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

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## Abstract

**Background** Despite evidence on the benefits for including children in their own (palliative) care, studies show that children are not sufficiently involved nor are their preferences sufficiently elicited in a developmentally appropriate manner. The aim of this scoping review is to provide an overview of characteristics of child development in the context of serious illness.

**Methods** A scoping review was performed using methods from Arksey and O'Malley and the Joanna Briggs Institute. A structured literature search was conducted in four databases: Medline, Embase, Psychinfo and CINAHL. Articles were included until October 2022. Thematic analysis was performed to present domains and key factors influencing child development.

**Results** We selected 24 out of 11,246 articles. We found different characteristics describing the ongoing development of seriously ill children in early to middle childhood, early adolescence, and middle to late adolescence. Key themes were: psychological/emotional aspects, general cognitive aspects, social aspects, coping strategy, conceptualization of illness, conceptualization of death, and communication about their illness. Several accelerators of ongoing development were found (e.g. cortical maturation, prior medical experience, social experience with adults) and several decelerators (e.g. stress, hospital admission, avoidance of illness-related communication in the family).

**Conclusion** Our review highlights essential aspects to consider when discussing illness and healthcare preferences with children at various developmental stages. However, our findings also underscore a significant gap in understanding the factors that impact the development of children with a serious illness. It is recommended to monitor development throughout the illness trajectory to gather more evidence and utilize this information to support the child's engagement in their own healthcare in a developmentally appropriate way.

**Keywords** Serious illness, Child development, Cognitive aspects, Pediatric advance care planning, Involvement, Decision-making, Childhood, Adolescence, Developmentally appropriate, Age-appropriate

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## Background

Children suffering from serious illness want to be involved in their own medical decision making [1]. However, studies show that children are not sufficiently involved and their preferences are not being elicited as often or consistently as they could be [2]. The doctor-parent-child interaction is usually dominated by the adult [3]. Nevertheless, the advantages of involvement in conversations about their health are clear for the child patient: an improved sense of control and autonomy, improved adherence to medical treatment, and improved health status through self-determination and self-efficacy [3–5].

Integrating palliative care for children with serious illness can meaningfully benefit families by enhancing satisfaction with treatment, managing difficult symptoms, improving communication with healthcare professionals, and ensuring better care coordination [6]. Palliative care supports quality-of-life decisions, including end-of-life considerations, and can be provided alongside curative or disease-controlling treatments from the moment of diagnosis of a serious illness [7]. It is crucial to have ongoing and early discussions about the child's quality of life with the child as well as the caregivers to make well-informed decisions, a goal pursued by pediatric advance care planning (pACP) [8].

Childhood is a key period for developing skills that carry into adulthood, greatly influenced by both social and biological factors [9]. Children's ability to make health decisions is shaped by their developmental stage, experience with the illness, and attitudes of parents and healthcare professionals towards their capacity [2]. While there is no universal agreement on the age of competence for decision-making, studies have shown that age 12 is considered appropriate for involvement in medical-decision making, with the requirement of favorable environmental factors [5, 10]. Therefore, the extent that children can participate in health decisions should depend on their ability and not on their calendar age [2, 11]. However, establishing their ability to participate is considered difficult, as child and adolescent development is highly individual. Neurological capacity can be somewhat assessed by testing certain capacities, however, mature neurological capacity does not automatically mean that a child is competent for any medical decision [12]. Decision-making competence differs between specific decisions and situations throughout a child's development [12]. Socioeconomic status, culture, peer environment and health are sources of variance that affect neurocognitive development in children [9, 13]. These factors determine the way children can, want and should participate in their own health care trajectory.

Several theoretical models, including Wallander and Varni's model of child adjustment to pediatric disorders [14] and Kazak's model of pediatric medical traumatic stress (PMTS) [15], delineate risk and protective factors for the ongoing development of children with serious illnesses. These encompass familial aspects (such as parental education and personality), medical variables (such as illness characteristics and treatment), and mediating factors (e.g., coping mechanisms, social support, communication) [16]. However, the literature lacks cohesive evidence on the appropriate way to involve children in medical decision making in a manner that suits their developmental abilities, their needs and preferences [17].

Therefore, we aim to provide an overview of characteristics and factors affecting child development in the context of serious illness. Our overview can help healthcare professionals to communicate in a developmentally appropriate way when discussing illness and health. For instance, initiatives like pACP, emphasizing the child's perspective on current and future care goals [18], stand to benefit from these insights.

This scoping review addresses the following research questions concerning the ongoing development of children with serious illness: (1) Which prevailing theories and constructs are identified?; (2) What typical developmental characteristics are observed?; (3) What factors influence ongoing development?

## Methods

A scoping review was performed using methods from Arksey and O'Malley [19] with further refinement from guidance by the Joanna Briggs Institute [20]. Descriptive analysis was conducted to present characteristics of child development and influencing factors. The review protocol was not registered. The PRISMA-ScR Checklist is used for reporting this scoping review [21].

### Search strategy

A structured computerized literature search was conducted in four databases: Medline, Embase, Psychinfo and CINAHL. The search strategy was developed in collaboration with an information specialist and included the following domains: serious illness, child, communication, theory (Table 1). Serious illness encompasses health conditions that carry a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregiver [22]. Chronic illness entails conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both [23]. In this study, we use "serious illness" to refer to serious and chronic illness. There was no restriction in publication date and we included articles published until 17 October 2022.

