

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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Source of funding: Dynamics of Youth, University Utrecht



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 \neq ability to participate in decisions
- 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, Psycinfo, 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 decelerating or accelerating child development
- Qualitative, thematic analysis to identify common themes: key elements of child development and influencing factors



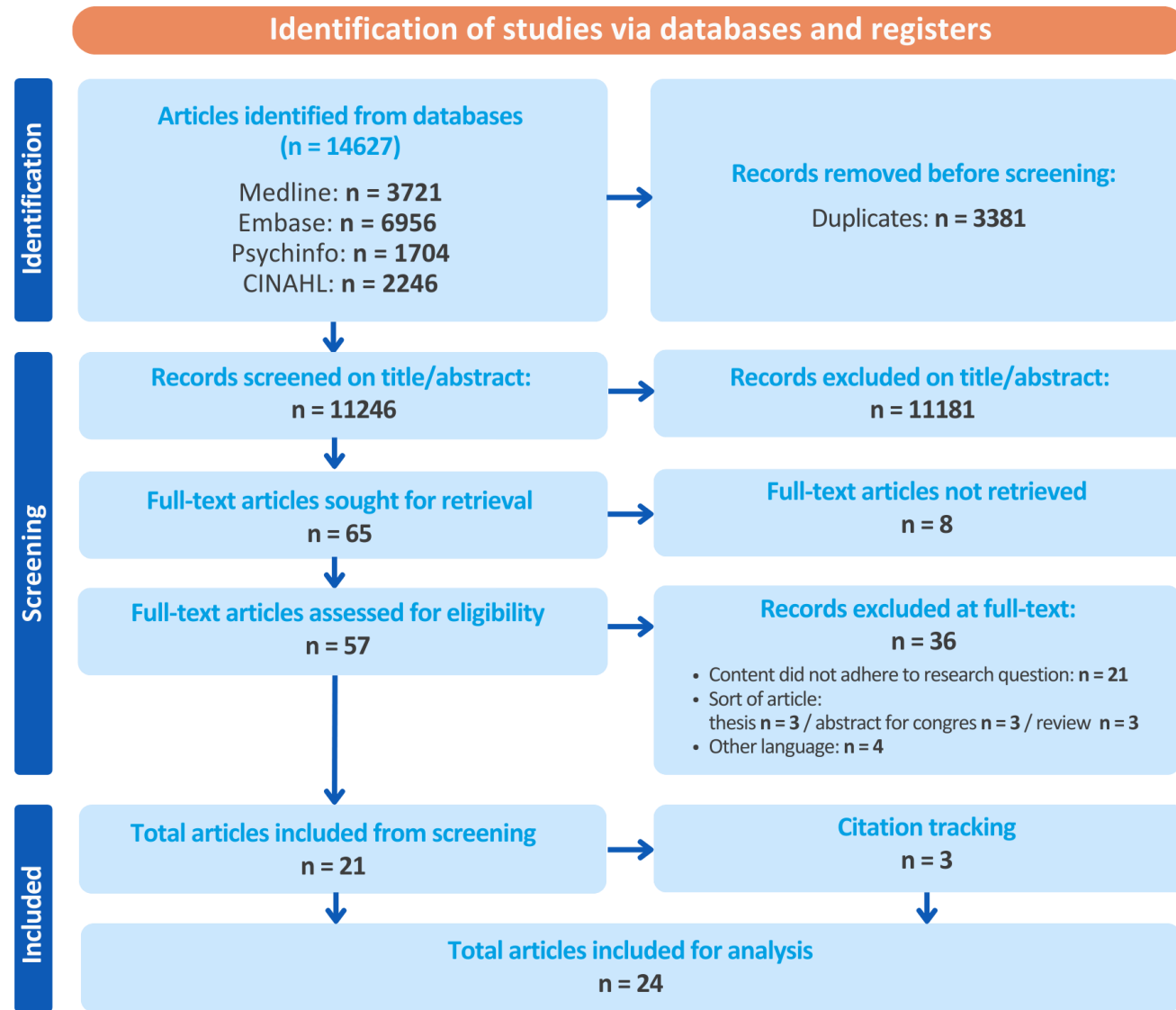


FIGURE 1. PRISMA FLOW DIAGRAM OF THE REVIEW PROCESS

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

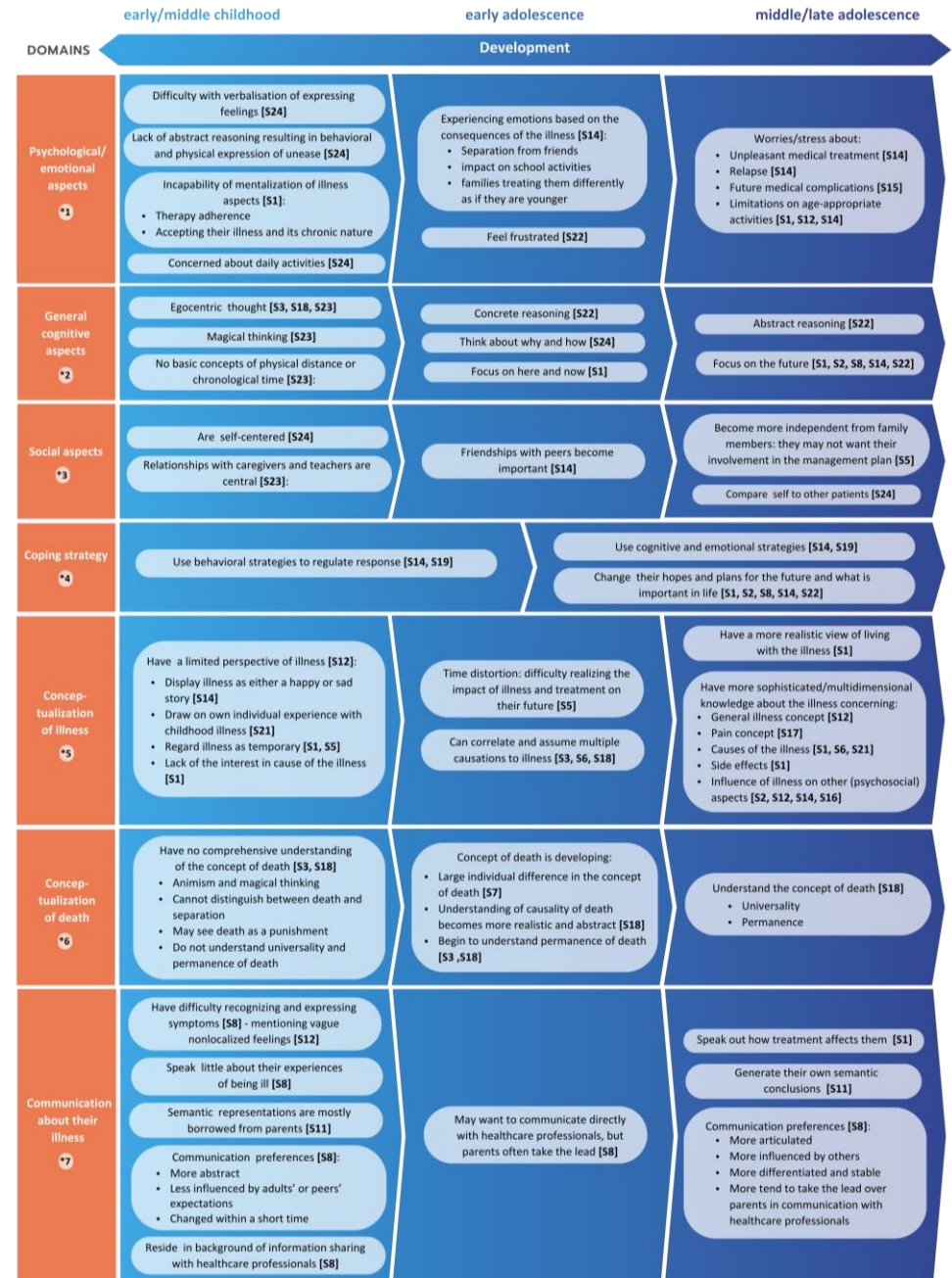
Other identified theories:

