WHAT ARE THE COMMON CHALLENGES FACED BY PATIENTS WITH CHRONIC ILLNESSES TRANSITIONING TO ADULT CARE?
What would be a good age to introduce transition programs?

- 10 - 12 years old
- 13 - 15 years old
- 16 - 18 years old
TRANSITION CARE IN CML

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ACKNOWLEDGEMENT

PHILIPPINE ALLIANCE OF PATIENT ORGANIZATIONS (PAPO)

DR. ERNESTO D’J YUSON

DR. MALOU ABIERA
Certain hematologic conditions can be complex and challenging for patients to successfully manage, especially when transitioning to a new health care team.

The majority of youth are unprepared for the change in care and they may not know their medical history, prescriptions, insurance information, or even how to make a doctor’s appointment.
As children (or teenagers) transition into adult care they may feel overwhelmed or forgotten in the new system once they leave pediatrics.

Recognizing the need to recognize this transition process we will try to explore the Pediatric to Adult Hematologic Care Transition.
DEFINITION of Transition Care: “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions, from child-centered to adult-oriented health care systems”
Transition from a dependent child to an independent adult is well recognized to be a gradual process taking a considerable amount of time.

What then should we expect young people with chronic medical conditions to make it in one hop?
“I WORRY THAT THE ADULT HOSPITAL WOULD BE A PLACE FULL OF DYING PEOPLE WITH A HORRIBLE SMELL”

- A YOUNG PATIENT AT A FOCUS GROUP
I visualize the adult hospital to have a robotic staff wearing white suits, who are not interested in any of my interests or concerns.
3 MAIN PLAYERS

PATIENT
FAMILY
MEDICAL TEAM
DEPENDENCE to INDEPENDENCE

LEAVING BEHIND LONG STANDING RELATIONSHIPS vs MAKING NEW ONES

A FEELING OF BEING NEARER TO COMPLICATIONS OF THE DISEASE AS THE PATIENT MOVES INTO ADULTHOOD
MAIN CAREGIVER/DECISION MAKER vs THE FEELING OF NOT BEING PART OF THE DECISION-MAKING PROCESS

OVERPROTECTIVENESS vs LEARNING “TO LET GO”
Difficulty of LETTING GO

NEED FOR ADDITIONAL SKILLS IN THE CARE OF THE ADOLESCENT PATIENT

Challenges in COMMUNICATION, COLLABORATION and PREPARATION between health teams
Assess the patient’s own knowledge and skills regarding his hematologic condition and its management.

Used by the pediatric care team to facilitate the conversation about the youth’s needed skills to manage his hematologic health and health care.

The forms indicate the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.
For adult patients, the forms should be utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).
Specifically related to the clinical condition that is to be included in the patient’s medical record upon transfer to the adult practice.

These forms should be completed, signed, and dated on the last page by the referring provider and patient/family.

The patient and/or family should review and give completed form to the new adult care provider.
WHAT ARE THE COMMON CHALLENGES FACED BY PATIENTS WITH CHRONIC ILLNESSES TRANSITIONING TO ADULT CARE?
MANAGING THE TRANSITION FROM PAEDIATRIC TO ADULT CARE

Yunus Borowczak, Parents’ Organisation for Children with CML
Germany

Advocacy Session #4
Living with CML
#CMLHZ19
19th May, 2019
My story of CML:

- 25th January, 2013: Diagnosis of CML
- Start of treatment with Imatinib; after half a year → medication change to Dasatinib
- January, 2013 – October, 2018: paediatric treatment at Children’s University Hospital in Tübingen, Germany
- January, 2019: transition to adult care in Mannheim, Germany
Paediatric care:

<table>
<thead>
<tr>
<th>Likes</th>
<th>Dislikes</th>
</tr>
</thead>
</table>
| • Nice, personal, and honest hospital staff  
• A lot of assistance  
• Child-friendly facility | • The only CML patient:  
➢ No contact to other paediatric CML patients over hospital  
➢ Doctors without any experience  
➢ Less available information about clinical trials, medication opportunities, etc. |
**Adult care:**

<table>
<thead>
<tr>
<th>Thumbs Up</th>
<th>Thumbs Down</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Experienced doctors</td>
<td>• Underestimation of CML</td>
</tr>
<tr>
<td>• More opportunities:</td>
<td></td>
</tr>
<tr>
<td>➢ Medication</td>
<td></td>
</tr>
<tr>
<td>➢ Clinical trials</td>
<td></td>
</tr>
<tr>
<td>➢ Proceeding of treatment</td>
<td></td>
</tr>
<tr>
<td>• Improvement of new friendships</td>
<td>• Independent self care</td>
</tr>
</tbody>
</table>
Conclusion:

• **Massive difference between paediatric and adult care** → huge impact on the life of a young patient
• Young patients need a strong environment including caring families, doctors etc.
• Acceptance and approaching of teachers and friends
• Carefully considered preperation, which includes all possible options
  ➢ **IMPORTANT:** start preperations before turning 18 / transition into adult care
• After transition: approaching of doctors, patient used to other environment
Thank you very much for your attention!

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