



# Children's complex care needs: a systematic concept analysis of multidisciplinary language

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## Abstract

Complex care in the arena of child health is a growing phenomenon. Although considerable research is taking place, there remains limited understanding and agreement on the concept of complex care needs (CCNs), with potential for ambiguity. We conducted a systematic concept analysis of the attributes, antecedents, and consequences of children's CCNs from a multidisciplinary perspective. Our data sources included PubMed, Cumulative Index to Nursing and Allied Health Literature, and PsycINFO. Inclusion criteria included publications in peer-reviewed journals between January 1990 and December 2017, written in the English language. One hundred and forty articles were included. We found that children's CCNs refer to multidimensional health and social care needs, in the presence of a recognized medical condition or where there is no unifying diagnosis.

**Conclusion:** Children's CCNs are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures. There remain extensive challenges to caring for these children and their families, precluding the possibility that any one profession can possess the requisite knowledge or scope to singularly provide high-quality competent care.

## What is Known:

- *Complex care is a growing phenomenon and population prevalence figures show that there is an increasing number of children with complex care needs (CCNs). However, the concept has not been systematically analyzed before, leaving it generally ill-defined and at times confusing.*

## What is New:

- *This is the first time this concept has been systematically analyzed and this analysis provides a much-needed theoretical framework for understanding the multidimensional nature of CCNs in children.*
- *Children's CCNs refer to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by family and healthcare structures. It is clear that the very nature of CCNs precludes the possibility that any one profession or discipline can possess the requisite knowledge or scope for high-quality competent care for this population.*

**Keywords** Child · Complex care · Concept analysis · Family · Multidisciplinary

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## Abbreviations

CCN Complex care needs

## Introduction

Complex care is a growing phenomenon and population prevalence figures show that there is an increasing number of children with complex care needs (CCNs) [36, 47, 146]. However, the concept has not been systematically analyzed before, leaving it generally ill-defined and at times confusing. The aim of this paper is to report on a systematic analysis of the concept of CCNs. Concept analysis typically “entails synthesizing existing views of a concept and distinguishing it from other concepts” with the purpose of resolving gaps or inconsistencies in the current knowledge base [70]. Evolutionary concept analysis seeks to go beyond offering a dictionary definition of a concept. It does this by breaking apart the cluster of key characteristics that through common use collectively form the *real* definition of a concept [109]. Examination of these characteristics is critical to understanding the concept. According to Rodgers [109], it is necessary to understand the antecedents, defined as events or phenomena usually found prior to concept occurrence, and the consequences that follow as a result. A thorough knowledge of the attributes, antecedents, and consequences of CCNs from a multidisciplinary perspective is important, given the wide engagement of many disciplines in the care of these children. Without a clear conceptual foundation, there is ambiguity which in turn can compromise the quality of research or theory construction as the area develops [134].

## Methods

Rodgers’ evolutionary method [109] was used to systematically analyze the concept of children’s CCNs. This method was selected to contextually situate the evolution of CCNs within the multidisciplinary care environment, and is particularly well suited to this issue given the changing and dynamic nature of complex care. According to Rodgers, concept development is evolutionary as it continues and may change over time and is influenced by contextual factors, which may be disciplinary, cultural, or theoretical. Analysis uses an inductive approach and seeks to identify what is common, the purpose of which is to identify data that is relevant to the attributes of the concept and its contextual features. Thematic analysis is used to identify major themes presented in the literature.

## Data sources and search strategy

A three-strand approach was used to create a systematic search. An initial scoping search was run in PubMed and

