Curtin School of Allied Health

Parent Quality of Life and Developmental Outcomes of Young Children

Evelyn Toh Kheng Lin
ORCID: 0000-0002-2559-6328

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007), last updated March 2014. The research study was conducted with participants recruited from two research sites, Joondalup Health Campus and St John of God Midland Hospital, as part of the Early Moves project. This project has been approved by the Ramsay Health Care Human Research Ethics Committee (Early Moves Study 1902) with reciprocal ethics approval from Curtin University (HRE2019-0739), and St John of God Human Research Ethics Committee (1767) with reciprocal ethics approval from Curtin University (HRE2021-0410).

Signature

Evelyn Toh Kheng Lin
Date: 30 June 2024

Statement of Contribution

This thesis is part of a larger research project led by Professor Catherine Elliott and the Early Moves team. Data collection for the study in Chapter Two began before the candidate enrolled in the MPhil program and was completed by the Early Moves team. Overall, the MPhil candidate contributed 65% to each study, including data cleaning, analysis, interpretation, and drafting of manuscripts. For the scoping review, the MPhil candidate additionally developed the search strategy (with support from a Curtin University librarian), conducted literature searches, retrieved and screened articles for inclusion, collated the instruments and extracted the data. Supervisors Dr. Caroline Alexander, Dr. Sarah Hall, and Dr. Ashleigh Thornton contributed to coding instrument domains for the scoping review. All supervisors contributed to the manuscript revision and editing process. Specific details of the MPhil candidate and each supervisor's contributions to the manuscripts are outlined below.

Chapter Two: Quantitative Paper

Names	**Conception and Design**	**Acquisition of Data and Method**	**Data Conditioning and Manipulation**	**Analysis and Statistical Method**	**Interpretation and Discussion**
E.K.L. Toh			✓	✓	✓
C. Alexander	✓	✓	✓	✓	✓
S. Hall	✓	✓	✓	✓	✓
A. Thornton	✓				
C. Elliott	✓	✓			✓

Chapter Three: Scoping Review

Names	**Conception and Design**	**Acquisition of Data and Method**	**Data Conditioning and Manipulation**	**Analysis and Statistical Method**	**Interpretation and Discussion**
E.K.L. Toh	✓	✓	✓	✓	✓
C. Alexander	✓		✓	✓	
S. Hall	✓		✓	✓	✓
A. Thornton	✓	✓	✓	✓	✓
C. Elliott	✓				✓

I acknowledge that these represent my contribution to the above research output, and I have approved the final version.

Name:	Date:
EKL Toh	30 June 2024
C Alexander	30 June 2024
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Abstract

Background: Parents of young children face unique challenges while balancing multiple responsibilities, which can impact on Quality of Life (QoL). Measuring parent QoL is important as it provides insights into parents' well-being, which, in turn, influences child outcomes and family functioning. Parent QoL refers to a parent's subjective assessment of overall life satisfaction or contentment. Although much research has been conducted on the QoL of parents with children diagnosed with developmental disorders, there is limited research on the QoL of parents with children who have typical development or undiagnosed developmental delays. Within the literature, there is inconsistency in how parent QoL is defined and assessed for young children, and its relationship with specific domains of early child development remains unclear.

Aim: This thesis aims to better understand the assessment of QoL in parents of young children and how it relates to early child development.

Methods: The first study, part of the Early Moves project, quantitatively explored the relationship between parent QoL and child development in children aged two years. Measuring parent QoL accurately is critical for understanding this relationship. To address this need, the second study conducted a scoping review to systematically identify QoL instruments used for parents of young children aged zero to five years. This review assessed the psychometric properties and domains of these instruments to evaluate their suitability for measuring parent QoL in studies like the first one. Together, these studies form a cohesive body of work aimed at both exploring the relationship between child development and parent QoL while providing an overview of the tools documented in the literature for parent QoL assessment.

Results: The quantitative analysis revealed a positive relationship between two-year-old children's social-emotional development and parent QoL, such that delayed child social-emotional development was associated with lower caregiver QoL, even after adjusting for parental education and household income. Findings from the scoping review indicated that generic QoL instruments are frequently used for assessing parent QoL, which are not specifically tailored for parents of young children, and many focus on individual health concerns. None of the instruments had been evaluated for all nine psychometric properties recommended by COSMIN. A basic qualitative content analysis was conducted to categorise itemised questions from QoL instruments into eight domains relevant to assessing QoL in parents of young children, including physical, social, and mental health, self-fulfilment, daily living, child symptoms, environment, and overall QoL.

