Lifelong Care for Children with Chronic Conditions:
Session 3

Re-imagining the Package of Care for Children Subgroup
July 9, 2021
Series objectives

• Share and get feedback on UNICEF’s working “*Integrated Chronic Lifelong Care for Children and Adolescents*” framework

• Present case studies on specific chronic conditions

• Draw lessons for broader programming and implementation
UNICEF’s Integrated Chronic Lifelong Care for Children and Adolescents Framework

- Chronic Conditions affecting Children and Adolescents: HIV, Diabetes, Rheumatic Heart Disease, Asthma, Disabilities, Sickle Cell Disease, Cancers, Hep B, Syphilis

- In contrast with high-income countries, Chronic Care for children and adolescents is a less-developed area in low-and-middle-income countries

- These countries have typically focused on “episodic” management of common childhood illnesses that significantly contribute to child mortality

- With shifting epidemiologies, in part due to improving economies and gains in child mortality; and with UNICEF's focus on a thrive and transform agenda, chronic conditions come more into focus
Associated Professor of Cardiology at Universidade Eduardo Mondlane (UEM) and Lead Investigator at the Non-Communicable Diseases (NCD) Division of the National Public Health Institute (Instituto Nacional de Saúde)
Care delivery systems for children and adolescents with severe or complex chronic NCDs

Ana Mocumbi, Co-Chair

UNICEF Series: Lifelong Care for Children with Chronic Conditions
July 9, 2021
Outline

• Current NCD paradigm
• PEN Plus Origins
• Lifelong Care for Children with Chronic Conditions
• Opportunities and Ways Forward
The current NCD paradigm focuses on 4 main diseases and modifiable risk factors

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<thead>
<tr>
<th>Current NCD Paradigm*</th>
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<tr>
<th>Noncommunicable Diseases</th>
<th>4 Diseases, 4 Modifiable Shared Risk Factors</th>
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<tbody>
<tr>
<td>Tobacco Use</td>
<td>Unhealthy diets</td>
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<tr>
<td>Cardiovascular</td>
<td>✔️</td>
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<tr>
<td>Diabetes</td>
<td>✔️</td>
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<td>Cancer</td>
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<td>Chronic Respiratory</td>
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* Mental Disorders and Road Traffic injuries have more recently been included as well (i.e., “5x5”)
The Lancet Commission on Reframing NCDs and Injuries was launched in 2013.
Some of the steepest gradients in years of life lost are for NCDIs affecting the poor.

Other NCDIs affecting the poorest:
- Sickle Cell Disease
- Rheumatic heart disease
- Type 1 diabetes
- Cervical Cancer
- Pediatric Cancers
- Congenital heart disease
- Household air pollution
- Schizophrenia
- Injuries
- Epilepsy
The Lancet NCDI Poverty Commission report

- NCDI Poverty is a huge gap in achieving UHC
- NCDI Poverty cause annually 800,000 deaths among <40y
- There’s a major gap in health financing for NCDIs
NCDI Poverty Network Member Countries

National Commissions 2016 - 2019

Malawi
Rwanda
Kenya
Afghanistan
Zambia
Zimbabwe
Haiti
Mozambique
Tanzania
Nepal
Uganda
Sierra Leone
Chhattisgarh State, India
Ethiopia
Liberia
NCDI Poverty Network – Strategic Initiatives

**Phase 1**
Situation analysis and priority-setting
- Prioritize conditions and interventions

**Phase 2**
Delivery Model Design
- Develop models for integrated delivery of priority interventions

**Phase 3**
Initial Implementation
- Establish training sites and national operational plans

**Phase 4**
National Scale-up
- Build financial and technical partnerships to support scale-up

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<tr>
<th>Strategic Initiative</th>
<th>Expanding the NCDI Poverty Network</th>
<th>Integration Science</th>
<th>PEN-Plus Partnership</th>
<th>NCDI Poverty Fund</th>
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<tr>
<td>Major Category</td>
<td>Policy &amp; Awareness</td>
<td>Research &amp; Design</td>
<td>Implementation, Service Delivery, &amp; Training</td>
<td>Financing &amp; Scale-up</td>
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PEN-Plus: A march towards UHC

Characteristics of Package of Essential NCD Interventions (PEN) -Plus clinics

- Decentralized, integrated, person centered
- **Severe diseases**: lethal, disabling, disproportionately affect the poorest and youngest
- **Rural majority**: Increased access to care by overcoming geographic and financial barriers
- **Promote decentralization**: training, supervision and mentorship of health center and community staff
Lifelong Care for Children with Chronic Conditions

PEN-Plus is an integrated delivery strategy for chronic care of severe NCDs at first-level hospitals (e.g. district hospitals)
What is PEN Plus?

