# Factors affecting child development in the context of serious illness: a scoping review

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This study is integral part of the follow-up research of the IMPACT project (Implementing Pediatric Advance Care Planning Toolkit) which focuses on enhancing children's involvement in their care

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## Introduction

#### **Pediatric palliative care**

Contributes to patient-centered care and well-informed decision making for caregivers, parents and children

#### Child's involvement in decision-making

- Calendar age ≠ ability to participate in deciscions
- Difficult to establish their ability to participate
- A child's development is highly individual

"Decision-making competence is not an on-or-off phenomenon, but differs over time and between specific decisions, situations and topics"

#### Aim of this study

To provide an overview of factors affecting child development in the context of serious illness.

#### **Research questions:**

- 1 Which prevailing theories and constructs are identified?
- 2 What typical developmental aspects are observed?
- 3 What factors influence ongoing development?



## **Methods**

#### **Scoping review**

Method based on:

- Arksey and O'Malley
- Joanna Briggs Institute

#### Literature search

- Databases: Medline, Embase, Psychinfo, CINAHL
- Domains: serious illness, child, communication, theory

#### **Study selection**

- Cognitive, social or emotional developmental aspects in children (0-18 years)
- Influential factors on development, in relation to illness

#### **Data collection and analysis**

- Extraction: study design characteristics, developmental theories, elements of development of 'young' and 'older' children, influencing factors declerating or accelerating child development
- Qualitative, thematic analysis to identify common themes: key elements of child development and influencing factors



#### Identification of studies via databases and registers **Articles identified from databases** (n = 14627) **Records removed before screening:** Medline: **n** = **3721** Duplicates: **n = 3381** Embase: **n = 6956** Psychinfo: **n = 1704** CINAHL: **n** = **2246 Records screened on title/abstract: Records excluded on title/abstract:** n = 11246 n = 11181 Full-text articles not retrieved Full-text articles sought for retrieval n = 8n = 65 **Records excluded at full-text:** Full-text articles assessed for eligibility n = 36 n = 57 • Content did not adhere to research question: n = 21 Sort of article: thesis n = 3 / abstract for congres n = 3 / review n = 3• Other language: n = 4 **Citation tracking Total articles included from screening** n = 3n = 21**Total articles included for analysis** n = 24



## Results

# Q1: Which prevailing theories and constructs are identified?

#### Piaget's theory of cognitive development

- Supported by authors: Development as a continuous process with overlapping stages, progression hindered by physical/social factors
- Contradicted by authors: Young children have incorrect reasoning for illness based on immanent justice

#### Other identified theories:

- Erikson's model of psychosocial development
- Werner's Orthogenetic principle
- Bronfenbrenner's ecological system theory
- Freud's psychosexual theory
- Carol Gilligan's theoretical model of interdependence and care in important relationships Life span development psychology
- Attachment theory
- Dynamic-maturational model of attachment
- Sullivan's interpersonal theory of psychiatry
- Fowler's model of faith development



## Results

Q2: What typical developmental aspects are observed?



early/middle childhood early adolescence middle/late adolescence Development DOMAINS Difficulty with verbalisation of expressing feelings [S24] Experiencing emotions based on the Lack of abstract reasoning resulting in behavioral consequences of the illness [\$14]: Worries/stress about: · Separation from friends and physical expression of unease [S24] Unpleasant medical treatment [S14] · impact on school activities • Relapse [514] Incapability of mentalization of illness · families treating them differently Future medical complications [S15] as if they are younger aspects [S1]: · Limitations on age-appropriate · Therapy adherence activities [S1, S12, S14] · Accepting their illness and its chronic nature Feel frustrated [S22] Concerned about daily activities [524] Egocentric thought [S3, S18, S23] Concrete reasoning [522] Abstract reasoning [S22] Magical thinking [S23] Think about why and how [S24] Focus on the future [S1, S2, S8, S14, S22] No basic concepts of physical distance or Focus on here and now [S1] chronological time [S23]: Are self-centered [S24] members: they may not want their Friendships with peers become involvement in the management plan [S5] Relationships with caregivers and teachers are important [S14] central [S23]: Compare self to other patients [S24] Use cognitive and emotional strategies [S14, S19] Use behavioral strategies to regulate response [514, S19] Change their hopes and plans for the future and what is important in life [\$1, \$2, \$8, \$14, \$22] Have a more realistic view of living with the illness [S1] Have a limited perspective of illness [S12]: Time distortion: difficulty realizing the Display illness as either a happy or sad impact of illness and treatment on story [S14] knowledge about the illness concerning: their future [S5] · Draw on own individual experience with General illness concept [S12] childhood illness [S21] Pain concept [S17] Can correlate and assume multiple · Regard illness as temporary [\$1, \$5] · Causes of the illness [S1, S6, S21] causations to illness [S3, S6, S18] Lack of the interest in cause of the illness · Side effects [S1] [51] · Influence of illness on other (psychosocial) aspects [S2, S12, S14, S16] Concept of death is developing: of the concept of death [S3, S18] · Large individual difference in the concept · Animism and magical thinking Understand the concept of death [S18] of death [S7] · Cannot distinguish between death and Understanding of causality of death Universality separation Permanence becomes more realistic and abstract [S18] · May see death as a punishment · Begin to understand permanence of death · Do not understand universality and [53,518] permanence of death Have difficulty recognizing and expressing symptoms [S8] - mentioning vague nonlocalized feelings [S12] Speak out how treatment affects them [S1] Speak little about their experiences Generate their own semantic of being ill [S8] conclusions [S11] Semantic representations are mostly May want to communicate directly Communication preferences [58] borrowed from parents [S11] with healthcare professionals, but More articulated parents often take the lead [58] Communication preferences [S8]: · More influenced by others · More differentiated and stable More abstract · Less influenced by adults' or peers' . More tend to take the lead over parents in communication with · Changed within a short time healthcare professionals Reside in background of information sharing with healthcare professionals [S8]

