EPEC-Pediatrics

Communicating with Children & Families : The Importance of Child Development in Paediatric Palliative Care

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Children's HOSPITALS AND CLINICS of Minnesota

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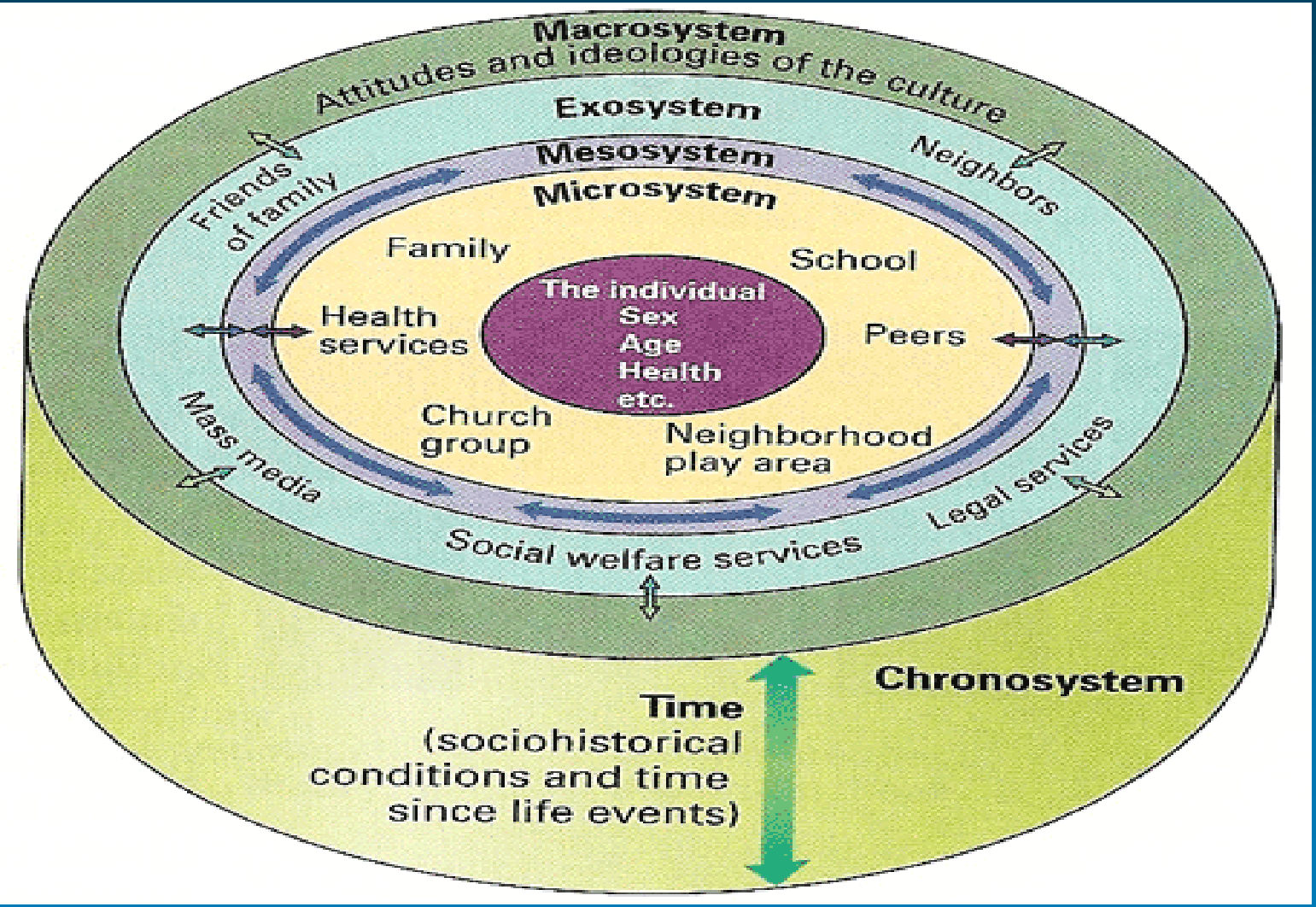
What is Child Development?