**Table 1** Search string for Medline. Search date: 17 October 2022

“Catastrophic Illness“[Mesh] OR “Neoplasms“[Mesh] OR “Terminal Care“[Mesh] OR “Chronic Disease“[Mesh] OR “critical illness“[Mesh] OR “palliative care“[Mesh] OR “Catastrophic Ill*“[tiab] OR “Neoplasm*“[tiab] OR “Terminal“[tiab] OR “life limiting condition*“[tiab] OR “life-limiting disease*“[tiab] OR “life threatening ill*“[tiab] OR “life limiting ill*“[tiab] OR “life threatening condition*“[tiab] OR “life limiting condition*“[tiab] OR “serious ill*“[tiab] OR “chronic disease*“[tiab] OR “chronic ill*“[tiab] OR “critical ill*“[tiab] OR “palliative care“[tiab]

And

pediatrics[MeSH] OR child[MeSH] OR Infan*[tiab] OR minor*[tiab] OR kid[tiab] OR kids[tiab] OR child*[tiab] OR adolescen*[tiab] OR juvenil*[tiab] OR youth*[tiab] OR teen*[tiab] OR underage*[tiab] OR pediatric*[tiab] OR paediatric*[tiab] OR school*[tiab] OR teenager*[tiab] OR youngster*[tiab] OR toddler*[tiab]

And

“Communication“[Mesh] OR “social cognition“[MeSH] OR “social behavior“[MeSH] OR “exploratory behavior*“[MeSH] OR “Personality Development“[MeSH] OR “psychology“[MeSH] OR “adaptation, psychological“[MeSH] OR “cognition*“[tiab] OR “express*“[tiab] OR “communicat*“[tiab] OR “social cognition*[tiab]OR “social behavior*“[tiab] OR “exploratory behavior*“[tiab] OR “Personality Development“[tiab] OR “psychology*“[tiab]

And

“concept formation“[MeSH] OR “Theor*“[tiab] OR construct*[tiab] OR concept*[tiab]

### Study selection

Studies written in English that address what cognitive, social or emotional developmental elements are common to certain developmental stages of the child (0–18 years old) and what factors might influence this development in relation to various aspects of illness, were included. Literature reviews, conference proceedings, and complete dissertations were excluded. Articles were excluded if only biological or neurological aspects of development were described. Two reviewers independently screened all abstracts in order to select appropriate articles on Title-Abstract level first and full-text level after. Uncertainties on inclusion were resolved through discussion, including a third reviewer. The reference lists of studies we included were reviewed for additional relevant articles.

### Data extraction and synthesis

Data was extracted using multiple tables designed for data extraction, considering the defined research questions. All articles were read full text and text elements concerning typical child developmental characteristics and factors that influence child development were extracted. A descriptive analysis was performed on this data. The two researchers who performed the title and abstract screening, reviewed data independently and manually coded data using inductive analysis to identify common themes across the collected data. Findings were compared during four extensive meetings and any discrepancies were resolved through discussion. The project team reviewed the final findings.

## Results

The study selection process is summarized in the PRISMA flow chart (Fig. 1). A total number of 11,246 unique hits were extracted from the four databases and subsequently screened for relevance. Eventually, 24 articles relevant to our research questions were selected (Table 2).

### Child development theories and constructs

Several theories of child development were discussed in the selected studies. The most prevalent theory cited was Piaget’s theory of cognitive development, which consists of four stages: (1) sensori-motor; (2) pre-operational thought; (3) concrete operations; (4) formal operations [24–35]. While some aspects of Piaget’s theory were supported by authors based on their study results, such as the idea of development as a linear process with overlapping stages and the potential for progression to be hindered by various physical and social factors, other aspects were contradicted. For example, articles stated that the notions that young children have incorrect reasoning or often provide an explanation for illness based on immanent justice were not supported [36–38]. Other theories were mentioned in the introductory background section of the selected articles but were often not elaborated on (see Additional file 1).

### Developmental characteristics throughout childhood and adolescence in the context of illness

Various characteristics of general childhood development were identified. Other factors are specific for children with an illness (see Fig. 2). The characteristics were organized into the following domains: (1) psychological/emotional aspects; (2) general cognitive aspects; (3) social aspects; (4) coping strategy; (5) conceptualization of illness; (6) conceptualization of death; (7) communication about their illness. Definitions of the domains are given in the legend of the figure. The characteristics identified in the various domains are interrelated and are not mutually exclusive, suggesting that they could overlap across different domains.

Figure 2 illustrates characteristics throughout development from young to older, consistent with the consensus that child development is an individual process. Characteristics in early/middle childhood include: a limited perspective on illness [39], difficulties in verbally expressing their feelings about being ill [40], and concerns about daily activities they are unable to participate in due to their illness [40]. Children developing towards early adolescence engage more in concrete reasoning [34], and thinking about why and how they got ill [40]. Their focus

