
بسم الله الرحمن الرحیم

An overview of special issues on Supportive and Palliative care in Children cancer

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Children cancer

Cure*All* framework: WHO Global Initiative for Childhood Cancer. Increasing access, advancing quality, saving lives

- **Every day, more than 1,000 children are diagnosed with cancer globally.**
- **Of the estimated 400,000 children diagnosed with cancer each year (**one in 500 children in their lifetime**)**
- **Iran pediatric cancer rates :** annual incidence of new cancer cases is about 3500; Ongoing annual cases is about 1700 cases ; ongoing under treatment cases is about 7000

(Oral communication Ref: MAHAK; IPHOS; MOH)

- More than 90% of children with cancer live in LMIC
- Increasingly, childhood cancer represents a substantive contributor to **disability-adjusted life years (DALYs),** surpassing select other childhood diseases and adult cancers :
  - DALYs are the sum of years of **potential life lost** due to **avoidable mortality** & the years of **productive life** lost due to **disability.**

World Health Organization

WHO Global Initiative for Childhood Cancer: An Overview

80% OF CHILDREN WITH CANCER WILL **SURVIVE** IN HIGH-INCOME COUNTRIES

ONLY ABOUT **20%** OF CHILDREN WITH CANCER WILL **SURVIVE** IN SOME LOW- AND MIDDLE-INCOME COUNTRIES

THE GOAL OF THE GLOBAL INITIATIVE IS TO ACHIEVE AT LEAST A

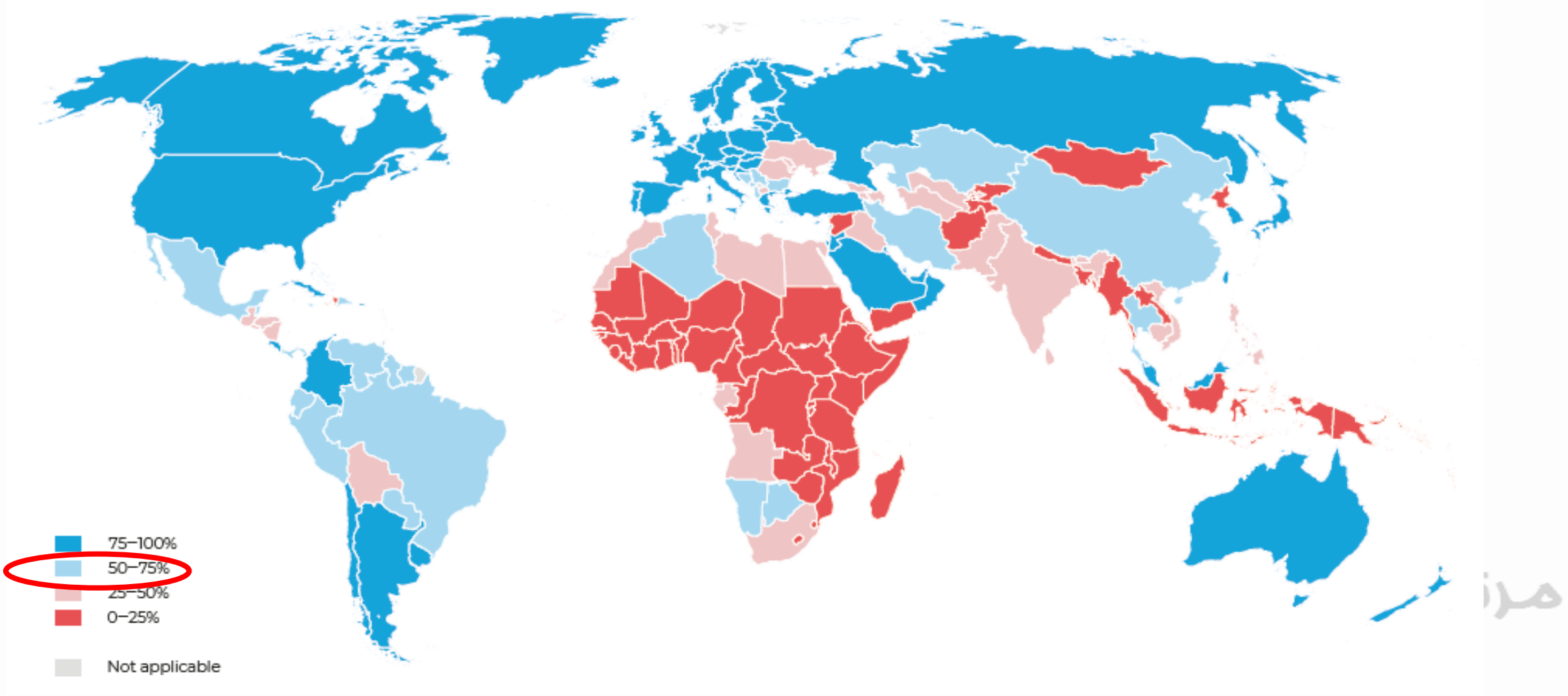
60% SURVIVAL

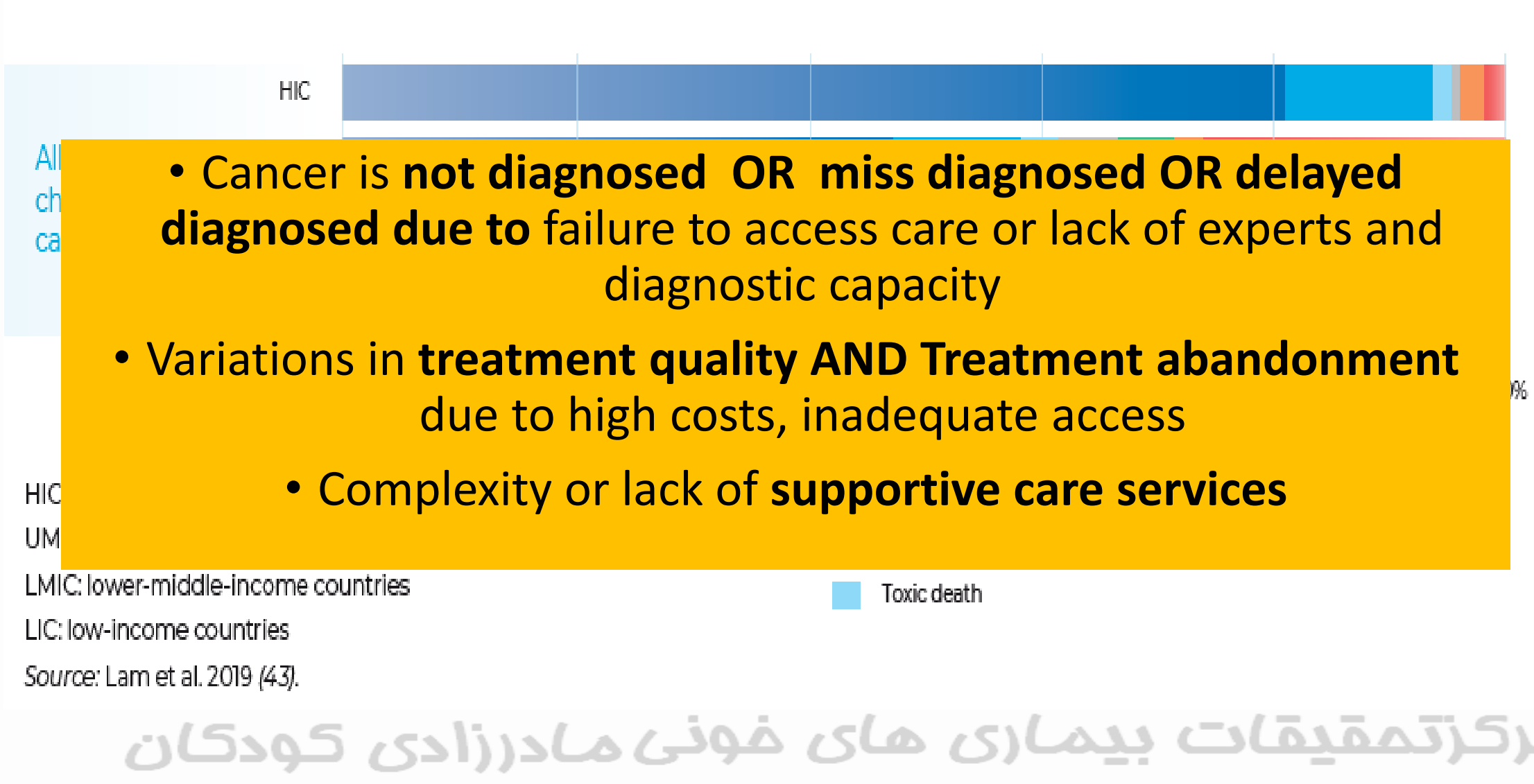
AND TO REDUCE SUFFERING FOR ALL CHILDREN WITH CANCER BY 2030.

1 MILLION

CHILDREN WITH CANCER CAN BE SAVED IN THE NEXT DECADE.