- Refers to the biological, psychological & emotional changes that occur between birth and early adulthood, as a child progresses from dependency to increasing autonomy
- The product of dynamic interactions between the child and the experiences provided by their family & social environment

Ecological Model of Development



- Urie Bronfenbrenner

Characteristics of Typical Development

- Reflects the maturation of a child's developing nervous system
- Skill acquisition occurs in a stepwise sequence, building on previous skills

  Eg. Sit, stand, walk
- Sequence is similar – but rates vary within a normative range (for typical development)

Developmental Domains

- **Communication**
  - speech & language
- **Gross Motor Function (ie. big muscles)**
  - balance, coordination
- **Fine Motor Function**
  - hand skills, finger dexterity
- **Problem Solving ('cognition')**
  - thinking skills – how a child learns to do things for themselves
- **Personal-Social Development**
  - emotional development, social interaction, & adaptive function/self-cares eg. feeding, toileting, dressing

Typical development is a continuum, but sometimes things get in the way…

- For example :
  - Biological / Physical Factors (eg. illness)
  - Psychosocial / Environmental Factors (eg. trauma, neglect)

- These factors can impact or even *interrupt* stages of developmental growth

What is ‘developmental capacity?

- A individual’s ability to understand and process emotional, cognitive & social dimensions of their life
- In typical development, it can grow in capacity & complexity over time
- Influenced by many factors

Developmental Capacity & Illness

- Interactions need to be adapted to fit the child's age / developmental stage
- The cognitive, emotional & behavioural status of a child impacts his/her ability to :
  - Understand their medical condition
  - Understand therapies they might require
- Developmental capacity influences the meaning children attach to their experiences

Developmental Capacity & Illness

- Understanding how children at different stages of development conceptualise themes like health, illness & death can help us better care for children throughout serious illness

- Knowing a child's developmental capacity can help us tailor strategies to best support them (eg. during procedures)

Objectives for the session

- Learn typical phases of cognitive, psychosocial & emotional growth in children
- Learn how children of different developmental capacity understand concepts of illness & death, and how this can impact care planning
- Learn interventions that can be used to work with children of diverse ages along the illness continuum, as well as at end of life

Understanding illness, loss & death is also influenced by experience

- Effect of prior losses ; experiences of death & dying
- Family / community teaching about appropriate responses to illness or loss
- Belief systems, faith or spirituality

Developmental Capacity & Himelstein's Five Spheres of Practice in PPC

- PHYSICAL concerns (eg. pain)
- PSYCHOSOCIAL concerns (fears, coping, communication, family well-being, resources)
- SOCIAL & PRACTICAL concerns (location of care, school, friends, planned events, 'hoped-for' events)
- ADVANCE CARE PLANNING (goals, wishes & related care plans)
- CULTURAL & SPIRITUAL concerns (hopes, life meaning, religious beliefs)

Development can impact on each of these spheres, and in turn be influenced by the ways in which these evolve

Theories of Child Development

- Bronfenbrenner's Ecological Model of Development
- Erik Erikson
- Jean Piaget

Child Development : Infancy

Erik Erikson	Jean Piaget	Dominant Developmental Tasks
0 – 2yrs **Trust vs Mistrust**	0 – 2yrs **Sensorimotor**	**Learning basic physical skills** **Sensory exploration** **Positive attachment builds on experiences of basic trust**

Infant attachment and loss

- Infants may not cognitively “miss” someone in the same way that older children do…

  -> But do they experience loss

- Loss is primarily experienced through their environment (eg. separation from their primary caregivers ; disruption of safety, nurturing, routines)

Infant attachment and loss

- Young children can get depressed too…!

