and teachers are uncertain whether preterm children should enter school at the appointed time or have delayed entry to make up for their early birth and prematurity. Furthermore, there continue to be open questions about whether teachers should be told that a child was born preterm and has complications as a result. This may help to alert the teacher to potential problems and their origins, but may lead to low expectations and adversely affect the child's support (self-fulfilling prophecy).

Finally, most children born extremely preterm receive special educational support. However, it is uncertain whether this makes any difference to their school achievement and long-term life chances. Thus, there is a very high degree of uncertainty over how and when to provide particular educational support. The major reason for this uncertainty is a lack of research; thus, evidence-based educational approaches are needed.

Recommendations

- There is an urgent need for research on:
  d. Educational outcomes and pathways of preterm children

  e. Information on delayed school entry and educational outcome

  f. Parent and teacher views on schooling and information needs regarding schooling.

- Development of information material on preterm birth and educational support for teachers and parents is needed.
- Training courses on educational needs and profiles of preterm children for teachers, special needs teachers, educational psychologists and aftercare services are needed.
- There should be special facilities and educational interventions for visual-spatial problems, attention regulation, working memory and maths.
- Member States should investigate the development of computer aided or virtual/digital teaching tools to allow parents to supervise special tutoring.

Aftercare services and follow-up

Appendix C

14. Financial and social burden – support of families / Family impact
15. Research

14. Financial and social burden – support of families / Family impact

Background

Whether or not siblings are concerned, preterm birth – without exception – has a major impact on the family. It is a stressful period of many weeks in which mothers and fathers are in the hospital daily, travel extensively, and are not able to pay (enough) attention to other children (if present), work, family and friends. The emotionally stressful period and uncertainty of the child's future affect parents' health and the impact on their life and relationship is considerable. As a result, there is an increased risk of developing post-traumatic stress syndrome.

Preterm birth in a family also has financial consequences for the parents, as absence of work, long-term travelling and stay in the hospital may have consequences.

Challenges

The preterm birth of a child may negatively affect the mother's career. After maternal leave (either prolonged or not) she has the right to return in her function. On the mothers' request, a permanent or temporary reduction of the working hours should be allowed. Also, fathers must have the right to some form of paternal leave, without negatively affecting his career.

Possible absence or sickness of the mother or father is understood in view of the emotionally and physically intense and difficult period of their child's hospitalisation. There is a need for special regulations for parents' leave if the health situation of the child doesn't allow for day care following home coming; e.g. when the child suffers from chronic lung disease.

Recommendations

- A place in the hospital where siblings can be cared for during their parent's visit to the neonatology ward is needed.
- When care of siblings is organised at home, or elsewhere, the associated costs should be compensated.
- With great urgency, prolonged maternal leave must be introduced and implemented into national and European law.
- Special attention should be paid to self-employed parents, working independently or having their own business.

- Parents should be compensated for the extra costs involved. This may be costs associated with:
  - travelling during the stay of their child in hospital
  - meals in the hospital
  - care for older brothers and/or sisters (see above)
  - parking costs
  - whenever necessary, their stay in the vicinity of the hospital (e.g. Ronald McDonald house).
- When health insurance companies do not compensate for such costs (insurance cover may vary considerably among countries), tax reducing measures are proposed.

15. Research

Background

Research into the development and outcome of interventions in the neonatal or post discharge period (in children who were born preterm, underweight or had neonatal complications) is essential for a number of reasons. Neonatal statistics indicate increasing survival of children at ever lower gestation or birth weight. However, it is unclear whether, with increased survival, long-term morbidity (from health to learning problems) has reduced or increased. Recent information indicates that morbidity may have remained the same despite decreased mortality, resulting in more children with impairments.

New interventions in neonatal care have been developed to improve treatment and survival. However, only continual monitoring will determine whether there are any long-term side effects or risks associated with treatments. From a public health perspective, it is important to understand the type of long-term problems experienced by at risk children. Original follow-up research focused on neurological problems, hearing loss or blindness. These areas are important, but the most frequent problems are in the area of learning disabilities, behavioural (i.e. attention) and emotional problems (from autistic features to anxiety), and social relationships. This finding has important implications for reducing the adverse impact of neurological problems, especially regarding the timing and duration of intervention, which patients should be targeted, and via which avenues or services.

Emerging studies reaching into adulthood indicate that children do not grow out of their problems; some may go resolve and others may newly occur. Follow-up into adulthood is necessary to understand the full social, economic and quality of life impact of increased survival.

Such follow-up studies are necessary to differentiate the children that are resilient and those most likely to benefit from interventions. Both follow-up and controlled intervention studies indicate that those born at higher low birth weight (>1500g), or moderate preterm to near full-term births (32-36 weeks' gestation), are most likely to benefit from educational or parenting intervention in improving cognitive outcome, compared with very or extremely preterm children. Thus, while major treatment costs are centred on the sickest children, the most benefit in terms of potential to improve function may be for those with mild problems.