Estimated childhood cancer 5-year net survival by country (2015–2019)

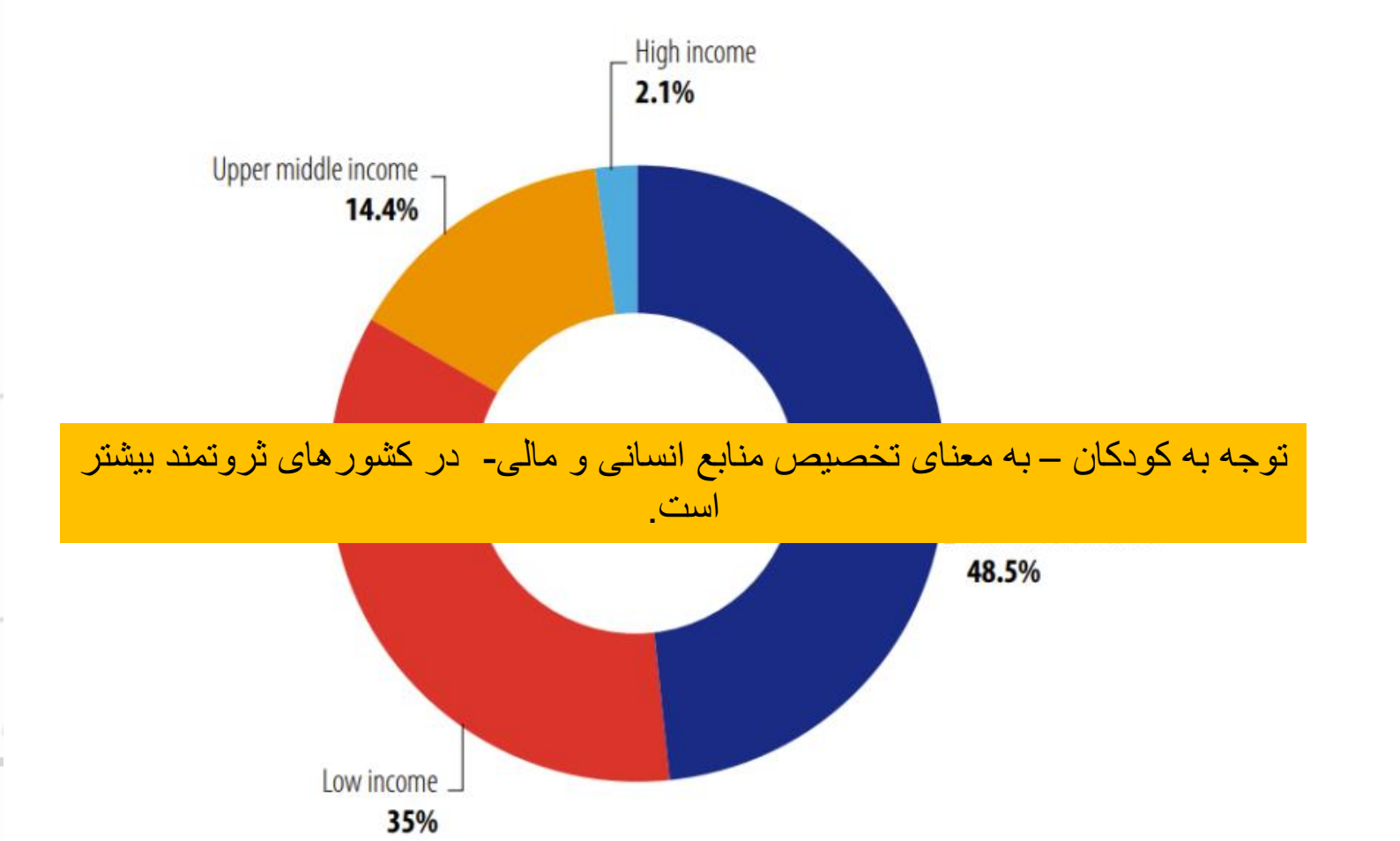




- Cancer is **not diagnosed OR miss diagnosed OR delayed diagnosed due to** failure to access care or lack of experts and diagnostic capacity
- Variations in **treatment quality AND Treatment abandonment** due to high costs, inadequate access
- Complexity or lack of **supportive care services**

CureAll framework: WHO Global Initiative for Childhood Cancer. Increasing access, advancing quality, saving lives. World Health Organization; 2021

Where do the kids who need Palliative Care live?



توجه به کودکان – به معنای تخصیص منابع انسانی و مالی- در کشورهای ثروتمند بیشتر است.