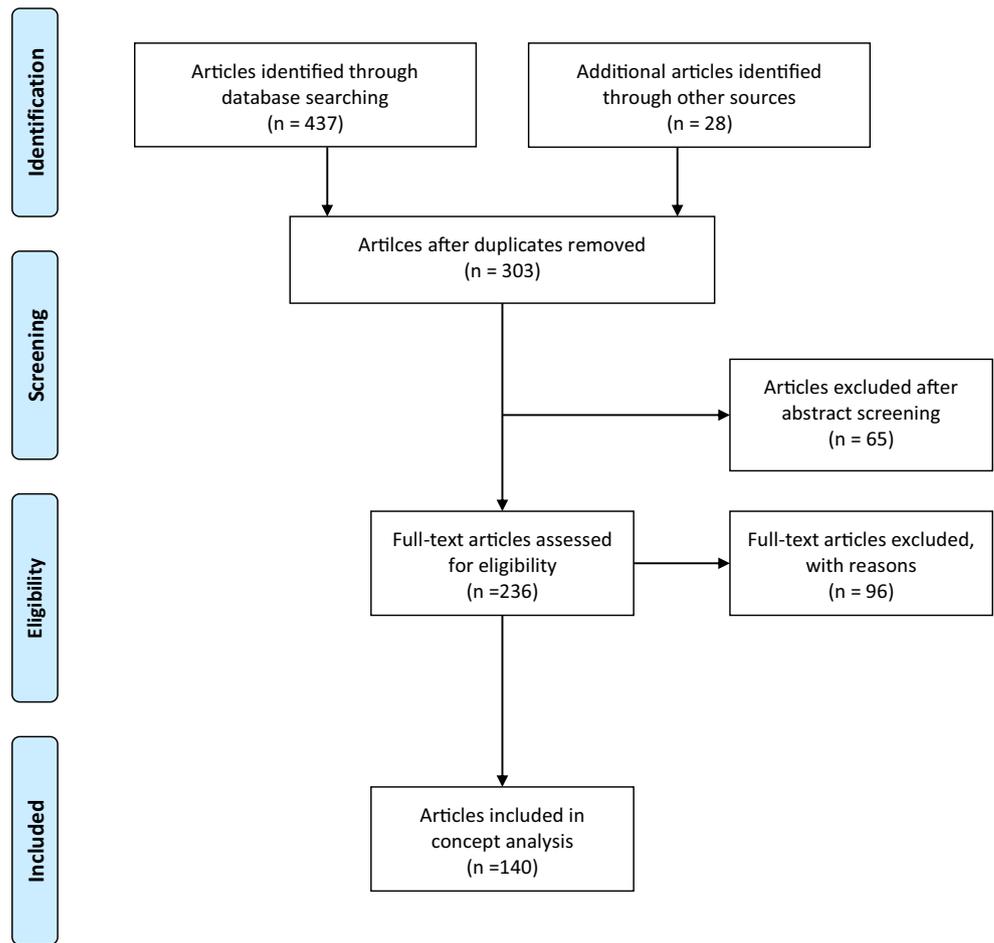
CINAHL to identify appropriate control language using MeSH and CINAHL Headings. A secondary scoping search was then conducted identifying appropriate keywords related to the following: complex needs, complex care, children, disability, and chronic illness. The final search was run using a combination of the keywords and control language based on three central concepts of children: complex care, disability, and chronic illness. PubMed, CINAHL, and PsycINFO were searched. The search was limited to English-language literature published from 1990 through to 31 December 2017 as the issue of complex health prior to this time generally referred to the medical management of children with challenging acute conditions in the secondary care environment. The reference lists of the resulting articles were reviewed to identify any other pertinent articles and only two articles were identified in the time period before 1990. An additional hand search was conducted and a gray literature search was completed using the following: OpenGrey, the Systems for Information on Grey literature in Europe (SIGLE), World Health Organization (WHO), National Technical Information Service USA (NTIS), and the National Academies Press.

The initial search retrieved 465 articles that met the inclusion criteria. Next MBr and CK reviewed the abstract of each article, with some articles read completely, to determine inclusion. Articles that did not examine complex care needs of a child were excluded. The review process yielded a final sample of 140 articles (Fig. 1).

## Data extraction and analysis

Each of the 140 articles was analyzed for data relevant to the attributes, antecedents, and consequences of CCNs, using a coding framework based on Rodgers’ evolutionary method [109] (Table 1). The development of these questions was the subject of considerable deliberation. Question 1 was straightforward; however, we had initially contemplated framing questions 2 and 3 as “Which factors (antecedents) are proposed to precede CCNs?” and “What are the consequences of CCNs?” Drawing on our own previous work and from discussion with wider clinical and academic colleagues, we collectively agreed that seeking to answer these questions would be too broad at this stage of knowledge development in the care of children living with CCNs. For example, if we were to fully answer the initial question 2 proposed, we would need to include exploration of all possible causes of CCNs (genetic and in-depth diagnostic issues) which were not the intended focus of this paper. As the focus of this analysis was to explore papers that reflect a child living with CCNs, we framed our questions to focus on the multidisciplinary language used to describe the antecedents (individual, historical, and sociocultural contexts) and consequences that can

**Fig. 1** Data search and selection process



influence this. The final questions used therefore reflect this early point in global understanding of CCNs where there is a dominant focus on seeking to address and alleviate burden.

