حکایت شمارهٔ ۱۰

بر بالین تربت یحیی پیغامبر علیه السلام معتکف بودم در جامع دمشق که یکی از ملوک عرب که به بی انصافی منسوب بود اتفاقاً به زیارت آمد و نماز و دعا کرد و حاجت خواست

درویش و غنی بنده این خاک درند — و آنان که غنی ترند محتاج ترند

آن گه مرا گفت از آن جا که همت درویشان است و صدق معاملت ایشان خاطری همراه من کنید که از دشمنی صعب اندیشناکم. گفتمش بر رعیت ضعیف رحمت کن تا از دشمن قوی زحمت نبینی.

به بازوان توانا و قوت سر دست — خطاست پنجه مسکین ناتوان بشکست

نترسد آن که بر افتادگان نبخشاید — که گر ز پای در آید کسش نگیرد دست

هر آن که تخم بدی کشت و چشم نیکی داشت — دماغ بیهده پخت و خیال باطل بست

ز گوش پنبه برون آر و داد خلق بده — وگر تو می‌ندهی داد روز دادی هست

بنی آدم اعضای یکدیگرند — که در آفرینش ز یک گوهرند

چو عضوی به درد آورد روزگار — دگر عضوها را نماند قرار

تو کز محنت دیگران بی غمی — نشاید که نامت نهند آدمی

Pediatric Palliative Care as a Component of High Quality Comprehensive Care

PEYMAN ESHGHI MD.
Professor of Pediatric Hematology&Oncology
Mofid Children Hospital
S.B.M.U.
26-08-1401

Educational session in “SUPPORTIVE CARE”; SIOP-2022

WHO EMRO meeting on palliative &supportive care , Cairo-2022

- Asya Agulnik, M.D., M.P.H., is an associate faculty member at St. Jude Children’s Research Hospital in the Department of Global Pediatric Medicine
- Justin Baker MD.; Pediatric oncologist, palliative care physician, faculty member at St. Jude Children’s Research Hospita
- Elena Ladas MD, is an associate faculty member at Colombia University

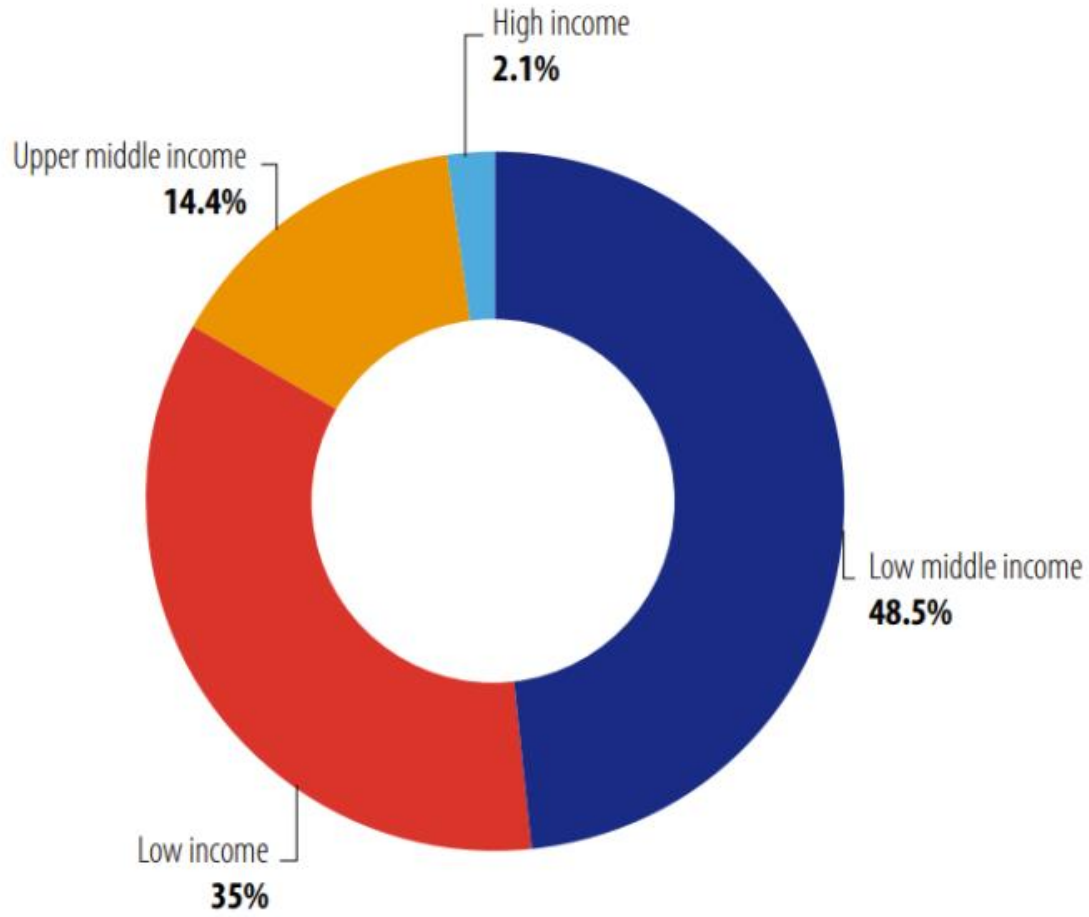
What is Palliative Care

- Palliative care (PC) is a holistic approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the **prevention and relief of suffering** by means of **early identification and assessment and treatment** of pain and other problems, **physical, psychosocial and spiritual** (WHO, 2015)
- Clearly proven to improve QoL, psychosocial outcomes and caregiver burden
- Can reduce overall cost of care while improving key quality metrics of care