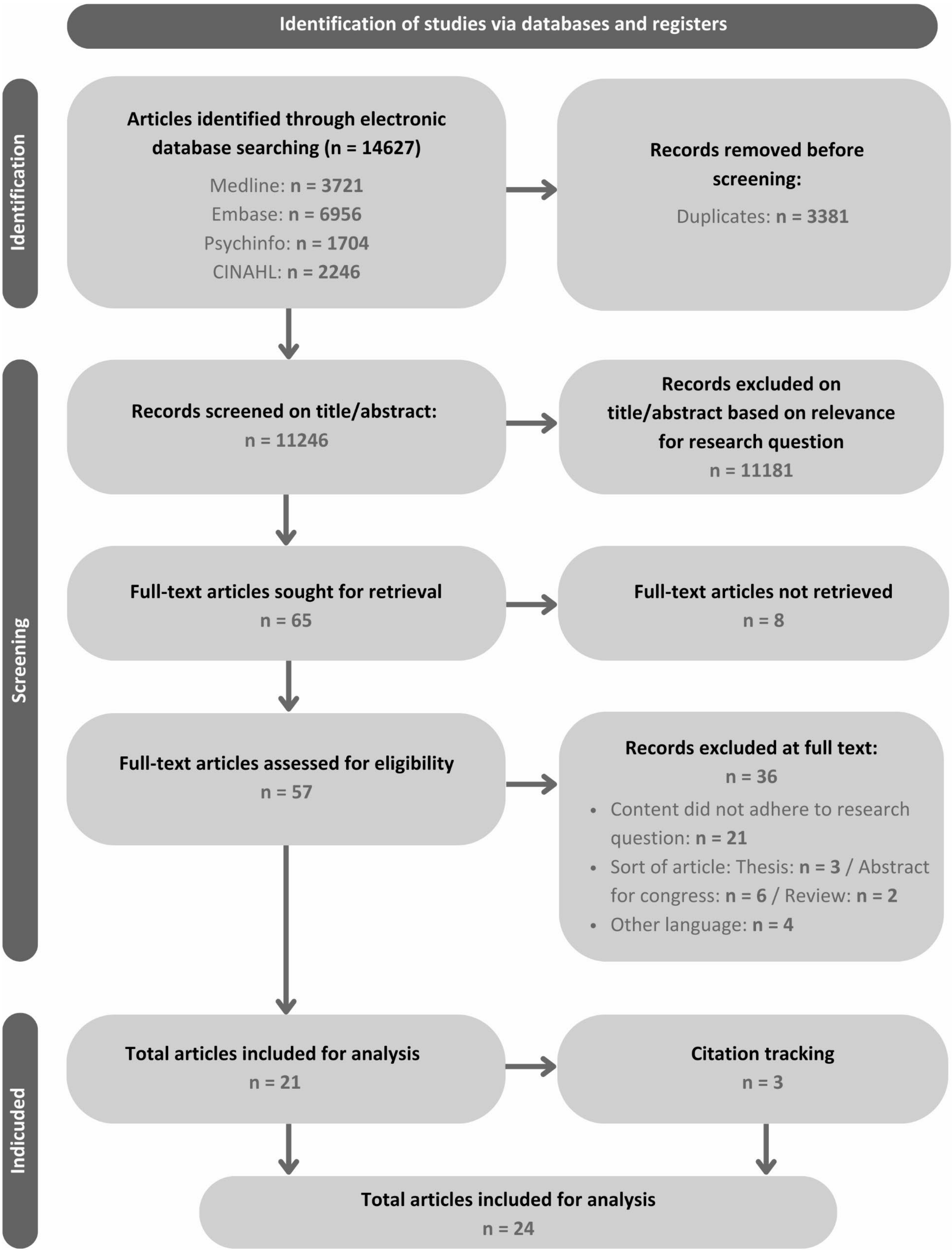


**Fig. 1** PRISMA flow diagram of the review process

**Table 2** Summary of studies included in the review

| S | Author (year) Country | Aim of the study | Design | Sample and setting, *n* |
|---|---|---|---|---|
| S1 | Admi (2007) [41]<br>**Israel** | To determine the importance of epilepsy in the lives of the participants, to examine their view of others' perceptions of people with epilepsy, to analyze their ways of managing disease-related information, and to analyze their ways of managing medical regimens | Qualitative interview study<br>Analyzing medical records | Adolescents and young adults with epilepsy (15–24), *n* = 14 |
| S2 | Allen (1984) [24]<br>**USA** | To assess the concerns of children with insulin-dependent diabetes mellitus and how the concerns relate to their understanding of diabetes | Qualitative interview study<br>Coding the response levels was based on the general progression from preoperational to formal operational thinking | Children with insulin-dependent diabetes mellites, type 1 (8–17), *n* = 34 |
| S3 | Bernardo (1982) [25]<br>**USA** | To integrate models of adaptation to disability and knowledge about children's cognitive development using Piagetian theory of cognitive development and Crate's stages of adaptation to chronic illness | *Unclear.* | *Unclear* |
| S4 | Brewster (1982) [26]<br>**USA** | To investigate the relationship between cognitive development and children's understanding of the cause of illness, intent of medical procedures, and role of the medical staff | Cross-sectional developmental design<br>Standardized cognitive tasks based on Piaget's developmental theory<br>Results were scored in ascending order of cognitive maturation | Chronically ill hospitalized children (5–12), *n* = 50 |
| S5 | Brown (1982) [27]<br>**USA** | The author spells out the main struggles adolescents face due to their chronic illness. And gives recommendations by age group (10–14, 15–18 years old) for loved ones and caregivers on how to support the child | *Unclear. Involves 1 case study* | *Unclear* |
| S6 | Cantrell (2013)[28]<br>**USA** | To develop a framework based on Piaget's cognitive development theory that considers the developmental progression of illness understanding and allows reintegration of concepts | *Unclear.* | *Unclear* |
| S7 | Clunies-Ross (1988) [38]<br>**UK** | To report on the concepts of death in children with leukemia (ideas about the causes of illness) | Qualitative interview study<br>Analyzing children's drawings using the Kinetic Family Drawing Revised Scale (KFD-R) | Children with leukemia (4–9), *n* = 21 |
| S8 | Gibson (2010) [45]<br>**UK** | To explore children's and young people's views of cancer care and to present a conceptual model of communication and information sharing | Cross-sectional developmental design<br>Three techniques were employed to offer a range of activities drawing on play and participation based on approaches:<br>Play and puppets (4–5)<br>Draw and write technique (6–12)<br>Activities day and interviews (13–19) | Children and adolescents with cancer at different disease stages (4–5, 6–12, 13–19), *n* = 38 |
| S9 | Hinds (1997) [29]<br>**USA** | To challenge and refine existing theories of adolescent development and to contribute to the revision of current theories (Freud; Piaget; Erikson; Sullivan; Fowler; Bronfenbrenner) to better account for the unique conditions and experiences of adolescents dealings with serious health challenges | *Unclear. It is an editorial. Describes two cases* | *Unclear* |
| S10 | Hinds (2005) [63]<br>**USA** | To identify the preferences of children and adolescents with advanced cancer about their end-of life care and the factors that influenced their decisions | Qualitative interview study<br>A descriptive decision-theoretic decision analysis model was used to analyze the data | Pediatric patients with advanced cancer (10–20), *n* = 20 |
| S11 | Kozlowska (2011) [44]<br>**AUS** | To describe an individual intervention– one component of a multimodal treatment program– to help children find skills for pain management | *Unclear. this is an underpinning of their intervention* | *Unclear. Not clear what number of examples they tested the intervention on.* |
| S12 | Campbell (1975) [39]<br>**USA** | To study development of concepts of illness, to provide information on how children's views of illness evolve and change over time | Mixed-methods design<br>Including semi-structured interviews children and mothers and questionnaires filled in by mothers | Children that were short-term patients in a pediatric hospital (6–12), *n* = 264, and their mothers |