Comparisons were made among the articles to identify whether similarities and differences existed between disciplinary-specific uses of the concept. The framework was reviewed by MBr and CK, who then organized recurring themes into categories (attributes, antecedents, and consequences).

## Results

### Key attributes of children’s CCNs

Synthesis of key themes and significant findings from the literature identified the defining global attributes of children’s CCNs as (a) heterogeneous and substantial, (b) individual and contextualized, and (c) continuing and dynamic.

### Heterogeneous and substantial

The multidimensional care required to manage multiple condition-related needs [12, 15, 19, 23, 25, 35, 42, 44, 46, 51, 61, 76, 82, 86, 96, 99, 107, 122, 123, 125, 128, 131, 133, 145, 150], in the context of developmental, social, and psychological needs, emerged as a key feature of children’s CCNs [46, 54, 61, 63, 71, 149]. Heterogeneous combinations of high-intensity needs [25, 33, 40, 42, 45, 51, 54, 76, 79, 96, 98, 99, 103, 128, 131, 145] spanned a wide range of care, including nutritional [1, 10, 11, 21, 25, 32, 69, 76, 82, 85,

**Table 1** Coding framework based on Rodgers’ evolutionary method

Number	Question
1.	What are the key attributes of the concept?
2.	Which factors (antecedents) are proposed to precede treatment burden?
3.	What are the consequences of treatment burden?

87, 136], respiratory [10, 11, 25, 69, 76, 90, 114], personal care and hygiene [25, 76, 79, 82, 85], toileting [25, 79, 85], sensory [5, 45, 62, 97, 132], technological [1, 3, 11, 16, 25, 33, 42, 82, 121, 128, 131, 136, 137], pharmacological [15, 25, 33, 35, 42, 49, 76, 96, 131], emotional [23, 37, 62, 107, 131], and palliative care needs [17, 42, 56, 66, 95, 119, 120, 131, 141]. Children with CCNs frequently required constant vigilance and monitoring [7, 23, 57, 80, 84, 87, 88, 131, 141]. Needs were present at all times across the acute-community care interface in a range of settings: home [3, 15, 25, 46, 57, 60, 61, 69, 83, 84, 87, 102, 133, 143, 145], school [4, 13, 21, 42, 62, 69, 94, 105], recreational [21, 62, 142, 144], community [15, 20, 22, 25, 31, 67, 68, 88, 131, 142, 144], and travel [82, 87, 120, 142].

The attribute geographical location of home care frequently emerged in the literature [4, 16, 17, 34, 50, 57, 65, 95, 113, 119, 120, 133] and was found to influence the type and intensity of care needs [12, 20, 77, 136, 142]. Estimates of the real time involved in caring for children with CCNs varied from 4 to 5 h per day [114] to 24-h nursing care [35, 76, 111, 114, 131] in the literature reviewed. However, it was also apparent that medical and nursing data alone could not provide an accurate sense of the time involved in meeting children's CCNs, given their frequent extension beyond the purely medical [14, 19, 29, 46, 133].

### Individual and contextualized

The concept analysis found cross-disciplinary agreement on the highly individual and unique nature of CCNs, which also emerged as inseparable from the family context. The individuality of the child and family was apparent in the broad recognition that diagnosis alone could not reflect the realities of complexity [12, 111]. Unpredictability in care trajectories was influenced by characteristics of the child including age [18, 62, 107, 117, 131], developmental stage [62, 80, 85, 88, 107], and medical status and stability [14, 22, 44, 68, 83, 86, 88, 132, 141]. Additionally, children with CCNs were presented as having unique family contexts that gave their needs individual meaning [3, 7, 12, 16, 17, 25, 44, 56, 68, 98, 145, 149]. The analysis revealed subtle differences in disciplinary focus; medical research tended to examine the wide variations in condition severity [13, 14, 33, 39, 40, 48, 50, 52, 73, 104, 114] while the importance of family context generally received greater attention within the nursing and social literature [3, 16, 18, 20, 22, 23, 25, 29, 60, 61, 68, 76, 77, 83, 85, 113, 117, 122, 131, 149, 150].