Systematic audits of neonatal services require not only neonatal monitoring of treatment, but also of long-term outcome that takes into account different population characteristics. This is necessary to improve quality of care.

15. Research

Challenges

The number of studies reporting the long-term outcomes of high-risk children is increasing daily, testifying the importance of follow-up in providing feedback to parents and demonstrating the efficiency of neonatal services.

There are major challenges:

- Funding of long-term research, monitoring of quality of care and trials for new innovative interventions
- The training of sufficient researchers and hospital staff to conduct high quality studies and routine follow-up of care practice
- The development of better integrated provisions for neonatal at risk children, including medical, social, psychological and educational services.

Follow-up studies vary widely in their methods, ranging from who is followed, at what ages, and with what methods; findings are often confusing for clinicians, parents and policy makers. However, accurate findings are necessary to draw appropriate conclusions regarding the prevalence of problems, changes in outcome over time, to draw implications for quality of care, and for the targeting of interventions. The major challenges are reliability (measuring outcomes accurately), validity (measure what is intended) and 'generalisability' (extrapolating findings beyond the sample studied to include all very preterm children).

A number of pitfalls identified have led to erroneous or biased conclusions regarding the outcome of high risk children:

- Studies that look forward (prospective) often find different rates of problems compared with studies looking back (retrospective studies). The former are considered more accurate, as they record information rather than having to go back to old records
- Many studies are based on admissions to one hospital, whilst others are based on geographically defined populations treated in different hospitals. Babies are born in different hospitals with different staff and different treatment approaches. Thus, findings from studies including a range of hospitals or records of whole countries are more likely to be valid and 'generalisable'
- Keeping the total sample of at risk children intact for follow-up is a major challenge. Families relocate and those with more social problems, or children with more severe handicaps, are less likely to participate. Thus, prevalence rates may be underestimated where there has been large dropout or the dropout rate is unknown
- Clinical follow-up often compares test results to test norms, i.e. to historical controls. However, some domains, such as IQ, show secular trends; i.e. the IQ of the current generation of children is higher than the one born just 10 years earlier. Thus, comparing such data to outdated norms underestimates the real problems of the at risk children (comparisons must be made with current full-term children)
- The follow-up needs to be long-term. For example, problems with mathematics or anxiety and depression are only detected at a later age. Rather than reducing with age, more problems are detected with increasing challenges, such as schooling in neonatal at risk children
- Outcomes may differ in at risk children than the general population, according to social factors such as social class, and need to be taken into account
- The follow-up studies should be conducted by an independent group not involved in neonatal care of the infants under investigation. Being involved in the care may bias judgement of the outcome. It has also been shown that those not satisfied with the neonatal care in a hospital are less likely to return for follow-up.

Similar challenges are apparent in assessing the effectiveness of aftercare, treatment or advice (e.g. from physiotherapy to advising delayed school entry). These need to be subjected to longitudinal observation studies or randomised controlled trials. In these trials, children are assigned to either a certain treatment or a control condition (e.g. treatment as usual). These trials are able to determine whether one treatment is more effective than another, or even damaging; thus, they are highly ethical as investigations are performed under controlled conditions rather than without systematic monitoring of treatment impact.

Recommendations

- Several EU Member States recommend follow-up of very preterm or very low birth weight children up to 2 years. However, systematic follow-up should be extended to those born moderately preterm (32-36 weeks), their families and other neonatal at risk children.
- Follow-up needs to continue into school age.
- Large amounts of funding are provided for initial neonatal care. Funding needs to be matched for:
  - Routine follow-up for quality purposes and improving care
  - Systematic research to allow planning of public health interventions and identification of how and by whom aftercare should be conducted
  - New intervention research including social, psychological and educational provisions.
- The development of parent screening measures and implementation of a two-stage screening process will make universal follow-up of neonatal at risk children feasible.
- Follow-up requires interdisciplinary teams; major problems are not strictly medical but include cognitive, behavioural and emotional problems and involve the whole family system.
- To avoid bias, follow-up teams should be multi-disciplinary and independent of the neonatal carers, and allow largest possible participation; even of those disapproving of their neonatal treatment.

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Abbott is committed to bringing together diverse stakeholders to find new solutions for patients, caregivers and societies around the world. Through an educational grant from Abbott, EFCNI was able to collaborate with pre-eminent maternal and newborn health professionals to develop Caring for Tomorrow, the EFCNI White Paper on Maternal and Newborn Health and Aftercare Services. This White Paper provides an evidence-based case and recommendations for policy makers, healthcare professionals, parents organizations and relevant others, for improving policies and clinical practices that will promote a healthy start in life.

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