	early/middle childhood	early adolescence	middle/late adolescence
DOMAINS <		Development	
Psychological/ emotional aspects	Difficulty with verbalisation of expressing feelings [524]  Lack of abstract reasoning resulting in behavioral and physical expression of unease [524]  Incapability of mentalization of illness aspects [51]:  Therapy adherence Accepting their illness and its chronic nature  Concerned about daily activities [524]	Experiencing emotions based on the consequences of the illness [\$14]:  • Separation from friends  • impact on school activities  • families treating them differently as if they are younger  Feel frustrated [\$22]	Worries/stress about:  - Unpleasant medical treatment [514] - Relapse [514] - Future medical complications [515] - Limitations on age-appropriate activities [51, 512, 514]
General cognitive aspects	Egocentric thought [\$3, \$18, \$23]  Magical thinking [\$23]  No basic concepts of physical distance or chronological time [\$23]:	Concrete reasoning [522] Think about why and how [524] Focus on here and now [51]	Abstract reasoning [522]  Focus on the future [51, 52, 58, 514, 522]
Social aspects	Are self-centered [\$24]  Relationships with caregivers and teachers are central [\$23]:	Friendships with peers become important [S14]	Become more independent from family members: they may not want their involvement in the management plan [55]  Compare self to other patients [\$24]
Coping strategy	Use behavioral strategies to regulate respons	se [S14, S19] Change their	itive and emotional strategies [\$14, \$19] hopes and plans for the future and what is ortant in life [\$1, \$2, \$8, \$14, \$22]
Concep- tualization of illness	Have a limited perspective of illness [\$12]:  Oisplay illness as either a happy or sad story [\$14]  Draw on own individual experience with childhood illness [\$21]  Regard illness as temporary [\$1, \$5]  Lack of the interest in cause of the illness [\$1]	Time distortion: difficulty realizing the impact of illness and treatment on the first trure [S5]  Can correlate and assume multiple causations to illness [\$3, \$6, \$1.8]	Have a more realistic view of living with the illness [\$1]  Have more sophisticated/multidimensional knowledge about the illness concerning: General illness concept [\$12] Pain concept [\$17] Causes of the illness [\$1, 56, 521] Side effects [\$1] Influence of illness on other (psychosocial) aspects [\$2, \$12, \$14, \$16]
Conceptualization of death	Have no comprehensive understanding of the concept of death [\$3, \$18]  • Animism and magical thinking  • Cannot distinguish between death and separation  • May see death as a punishment  • Do not understand universality and permanence of death	Concept of death is developing:  Large individual difference in the concept of death [57]  Understanding of causality of death becomes more realistic and abstract [518]  Begin to understand permanence of death [53,518]	Understand the concept of death [S18]  • Universality  • Permanence
Communication about their illness	Have difficulty recognizing and expressing symptoms [58] - mentioning vague nonlocalized feelings [512]  Speak little about their experiences of being iii [58]  Semantic representations are mostly borrowed from parents [511]  Communication preferences [58]:  More abstract  Less influenced by adults' or peers' expectations  Changed within a short time  Reside in background of information sharing with healthcare professionals [58]	May want to communicate directly with healthcare professionals, but parents often take the lead [58]	Speak out how treatment affects them [S1]  Generate their own semantic conclusions [S11]  Communication preferences [S8]:  • More articulated  • More influenced by others  • More differentiated and stable  • More tend to take the lead over parents in communication with healthcare professionals