Conclusions: There is a need for a clear conceptual framework to assess parent QoL, to ensure consistency and applicability across research endeavours. Understanding the relationship between parent QoL and early child development can help to inform family-centred approaches to early intervention. In future, longitudinal studies are recommended to provide insights into the direction of effects in the relationship between parent QoL and child development.

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List of Abbreviations

ADHD: Attention-deficit/hyperactivity disorder
AOM: Acute otitis media
CarCGQoL: Caregiver’s Congenital Glaucoma Quality of Life Questionnaire
ILI: Influenza Like Illnesses
CINAHL: Cumulative Index to Nursing and Allied Health Literature
ColiQ: Infant Colic Questionnaire
COSMIN: COnsensus Standards for the selection of health Measurement Instruments
DFI: Dermatitis Family Impact
ENT: Ear, Nose and Throat
EQ-5D-3L: European Quality of Life 5 Dimensions 3 Level Version
EQ-5D-5L: European Quality of Life 5 Dimensions 5 Level Version
EUROHIS-QOL-8: European Health Interview Survey-Quality of Life
GDP: Gross domestic product
HIP-QL: Hearing-Related Infant/Toddler and Parent Quality of Life
HRQoL/HRQL: Health-related Quality of life
ICCAP: Impact of a Child with Congenital Anomalies on Parents
IH-QoL: Infantile Hemangioma Quality of Life
IoFS: Impact on Family Scale
ITQOL-SF47: Infant and Toddler Quality of Life Questionnaire–47
MAPP-QOL: Maternal Postpartum Quality of Life
MCQLI: Multicultural Quality of Life Index
PACQLQ: Paediatric Asthma Caregiver’s Quality of Life Questionnaire
PedsQL: Paediatric Quality of Life
PedsQL-FIM: Paediatric Quality of Life - Family Impact Module
PARAOM-QOL: Parental Acute Otitis Media Quality of Life
PGWBI: Psychological General Well-Being Index
PQoL-AD: Parent QoL of Children with Atopic Dermatitis
PQoL: Perceived Quality of Life Scale
PRISMA: Preferred Reporting Items
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analysis – Extension for Scoping Reviews
PROMIS: Patient-Reported Outcomes Measurement Information System
QLI: Quality of Life Index
QLQ- FYCDD: Quality of Life Questionnaire for Families of Young Children with Developmental Delays
QoL/QL: Quality of Life
QoLS: Quality of Life Scale (QoLS)
RSV: Respiratory syncytial virus
SD: Standard Deviation
SF-12: Short-Form-12
SF-36: Short-Form-36
SWLS: Satisfaction With Life Scale
VAS: Visual analogue scale
WHO: World Health Organisation
WHOQOL-BREF: World Health Organisation Questionnaire on Quality of Life: BREF

Chapter One: General Introduction

1.1. Definition and History of Quality of Life (QoL)

The concept of quality of life (QoL) has undergone significant evolution reflecting changing societal attitudes, healthcare practices, and research methodologies [1]. Today, QoL is typically defined as one’s perception on constructs encompassing an individual's wellbeing and satisfaction across different aspects of life [2]. It is understood to be influenced by personal values, cultural norms, societal expectations, and individual aspirations, and is often interpreted as the degree to which individuals perceive their lives to be fulfilling, meaningful, and satisfying, considering their own goals, desires, and standards [3]. However, we have not always understood it this way.

Historically, the notion of QoL began with the unidimensional perspective. This view, rooted in early economic theories, emphasised a single overarching measure and often focused on indicators such as income or material possessions [4]. For example, Classical Utilitarianism, developed by philosophers like Jeremy Bentham and John Stuart Mill, proposed that the ultimate goal of human action should be the maximisation of utility, defined in terms of pleasure or happiness, and the minimisation of pain or suffering [5]. From this perspective, individuals' wellbeing was often equated with the pursuit of pleasure and the accumulation of material wealth, leading to a unidimensional understanding of QoL centred around economic prosperity [6]. Similarly, welfare economics, as espoused by scholars like Arthur Cecil Pigou and Alfred Marshall, focused on the allocation of resources to maximise social welfare or utility [7]. This approach often relied on economic indicators such as gross domestic product (GDP), income per capita, and consumption levels to measure societal wellbeing [8]. While this unidimensional perspective provided a simplified understanding of QoL, scholars argued that it failed to capture the full spectrum of human experiences and neglected other important dimensions [9].