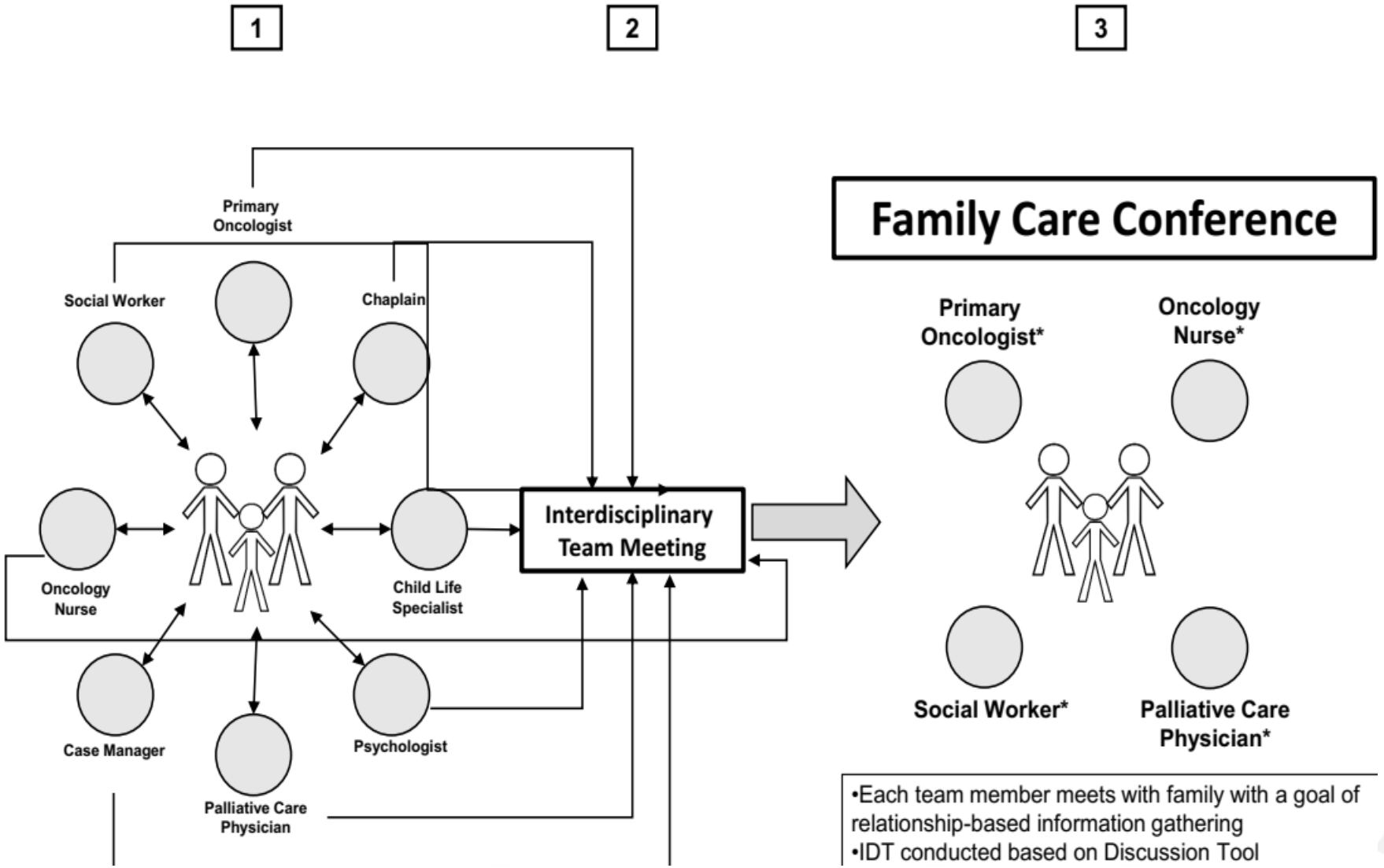
Differences between PPC and Adult PC

- Prognosis, life expectancy and functional outcome often less clear.
- More frequent need to integrate palliative care with intensive disease-modifying or life-sustaining treatments due to unclear prognosis.
- Care often requires a dual focus on growth/development and potential for death.
- Greater emotional burden for family members and clinicians because serious and life-threatening illnesses are not commonly considered normal conditions for children.
- Patients undergo continual developmental change: physical, hormonal, cognitive, expressive and emotional.
- Patients have changing information needs, recreational and educational needs, and modes of coping with stress. Thus, child life specialists, play therapists and behavioural specialists can greatly enhance palliative care for children.
- Patients may have congenital anomalies of uncertain type or rare genetic conditions.
- Some genetic conditions may affect multiple children in a family and create a sense of guilt in parents.
- Expertise needed both to discern a child's emotional and cognitive development and to communicate in a manner appropriate for the child's emotional and cognitive development: to provide the most appropriate amount and kind of information about the illness and to elicit the child's preferences for care.

Where do the kids who need Palliative Care live?