- 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

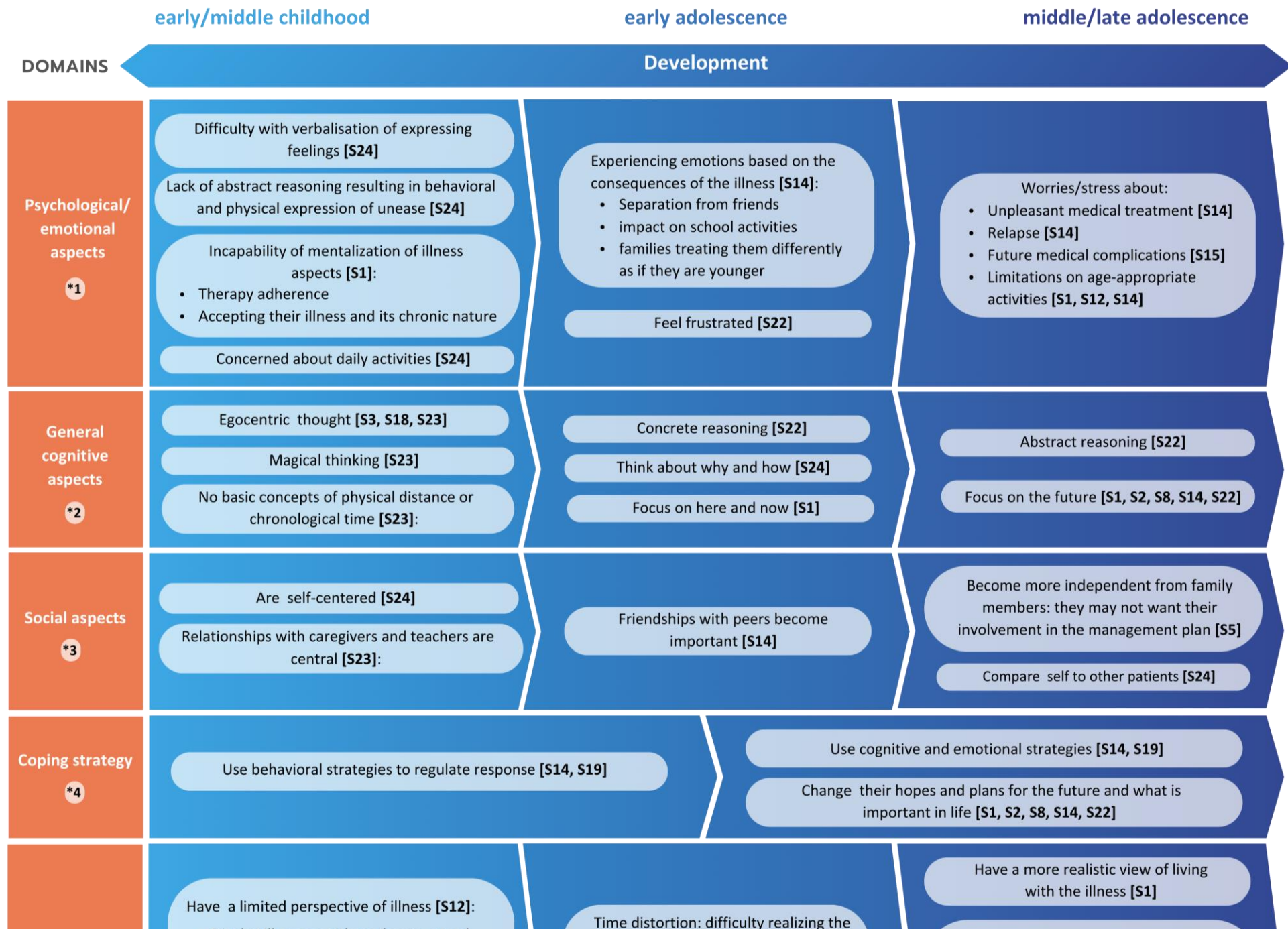