### Continuing and dynamic

Children's CCNs were characterized as having a constantly changing nature, due to the potential for deterioration and improvement (intermittent or prolonged) and advances or

challenges in care provision [14, 23, 34, 39, 44, 46, 60, 65, 67, 73, 88, 99, 102–104, 117, 133, 141] emerging through the ongoing care adjustments required during the physical and psychological development of a child [42, 69, 82, 83, 85, 132, 133, 150]. As developmental milestones were missed [80, 143], increased physical and technical care was often necessary [7, 14, 48, 51, 54, 56, 71, 78, 80, 85, 88, 106, 112, 141, 142, 148, 150]. There was cross-disciplinary recognition of these increased CCNs through multiple transition points, as children and families adjusted to changing services and care plans during transitions from hospital to home [15, 16, 19, 20, 35, 45, 52, 75, 76, 96, 111], children's to adult services [14, 19, 28, 31, 59, 71, 78, 112], and/or from curative to palliative care [42, 56, 66, 95, 131].

### Antecedents of children's CCNs

Having identified key global attributes of children's CCNs, the next step in this concept analysis involved the identification of the antecedents of the concept, which are phenomena or events that provide individual, historical, and sociocultural contexts as foreground to the unique and dynamic nature of CCNs. These included (a) child and family characteristics, (b) medical advances, and (c) existing healthcare systems.

#### Child and family characteristics

In addition to the age and developmental stage of the child which were identified previously as attributes of children's CCNs, gender [65, 73, 112] and race [10, 73, 74] were found to be strong foreground factors that offer individual context to the nature of the CCNs. The gender of children with CCN was a factor influencing many elements of the children's and families' experiences. Having special healthcare needs, and particularly those with greater medical complexity, was more likely to be associated with being male [73], while being a parent of a male child with a disability was associated with lower reported quality of life and family functioning scores [65]. Being a female child with special healthcare needs was a predictor of the provision of adequate services to support transition to adult healthcare services [112]. Poorer health outcomes and life expectancy were observed in children from minority ethnic groups across a range of chronic and complex conditions [10] and difficulties accessing healthcare services are reported in minority groups, particularly immigrant families [74]. The increasing development of disease-specific registries and national databases offers greater illumination of these health disparities, but those which operate on broad ethnic groupings may limit exploration of outcomes for children from ethnic subgroups or multi-racial families.

The diversity in the stability and severity of the child's underlying medical conditions emerged as a significant

influencing factor on CCNs [5, 12, 33, 40, 60, 92, 97, 127, 129, 132, 133]. Some of the literature focused on complex needs associated with specific illnesses or conditions, including heart failure [86], cerebral palsy [14, 98, 148], spina bifida [79], Russell-Silver syndrome [136], tracheotomy [10], Apert syndrome [62], complex pain [49, 67], Prader-Willi syndrome [83], tuberous sclerosis [104], complex epilepsy [38], and complex colorectal conditions [41]. A number of articles discussed CCNs by diagnostic groupings of children, including children with disabilities [3, 23, 44, 48, 55, 58, 65, 71, 103, 125, 137–139, 150], chronic conditions [10, 81, 102], life-limiting conditions [24, 95, 119, 133, 138], technology dependence [3, 11, 12, 33, 35, 37, 40, 51, 69, 73, 114, 115, 118, 121], solid organ transplant [57, 76], neurodevelopmental disabilities [56, 149], severe congenital malformations [18], rare diseases [92], chronic neuromotor disability [106], intellectual disabilities [53], and general pediatric neurologic disorders [130]. In much of the literature reviewed, CCNs were presented as crossing traditional diagnostic boundaries, which prompted the call for the need for clearer definitions of CCNs and the need for more accurate prevalence data [121] to avoid the risk of oversimplification of children's needs [2]. Moreover, such systems posed further difficulties for the unknown population of children lacking a unifying diagnosis, whose uncertain medical status already represented a barrier to service access that emerged as a growing cross-discipline concern [5, 11, 45, 67, 92, 130, 133, 138].