Multidisciplinary Care + IDT



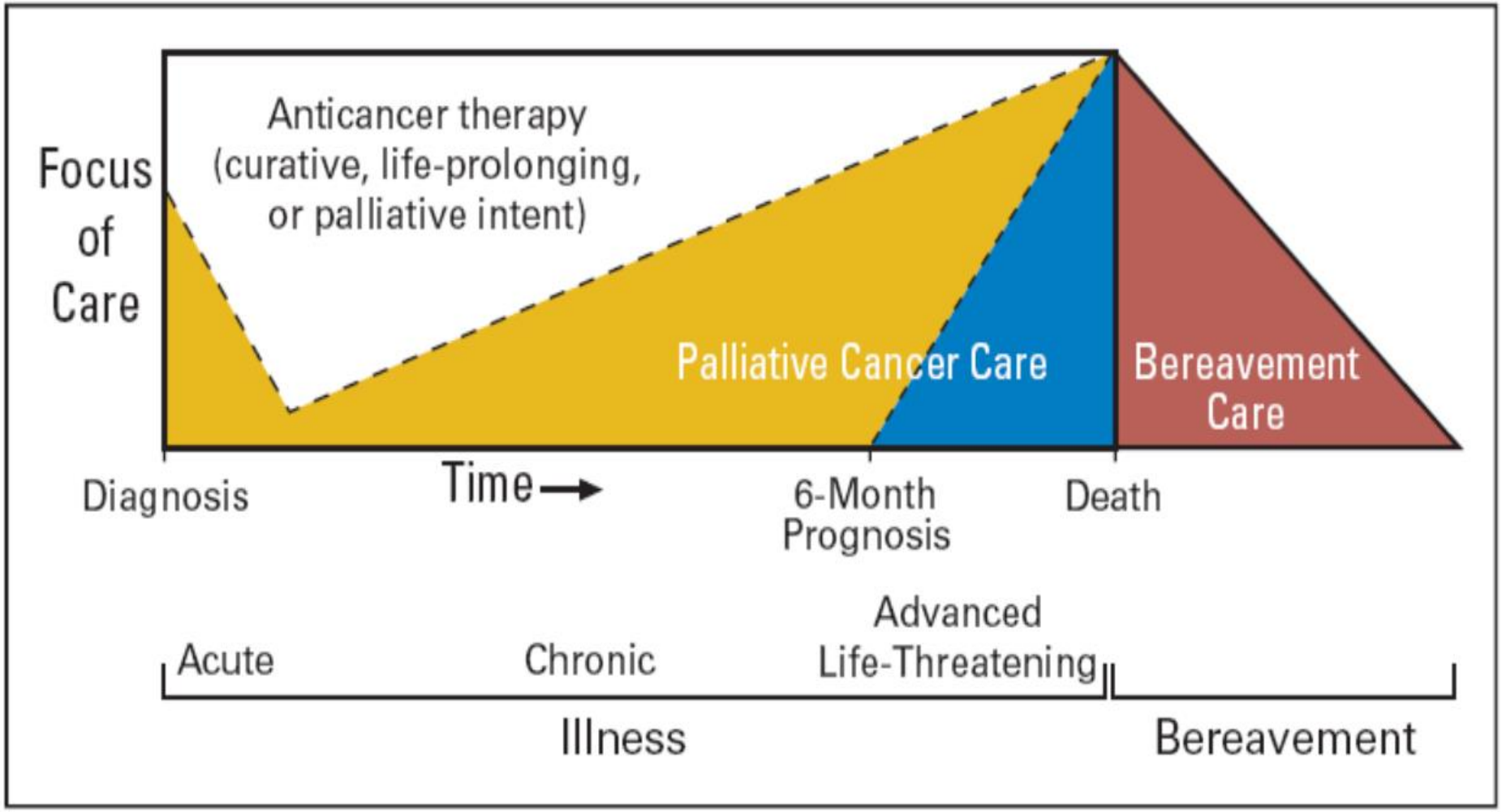
Key Concepts in PPC

- ***INVOLVE THE CHILD***
  - What are their questions/concerns
  - Welcome questions even though there may not be an immediate answer
  - Help children not to feel alone

- ***Communication should be:***
  - Culturally appropriate
  - Honest
  - Child-centered
  - Developmentally appropriate
  - Timely, linked to concrete experience

Tell the truth

Model of *INTEGRATED* palliative care



Model of *INTEGRATED* palliative care Childhood Cancer Pathway – WHO 2020

Early detection	diagnosis	Treatment & palliative care	Survivorship care
• Awareness of key symptoms • Primary care evaluations • Referral for diagnosis	• Diagnostic procedures • Histopathological confirmations • Clinical and radiological staging	• Multidisciplinary care • Disease directed therapy • Supportive care • Palliative care	• Manage long term physical , psychosocial effects • Prevent surveil for new , recurrent cancer • Routine primary care