Myths and Misconceptions of Children Cancer
Children do not develop cancer
Childhood cancers are preventable
Most children with cancer die of their disease
Childhood cancer is one disease, treated with a standardized approach
Childhood cancer chemotherapy is expensive
Even if children survive cancer, they are left with permanent and severe disabilities

Causes of death in 6-11m – Iran – GBD 2023

Age	Rank	Cause of death	2019	2022	2023
6-11 months	**1**	Congenital birth defects	696	543	511
6-11 months	**2**	Neonatal disorders	242	162	149
6-11 months	**3**	Endocrine, metabolic, blood, and immune disorders	161	123	116
6-11 months	**4**	Lower respiratory infections	132	77	77
6-11 months	**5**	Road injuries	114	75	68
6-11 months	**6**	Foreign body	57	42	38
6-11 months	**7**	Sudden infant death syndrome	39	31	29
6-11 months	**8**	Idiopathic epilepsy	41	29	26
6-11 months	**9**	Other cardiovascular and circulatory diseases	41	28	26
6-11 months	**10**	Diarrheal diseases	47	29	25
6-11 months	**11**	Chronic kidney disease	34	24	22
6-11 months	**12**	Cardiomyopathy and myocarditis	31	20	18
6-11 months	**13**	Falls	28	20	18
6-11 months	**14**	Leukemia	22	17	16
6-11 months	**15**	Other chronic respiratory diseases	20	15	15
6-11 months	**16**	Other malignant neoplasms	20	15	14
6-11 months	**17**	Fire, heat, and hot substances	15	12	11
6-11 months	**18**	Exposure to mechanical forces	19	13	11
6-11 months	**19**	Drowning	18	12	11
6-11 months	**20**	COVID-19	0	18	11

Causes of death in 12-23m – Iran – GBD 2023

Real rank of Total cancer death rates
44

Age	Rank	Cause of death	2019	2022	2023
12-23 months	1	Congenital birth defects	311	245	230
12-23 months	2	Road injuries	178	114	102
12-23 months	3	Lower respiratory infections	83	49	49
12-23 months	4	Endocrine, metabolic, blood, and immune disorders	57	42	39
12-23 months	5	Falls	44	30	27
12-23 months	6	Drowning	46	28	25
12-23 months	7	Neonatal disorders	39	26	24
12-23 months	8	Foreign body	36	25	22
12-23 months	9	Leukemia	30	23	21
12-23 months	10	Fire, heat, and hot substances	27	22	21
12-23 months	11	Cirrhosis and other chronic liver diseases	26	19	18
12-23 months	12	Other cardiovascular and circulatory diseases	28	19	17
12-23 months	13	Idiopathic epilepsy	26	17	15
12-23 months	14	Diarrheal diseases	28	17	15
12-23 months	15	Brain and central nervous system cancer	16	13	12
12-23 months	16	Exposure to mechanical forces	21	13	12
12-23 months	17	Other chronic respiratory diseases	15	11	11
12-23 months	18	Other malignant neoplasms	15	12	11
12-23 months	19	Chronic kidney disease	15	10	9
12-23 months	20	COVID-19	0	17	9

Causes of death in 2-4 yrs – Iran – GBD 2023

Age	Rank	Cause of death	2019	2022	2023
2-4 years	1	Road injuries	469	326	291
2-4 years	2	Congenital birth defects	317	266	247
2-4 years	3	Leukemia	78	64	59
2-4 years	4	Falls	84	62	56
2-4 years	5	Endocrine, metabolic, blood, and immune disorders	75	60	55
2-4 years	6	Drowning	91	62	54
2-4 years	7	Fire, heat, and hot substances	67	56	53
2-4 years	8	Lower respiratory infections	80	49	49
2-4 years	9	Exposure to mechanical forces	61	42	37
2-4 years	10	Other cardiovascular and circulatory diseases	51	37	33
2-4 years	11	Brain and central nervous system cancer	42	35	33
2-4 years	12	Foreign body	45	34	31
2-4 years	13	Idiopathic epilepsy	43	32	28
2-4 years	14	Cirrhosis and other chronic liver diseases	25	20	18
2-4 years	15	Neonatal disorders	28	20	18
2-4 years	16	Chronic kidney disease	25	19	18
2-4 years	17	Other malignant neoplasms	23	19	17
2-4 years	18	Interpersonal violence	19	16	14
2-4 years	19	Stroke	24	16	14
2-4 years	20	Other unintentional injuries	23	15	14

What is Supportive & Palliative Care

- Palliative care (PC) is **a HOLISTIC approach** that **improves the Quality of Life(QoL)** 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)
  - In common terms mostly focuses on : Complex symptom management; Advance care planning ;Goals-of-care discussions ;Psychosocial and spiritual support ;End-of-life care when needed
- Supportive care (SC) focuses on **preventing and managing** the **physical and psychological effects** of **cancer and its treatment , including :** Managing chemotherapy-induced nausea and vomiting ;Treating pain ;Blood transfusions ;Infection prevention and treatment ;Nutritional support ;Rehabilitation ;Psychological support ;Managing treatment toxicities.