The individual family context for all CCNs emerged as similarly diverse and equally significant. Multiple personal and environmental factors interacted in ways that were difficult to quantify, shaping not just families' care preferences [25, 28, 30, 42, 131, 145] and perceptions of support needs [133], but also health outcomes [65] and the experience of living with a child with CCNs [48, 66, 114]. Cross-disciplinary recognition of the importance of family preferences and culture has grown over time [1, 7, 19, 20, 30, 40, 45, 46, 60, 61, 68, 69, 77, 87, 92, 95, 103, 141, 149]. In particular, this pertains to issues of race [10, 55, 65, 91], ethnicity [4, 10, 57, 73, 74, 80, 102], geographical location [4, 16, 20, 34, 50, 95, 119, 150], language [4, 16, 18, 28, 39, 41, 48, 57, 87, 150], and culture [1, 4, 21, 39, 44, 46, 54, 57, 66, 102, 136]. The context of the family found in the literature pertained to the socio-economic status of the family [3, 4, 7, 18, 48, 66, 102, 103, 119, 150] and included reference to employment [80, 91], legal [57, 102], insurance [35, 73, 102], and health status [50, 65], as well as families' structures [18, 65, 117, 150], strengths [18, 30, 139, 142, 150], support systems [29, 66, 82, 107, 117, 119, 150], beliefs [1, 66, 114, 119, 138], values [1, 46, 66], expectations [28, 99, 139], cohesion [7], and capacity for coping [7, 18, 20, 29, 48, 74–76, 102, 103, 107, 133, 139]. It was apparent that family context influenced the medium for care delivery and the opportunities for children with CCNs to live meaningful lives [68].

## Medical advances

Within the last 30 years, coinciding with changing sociocultural attitudes towards social inclusion [1, 7, 21, 44, 48, 53, 71, 114, 126], western medical, technological, and pharmaceutical advances have clearly increased the survival and lifespan of children living with once-fatal conditions [33, 114]. Nonetheless, it was apparent from the medical [1, 2, 10, 40, 45, 48, 51, 54, 56, 66, 73, 79, 89, 103, 115] and nursing literature [3, 4, 21, 43, 68, 69, 80, 93, 121, 143] that those advances had also led to a growing pediatric population living with secondary conditions and/or disabilities with CCNs. Further, there was strong cross-disciplinary consensus that social and community service developments had not kept pace with medical progress [19, 54, 60, 69, 96, 99, 107, 131, 137, 143]. This shortfall included training and workforce development for healthcare professionals whose job descriptions had rapidly evolved in a climate of advancement and cost containment [4, 8, 17, 46, 61, 95, 149].

The nursing literature in particular also highlighted the concurrent international shift towards deinstitutionalization of children with CCNs [4, 7, 44, 53, 60, 61, 69, 80, 84, 85, 93, 142–144]. Broad acceptance of an increasingly holistic ontology [7, 34, 44, 46] shaped a changed cultural understanding of the acute hospital setting as inappropriate for meeting children's developmental needs in the long term [57, 60, 61, 65, 111], and an acceptance that, where possible [48, 54, 115], families should remain together [39, 69, 77, 93]. The growing number of children who are technology dependent strengthened international resolve for providing comprehensive care within the home setting [14, 19, 22, 23, 34, 35, 39, 40, 44, 45, 48, 60, 61, 73, 93, 126]. This more family-oriented shift also represented valuable cost efficiencies within existing healthcare systems [61, 85, 125, 142].

## Existing healthcare systems

The international lack of integrated care systems emerged as a significant barrier to competent, comprehensive care delivery for children's CCNs across all disciplines in the literature reviewed. It was apparent that the existing provision of care at home was considered unsustainable [93], frequently due to structural factors relating to funding and resources that were deemed inadequate to meet the needs of a growing population [4, 5, 8, 22, 33, 34, 39, 40, 44–46, 60, 67, 69, 71, 77, 78, 82, 86, 88, 89, 93, 95, 100, 111, 114, 116, 122, 136, 137]. Throughout our review, community service provision emerged as fragmented and inconsistent, fluctuating with the child's geographical location [14, 19, 21, 22, 34, 43, 45, 46, 53, 65, 69, 71, 72, 92, 93, 95, 96, 102, 103, 111, 114, 123, 142]. The quality of interagency collaboration, planning, and coordination also frequently emerged as inadequate [5, 30, 46, 72, 90, 95, 122] and in need of systems-level reform [16, 22,