**Table 2** (continued)

| S | Author (year) Country | Aim of the study | Design | Sample and setting, *n* |
|---|---|---|---|---|
| S13 | Carandang (1978) [36]<br>**USA** | To evaluate illness conceptualizations by children at different stages of cognitive development and to evaluate the role of sibling illness on conceptualizations about illness | Mixed-methods design<br>Including interviews and Piagetian tasks of physical conservation | Children with a healthy sibling (6.5–15) *n* = 36, or a chronically ill sibling with diabetes (6.5–15) *n* = 36, and their mothers |
| S14 | Claflin (1991) [37">]<br>**USA** | To examine how information disclosure related to the child's age and whether disclosure mediates the socioemotional distress of the illness as assumed in the protective approach | Qualitative interview study<br>Including interviews with children and<br>group interviews family | Children with cancer (< 9, 9–14, 14> ) *n* = 43, and their families |
| S15 | Kury (1995) [42]<br>**USA** | To evaluate whether previous medical experience is associated with more sophisticated conceptions of illness causality among chronically ill children | Mixed-methods design<br>Including semi-structured interviews and intelligence subtests | Chronically ill children (4–16), *n* = 64 |
| S16 | Mouratidi (2016) [30]<br>**GR** | To explore possible age differences in children's (subjective) perceptions of illness and health and to what extent these differ from adults' perceptions | Thematic content analysis design with a drawing-based method | Children from nursery and primary schools (5–11) *n* = 347, and adults (µ 20.6), *n* = 114 |
| S17 | Neul (2003) [31]<br>**USA** | To explore whether cognitive development level and chronological age were related to sickle-cell disease (SCD) knowledge and pain conceptualization in young children with SCD | Mixed-methods design<br>Including a multiple-choice questionnaire, sentence completion tasks and<br>Piagetian conservation tasks | Children with SCD (6–13), *n* = 44 |
| S18 | Poltorak (2006) [32]<br>**USA** | To explore how children's understanding of death develops through various cognitive and developmental stages. The study seeks to integrate insights from both cognitive developmental and psychoanalytic perspectives to provide a comprehensive framework that can help clinicians, caregivers, and parents approach the topic of death in a developmentally informed manner | *Unclear.* | *Unclear* |
| S19 | Schmidt (2003) [43]<br>**DE** | To delineate major issues involved in the study of coping with chronic conditions in childhood. The article lists and specifically discusses currently existing tests to ascertain coping strategies in children with chronic conditions | *Unclear. More like a critical reading to find a connection between coping and development in literature.* | *Unclear* |
| S20 | Sezgin (2020) [46]<br>**USA** | To understand the life journey (to independence) of adolescents with chronic diseases and their caregivers. This study proposed a new perspective to the life journey, transition stages, and personal archetypes from a patient centered approach | Qualitative design including face-to-face interviews complemented with visual materials | Chronically ill adolescents (13–18), *n* = 13, and one of their caregivers |
| S21 | Sigelman (1993) [33]<br>**USA** | To trace developmental changes in the content and organization of knowledge (theoretical perspective). To emphasize that it is useful to shift from a Piagetian perspective, with its emphasis on the complexity of thinking about disease, to theoretical perspectives that focus on developmental changes in the content and organization of knowledge | Cross-sectional descriptive survey design | 152 Middle-class children (µ9, µ11, µ13), *n* = 152, and psychologists' college students (µ19), *n* = 58 |
| S22 | Thies (1999) [34]<br>**USA** | To test the hypothesis 'cognitive appraisal of stress changes with cognitive development' | Mixed-methods design including structured interviews by the Stress Appraisal Protocol, rating emotions on Likert scale and<br>the Piagetian task of causal reasoning | Chronically ill children (8–9, 11–12, 14–16), *n* = 79 |
| S23 | Werner- Lin (2018) [35]<br>**USA** | To offer recommendations for parental disclosure of genetic risk to children, case examples with critical discussion of relevant topics, common child questions with sample scripted responses, and additional printed and online resources. Recommendations are based on well-established theories of child development, empirical research on family communication of hereditary cancer risk, and clinical counseling experience | *Unclear. More like a critical reading of well-established theories of child development and a how-to to disclosure genetic risk to children.* | *Unclear* |

**Table 2** (continued)

| S | Author (year) Country | Aim of the study | Design | Sample and setting, *n* |
|---|---|---|---|---|
| S24 | Yeh (2001) [40]<br>**TW** | To establish a conceptual framework for the adaptation process of Taiwanese children with cancer. Comparison with Roy's adaptation theory is discussed. | Mixed-methods design including in-depth interviews, observations, medical chart review and researchers' reflective journals review | Pediatric cancer patients with different illness trajectories (µ11.4), *n* = 34, and their caregivers |

however is still predominantly on the present 'here and now' [41], rarely fully realizing the impact of illness and treatment on their future [27]. Developing into middle/late adolescence, abstract reasoning increases and worrying about relapse, future medical complications and limitations on age-appropriate activities are reported [34, 37, 39, 41, 42]. It was highlighted that cognitive operations necessary to imagine different scenarios is a complex task for children and that the use of cognitive coping strategies in hypothetical problem situations increases with the age of the child [37, 43].