May present as :

- Failure to Thrive
- Generalised lack of vigour / lack of interest in their surrounds
- Developmental delay
- Developmental regression

Younger children who are seriously unwell…

Children may experience :

- **Inconsistency of their environment**
- **Inconsistent physical and / or emotional presence of their parent or carer**
- **A loss of competency (eg. around self-feeding, sitting / crawling on their own)**

Children may be *unable* to work on or achieve developmental tasks of this stage

An infant's world is small.. but no less important

We can help support families by:

- Ensuring their child is comfortable
- Helping to provide a predictable & secure environment with the consistency of a loving presence (parent or carer)
- To be held as much as is comfortable for them
- To be surrounded by familiar sights, sounds, smells
- To support family members – so they can be present for their child, as well as for each other

Case Example 1

Development : Pre-School Age

Erik Erikson	Jean Piaget	Dominant Development Tasks
2 – 3 yrs Autonomy vs Shame and Doubt 4 – 6 yrs Initiative vs Guilt	2-6 yrs Pre-Operational	Growing independence / autonomy Development of physical skills (eg. walking, talking, toileting) Ego Development & Ego Protection Symbolic & Imaginative Play Secure attachment allows exploration with safe return; fosters confidence

Younger (and older) children who are seriously unwell…

Children may experience :

- **Inconsistency of their environment**
- **A loss of competency / structure or routine**
- **Inconsistency of a physical and / or emotional presence of their parent or carer**

Developmental Capacity of Children Aged 2–6 yrs

- May become confused / frustrated by limits imposed by their illness or treatments
- May not cognitively understand why these things are happening to them / why they are required
- Behaviour may regress when overwhelmed
- Tend to act out their feelings of loss, grief or anxiety rather than verbalise them
- May not possess the words or concepts to express their frustration

Understanding of Death, Children Aged 2–6 yrs

- Concrete understanding ; defined by experiences
  - "When you are dead you still have to eat & sleep" ;
  - "You can still play or go to work"

- But also 'magical thinking'
  - May fictionalize death or dying
  - May have unrealistic associations of the *cause* of dying, eg. "Bad actions or thoughts can cause illness or death"

- Egocentric view of the world : "I caused it"
  - Illness may be seen as 'punishment for bad behaviour'

Understanding of Death, Children Aged 2–6 yrs

- Pre-school children are very observant …
  … But not always right.!
  Eg. “Going to the hospital makes you die…”

- Do not grasp the finality of death :

eg. ‘Someone or something can make you “get alive” again’

- May see illness or death as a failure on the part of adults who “should be able to make it go away”

Egocentricity : hence may assume that their feelings & perceptions are universal!

How do we help pre-school aged children?

- Ensuring their child is comfortable
- Create a safe, secure and relatively predictable environment
- Support routine : keep things familiar if possible
- Explain things in a developmentally-appropriate way ; use play therapy / Child Life specialists
- Help family members support their child :
  - Help parents be ‘Bigger, Stronger, Wiser & Kinder’ (Circle of Security)

Child Development : School Age, 6-12 years

Erik Erikson	Jean Piaget	Dominant Development Tasks
6 – 12 yrs Industry vs. Inferiority	6 – 12 yrs Concrete Operational	Accumulation of skills & knowledge Pride in accomplishment Social development Balancing imagination & logic

Understanding of Illness & Death in School Aged Children, 6–12 yrs

- May worry about ‘body integrity’
  - May become anxious about changes in their body -> ‘invasion’ or contagion
- Now able to draw a clear separation between ‘alive’ and ‘dead’
  - Understand that death is appropriate for ‘old people,’ animals etc
  - See death as final, but happening to others, “not me”
  - Tend to feel exempt, or able to flee / avoid

Understanding of Death, School Aged Children, 6–12 yrs

- May be fascinated with death
- Associate death with the disintegration of the body : may be curious about burial details & funerals
- May anthropomorphize death (may believe in ghosts, the bogieman etc)

Case Example 2

How do we help & support families when a young child is dying?

- A dying child's world & the world of their family may feel overwhelmed by this reality
- Moments 'outside' of this time, no matter how small, can & should be recognised & celebrated
- Help the child & their family to remember good things – create shared memories ; support & enable moments of fun

When a young child is dying…

- Support a child's sense of self
- Support the child's resiliency
- Be honest & help the child to understand what is happening to them in terms they can understand & relate to

Allow them other ways to express their feelings :

eg. Art therapy ; story-telling or bibliotherapy

Create new / alternative resources for coping :

eg. Active imagination exercises, visual imagery

Let’s tell a story…

… Once upon a time there was a child named _____ who felt very ____ (sad, confused, worried, glad) because…

… And the first thing that happened that made him / her feel ____ was…

… And something helped…

What do you think helped?