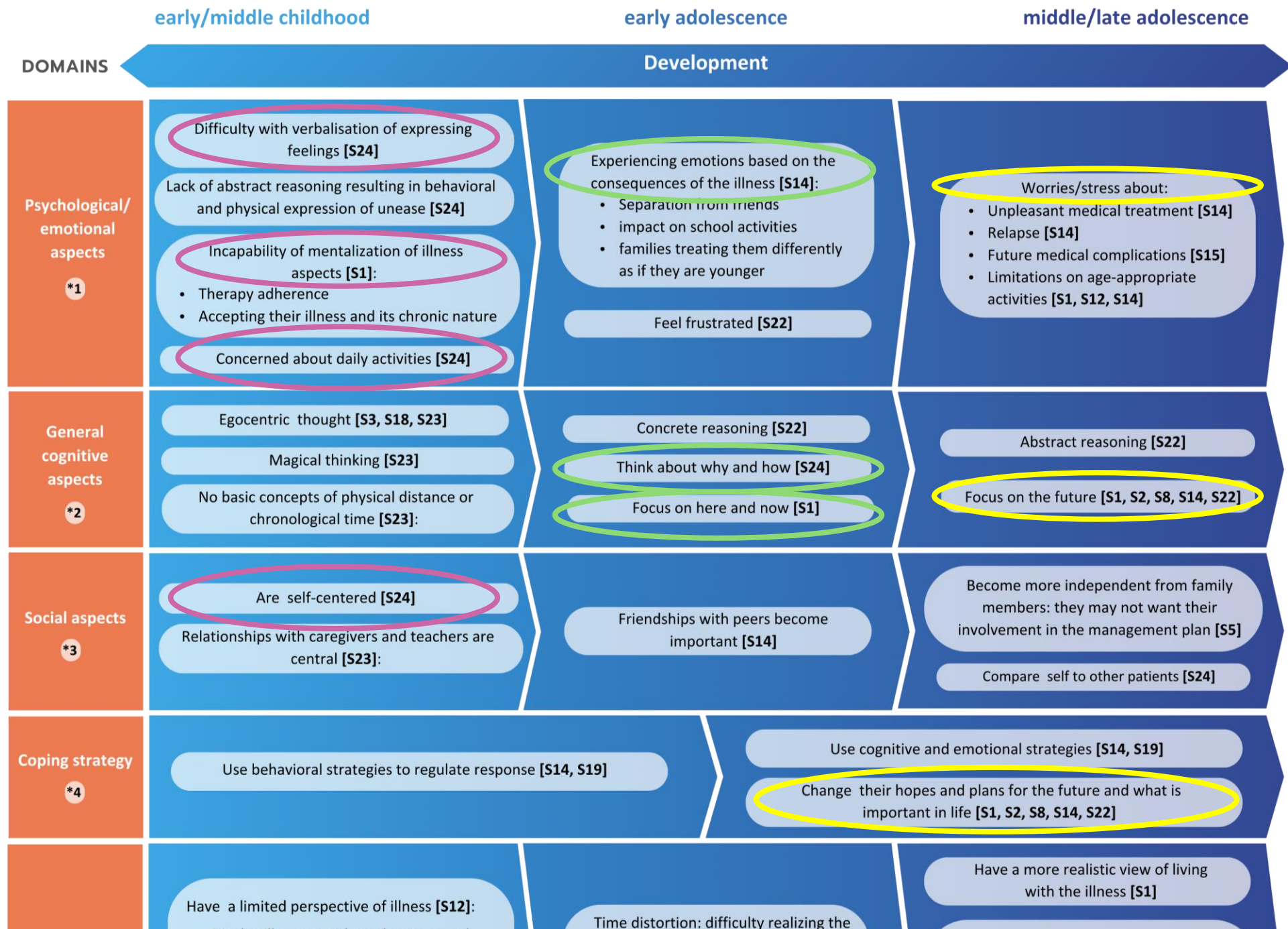
Results

Q2: What typical developmental aspects are observed?