#### **Development DOMAINS** Difficulty with verbalisation of expressing feelings [S24] Experiencing emotions based on the consequences of the illness [S14]: Lack of abstract reasoning resulting in behavioral Worries/stress about: Psychological/ Separation from friends and physical expression of unease [S24] Unpleasant medical treatment [S14] · impact on school activities emotional Relapse [\$14] families treating them differently Incapability of mentalization of illness aspects Future medical complications [S15] as if they are younger aspects [S1]: · Limitations on age-appropriate \*1 Therapy adherence activities [S1, S12, S14] Accepting their illness and its chronic nature Feel frustrated [S22] Concerned about daily activities [S24] Egocentric thought [S3, S18, S23] Concrete reasoning [S22] General Abstract reasoning [S22] cognitive Magical thinking [S23] Think about why and how [S24] aspects No basic concepts of physical distance or Focus on the future [S1, S2, S8, S14, S22] Focus on here and now [S1] \*2 chronological time [S23]: Become more independent from family Are self-centered [S24] members: they may not want their Social aspects Friendships with peers become involvement in the management plan [S5] Relationships with caregivers and teachers are important [S14] \*3 central [S23]: Compare self to other patients [S24] Use cognitive and emotional strategies [S14, S19] Coping strategy Use behavioral strategies to regulate response [S14, S19] \*4 Change their hopes and plans for the future and what is important in life [S1, S2, S8, S14, S22] Have a more realistic view of living

Time distortion: difficulty realizing the

Have a limited perspective of illness [S12]:

with the illness [S1]

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important in ine [31, 32, 36, 314, 322]

#### Have a more realistic view of living with the illness [S1] Have a limited perspective of illness [S12]: Time distortion: difficulty realizing the Display Illness as either a nappy or sad Have more sophisticated/multidimensional impact of illness and treatment on Concepstory [S14] knowledge about the illness concerning: their future [S5] tualization General Illness concept [S12] · Draw on own individual experience with of illness childhood illness [S21] Pain concept [S17] Can correlate and assume multiple • Regard illness as temporary [S1, S5] Causes of the illness [S1, S6, S21] \*5 causations to illness [S3, S6, S18] · Lack of the interest in cause of the illness • Side effects [S1] [S1] Influence of illness on other (psychosocial) aspects [S2, S12, S14, S16] Have no comprehensive understanding Concept of death is developing: of the concept of death [S3, S18] Large individual difference in the concept · Animism and magical thinking Understand the concept of death [S18] of death [S71 · Cannot distinguish between death and tualization Universality Understanding of causality of death separation of death Permanence becomes more realistic and abstract [\$18] • May see death as a punishment \*6 Begin to understand permanence of death · Do not understand universality and [S3,S18] permanence of death Have difficulty recognizing and expressing symptoms [S8] - mentioning vague Speak out how treatment affects them [S1] nonlocalized feelings [S12] Speak little about their experiences Generate their own semantic of being ill [S8] conclusions [S11] Communication Semantic representations are mostly about their May want to communicate directly borrowed from parents [S11] Communication preferences [S8]: with healthcare professionals, but illness More articulated parents often take the lead [S8] More influenced by others Communication preferences [S8]: \*7 More abstract More differentiated and stable · Less influenced by adults' or peers' More tend to take the lead over expectations parents in communication with Changed within a short time healthcare professionals

Reside in background of information sharing with healthcare professionals [58]

# Results

# Q3: What factors influence ongoing development?

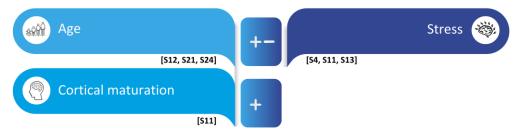
- Evidence was diffuse
- Several studies found shaping factors of child development, without specifying a unified direction of the impact
- Accelerators and declerators found in results >



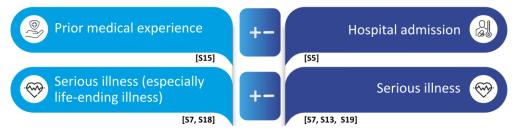
#### **ACCELERATOR**

#### **DECELERATOR**

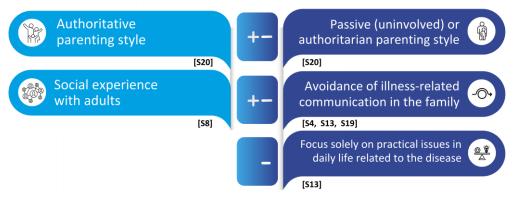
#### PHYSICAL/PSYCHOLOGICAL FACTORS:



#### **MEDICAL FACTORS:**



#### SOCIAL/FAMILY-RELATED FACTORS:



# **Conclusion and discussion**

- Highlighting the importance of understanding factors influencing childhood development in the context of serious illness.
- Theories are mostly outdated and don't integrate full aspects range: psychological, emotional, social, cognitive
- Critical gap in evidence
- Future research: creating flexible, multidimensional models that integrate psychological, emotional, social and cognitive aspects of development



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