### Factors influencing ongoing development in the context of serious illness

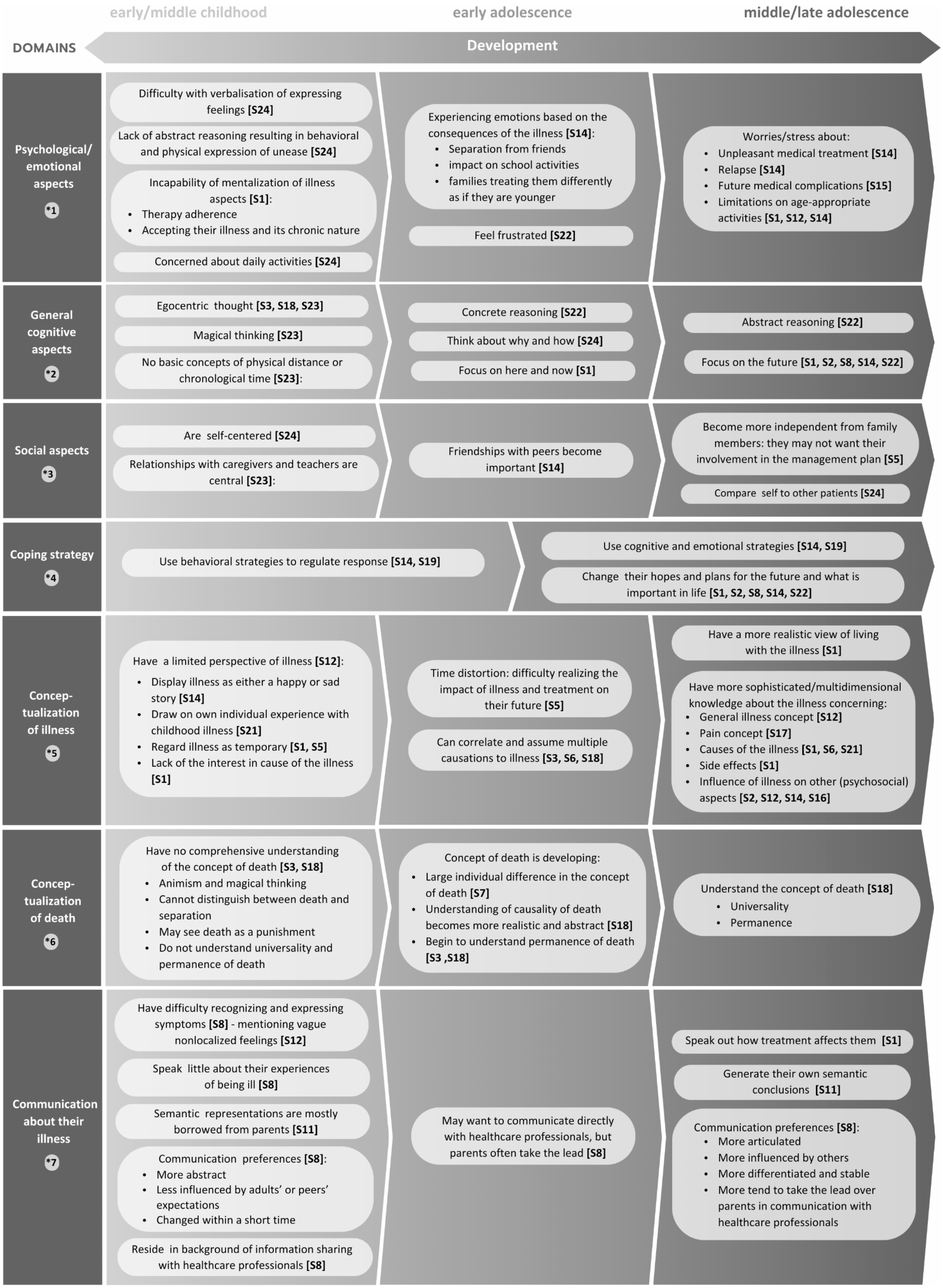
Evidence on accelerating and decelerating factors of ongoing child development was diffuse (see Fig. 3). Age was reported as an obvious accelerator [39], as higher age often goes hand in hand with more knowledge on the illness [39], cortical maturation and increased cognitive abilities, which allows older children to generate own semantic conclusions [44]. Stress may serve as a decelerator through mechanisms hypothesized: (1) egocentric or magical thinking is retained serving as an important defense mechanism; (2) limited capacity to identify and differentiate body states when distressed [26, 36, 44]. The illness itself can either accelerate cognitive development, for example through a maturational effect [29], or it can slow development through information deficit [36, 38]. Prior medical experience may relate to more specific illness concepts rather than to general conceptions of illness causality [42]. Furthermore, social experience with adults was deemed important to accelerate development by helping children learn new dialogues and integrate them into their own speech [45]. Parenting style was found to be influential. Authoritative parenting by offering a democratic climate of both high support and adapted control stimulates the child development over a passive (indulgent or uninvolved) or authoritarian parenting (providing strict control without being supported) [46]. Moreover, the way of communicating about illness in family settings impacts the child's development [38, 44]. Several studies found shaping factors of child development, without specifying a unified direction of the impact (see Fig. 4).

## Discussion

Our scoping review aimed to outline current scientific literature on childhood development amidst serious illness. Recognizing children's development is vital for fostering productive collaboration among patients, families and healthcare professionals. Effective communication, a WHO standard for enhancing pediatric care, contributes to alignment with children's needs and preferences [47]. Additionally, the interplay between physiological, psychosocial, functional, and developmental factors influences children's coping abilities and overall adjustment to illness [14]. Supporting children's involvement in their own healthcare promotes feelings of being valued, increases a sense of control, and mitigates anxiety, which are essential for positive coping and adjustment outcomes [1, 3].