| DOMAINS | early/middle childhood | early adolescence | middle/late adolescence |
|--|--|---|---|
| | Development | | |
| Psychological/emotional aspects *1 | <ul style="list-style-type: none"> Difficulty with verbalisation of expressing feelings [S24] Lack of abstract reasoning resulting in behavioral and physical expression of unease [S24] Incapability of mentalization of illness aspects [S1]: <ul style="list-style-type: none"> Therapy adherence Accepting their illness and its chronic nature Concerned about daily activities [S24] | <ul style="list-style-type: none"> Experiencing emotions based on the consequences of the illness [S14]: <ul style="list-style-type: none"> Separation from friends impact on school activities families treating them differently as if they are younger Feel frustrated [S22] | <ul style="list-style-type: none"> Worries/stress about: <ul style="list-style-type: none"> Unpleasant medical treatment [S14] Relapse [S14] Future medical complications [S15] Limitations on age-appropriate activities [S1, S12, S14] |
| General cognitive aspects *2 | <ul style="list-style-type: none"> Egocentric thought [S3, S18, S23] Magical thinking [S23] No basic concepts of physical distance or chronological time [S23]: | <ul style="list-style-type: none"> Concrete reasoning [S22] Think about why and how [S24] Focus on here and now [S1] | <ul style="list-style-type: none"> Abstract reasoning [S22] Focus on the future [S1, S2, S8, S14, S22] |
| Social aspects *3 | <ul style="list-style-type: none"> Are self-centered [S24] Relationships with caregivers and teachers are central [S23]: | <ul style="list-style-type: none"> Friendships with peers become important [S14] | <ul style="list-style-type: none"> Become more independent from family members: they may not want their involvement in the management plan [S5] Compare self to other patients [S24] |
| Coping strategy *4 | <ul style="list-style-type: none"> Use behavioral strategies to regulate response [S14, S19] | <ul style="list-style-type: none"> Use cognitive and emotional strategies [S14, S19] | <ul style="list-style-type: none"> Change their hopes and plans for the future and what is important in life [S1, S2, S8, S14, S22] |
| Conceptualization of illness *5 | <ul style="list-style-type: none"> Have a limited perspective of illness [S12]: <ul style="list-style-type: none"> Display illness as either a happy or sad story [S14] Draw on own individual experience with childhood illness [S21] Regard illness as temporary [S1, S5] Lack of the interest in cause of the illness [S1] | <ul style="list-style-type: none"> Time distortion: difficulty realizing the impact of illness and treatment on their future [S5] Can correlate and assume multiple causations to illness [S3, S6, S18] | <ul style="list-style-type: none"> Have a more realistic view of living with the illness [S1] Have more sophisticated/multidimensional knowledge about the illness concerning: <ul style="list-style-type: none"> General illness concept [S12] Pain concept [S17] Causes of the illness [S1, S6, S21] Side effects [S1] Influence of illness on other (psychosocial) aspects [S2, S12, S14, S16] |
| Conceptualization of death *6 | <ul style="list-style-type: none"> Have no comprehensive understanding of the concept of death [S3, S18] <ul style="list-style-type: none"> Animism and magical thinking Cannot distinguish between death and separation May see death as a punishment Do not understand universality and permanence of death | <ul style="list-style-type: none"> Concept of death is developing: <ul style="list-style-type: none"> Large individual difference in the concept of death [S7] Understanding of causality of death becomes more realistic and abstract [S18] Begin to understand permanence of death [S3, S18] | <ul style="list-style-type: none"> Understand the concept of death [S18] <ul style="list-style-type: none"> Universality Permanence |
| Communication about their illness *7 | <ul style="list-style-type: none"> Have difficulty recognizing and expressing symptoms [S8] - mentioning vague nonlocalized feelings [S12] Speak little about their experiences of being ill [S8] Semantic representations are mostly borrowed from parents [S11] Communication preferences [S8]: <ul style="list-style-type: none"> More abstract Less influenced by adults' or peers' expectations Changed within a short time Reside in background of information sharing with healthcare professionals [S8] | <ul style="list-style-type: none"> May want to communicate directly with healthcare professionals, but parents often take the lead [S8] | <ul style="list-style-type: none"> Speak out how treatment affects them [S1] Generate their own semantic conclusions [S11] Communication preferences [S8]: <ul style="list-style-type: none"> More articulated More influenced by others More differentiated and stable More tend to take the lead over parents in communication with healthcare professionals |