- builds on the WHO PEN for common NCDs
- seeks to increase coverage of high-quality care for less common but more severe conditions by decentralizing services normally available only at tertiary referral centers.
- provides mid-level health workers (e.g. nurses, clinical officers) with the shared competencies needed to deliver integrated care for groups of related conditions, including psychosocial support and palliative care.
- strengthens WHO PEN services at lower-level facilities by providing training, mentorship, and supervision
PEN-Plus addresses gaps in care for severe NCDIs among the poor

<table>
<thead>
<tr>
<th>Sample list of conditions</th>
<th>WHO PEN</th>
<th>PEN-Plus</th>
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<tbody>
<tr>
<td></td>
<td>• Type 2 Diabetes, Stage 1 and 2 Hypertension, Asthma and COPD, asymptomatic rheumatic heart disease</td>
<td>• Sickle Cell Anemia, Type I and Insulin-dependent diabetes, Malignant Hypertension, Advanced Rheumatic and Congenital Heart disease, Cirrhosis, Malignancies</td>
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<tr>
<th>Facility level</th>
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<tr>
<td></td>
<td>• Most peripheral</td>
<td>• First-Referral</td>
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<tr>
<th>Disease prevalence</th>
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<tr>
<td></td>
<td>• High</td>
<td>• Low</td>
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<table>
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<th>Disease severity</th>
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<tr>
<td></td>
<td>• Low</td>
<td>• High</td>
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<tr>
<th>“Therapeutic window”</th>
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<tbody>
<tr>
<td></td>
<td>• Wide</td>
<td>• Narrow</td>
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<tr>
<th>Training model</th>
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<tr>
<td></td>
<td>• Short, didactic</td>
<td>• Longer, didactic + clinical practice</td>
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An ecosystem for chronic care

PEN Plus is part of an ecosystem of chronic care – the piece where care and treatment is provided at first level hospitals (e.g. district hospital)
An ecosystem for chronic care

For example, adolescents with Type 1 Diabetes can receive diagnosis, insulin titration, laboratory monitoring, and treatment of complications such as DKA.
An ecosystem for chronic care

Or, a child with congenital heart disease can receive diagnosis, echocardiography, follow up clinical monitoring and treatment, and referral for surgical evaluation.
An ecosystem for chronic care

The PEN Plus model allows for referral to central or tertiary hospitals when needed.

And primary care clinics can escalate care to PEN Plus for new patients or complex conditions.
An ecosystem for chronic care

In addition, the relationship between levels of care provides a platform and opportunity for training and mentorship.

Which also strengthens primary health care.
Opportunities & Ways Forward

PEN Plus implementation contributes to address the lack of NCD policy for children
Why PEN Plus for children/adolescents?

DALYs in LMICs in people under 20 years (GBD 2019)

NCDs (blue) = 23% of DALYs

Very diverse set of conditions
Review

Personalized Nutrition Approach in Pregnancy and Early Life to Tackle Childhood and Adult Non-Communicable Diseases

Shaikha Alabduljabbar, Sara Al Zaidan, Arun Prasath Lakshmanan and Annalisa Terranegra

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* Correspondence to: aterranegra@sidra.org; Tel.: +974-4003796

Abstract: The development of childhood and adult non-communicable diseases (NCDs) is associated with environmental factors, starting from intrauterine life. A new theory finds the roots of epige-netic programming in parental gametogenesis, continuing during embryo development, fetal life, and finally in post-natal life. Maternal health status and poor nutrition are widely recognized as implications in the onset of childhood and adult diseases. Early nutrition, particularly breastfeeding, also plays a primary role in affecting the health status of an individual later in life. A poor maternal diet during pregnancy and lack of breastfeeding can cause a nutrient deficiency that affects the gut microbiota, and acts as a co-factor for many pathways, impacting the epigenetic controls and transcription of genes involved in the metabolism, angiogenesis, and other pathways, leading to NCDs in adult life. Both maternal and fetal genetic backgrounds also affect nutrient absorption.