Most classical theories of child development stem from the 1950s to the 1980s. In our study, we did not find recent comprehensive perspectives or multidimensional theories that integrate psychological, emotional, cognitive and social aspects of development, within the context of serious illness. However, research on the influence of specific risk factors on the favorable development of children, or on specific areas such as emotion regulation, attachment, decision-making and illness identity, continues to evolve and the essential relevance of the earliest years of life is increasingly recognized by researchers as well as policy makers [48]. Insights into the mechanisms through which these factors affect development in children with serious illness remains limited. This may be attributed to the complex and dynamic nature of child development, which resists rigid categorization.

Similar challenges to those encountered in pediatric palliative care research may contribute to the lack of studies in this area. Factors such as a broad range of patient diversity and small population sizes, driven by the diverse causes and durations of pediatric serious illness, as well as varying condition severity and dynamics, pose significant hurdles [49]. Additionally, the complex and interdependent relationships between children, families, and caregivers across developmental stages present conceptual and technical challenges for analysis [49]. Moreover, the lack of diversity in publications is a notable issue in the field of child development research [51]. Although



| DOMAINS | early/middle childhood | early adolescence | middle/late adolescence |
|---|---|---|---|
| **Psychological/ emotional aspects** *1 | Difficulty with verbalisation of expressing feelings **[S24]**<br>Lack of abstract reasoning resulting in behavioral and physical expression of unease **[S24]**<br>Incapability of mentalization of illness aspects **[S1]**: • Therapy adherence • Accepting their illness and its chronic nature<br>Concerned about daily activities **[S24]** | Experiencing emotions based on the consequences of the illness **[S14]**: • Separation from friends • impact on school activities • families treating them differently as if they are younger<br>Feel frustrated **[S22]** | Worries/stress about: • Unpleasant medical treatment **[S14]** • Relapse **[S14]** • Future medical complications **[S15]** • Limitations on age-appropriate activities **[S1, S12, S14]** |
| **General cognitive aspects** *2 | Egocentric thought **[S3, S18, S23]**<br>Magical thinking **[S23]**<br>No basic concepts of physical distance or chronological time **[S23]**: | Concrete reasoning **[S22]**<br>Think about why and how **[S24]**<br>Focus on here and now **[S1]** | Abstract reasoning **[S22]**<br>Focus on the future **[S1, S2, S8, S14, S22]** |
| **Social aspects** *3 | Are self-centered **[S24]**<br>Relationships with caregivers and teachers are central **[S23]**: | Friendships with peers become important **[S14]** | Become more independent from family members: they may not want their involvement in the management plan **[S5]**<br>Compare self to other patients **[S24]** |
| **Coping strategy** *4 | Use behavioral strategies to regulate response **[S14, S19]** | Use cognitive and emotional strategies **[S14, S19]**<br>Change their hopes and plans for the future and what is important in life **[S1, S2, S8, S14, S22]** | |
| **Conceptualization of illness** *5 | Have a limited perspective of illness **[S12]**: • 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]** | Time distortion: difficulty realizing the impact of illness and treatment on their future **[S5]**<br>Can correlate and assume multiple causations to illness **[S3, S6, S18]** | Have a more realistic view of living with the illness **[S1]**<br>Have more sophisticated/multidimensional knowledge about the illness concerning: • 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 | Have no comprehensive understanding of the concept of death **[S3, S18]** • 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 **[S7]** • Understanding of causality of death becomes more realistic and abstract **[S18]** • Begin to understand permanence of death **[S3 ,S18]** | Understand the concept of death **[S18]** • Universality • Permanence |
| **Communication about their illness** *7 | Have difficulty recognizing and expressing symptoms **[S8]** - mentioning vague nonlocalized feelings **[S12]**<br>Speak little about their experiences of being ill **[S8]**<br>Semantic representations are mostly borrowed from parents **[S11]**<br>Communication preferences **[S8]**: • More abstract • Less influenced by adults’ or peers’ expectations • Changed within a short time<br>Reside in background of information sharing with healthcare professionals **[S8]** | May want to communicate directly with healthcare professionals, but parents often take the lead **[S8]** | Speak out how treatment affects them **[S1]**<br>Generate their own semantic conclusions **[S11]**<br>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 |

**Fig. 2** (See legend on next page.)

(See figure on previous page.)

**Fig. 2** Developmental characteristics throughout childhood and adolescence

*Legend Fig. 2. Definitions on some of the defined domains [62]: (1) psychological/emotional aspects: the experiences, behaviors, traits, attitudes and emotions that characterize that development group; (2) general cognitive aspects: skills involved in performing the tasks associated with perception, learning, memory, understanding, awareness, reasoning, judgment, intuition and language; (3) social aspects: the gradual acquisition of certain skills (e.g., language, interpersonal skills) and behavior that enable to interact with others and to function as a member of society; (4) coping strategy: an action, a serious of actions, or a thought process used in meeting a stressful or unpleasant situation or in modifying one's reaction to such a situation; (5) and (6) conceptualization of illness and death: the process by which a person abstracts a common idea from one or more particular examples and learns the defining features or combination of features that are characteristic of the concepts 'illness' and 'death'; (7) communication: the transmission of information, which may be by verbal or nonverbal means

Central and South America, Africa, Asia, and the Middle East collectively represent the majority of the global population, research studies predominantly originate from the USA, leading to underrepresentation from these regions [50].

While existing research underscores the necessity of involving children and adolescents in their healthcare in developmentally appropriate manners, practical tools or interventions for achieving this are lacking [18]. pACP, aimed at facilitating communication about preferences and future care goals in serious illness, could benefit from strategies tailored to children's developmental stages. In particular adolescence represents an opportune time for acquiring skills crucial for social interaction, like communication [12]. Therefore, initiating pACP at diagnosis and then continuing it could cultivate the skills necessary for active participation in their healthcare and specifying desired levels of involvement.