Child Development: Adolescence

Erik Erikson	Jean Piaget	Dominant faith-development tasks
13yrs - Young Adult **Identity vs Role Confusion**	13 yrs + **Formal Operational**	**Personal identity formation** Seek belonging & acceptance in social participation **Abstract thinking** Preparation for work / career

Understanding of Illness & Death in Adolescence

- Understand concrete & abstract concepts
  - Can understand the biological processes of illness, dying & death
  - Understand the permanence & reality of death (as applicable to them)
- May engage in high-risk behaviours because they may consider themselves ‘exempt from consequences’
- Emotions are more in line with those of adults

What matters most to Adolescents & Young Adults?(AYA)

- Loss of independence
- Stigmatisation
- Increased social isolation

  ? Role of social media
- Fear of being forgotten -> legacy making
- May want to make their own choices / express preferences regarding end of life

Case Example 3

Interventions for AYA

- **Build rapport**
  - Spend time talking without a parent present
  - Get to know the teen as an individual / independent being
  - Find out what is important to them
- **Encourage independence & autonomy**
  - Involve the teen in decision-making
  - Consider giving responsibility to the teen for scheduling of events eg. medical appointments, hospice visits

Interventions for AYA

- Encourage school attendance & participation if desired
  - Accomplishing academic goals may be an important objective for ill teens
- Encourage the family to maintain routines as much as possible
  - Have age-appropriate expectations for the teens' behaviours & activities
  - Limits & structures may be comforting during times of stress

Interventions for AYA

- Support time spent with peers
  - Decrease isolation
  - Encourage involvement in social groups that are important to the teen
- Encourage teens to maintain hobbies, activities, interests that are important to them

Helping families talk to their child about death & dying

- Families often need assistance
- Find out about the child's and family's wishes (including cultural, religious or social customs)
- "How much should we tell our child?"
- Share research : allows open communication to discuss any aspect of the illness experience

Kreicbergs 2004 : nationwide study of 429 bereaved parents in Sweden

- Of the 147 parents who had talked about death with their child, none of them regretted it
- Of the parents who did not discuss death with their child, 27% regretted not having done so
- Parents who sensed their child was aware of his / her imminent death were more likely to regret not having talked about it (47%)

Helping families talk to their child about death & dying

- If family values permit this conversation, parents benefit from assistance -> talk it through with parents first
- Parents know their child best : go through some ‘ who, what, where, when, how’s ’
- Recommend starting the conversation with something the child can recall
- Be as honest as possible

Talking to children : the most difficult conversations

- Allow for silence
- Respond to questions
- Take a break to process
- Come back when ready (there may well be more questions!)

The goal is for facilitated and supported communication to happen within the family, but at the pace that is right for them.

Preparing parents for sensitive questions…

- What's going to happen?
- Will I die?
- Did I do something wrong?
- Why didn't the treatment work?
- When will I die?
- Will you be ok?
- What will dying be like? Will it hurt?
- Who will be with me?
- What happens after I die?

“ What’s going to happen to me? ”

The following may be helpful to explain to the child :

- **What can and cannot be done**
- **Focus on concrete events & steps**
- **Break the process down : what will it feel like? what will happen first, then what?**
- **Tell the truth**
- **Use language that will fit the child’s experience & level of understanding**

When cure is no longer possible…

- **Remember : there is ALWAYS still room for hope – may need to shift goals slightly**

- **Reassure the child :**
  - **They will not be abandoned**
  - **They will have people around who they love / who love them**
  - **All efforts will be made to control their pain**
  - **The team will work hard to make sure they will ‘live as long as possible, as well as possible’**
  - **Focus on the here & now / on active steps**

Adolescents and Young Adults

- Adolescents : cognitively may be more like adults
- Monitor / consider anxiety or depression
- Risk of social isolation