Keywords: NCDs; pregnancy; child; childhood obesity; obesity; epigenetics; nutrition; personalized nutrition; long-term outcomes; metabolic diseases; lifestyle; risk factors; prevention; intervention; health; mother; child; maternal nutrition; childhood obesity; NCDs; personalized nutrition; genetics; interactions; metabolism; infant; child; childhood; adult;

Summary

Evidence for the effect of preconception and periconceptional risk factors on child-life outcomes such as obesity and other non-communicable diseases (NCDs) in later life is growing. Issues such as maternal malnutrition need to be addressed before pregnancy, to prevent a transgenerational passage of risk of NCDs. The aim of this review was to evidence for preconception interventions to prevent obesity and other non-communicable diseases in children.
The current NCD paradigm focuses on 4 main diseases and modifiable risk factors.

**TASK SHIFTING/SHARING**  
Shared competencies for NCD care

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**FIGURE 1** Conceptual framework of factors affecting the intergenerational transmission of risk for NCDs. The life course model of NCDs and DOHaD both suggest that the mother’s nutritional status and health behaviors, before and during pregnancy, can have effects on fetal growth and development. This has further long-term consequences on the health of the mother and child. For example, pre-pregnancy BMI is a risk factor for both gestational diabetes and future type 2 diabetes in the mother and childhood obesity for the baby. OB/GYNs and midwives are stakeholders who come in contact with women during these stages most frequently. Knowledge and understanding of DOHaD among healthcare practitioners will determine the extent to which these issues are communicated with women or couples.
Figure 3  Frequency of reported interventions delivered, by NCD condition. CVD, cardiovascular disease; NCD, non-communicable disease.

“Absence of national NCD policy for children is a major challenge. The burden of care rests mainly on the parents/caregivers. A national strategic intervention on the importance of awareness generation on the causes, risk factors, prevention and treatment of NCDs for families and communities is essential. Government support through national health and social policy initiatives are essential.”

URI: http://ugspace.ug.edu.gh/handle/123456789/25285
For children and adolescents prevention alone is not enough!

- Many PEN Plus conditions occur in young children and adolescents, and many of these cannot be addressed with prevention alone:
  - Type 1 Diabetes
  - Sickle Cell Disease
  - Congenital Heart Disease
  - Nephrotic Syndrome
  - Childhood Cancer

- Many may benefit from prevention but also need treatment once they occur:
  - Rheumatic Heart Disease
  - Severe or complicated epilepsy
  - Congenital anomalies
  - Injury
Severe chronic NCDs in children and adolescents may be each individually rare --> However, as a group, we see a lot of illness and suffering.

PEN-Plus is a piece of the puzzle for comprehensive prevention and treatment for children and adolescents.

- Complementary to prevention agenda
- A platform for care delivery for complex conditions
- Supports mentorship and quality for primary care
- Opportunity for integrating other primary and preventive services
Acknowledgments

• Dr. Emily Wroe
• NCDI Poverty Co-Secretariat
• NCDI Poverty Network Members

Thank you very much for your attention!
Wrapping up

• **Key messages**
  
  - Low case numbers is a challenge- rationale for an approach to chronic lifelong care that bundles chronic conditions and looks at critical health system inputs to integrate some elements of care at Primary Health Care level.
  - An integrated approach and multidisciplinary teams seem to be a more cost-efficient and practical way to achieve this, this includes connections to tertiary care.
  - A life-course approach will be needed to adjust care as children enter adolescence and adulthood.
  - A better understanding of pediatric experience of care and support for chronic illness to be recognized and addressed.
  - Patient and family engagement and advocacy is needed for inclusion of NCDs, chronic care in LMICs in UHC and PHC initiatives- including inclusion in national health sector plans, policies, and ultimately integrated budgets.
Lifelong Care for Children with Chronic Conditions Discussion Series

Engage with the co-chairs:

- Cara Endyke Doran- cendykedoran@globalcommunities.org
- Raoul Bermejo- rbermejo@unicef.org

Reach out to the Child Health Task Force at childhealthtaskforce@jsi.com

Series Dates & Case Study Discussions:

- **May 14th:** Congenital heart disease
- **June 25th:** HIV, type 1 diabetes & sickle cell disease
- **July 9th:** Integrated NCD package of services

**Time:** 9 - 10:30am EDT [GMT-4]

Check out the Task Force Child Health for important resources!

- Subgroup information, recordings and presentations from previous webinars are available on the subgroup page of the Child Health Task Force website: www.childhealthtaskforce.org/subgroups/expansion