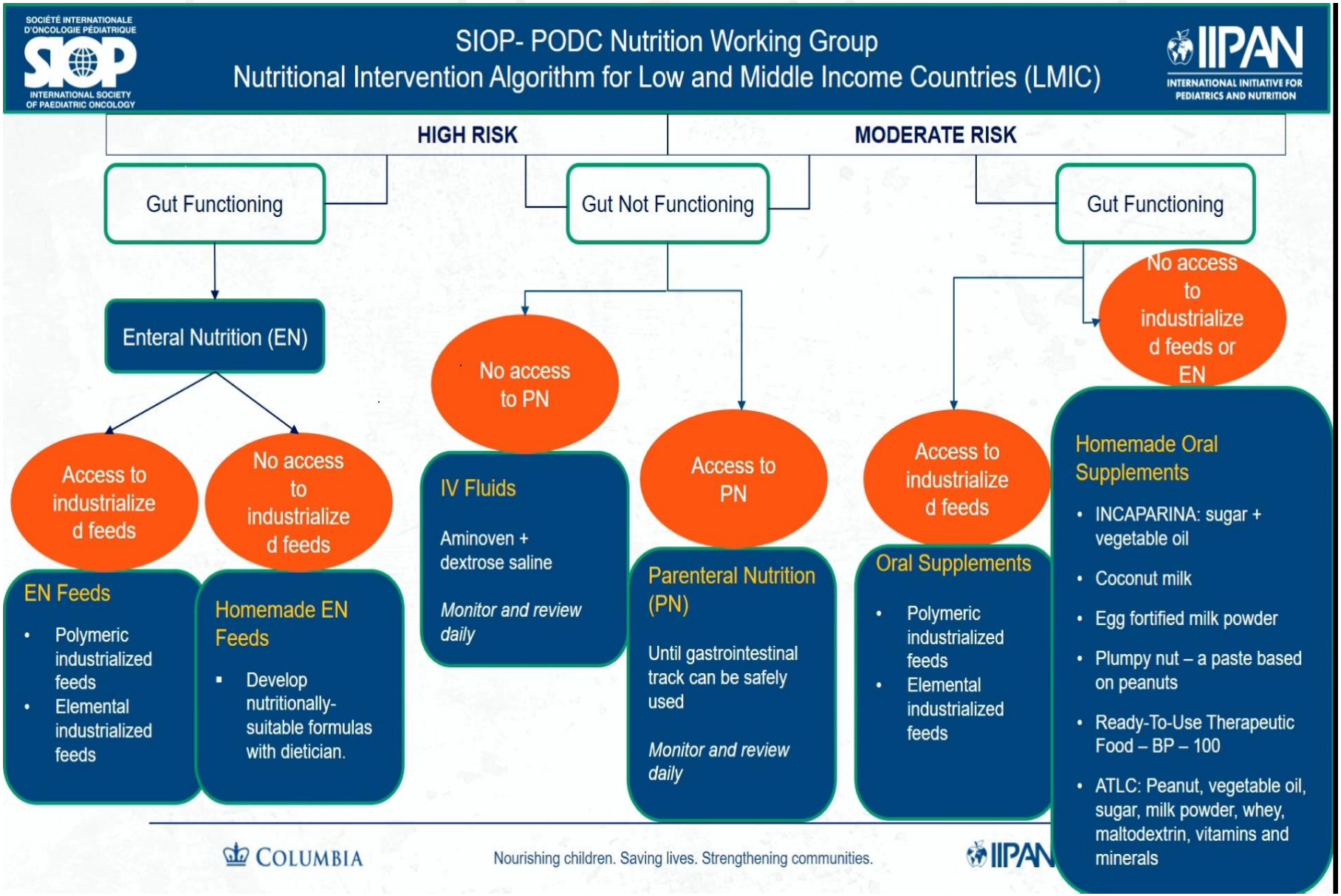
"Embedded QoLA" model of Integrated PPC

Palliative care programs provided by hospitals in EMR

COUNTRY	OUTPATIENT CLINICS	CONSULT SERVICE[1]	HOSPITAL PC UNIT[2]	MIXED PROGRAMS[3]	POPULATION, TOTAL
Saudi Arabia	9	9	8	8	31,540,372
Jordan	2	2	1	1	7,594,547
Lebanon	0	3	1	0	5,850,743
Kuwait	1	1	1	N/A	3,892,115
Oman	1	1	0	0	4,490,541
Qatar	N/A	N/A	1	N/A	2,235,355
UAE	1	1	1	N/A	9,156,963
Morocco	N/A	1	1	1	34,377,511
Tunisia	N/A	N/A	2	N/A	11,107,800
Egypt	4	2	2	N/A	91,508,084
Sudan	1	2	1	2	40,234,882
Iran	1	1	1	0	79,109,272
Pakistan	N/A	N/A	2	N/A	188,924,874
Iraq	0	0	0	0	36,423,395
Occ. Pal. Terr.	0	0	0	0	4,500,000

% Nursing schools with mandatory PC course

Egypt	0%	Informal training available
Iran	0%	Sub-speciality
Iraq	0%	Official recognition of specialization done abroad
Lebanon	100%	Specialty
Pakistan	4%	Special area of competence or another advanced accreditation diploma
Palestine	0%	Official recognition of specialization done abroad recognized
Morocco	0%	Informal process of training is available
Jordan	67%	Sub-speciality
Kuwait	100%	Abroad specialization recognized
Qatar	100%	Sub- speciality
Oman	100%	Specialization process in progress
Saudi Arabia	17%	Sub-specialit



Homemade Supplements

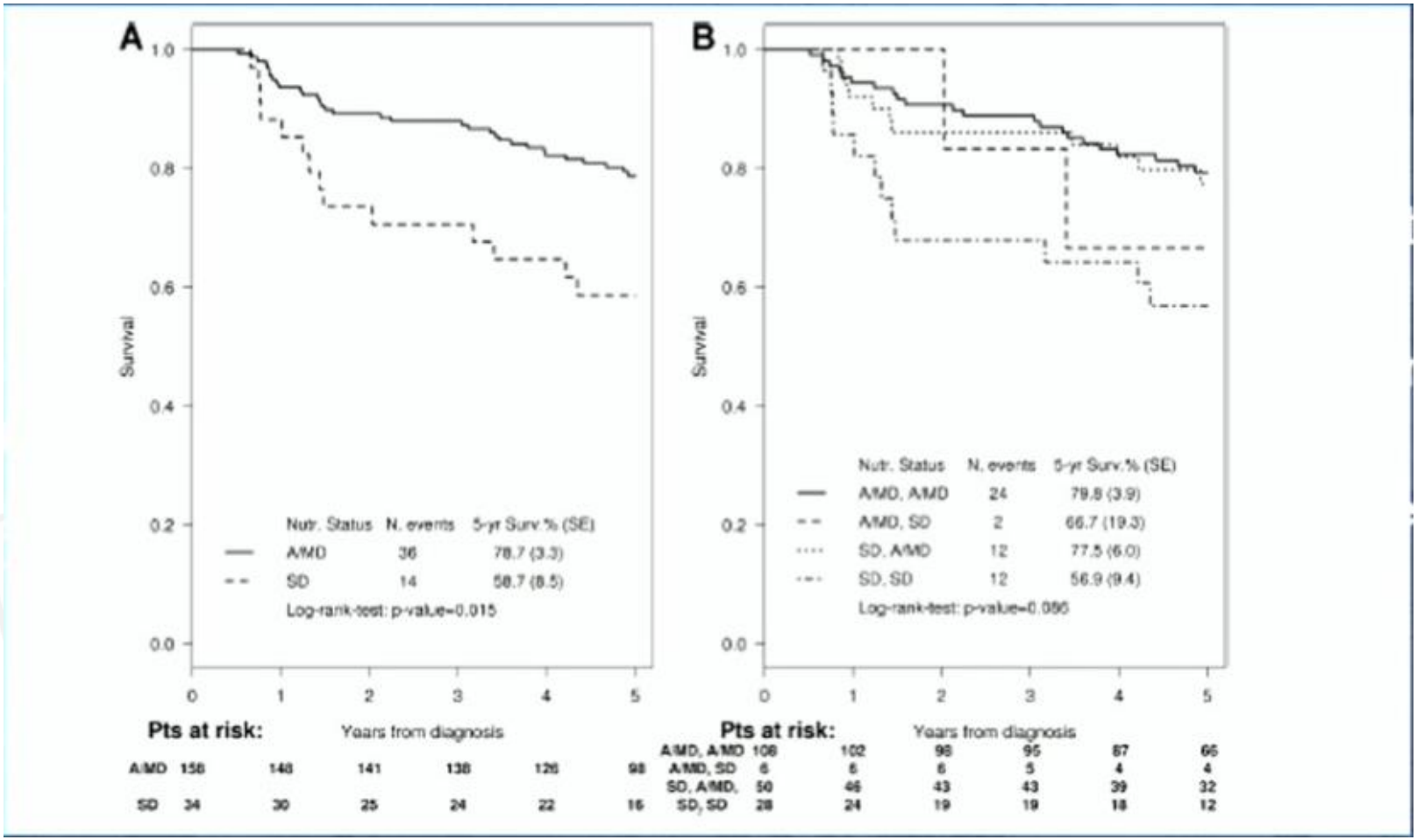
Homemade oral supplements for patients with cancer: descriptive analysis

Adriana GARÓFOLO[1]
Fernanda Rodrigues ALVES[2]
Maria Aurélia do Carmo REZENDE[3]
Rev. Nutr., Campinas, 23(4):523-533, jul./ago., 2010