40, 55, 79] to provide healthcare professionals with the necessary flexibility [46, 122, 149], resources [22, 46, 57, 60, 61, 71, 127, 149], and remuneration [116, 122] to support improvements. While these issues have recently received more attention [34, 39, 51, 75, 90, 129], concerns regarding the lack of a skilled workforce persist [45, 46, 60, 61, 149]. Carer competence, knowledge, and experience were frequently queried [45, 95, 111, 136, 141] in the midst of repeated calls for regulation and oversight on the training of home healthcare staff [16, 45, 52, 72, 119]. Common sources of unnecessary confusion and concern related to the lack of consensus on essential qualifications for children's nursing [4, 16, 17, 45, 90], poorly articulated roles [5, 17, 72, 122], and the need for a shared vision of inter-agency multidisciplinary working [2, 22, 44, 122]. Furthermore, in light of the need for greater evidence-based decisions pertaining to CCNs [2, 106], practitioners' personal and professional biases [11, 56, 66, 114] emerged, alongside hospital ethos [66], cultures [44, 46, 104], and prevailing institutional care practices [9–11, 79] as exerting influence over care decisions.

## Consequences

The concept analysis identified three main areas of consequence, reflecting the multifaceted impacts of children's CCNs at individual and societal levels: (a) clinical care of the child, (b) family impact, and (c) structural and political impacts.

### Clinical care of the child

The concept analysis found that complexity in children's care needs are derived from the multiple domains and levels of complex care required throughout the lifespan. Typically, parent(s) assumed the responsibility for their child's care as primary caregivers [7, 22, 23, 44, 45, 50, 69, 84, 85, 121, 133, 150]. However, parents' associated willingness and capacities to care varied [48, 115] particularly given the lack of alternative options [69, 93, 117]. Parents' readiness for caregiving, which shaped families' ongoing experiences [45, 75, 114, 137], related to the quality of pre-discharge practices of training and preparation [40, 50, 60, 75, 150]. In addition to delivering levels of highly skilled, technical nursing care, once the preserve of healthcare professionals [1, 7, 40, 85, 121, 122, 143], parents also had to physically [38, 50, 65, 98, 103] and psychologically [38, 98, 149] adjust to their caring responsibilities and the medicalization of their family home [44, 46, 69, 138, 144], and the steady, continued presence of healthcare staff therein [46, 60, 61, 69, 111]. While daily care such as feeding, dressing changes, bowel washouts, oxygen therapy, urinary catheterization, suction, bathing, and drug administrations were provided in the home setting [3, 68, 69, 85, 87, 88, 141, 143], children also traveled to regular

appointments in multiple settings, for scheduled and unscheduled care.

It has become clearer over time that the heterogeneity of needs required a more coordinated multidisciplinary team approach to individualized care delivery [19, 51]. Healthcare teams are evolving to include multiple healthcare professionals, specialists, and community providers whose diverse skills reflect the complexity of needs of the child and their family [1, 4, 11, 17, 21–23, 30, 31, 34, 37, 39, 40, 44, 45, 51, 52, 60, 61, 67, 68, 72, 77–79, 90, 94, 95, 97, 103, 111, 116, 117, 122, 141, 150]. This clearly identifies that children's CCNs preclude the possibility that any one professional or discipline can possess the requisite knowledge for high-quality, comprehensive care [54, 68, 90]. However, the associated organizational burden still frequently falls on parents [22, 40, 138], despite policy commitments to provide families with designated care coordinators [22, 30, 39, 100, 111, 137]. Moreover, families' efforts to secure services were often described as time-consuming, complicated, and stressful [138, 139].

### Family impact

There was cross-disciplinary agreement that CCNs had significant, dynamic, and contextualized impacts on every aspect of family life. Care relationships are interdependent so the whole family unit is affected [23, 30, 67, 83, 103, 125, 126, 133, 136, 138, 144, 150], as a now medicalized life revolves around the routines of caregiving [56, 69, 80, 85, 111, 144]. However, it is noted that there is a paucity of the voice of the child with CCNs, their siblings, and their grandparents [16, 18, 28, 42, 45, 60, 67, 69, 117, 128, 137, 145].