The study of QoL has evolved significantly over time, acknowledging its intricate and multifaceted nature. Initially, QoL assessments predominantly relied on objective evaluations alone, which primarily examined social, economic, and health indicators to infer wellbeing [10]. Many of these objective indicators primarily evaluate the potential opportunities available to individuals for enhancing their QoL, rather than directly measuring QoL itself [11]. Over the years, there has been a shift towards emphasising subjective evaluations, which consider the individual's personal perceptions, emotions, and interpretations of their life circumstances [12]. These subjective assessments encompass aspects such as life satisfaction, happiness, fulfillment, and overall sense of wellbeing, providing a more intimate and nuanced understanding of an individual's lived experience [11]. By integrating both objective and subjective dimensions, contemporary approaches to QoL offer a more comprehensive, multidimensional, and holistic perspective, reflecting the true complexity of human wellbeing [13].

This broader understanding of QoL aligns with the World Health Organisation's (WHO) influential redefinition of health in 1948 [14]. The WHO's definition represented a major shift from traditional perspectives that focused mainly on physical health, broadening the concept to encompass mental and social dimensions as well [14]. George Engel further expanded upon this definition by advocating for a model that integrates biological, psychological, and social domains, proposing a systematic approach to integrate these dimensions in understanding health and illness [15]. These holistic perspectives underscored the interconnectedness of various aspects of an individual's life and highlighted the importance of addressing broader determinants of health [16].

As our understanding of QoL evolved alongside these broader health perspectives, there emerged a complementary concept known as health-related quality of life (HRQoL). This shift reflected a growing recognition among researchers and practitioners that individuals' wellbeing was intricately linked to their health status, particularly physical and mental health [17]. As medical treatments advanced, it became apparent that while some interventions extended lifespans, they could also negatively impact one's life's satisfaction [18]. For instance, aggressive cancer treatments such as chemotherapy may prolong life but often come with severe side effects such as nausea, fatigue, and cognitive impairment, significantly reducing a patient's overall satisfaction with life [19]. The emphasis on HRQoL among healthcare professionals and researchers thus led to the development of numerous assessments designed to understand the effects of health and illness on individuals' lives [20]. This approach increasingly aimed to capture the holistic experiences of individuals, integrating the input from both medically unwell patients and other stakeholders to provide a more comprehensive evaluation of wellbeing [20].

The widespread emphasis on HRQoL is seen in ongoing scholarly debates regarding the domains comprising QoL. Two prominent models highlight this focus, with the Wilson & Cleary model of HRQoL, published in 1995, merging biomedical and social science paradigms [21]. This model encompasses five interconnected domains: biological and physiological variables, symptom status, functional status, general health perception, and overall HRQoL, complemented by two related domains, individual and environmental characteristics [21]. It was theorised that the latter domains may not directly determine HRQoL but can influence other aspects or outcomes that ultimately affect HRQoL [21]. Ten years later Ferrans published his model on HRQoL, which is applicable across various healthcare disciplines [22]. It suggests similar domains as Wilson and Cleary’s model but asserted the importance of biological factors affecting HRQoL [22]. Ferrans also eliminated the "nonmedical factors" component, such as socioeconomic status, asserting that it overlaps with individual or environmental characteristics [22]. Some scholars agreed with this exclusion, contending that the factors were not directly linked to health [23]. These models thus indicate an emphasis on health and a patient-centred approach.

In parallel, other related constructs have also emerged that are conceptually similar to QoL, including “wellbeing” and “burden”. While QoL constitutes a significant portion of the literature, these related terms are often used interchangeably or in conjunction with QoL.

The concepts “QoL” and “wellbeing” have followed distinct yet increasingly converging paths in the exploration of human satisfaction, with frameworks such as the International Classification of Functioning, Disability and Health (ICF) [24] incorporating both concepts into their model [25]. Both concepts rely on individuals' subjective assessments and utilise a multidimensional approach to evaluate life experiences, stemming from their origins in medical contexts and considerations of health beyond mere absence of disease [11]. However, they also exhibit distinct differences in their emphasis and scope. “Wellbeing”, rooted in hedonic philosophy and popularised by Diener in the 1980s [26], focuses on achieving a balance between positive and negative emotional states, but places more emphasis on the positive aspects by assessing life satisfaction and emotional responses that reflect an individual's overall happiness [27]. In contrast, QoL provides a broader perspective encompassing physical health, psychological state, social relationships, and the wider cultural and environmental context [28].