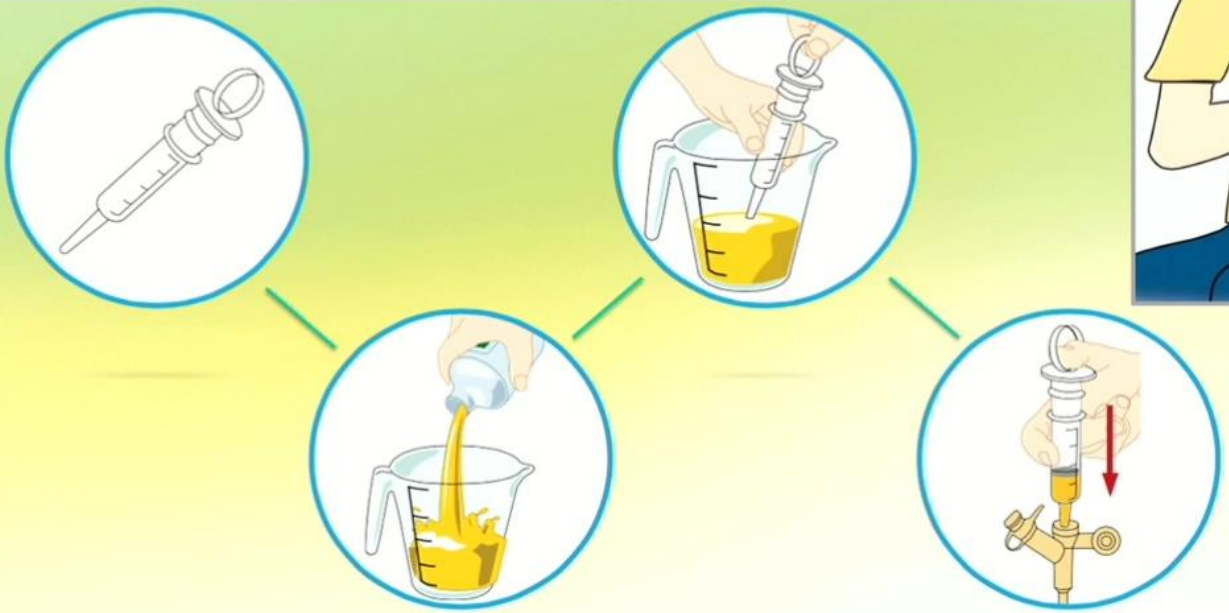
Homemade oral supplement: a proposal for the nutritional recovery of children and adolescents with cancer

Fernanda Rodrigues ALVES[2]
Adriana GARÓFOLO[3]
Priscila dos Santos MAIA[4]
Fernando José de NÓBREGA[5]
Antonio Sergio PETRILLI[6]
Rev. Nutr., Campinas, 23(5):731-744, set./out., 2010

- Much lower amounts of certain micronutrients
- 5 x cheaper
- Both groups presented similar protein and energy intakes and improvements in nutritional status



Syringe Feeding



COLUMBIA

Nourishing children. Saving lives. Strengthening communities.

IIPAN

Original research

Neutropenic versus regular diet for acute leukaemia induction chemotherapy: randomised controlled trial

Conclusions : A neutropenic diet (Restriction of raw fruits and vegetables)did not prevent infections, reduce mortality or change stool microbial flora in patients with acute leukaemia.

org/10.1136/spcare-2022- patients receiving treatment for acute leukaemia

income countries (LMICs) advocate a

Dietary Recommendations

- American Cancer Society Food Safety Guidelines
- Only pasteurized dairy products
- Uncooked fish, meat, and eggs and raw nuts excluded
- Ensured water; no tap water

Results We randomised 200 patients, 98

⇒ The RONALIC study will help bust the

Pediatr Blood Cancer 2016;63:1339–1348

A Framework for Adapted Nutritional Therapy for Children With Cancer in Low- and Middle-Income Countries: A Report From the SIOP PODC Nutrition Working Group

Elena J. Ladas, PhD, RD,[1,2*] Brijesh Arora, MD, DM,[3] Scott C. Howard, MD,[4] Paul C. Rogers, MD,[5] Terezie T. Mosby, EdD, RD,[6] and Ronald D. Barr, MB ChB, MD[7]

The utilization of adapted regimens for the treatment of pediatric malignancies has greatly improved clinical outcomes for children receiving treatment in low- and middle-income countries (LMIC). Nutritional depletion has been associated with poorer outcomes, increased abandonment of therapy, and treatment-related toxicities. Surveys have found that nutritional intervention is not incorporated routinely into supportive care regimens. Establishing nutritional programs based upon institutional resources may facilitate the incorporation of nutritional therapy into clinical care in a way that is feasible in all settings. We present a framework for establishing and monitoring of nutritional care based on the infrastructure of institutions in LMIC. Pediatr Blood Cancer 2016;63:1339–1348.

Key words: adapted guidelines; international outreach; low- and middle-income countries; nutrition; nutritional status

TABLE I. Characteristics of Infrastructure and Personnel Service Line Levels Relevant for Selection of SIOP-PODC Adaptive Nutritional Therapy

Service	Level 0	Level 1	Level 2	Level 3	Level 4

TABLE II. Nutritional Services for Each Level of Care Defined by SIOP-PODC

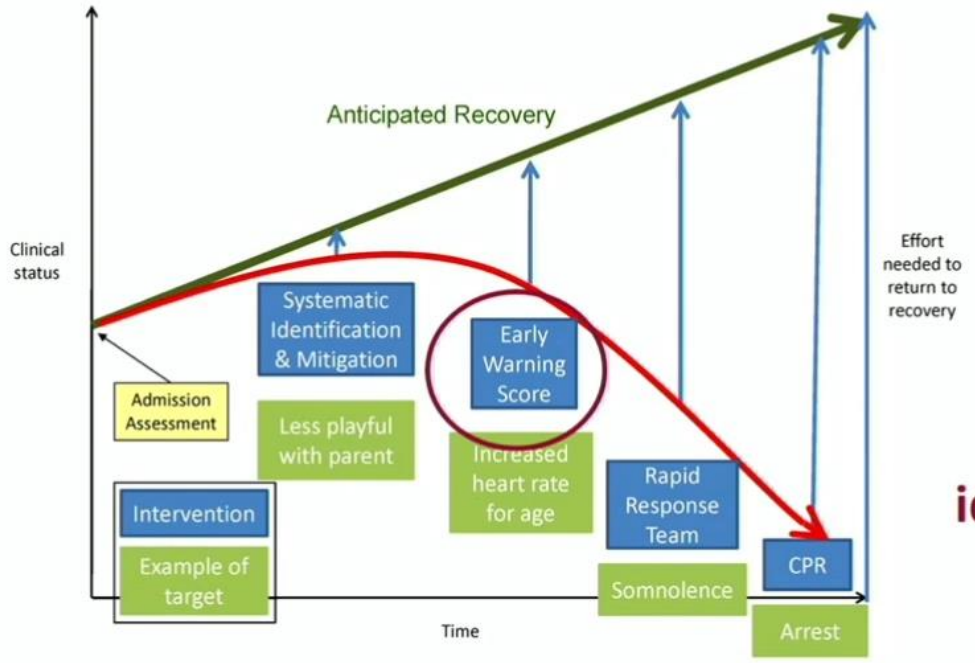
Service	Level 0	Level 1	Level 2	Level 3	Level 4
Level nutritional care	None	Basic	Limited	Optimal	Maximal

TABLE III. Impact Variables for Nutritional Program Evaluation in Pediatric Oncology

Category	Outcome variables

Pediatric Early Warning Systems (PEWS)

Clinical Deterioration in Hospitalized Children



Children with cancer and blood disorders are at high-risk for deterioration

- One in three require critical care during cancer treatment
- Higher mortality during critical illness

Systems to facilitate **early identification** and **action** can improve outcomes

Tume 2007, Brady 2013

What are PEWS?