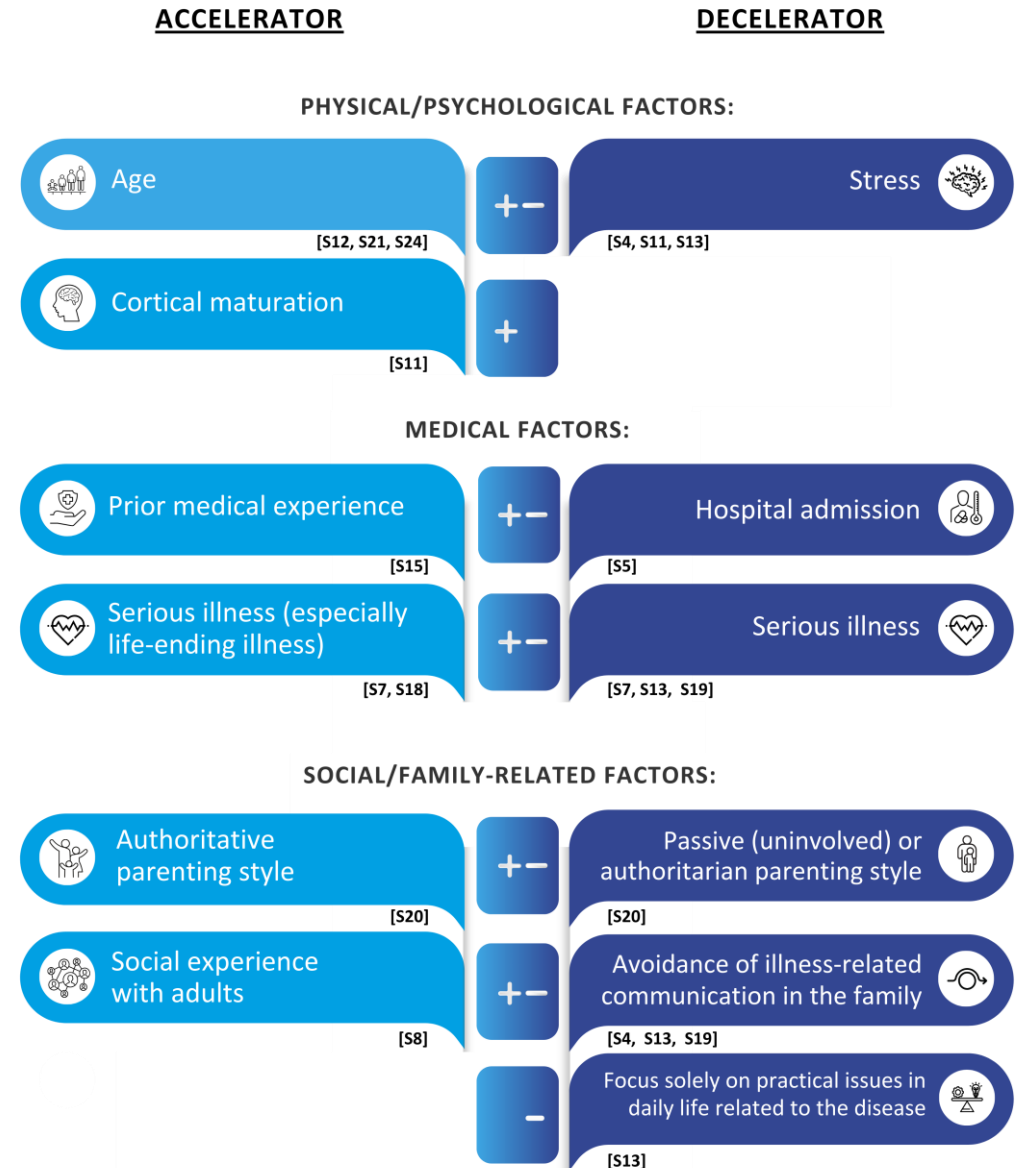


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Results

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 decelerators found in results →



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



Thank you!



UMC Utrecht
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