Parents experienced impact on their coping and empowerment from both subjective and objective pressures, across physical and psychosocial domains, including but not limited to physical health [22, 26, 30, 38, 40, 45, 50, 60, 67, 85, 93, 103, 114, 133, 138, 142], financial [40, 48, 54, 55, 83, 103, 115, 129], employment [3, 60, 71, 77, 91, 135, 136, 142, 150], time [23, 44, 58, 60, 103, 129, 133, 136, 142], mental health [3, 13, 22, 29, 40, 45, 50, 51, 54, 55, 58, 60, 68, 69, 72, 80, 83, 103, 117, 126, 127, 129, 133, 136, 140–142, 150], social isolation [26, 83], identity [56, 60, 80, 136, 143, 144], dependency [67, 93, 136], and parenting in public [46, 61, 69, 111].

A growing body of literature on the positive impact of having a child with CCNs included increased family cohesion and sense of community [57, 67, 83, 143], increased tolerance [103], and enhanced personal growth of family members [140]. A small number of articles also noted differences between parents/guardians and professionals' perceptions of quality of life for children with profound disabilities, with parental views generally more positive [56, 97, 132].

However, it was found that parents/guardians typically subjugated their own needs for their child's needs [53, 54, 93], often leading to unmet psychosocial, financial, and physical

needs of the parents [5, 26, 65, 104, 106, 138], due to the unrelenting intensity of caregiving [84, 88, 93], especially in the absence of adequate respite care [22, 84, 85, 119, 137, 150].

Increasingly, there is a focus on the impact of having a child with CCNs on the mental health of their parents [9, 26, 57, 74, 114, 123, 126, 130]. Families from minority groups [10, 93], families with low incomes [115, 119], and immigrants [44, 57, 102] were found to be at particularly high risk of adverse health outcomes.

### Structural and political impact

This concept analysis on CCNs found multiple structural weaknesses across international healthcare systems [5, 16, 20, 31, 35, 42, 52, 78, 90, 93, 122]. Pressure on those systems emerged as a dominant consequence of trying to cope with increasing number of children with CCNs [3, 12, 26, 48, 55, 69, 71, 73, 77, 89, 92, 94, 122, 143]. This included high resource utilization, hospital admission, and readmission rates [11, 33, 54, 148]. CCNs increasingly seem to drive clinical and research agendas, and there was strong cross-disciplinary consensus that increased investment in community supports for integrated services could ameliorate families' care burden [1, 16, 30, 33, 40, 47, 51, 54, 55, 69, 72, 78, 81, 94, 122, 143]. Mental health services [37, 69, 73, 114, 115, 126] and workforce development, especially staff training and recruitment [16, 17, 46, 61, 69, 95, 133], emerged as in particular need of attention as the preventable nature of many aspects of families' struggles was apparent across all disciplines [55, 71, 133, 142]. Moreover, it was found that systemic failures in providing healthcare had damaged trust in the parent-provider relationships and the quality of care delivery, and risked negative health outcomes for children with CCNs and their families [8, 44, 73, 85, 133]. This was despite stated political recognition of the need for adequately funded and supported integrated care pathways [126]. At a wider level, it was suggested that these failures added pressure on acute services as families struggle to cope in the wake of continued policy failings [39, 60, 69, 72, 93, 119, 142].

### Discussion

This concept analysis provides a much-needed theoretical framework for understanding the multidimensional nature of complex care needs in children. We found that *children's CCNs refer to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by healthcare structure.* The key characteristics of the attributes, antecedents, and consequences are presented in Fig. 2. They are deliberately