The term “burden” has also often been used together or synonymously with “QoL”. “Burden” is frequently employed in health economics literature, particularly in the assessment of costs associated with a disease [29]. “Caregiver burden” was originally conceptualised in the 1960s for families of people with schizophrenia [30], and burden instruments initially focused on caregiving tasks and the emotional or psychological strain they imposed on caregivers [31]. Lazarus' stress-appraisal-coping model provides a theoretical framework for many researchers on the concept of burden, highlighting the impact of stress on burden [32]. While some aspects of burden align with QoL, burden primarily focuses on the challenges and strains associated with caregiving or managing specific situations, whereas QoL offers a more comprehensive assessment of an individual's overall satisfaction across various life domains [31]. The interchangeable usage of “wellbeing” and “burden” with “QoL” in the literature suggests a nuanced relationship where these terms can sometimes overlap, indicating a complex understanding of how QoL is perceived and assessed across different contexts and disciplines.

1.2. Parent QoL

While research on QoL has traditionally focused on individuals with health conditions, it is also important to look at the role of caregivers, commonly family members of receivers of care, who provide care informally [33]. Informal caregivers provide unpaid and continuous assistance with daily life activities of a care receiver of any age [34]. The care receiver may be, for example, an elderly parent with dementia, an adult with chronic illness, or a typically developing young child. This caregiving responsibility can entail a multitude of challenges and burdens that can impact the wellbeing of the caregiver.

While numerous studies have explored the QoL of caregivers, including parents, spouses, and children caring for older individuals [35] coping with conditions such as cancer [36], dementia [37] and stroke [38], there is a growing interest in understanding the QoL of parents specifically. Parent QoL refers to parents' subjective assessment of their overall life contentment, drawing from perceptions across various life domains [39]. As primary caregivers for children under the age of eighteen years [40], parents play a pivotal role in shaping the caregiving experience within this demographic [41]. Parents, whether they are caring for children with complex or additional needs, or typically developing children, may face unique challenges while balancing other responsibilities.

In the literature, parent QoL is often conceptualised as a multifaceted construct that encompasses various dimensions reflecting the unique experiences and challenges of parenting [42]. Key components typically include physical health, emotional well-being and social relationships, which relate to the demands of caregiving and the impacts on a parent's physical and psychological state [42] [43] [44]. A review on parents with children with autism found physical health to be the most impacted dimension of parent QoL [42]. The authors theorised this to be due to the 'objective' demands of caregiving, such as sleep disruption and constant supervision, which are unavoidable in caring for a young child [42]. Although parents often report positive emotional rewards, including increased spirituality and personal growth when raising a child with ASD, these benefits primarily help guard against emotional distress rather than the ongoing physical toll [42].

1.2.1. Parent QoL of Children with Complex or Additional Needs

Most QoL research concerning parents has focused on those caring for children with complex needs, such as chronic illness [45] or diagnosed developmental disorders [46]. Caring for children with illness or disabilities may provide opportunities for profound personal growth and a deepened sense of purpose [47]. Many parents derive satisfaction and resilience from their caregiving roles, contributing positively to their own emotional fulfillment and family cohesion [48]. However, it can also be associated with challenges and burden that may impact the wellbeing of parents [33] and can lead to a risk of burnout [41].

A meta-analysis on parents of children with asthma found that overall parent QoL was related to physical and psychological functioning in some studies, while social functioning was listed for another [49]. A systematic review on parents of children with autism highlighted physical and mental health as core domains [42], while a systematic review on parents of children with cerebral palsy indicated that physical health, psychological health, self-efficacy, and social support were the key domains of parent QoL [43]. Evidently, across the literature, there is inconsistency in how parent QoL is defined and assessed and there is currently no theoretical model describing or explaining parent QoL or its domains. This suggests that parent QoL is a complex construct, and that universal agreement on the domains that comprise parent QoL is lacking. However, within the literature, three common domains are observed to frequently emerge: physical, emotional and social.