Children's needs, preferences and capacities to be involved in their own healthcare may vary at different stages in the healthcare trajectory [51]. Developing and implementing a tool for healthcare professionals to map changes in this for children with a serious illness may help tailoring their approach to train children to be involved in their current and future healthcare decisions. Therefore, studies to map best practices and test different ways of asking questions to children are crucial for refining communication strategies in pediatric healthcare settings. Rigid frameworks should not be strived for, as flexibility and sensitivity to each child's unique needs and capacities are key in fostering meaningful involvement in their healthcare decisions. Existing systems in clinical practice, like the collection of generic patient reported outcomes (PROMs) through the KLIK portal, assess children's well-being across various domains over time [52–54]. Integration of assessing certain developmental aspects might offer a more comprehensive understanding of children's overall health and the mutual influences on each other, potentially providing insights into how to effectively engage the child in his or her own healthcare. Examining illness conceptualization in particular is important, and is influenced by cognitive as well as psychological, emotional and social factors and could be integrated in such systems. Beyond verbal communication, various behaviors, such as play activities, offer insight into development and can contribute to engaging children in a suitable manner, potentially preventing adverse health outcomes [55].

The aim of this scoping review was to explore literature on factors affecting child development in the context of serious illness, rather than constructing a comprehensive model of child development. Consequently, certain known protective and risk factors for child development, evidently also applicable to children with serious illness, were possibly not covered. Family communication and parenting style emerged as important factors in this scoping review. While some aspects of family communication are trainable, parents often encounter difficulty with coping with loss, particularly towards the end of life of the child, which may hinder their ability to fully consider the child's perspective or actively involve him in decision-making [56]. pACP programs such as IMPACT and BOOST aim to facilitate communication between parent(s), child and healthcare professionals [8, 57], but could benefit from more evidence on developmentally appropriate ways to do so [18]. Other potentially family-related factors such as resilience, material resources, aberrant or suppressed play, and socio-economic status [55, 58] were not encountered in this review. This omission may be attributed to the difficulty of modifying these factors in healthcare settings, thus deeming them less pertinent for inclusion in the literature that was selected for the purpose of this review.

A limitation of our scoping review is that we did not include gray literature such as policy documents and academic textbooks. Especially the part on existing child development theories thus gives limited insights. Furthermore, only English literature was included. Although we aimed for comprehensiveness by using broad search terms and using terms such as chronic and serious illness, it cannot guarantee the inclusion of all relevant literature. The studies primarily covered illnesses where development follows a typical trajectory, albeit with potential delays [59]. Conditions involving profound delays and following an atypical development trajectory, such as genetic disorders, disorders defined by one or more behavioral deficits, intellectual disability of unknown etiology and disorders resulting from environmental factors [60] were not addressed in the selected studies. In our search, we focused on characteristics of

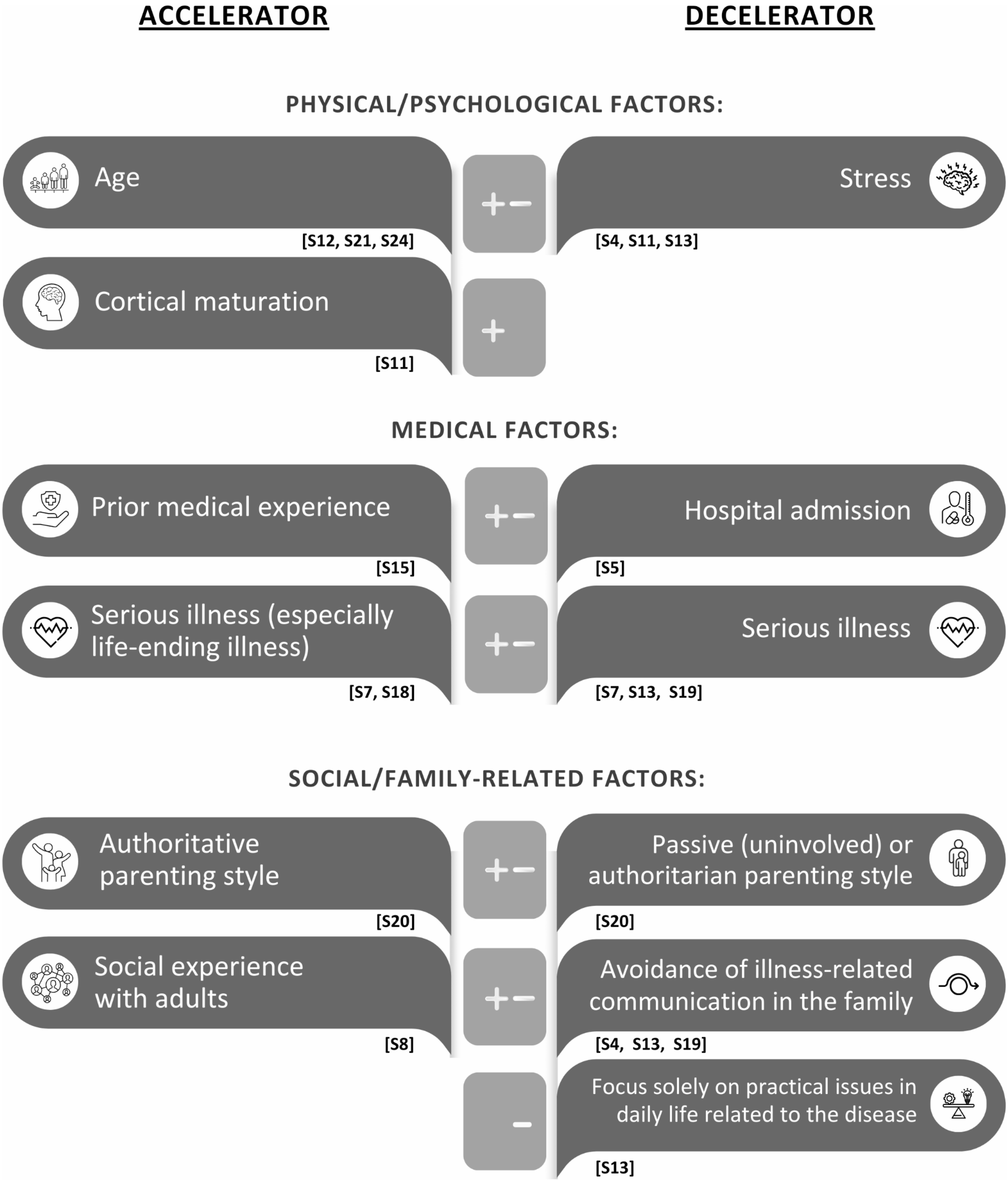


**Fig. 3** Influencing factors of child development

child development within the context of serious illness, as well as theories or constructs related to child development. This focus was driven by our primary interest in understanding how these factors influence children's ability to discuss their illness and their overall quality of life. We excluded articles that focused solely on biological factors, although such studies could offer valuable insights into aspects that interventions could target, such