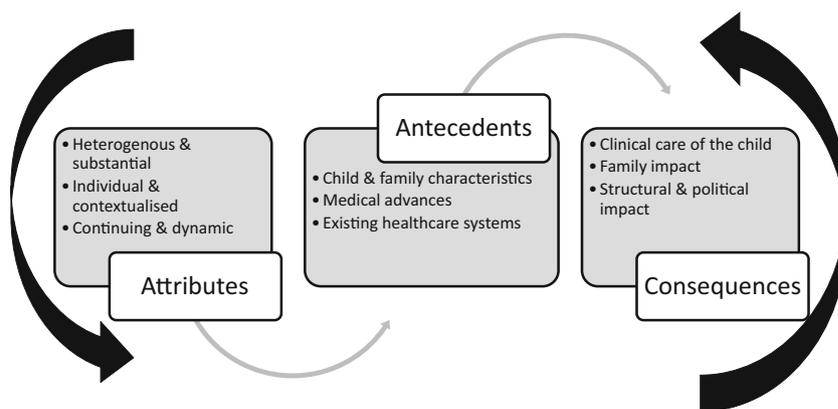
depicted encompassed by two arrows representing the dynamic and evolving nature of our understanding of CCNs, reflecting the reality that how we come to understand the consequences of CCNs may subsequently impact on our understanding of the attributes and individual, historical, and sociocultural contexts.

Key issues emerging from the concept analysis include questions about access to care, parental readiness to care, and lack of integrated care systems which challenges equity of provision of care. The emergence of these issues supports the ongoing move away from a mono-dimensional system, based on a traditional approach of medical management of children living with CCNs. They highlight the value and need for the contribution of a narrative lens and a constructivist paradigm.

At present, the integration of health services is generally found to be insufficient, with wide variation in the governance of, and access to, care for these children and their families. It is acknowledged that there remain extensive challenges to this. These include communication of the needs of the child and family at the acute-community interface, confusion over points of accessing care, and no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multi-disciplinary team when families cross within and between acute and community care services [16, 19]. The geographical spread of the literature reviewed highlights that the challenges found are shared internationally, with recommendations for the need for a seamless service to avoid over-burden on parents and more effective communication processes to enhance continuity of care [108, 140]. Adopting appropriate processes is essential for continuity of care, the absence of which can lead to difficulty delivering safe and efficient care. While a number of benchmarks for care of children with complex care needs have been developed to support this [6, 110], little is understood about the specific processes and procedures that contribute to the success or failure of such models for this group of children, and it remains difficult to fully implement these standards in the absence of mapped out access to care for this population.

It is evident from this analysis that while some literature focuses on the positives for parents with a child with complex care needs, the majority of published research identifies that they are very burdened by becoming the primary care giver for their child. There is also very limited mention of accountability concerns. Internationally, the governance of care for children with CCNs in the community remains unclear and is compounded by the fragmented nature of health service delivery to this population. In some respects, this feeds in to the repeated findings that the stress of having a child with CCNs may challenge family functioning. Continued research into complex care, its definition, assessment, and impact is needed to understand how children and their families, and health and social care professionals experience and implement treatment

**Fig. 2** Attributes, antecedents, and consequences of CCNs



that suits the realities of daily life. It is important that this research has a strong multidisciplinary focus where necessary, as the very nature of CCNs precludes the possibility that any one profession or discipline can possess the requisite knowledge or scope for high-quality competent care for this population.

In parallel with progressing a multidisciplinary focus in research, the care and management of children with complex care needs is an ideal arena for the development of inter-professional education programs, which can contribute to providing healthcare professionals with the skills and knowledge needed to work in a collaborative manner [27, 64, 147], and improve enhanced health care delivery [101, 124], particularly given the complexity of patients' healthcare needs and the range of healthcare providers and organizations involved when a child has CCNs.

### Limitations

Given the lack of clarification of the concept of complex care to date, the insights from this review provide a valuable foundation on which to further develop this concept. Nonetheless, this review has limitations that must be considered. CCNs were referred to here in context of the family setting. We acknowledge there are a significant number of children with complex care needs who live outside that setting for many different reasons, such as those in foster care or residential care facilities. These children are particularly vulnerable to adverse health and psychological outcomes. Specific characteristics of this group could not be identified due to the paucity of literature on this population.

### Conclusion

It is clear that the very nature of CCNs precludes the possibility that any one profession or discipline can possess the requisite knowledge or scope for high-quality competent care for

this population. It is important that research in this area has a strong multidisciplinary focus to enable the breadth and depth of exploration required to understand the optimum care required for these children and their families.

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### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** This article does not contain any studies with human participants or animals performed by any of the authors.

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