What is Supportive & Palliative Care

- It is an integrated model in which palliative care is provided from the beginning of the diagnosis and continues throughout the course of the disease regardless of whether the outcome is treatment or death.
- Palliative care in critically ill patients does not hasten death AND is not equivalent to euthanasia.
- Can reduce overall cost of care while improving key quality metrics of care
- Should be provided in Home/Clinic/Hospital/Hospice
  - The best model is :

Supportive care for all patients & Palliative care for those with additional needs,

Integrated and delivered concurrently with cancer-directed therapy.

Special issues of Pediatric Palliative care

- **More emotionally charged** because of societal expectations regarding childhood and the rarity of child death
  - Cancer is More **unbelievable** than adults
- **Longer life span and longer life expectancy :**
  - require a longer time to face problems and life-long consequences Manage long-term physical, psychosocial effects
  - More cost effective
- Less dependence to Hospice care and discussion
- **Growth, development, continuous and rapid physiological, hormonal, emotional and behavioral changes**
- **Education** issue and schooling
- More focus on **family structure**: parental problems, guilt, over-support, parental differences, genetic problems and subsequent pregnancies, damage to siblings.
- National policies for **population rejuvenation**

Supportive and Palliative care in Children Cancer

1. **Specialized and subspecialized management of clinical symptoms**:
    1. mucositis;
    2. more difficult assessment of pain & **pain relief:**provided with play or music therapy using distraction techniques, role play and pharmacological support
    3. weight-based medication dosage and age-related pharmacokinetics;
    4. more nonverbal anxiety;
    5. coping with and treating anorexia;
    6. collaboration in physical medicine and rehabilitation treatments;
    7. assessment of hearing and vision complaints ;
    8. **Nutrition**
    9. **Infection prevention and control**
    10. **Nursing with** specialized competencies of paediatric oncology care : Iv access ; Bladder catheterization ; NG tube ; immobilization ; etc

Continue:

2. **FAMILY-CENTRED :** In pediatric oncology, patient`s autonomy does not take precedence and the family is considered part of the patient unit legally and ethically.
    2. Major concerns : Parental distress ;Sibling needs ;Financial burden ;Caregiver exhaustion
    3. Palliative team`s main action: Family communication ;Sibling support programs ;Bereavement preparation ;Care coordination
3. **Prognostic perspective:**Children often have Higher cure rates & Potential for long-term survival than adults :
    2. More hope leads to more stress on treatment team and family
    3. Pediatric palliative care frequently runs concurrently with aggressive disease-directed therapy for prolonged periods
4. **Ethical Challenges:**Pediatric patients usually cannot provide **full legal consent**.
    2. Issues include:Parental decision-making ;Child assent ; Experimental therapies ;Treatment refusal ; future fertility ; Goals-of-care discussions ; Code status
    3. Questions often arise such as: How much should a teenager participate in decisions? When should clinicians challenge parental requests for non-beneficial treatment?

Continue:

5. Developmental Considerations: Children's understanding of illness changes with age.
   - Infants and Toddlers :
     - Concerns : Separation anxiety ; Procedural pain ; Disruption of attachment ;
     - Care priorities : Comfort measures ; Parent presence ; Minimizing invasive procedures
   - School-Age Children :
     - Concerns: Fear of procedures ; Missing school ; Loss of normal activities
     - Care priorities : Honest age-appropriate explanations ; School reintegration ; Peer connections
   - Adolescents:
     - Concerns: Independence ; Body image ; Fertility ; Social relationships ; Future plans
     - Care priorities : Inclusion in decision-making ; Privacy ; Fertility preservation discussions ; Psychological support
     - Special **Adolescents and young adults (AYA) care**
6. Social and educational development: supporting school and having **access to play and developmental activities**(including **in-hospital schooling programmes**, dedicated play areas, **play therapists and music/art therapies**,)