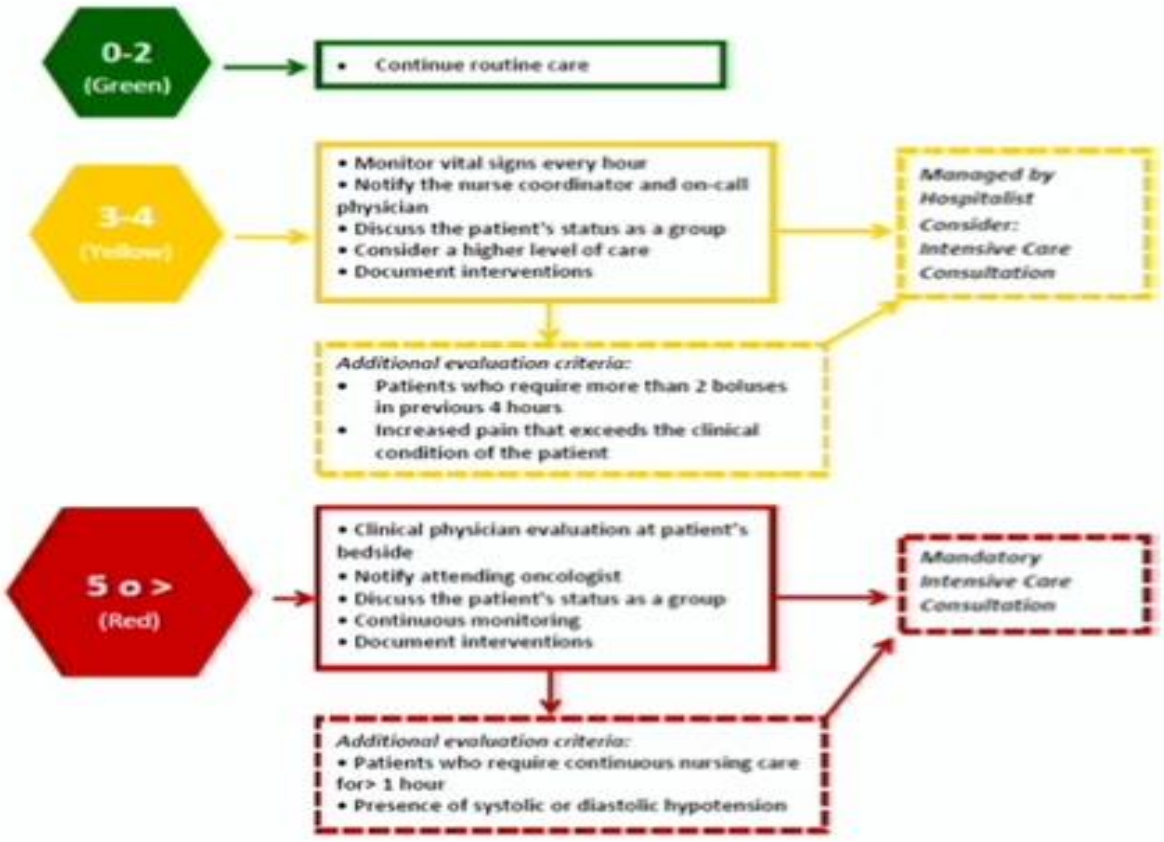
Pediatric Early Warning *Systems*

Systems to improve **early identification** of **clinical deterioration** in hospitalized patients

PEWS Scoring Tool

	0	1	2	3	Result
Behavior / Neurologic	• Alert/Sleeping appropriately • Patient is at baseline state of alertness	• Sleepy, drowsy when not stimulated • Responds only to verbal stimuli	• Irritable, difficult to console • Responds only to painful stimuli	• Lethargic, confused, without strength • Unresponsive • Seizures • Unreactive pupils or with anisocoria	
Cardiovascular	• Appropriate skin color for patient • Capillary refill ≤ 2 seconds • Normal peripheral pulses	• Pale • Vasodilated • Capillary refill 3-4 seconds • Mild tachycardia*	• Capillary refill 4-5 seconds • Moderate Tachycardia* • Diminished peripheral pulses	• Mottled • Fill capillary> 5 seconds • Severe tachycardia* • Symptomatic bradycardia • Irregular rhythm (not sinus)	
Respiratory	• Within normal parameters • No retractions • Normal breathing pattern • Saturation >95%	• Mild tachypnea* • Mild work of breathing (nasal flaring, intercostal retraction) • Up to 1 L of oxygen via nasal cannula (NC) • Saturation 90% -94% without oxygen	• Moderate tachypnea* • Moderate work of breathing (nasal flaring, intercostal retraction, grunting, use of accessory muscles) • 1-3 L of oxygen via NC • Nebulization every 4 hrs • Saturation 88-89% without oxygen	• Severe tachypnea* • Respiratory rate below normal for age* • Severe work of breathing (head-bobbing, thoraco-abdominal dissociation) • Oxygen via facemask with reservoir (not post-sop) • > 3 L oxygen via NC • Nebulization > every 4 hours • Saturation <90% with oxygen • Apnea	
Nurse concern	Not concerned	Concerned			
Family concern	Not concerned and present	Concerned or absent			
				TOTAL	

PEWS Algorithm



For immediate assistance at any time:

CALL the PICU: 255

The items and related sub scores of the modified Bedside Pediatric Early Warning System score