- Address fears
  - Of abandonment
  - Of being separated from friends or family
- Acknowledge & accept range of feelings, talk about these
  - It is okay to feel confused, sad, angry, to want to be alone sometimes
- Support & encourage participation in normal daily routines ; maximise quality of life

“ Will I die? ”

- **First instinct response ?!**
- **Help parents**
  - **Name this possibility**
  - **Don’t camouflage the message with vague terms (or professional jargon)**
  - **Provide strategies that will help parents respond**
- **One technique…**
  - **“What are you most worried about?”**
  - **“It would help me better answer your question if you can tell me why you’re asking me…”**
- **Be as honest and straightforward as possible**
  - **Feelings of security & trust are maintained through honest communication**

“ Why didn’t the treatment work? ”

- **Reassure the child :**
  - **Nothing they did or said made this happen**
- **Differentiate for the child :**
  - **The *treatment* failed**
  - ***They* did not fail**

“ When will I die? ”

- Assess the child’s clinical status
- Be as honest about prognosis as you can, within reason of the facts

… But there is always uncertainty!

Better approach?

- Take it day by day : ‘one day at a time’

“ Will my parents & family members be okay? ”

- **Children may not voice their fears directly**
- **Ask the child : “Who are you worried about most?” “Why?” (may be parents, sibling, a single parent)**
- **Dispel misconceptions**
- **Help open up communication between the child & their family**
- **Offer reassurance**

-> The team will continue to support the child & family as they go through this difficult process

“ What will dying be like? ”

- **Ask the child what he / she thinks dying is like**
- **What do others think about dying? the afterlife or related concepts?**
- **What beliefs does the child’s community share?**
- **Encourage the child to imagine with you**

-> Try to create a positive image of what is possible (certain books may help start discussion)

“ Will it hurt? ”

- **Reassure the child : in almost all situations, we can assist them to be comfortable**

- **Children may have preferences : eg. some / mild discomfort so they can be more awake to spend time with family & friends**

“ Where will I be after I die? ”

- **Anxiety / distress about death may be influenced by their developmental capacity to anticipate the future**
- **Discuss belief systems / faith or spirituality if relevant to the child and their family**

“ Who will be with me? “

Ask the child :

- **Who do they wish to be with them?**

If it is feasible to leave hospital..

- **Where would they prefer to be at the end of their life?**

-> Discussing these issues openly together can bring increased comfort to the child

-> ‘Knowing the child’s wishes’ can also bring comfort to parents

Interventions to Enhance Communication : Younger Children

- Play is the language & vehicle for a younger child's expression
- Games, therapeutic toys, stuffed animals
- Medical play
- Art (dough, finger paints, sand art /therapy)

Interventions to enhance communication : older children

- Animal-assisted therapy (for everyone!)
- Therapeutic or personal artbooks, blogs, mock wills or advance planning, photography, video or other art media for legacy making
- Bibliotherapy : uses literature & story telling to reduce anxiety, gain insight, enhance self understanding
- Adolescents & young adults in particular may benefit from writing

Strategies to enhance communication with Adolescents and Young Adults…

- **Practical tips for working with AYA**
  - **LISTEN**
  - **Meet them where they are in the process**
  - **Be present without judgment**
  - **Peer support : space to ‘normalize’ their experience with that of other teens with serious illness**

- **Advanced care planning**
  - **Involvement in shared decision-making**

Adolescents and Young Adults

- **Leaving a legacy**
  - Focus on accomplishments
  - Begin early when they have energy
  - Balance between honouring AYAs & parental views / needs
- **Projects**
  - Videos
  - Writing a journal
  - Planning their service
  - Writing a will

Summary

- Recognize the impact of developmental status on a child's illness experience
- Identify family preferences regarding the inclusion of their child in decision-making processes
- Encourage children to participate in decision making to the level of their developmental capacity

- Provide opportunities for children to express themselves through multiple modalities
- Recognize that even very young children can experience loss
- Prepare families well so they feel supported & equipped in caring for their child

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