7. Spiritual and Existential Concerns : God ; Wishes ; Difference ; Death ; etc

Well-established models for pediatric cancer supportive and palliative care

- Model 1: Comprehensive Pediatric Cancer Center Model (High-Income Countries): Integrated multidisciplinary specialists management
- Model 2: Embedded Oncology-Led Palliative Care (Common in middle-income countries) : In this model pediatric oncologist is the first line manager for both SC and PC and other specialist palliative consultation occurs only for advanced ,refractory cases ,or for legal and ethical issues
- Model 3: WHO Public Health Model for LMICs. The World Health Organization advocates a Four Pillars public-health approach: Policy;Education ;Drug availability ; service implementation
- Model 4: Shared-Care / Hub-and-Spoke Model: Commonly used in parts of:IndiaBrazilMexicoSouth Africa
- Model 5: Community-Based Pediatric Palliative CareParticularly important where hospital access is limited.

Essential Supportive Care Package for Resource-Limited Settings

- Many experts argue that supportive care **should be prioritized alongside chemotherapy.**
- Minimum package includes:
  - Infection management
  - Transfusion support
  - Nutrition
  - Pain management
  - Psychosocial care
  - End-0f-Life care (home care & Bereavement)
- Without these services, survival gains from chemotherapy alone may be limited.

- https://global.stjude.org/en-us/about/our-impact.html?project=global+comfort+promise+package
- https://cankidsindia.org/

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وزارت بهداشت، درمان و آموزش پزشکی