Modified BedsidePEWS score item	Sub score ranges	Sub scores			
Respiratory rate (breaths / minute)	Deviation from normal ranges (0: normal value to 4: major deviation) by age group (0-3 months, 3-12 months, 1-4 years, 4-12 years, >12 years)	0	1	2	4
Respiratory effort	Deviation from normal respiratory effort (0: normal to 4: severe increase/any apnea)	0	1	2	4
Oxygen saturation	Deviation from expected values (0: >94%; 2: ≤90%)	0	1	2	
Oxygen therapy	0: room air; 2: extra oxygen (< 2L/min); 4: High flow nasal cannula or non-rebreathing mask	0		2	4
Heart rate (beats/minute)	Deviation from normal ranges (0: normal value to 4: major deviation) by age group (0-3 months, 3-12 months, 1-4 years, 4-12 years, >12 years)	0	1	2	4
Capillary refill time	0: <3 seconds or 4: ≥3 seconds	0			4
Systolic blood pressure	Deviation from normal ranges (0: normal value to 4: major deviation) by age group (0-3 months, 3-12 months, 1-4 years, 4-12 years, >12 years)	0	1	2	4
Temperature	Deviation from normal ranges (0: 36.5 °C – 37.5 °C to 2: < 36.0 °C or > 38,5 °C	0	1	2	

Adapted from Parshuram, et al. Development and initial validation of the Bedside Paediatric Early Warning System score. Crit Care. 2009;13(4):R135.

Validity of PEWS/EVAT

Validation of a Pediatric Early Warning Score in Hospitalized Pediatric Oncology and Hematopoietic Stem Cell Transplant Patients

Asya Agulnik, MD, MPH[1]; Peter W. Forbes, MA[2]; Nicole Stenquist, BA[1]; Carlos Rodriguez-Galindo, MD[3]; Monica Kleinman, MD, FAAP[1]

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Validation of a Pediatric Early Warning System for Hospitalized Pediatric Oncology Patients in a Resource-Limited Setting

Asya Agulnik, MD, MPH[1,2]; Alejandra Méndez Aceituno, MD[3]; Lupe Nataly Mora Robles, MD[4]; Peter W. Forbes, MA[5]; Dora Judith Soberanis Vasquez, RN[6]; Ricardo Mack, MD[3,7]; Federico Antillon-Klussmann, MD, PhD[6,7]; Monica Kleinman, MD[8]; and Carlos Rodriguez-Galindo, MD[1]

- **PEWS/EVAT is valid** to predict need for **unplanned ICU transfer** in children with cancer
  - Scores elevated for 12 to 24 hours prior to PICU transfer
- **Higher PEWS/EVAT** at PICU admission predicts **organ dysfunction, higher severity of illness**, **critical interventions** (mechanical ventilation, vasoactives), and **mortality**

Agulnik *et al PCCM* 2016 and *Cancer* 2017

Impact of PEWS on Perceived Quality of Care During Deterioration

Conclusion: Providers that care for children with cancer find PEWS valuable to improve the quality of hospital care, regardless of hospital resource-level. Identified challenges, including inadequate critical care resources and challenges with technology, differ by hospital resource-level. These findings build on growing data demonstrating the positive impact of PEWS on quality of care and encourage wide dissemination of PEWS in clinical practice.

Keywords: cancer, critical care, pediatric oncology, early warning systems, clinical deterioration, qualitative analysis

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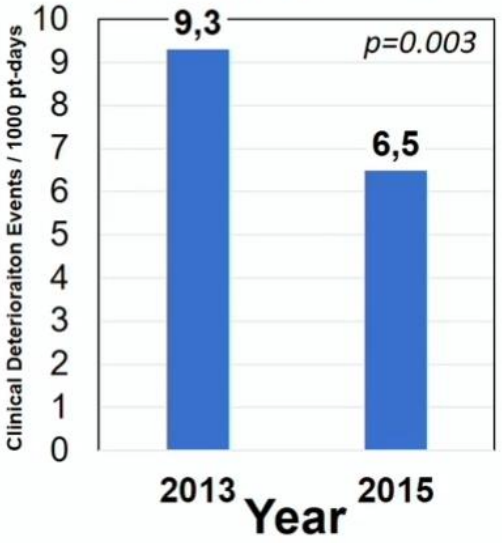
Impact on *Patients*

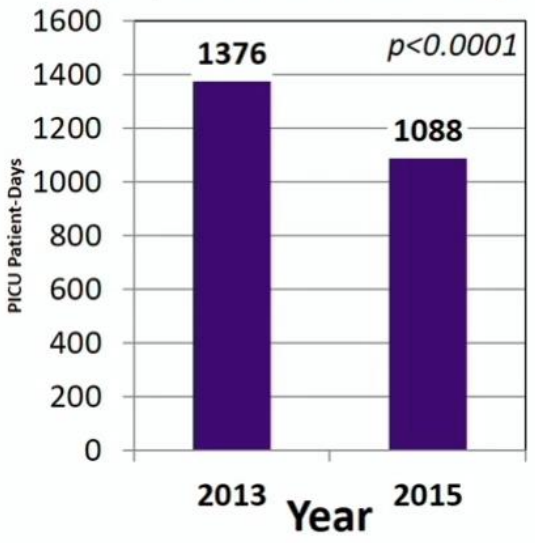
Improved Outcomes After Successful Implementation of a Pediatric Early Warning System (PEWS) in a Resource-Limited Pediatric Oncology Hospital

Asya Agulnik, MD, MPH[1,2]; Lupe Nataly Mora Robles, MD[3]; Peter W. Forbes, MA[4]; Doris Judith Soberanis Vasquez, RN[5]; Ricardo Mack, MD[3,6]; Federico Antillon-Klussmann, MD, PhD[3,6]; Monica Kleinman, MD[7]; and Carlos Rodriguez-Galindo, MD[1]

Clinical Deterioration Events



PICU Patient-Days (Unplanned Transfers)



PEWS implementation **reduced clinical deterioration** events and **PICU utilization**

Agulnik *et al* Cancer 2017

Impact on *Patients*

frontiers in Oncology

ORIGINAL RESEARCH
published: 23 June 2021
doi: 10.3389/fonc.2021.660051

Impact of PEWS on Perceived Quality of Care During Deterioration in Children With Cancer Hospitalized in Different Resource-Settings

Marcela Garza[1], Dylan E. Graetz[1], Erica C. Kaye[2], Gia Ferrara[1], Mario Rodriguez[3], Dora Judith Soberanis Vásquez[4], Alejandra Méndez Aceituno[5], Federico Antillon-Klussmann[3,6], Jami S. Gattuso[7], Belinda N. Mandrell[7], Justin N. Baker[2], Carlos Rodriguez-Galindo[1] and Asya Agulnik[1,8]