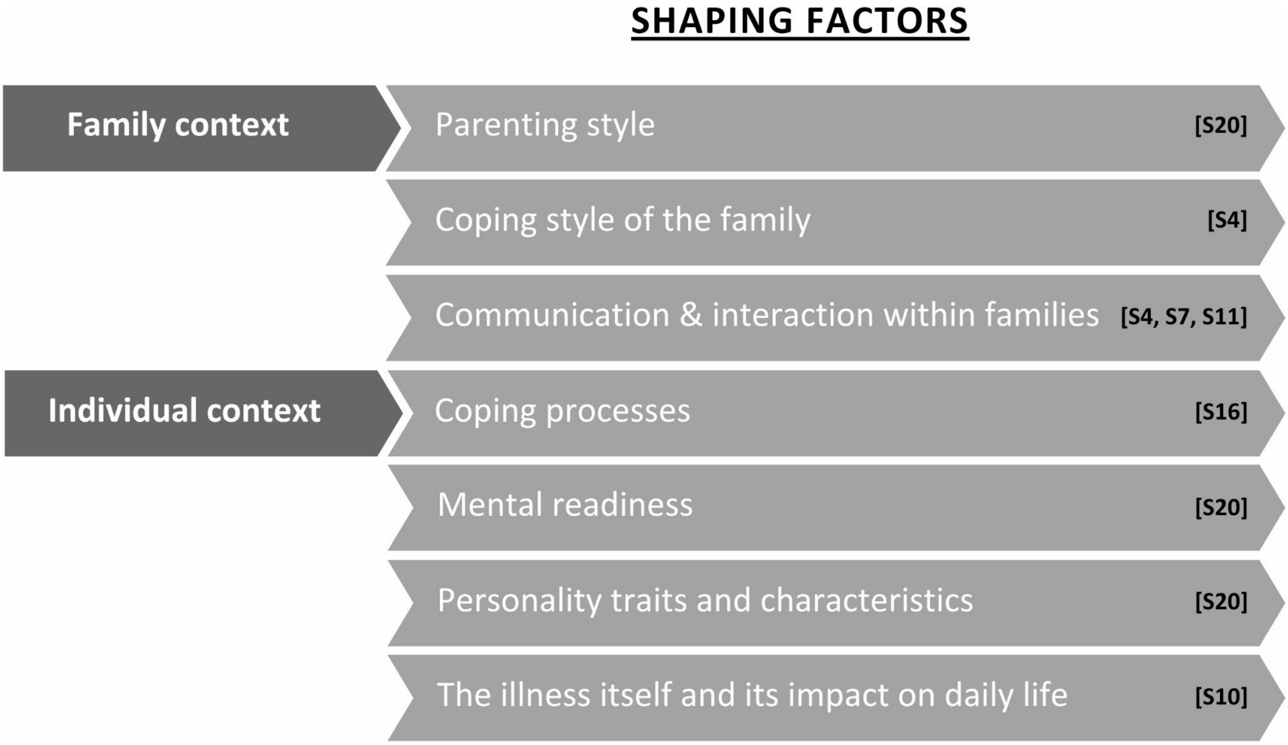


**Fig. 4** Shaping factors of child development

as emotion-related neural pathways for early intervention which would ultimately help children better manage their emotions [61]. While including these articles might have provided a more comprehensive overview of factors affecting child development, it was not considered feasible to report this breadth of research into one scoping review. Strengths are that we searched four databases and inclusion of studies to the next phase was discussed in detail with three researchers. As we performed a scoping review, we did not aim to rate the quality of the included studies. However, it was notable that for some of the included studies, both the method of data collection and the population were unclear, underscoring the necessity for new high-quality studies.

## Conclusion

This article provides a comprehensive overview of characteristics concerning the ongoing development of children in the context of serious illness. It sheds light on the intricate interplay of psychological, emotional, social, and cognitive factors that impact the extent and manner in which children can meaningfully participate in their healthcare decisions. Moreover, our findings revealed a significant gap in understanding the factors that influence the ongoing development of seriously ill children. These insights highlight the need for further research aimed at elucidating these factors and their implications for pediatric healthcare. Moving forward, our findings lay the groundwork for future research endeavors focused on enhancing the involvement of children and adolescents living with serious illness in healthcare in alignment with their developmental stage.

### Abbreviations

| | |
|---|---|
| pACP | Pediatric advance care planning |
| PRISMA-ScR | Preferred Reporting Items for Systematic Reviews and Meta-Analyses Scoping Review |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| PROM | Patient Reported Outcome Measure |

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-025-01751-0.

Supplementary Material 1

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### Author contributions

Conception and design of the work: JCF, AVD, LLR. Drafting the work: AVD, JCF, LLR. Critical revision for important intellectual content: AVD, JCF, LLR, JB, MCK, MS, PAB, SLN. All authors have read and approved the final manuscript.

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### Data availability
No datasets were generated or analysed during the current study.

## Declarations

### Ethics approval and consent to participate
Not applicable.

### Consent for publication
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### Competing interests
The authors declare no competing interests.

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