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Mofid Children's Hospital
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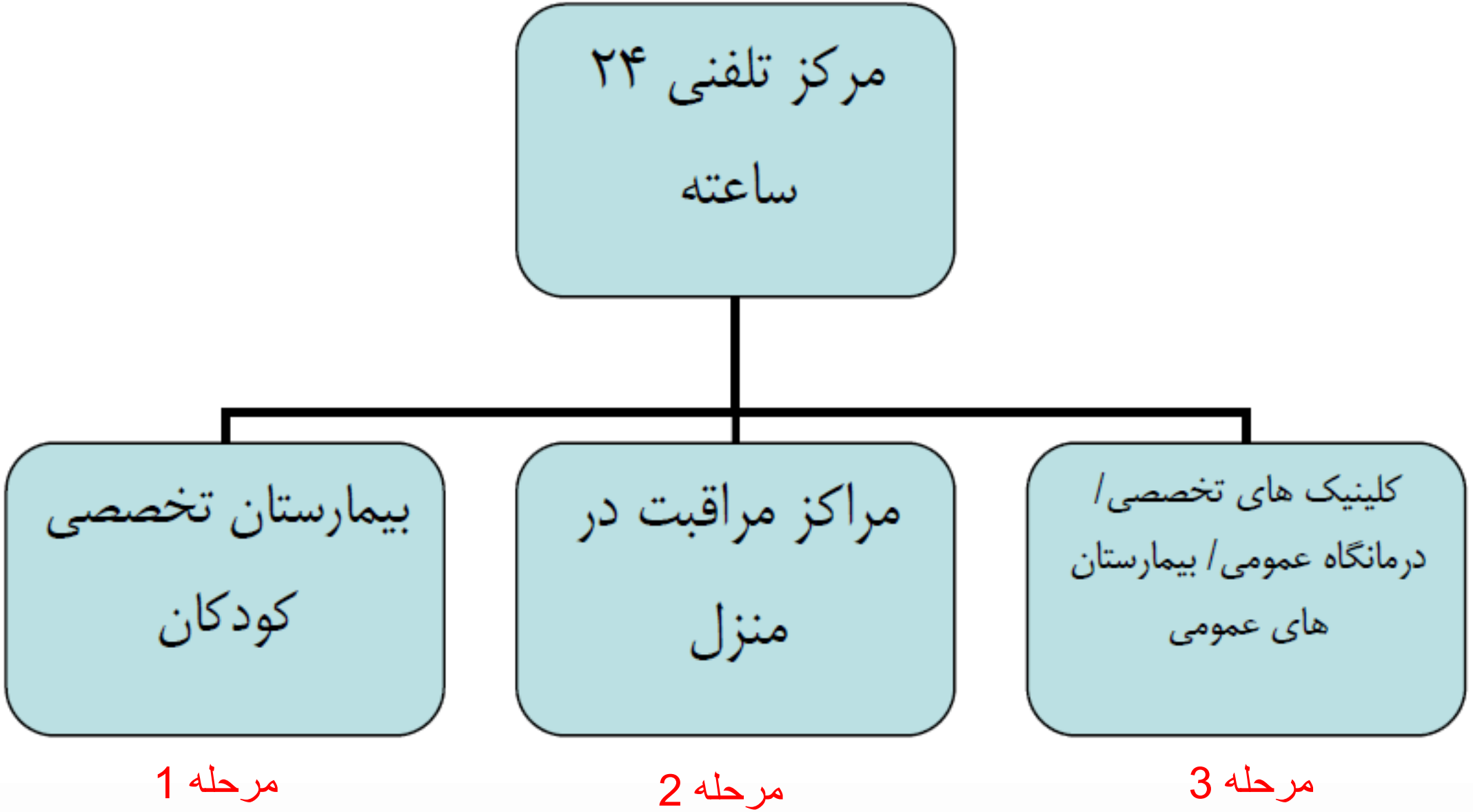
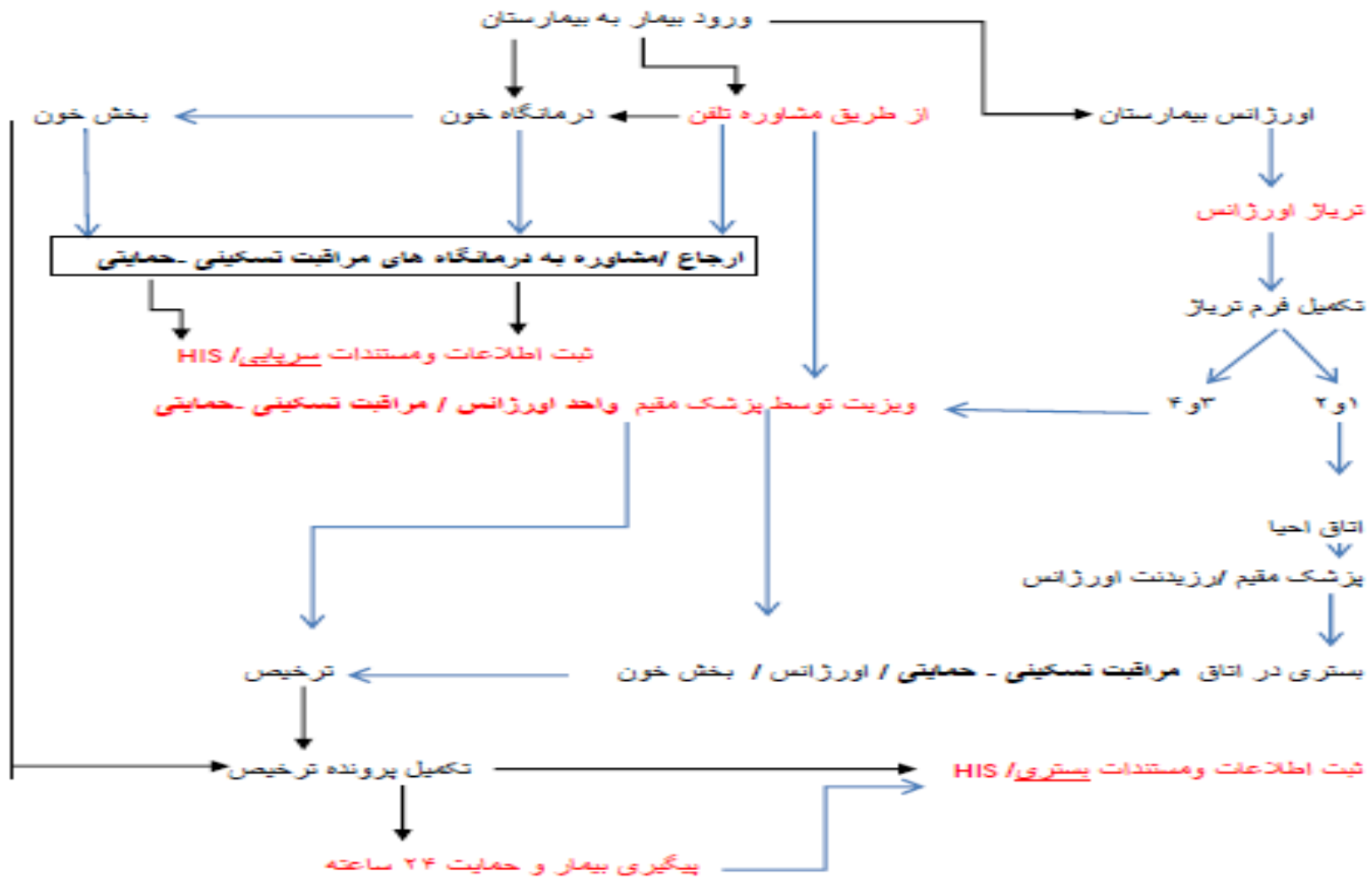
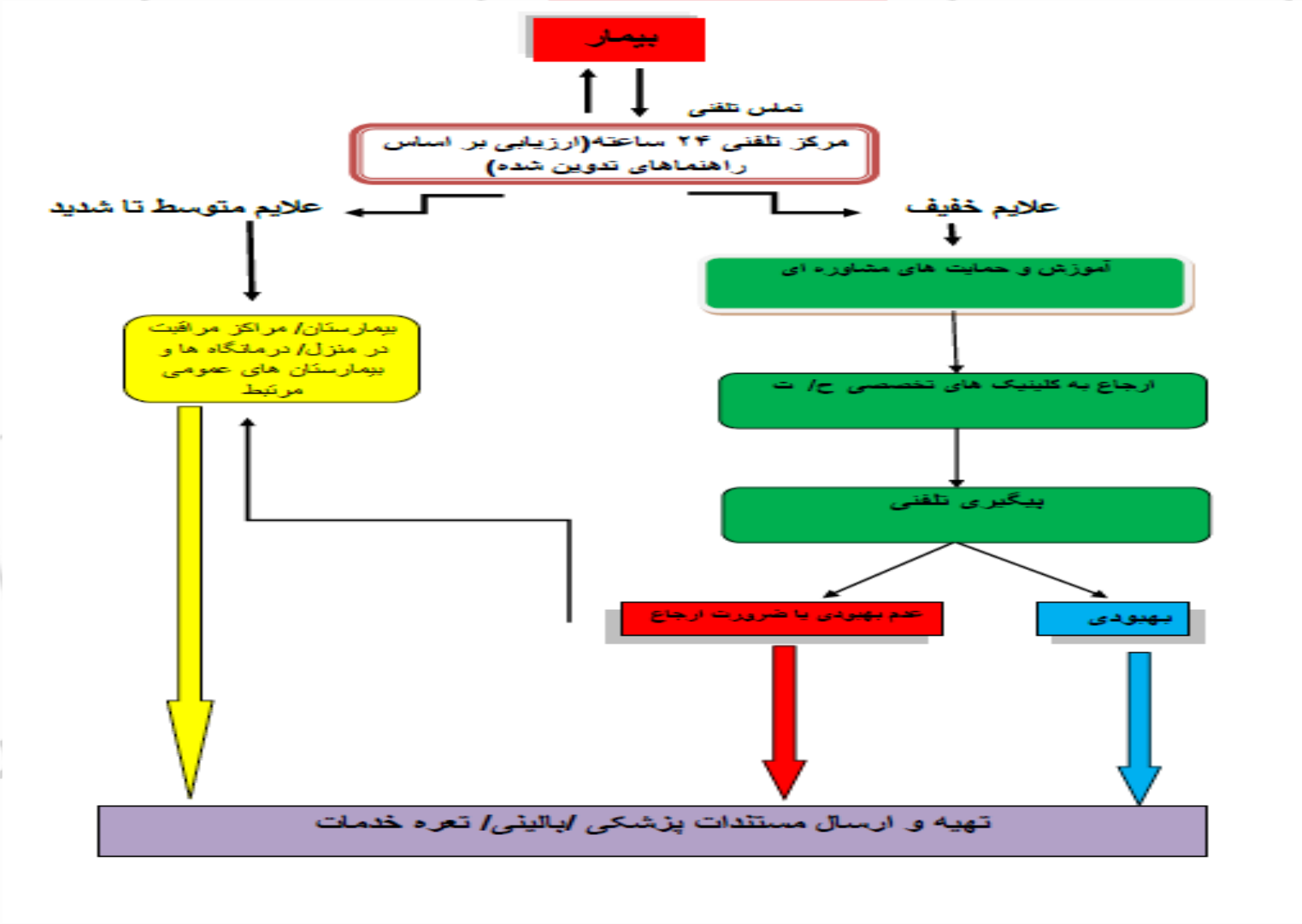

مرکز تلفنی ۲۴ ساعته
کلینیک های تخصصی/ درمانگاه عمومی/ بیمارستان های عمومی
مراکز مراقبت در منزل
بیمارستان تخصصی کودکان
مرحله 3
مرحله 2
مرحله 1

فلو چارت خدمات در مراجعه به بیمارستان



فلو چارت خدمات تلفنی /مشاوره



عقد تفاهم نامه با موسسه مکسا و آغاز همکاری از سال1402

قطع همکاری و پایان تفاهم نامه با تنها مرکز تسکینی حمایتی مورد تایید وبدا در سال 1404