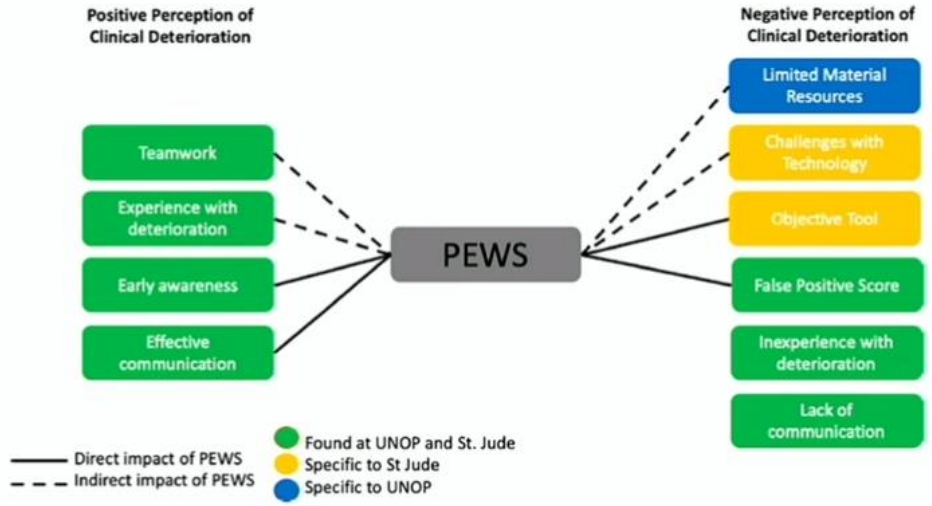
St. Jude Children's Research Hospital
Finding cures. Saving children

UNOP UNIDAD NACIONAL DE ONCOLOGÍA PEDIÁTRICA

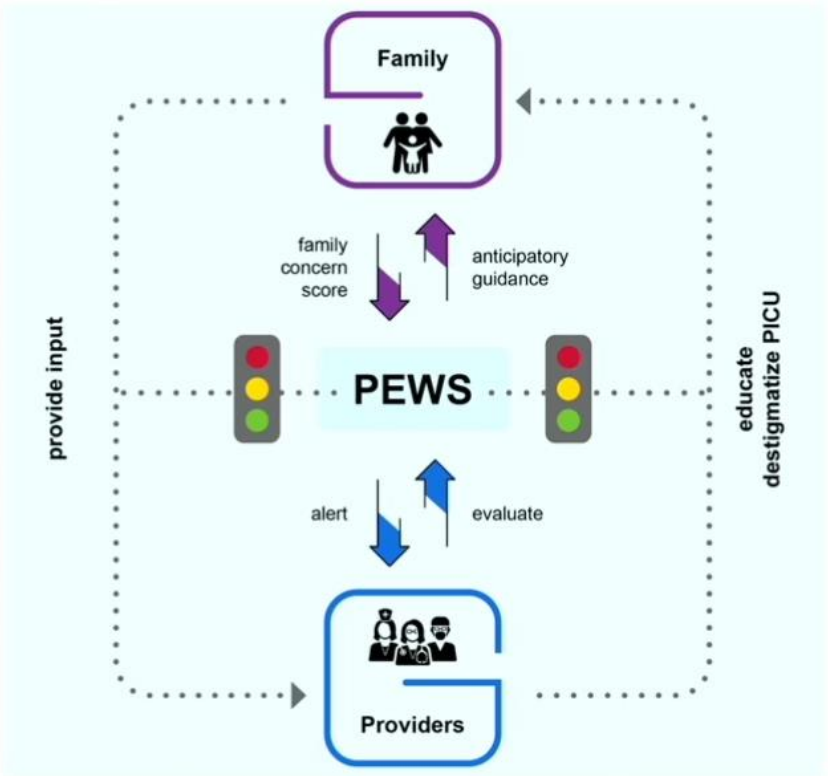
Dr. Marce Garza

Dr. Dylan Graetz
Faculty, St. Jude Global

- Qualitative study about the impact of PEWS/EVAT
- 83 interviews with medical staff at St. Jude and UNOP
- PEWS seen as valuable to improve quality of hospital care, regardless of hospital resource-levels



Impact on *Families*



Nithya Gillipelli
Medical Student

Dr. Dylan Graetz
Faculty, St. Jude Global

Pediatric Early Warning Systems (PEWS) improve provider-family communication from the provider perspective in pediatric cancer patients experiencing clinical deterioration

Srinithya R. Gillipelli[1,2] | Erica C. Kaye[3] | Marcela Garza[2] | Gia Ferrara[2] | Mario Rodriguez[4] | Dora Judith Soberanis Vasquez[5] | Alejandra Mendez Aceituno[6] | Federico Antillón-Klussmann[4,7] | Jami S. Gattuso[8] | Belinda N. Mandrell[8] | Justin N. Baker[3] | Carlos Rodriguez-Galindo[2] | Asya Agulnik[2] | Dylan E. Graetz[2]

- PEWS improves **family – provider communication** by including the family as part of the care team

Gillipelli...Agulnik, Graetz *Cancer Medicine* 2022

Impact on the *Institution*

Cost-Benefit Analysis of Implementing a Pediatric Early Warning System at a Pediatric Oncology Hospital in a Low-Middle Income Country

Asya Agulnik, MD, MPH [1]; Federico Antillon-Klussmann, MD, MMM, PhD [2,3]; Dora Judith Soberanis Vasquez, RN [2]; Rosa Arango, MBA [2]; Elmer Moran, MA [2]; Victor Lopez, MD [2]; Carlos Rodriguez-Galindo, MD [1]; and Nickhill Bhakta, MD, MPH [1]

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Dr. Nickhill Bhakta
Faculty, St. Jude Global

- Cost of PEWS implementation at UNOP in 2014 was ~$14,000
  - $7 per hospital admission that year
- Implementation of PEWS resulted in a **cost-savings of over $350,000** in 2015

Conclusion: Implementation of PEWS can improve quality of care and reduce hospital costs though reducing unplanned PICU transfer

Proyecto EVAT *Implementation Outcomes*

EVAT

Since **April 2017**:

> **11,100 nurses and physicians** trained in PEWS

> **41,000 hospital admissions** benefited from PEWS use in their care

Agulnik et al, *Cancer*, in press