Studies examining the physical health aspect of parent QoL have found that a substantial proportion of parents of children with cerebral palsy [43], attention-deficit/hyperactivity disorder (ADHD) [44], autism [50], cancer, [51] and asthma [49] reported lowered satisfaction with their physical health and encountered difficulties in performing daily tasks due to moderate to severe physical pain [52]. Mothers reported the most pronounced negative health effects, such as chronic fatigue and sleep deprivation as direct consequences of their caregiving responsibilities [53]. Moreover, several parents coping with personal health conditions like diabetes or hypertension expressed that, while their ailments may not have stemmed directly from caregiving duties, they often felt compelled to prioritise the healthcare needs of their child [53]. Caregivers also often perceived these challenges as more acute in the early years of caregiving but reported greater health deterioration in later years [53]. For example, parents of children with disabilities reported higher rates of hypertension, heart disease, and cancer in later life compared to those with typically developing children [54].

Parents of children with complex needs may also grapple with emotional challenges, a critical component of their QoL. While some parents may experience a sense of peace due to their empathy, compassion, and personal growth through caregiving roles [55], many describe significant challenges. For instance, frequent hospitalisations and the decision to place a child outside the home due to inadequate support can lead to depression [56] [57]. Financial strain, difficulties in securing government or insurance funding, and a lack of essential services can further contribute to parental anxiety and stress [52]. In cases where children are dependent on long-term technology such as ventilators, parents have reported experiencing increased levels of sadness and frustration compared to those caring for able-bodied children [58]. These parents also frequently experienced feelings of loss and grief over their child not reaching anticipated milestones, such as achieving independence in adulthood [59]. The sense of loss may also be compounded by fears about their child’s future, including who will care for them when the parents are no longer able [53]. Additionally, parents of children with developmental disabilities may harbor anxieties about their child's ability to navigate adult life, secure employment, and integrate into social support networks [60]. Despite their efforts to advocate for and plan their child's future, caregivers may feel overwhelmed by the task of ensuring a secure and fulfilling life for their children [59]. Thus, the emotional aspect of caring for children with complex needs can significantly impact a parent’s QoL, influencing their ability to cope with ongoing challenges.

The caregiving journey for parents of children with illness or disabilities may also exact a toll on their interpersonal relationships and social connections, leading to feelings of isolation and loneliness. The demands of caregiving can strain relationships with spouses, family members, and friends, as caregivers may struggle to find time and energy to nurture these connections [61]. For instance, mothers caring for children with disabilities reported a poorer sexual quality of life due to stress from heavy caregiving responsibilities [62]. Parents of children with disabilities also reported feeling less support from the community [63], due to prioritising their child's needs over their own social lives. This can potentially lead to feelings of detachment and disconnection from their broader social networks, as parents may fear that others may not understand their circumstances [64]. Some parents may turn to support groups and online forums to connect with others who share similar experiences, finding solace in the understanding and empathy of fellow caregivers [65]. Others may seek professional counselling or therapy to process their emotions and develop coping mechanisms for managing stress and anxiety [66]. However, there are a subset of parents who may be unaware of these resources or feel embarrassed to reach out to receive help [66].

1.2.2. Parent QoL of Typically Developing Children

While much of the existing research focuses on parents of children with complex or additional needs, it is important to recognise that parents of typically developing children can also face challenges that impact their QoL. Balancing parenting responsibilities with personal and professional commitments can be demanding and challenging [67]. For instance, parents may encounter physical health challenges stemming from insufficient time, limited access to reliable or affordable childcare services, and a tendency to prioritise their childcare responsibilities over their own needs [68]. Their own health concerns may be frequently overlooked and sometimes worsened. Therefore, these physical health difficulties may contribute to reduced QoL of parents.

The emotional component of caring for children may also potentially influence parent QoL. On one hand, mothers reported deriving a sense of purpose, fulfillment, and unconditional love from their role as caregivers, fostering strong bonds with their children and experiencing moments of joy, pride, and resilience in the face of adversity [69]. On the other hand, parenting may also give rise to significant emotional challenges and distress for parents. For instance, many parents expressed that balancing the daily demands of childcare and family responsibilities, alongside time pressures and persistent concerns about the future, led to significant emotional distress. [70] [71].

Parents may also navigate a range of social challenges that impact their QoL. Interpersonal relationships within their social circles, including family, friends, and community, play a crucial role in a parent’s life [72]. Balancing social obligations with parenting responsibilities can lead to feelings of isolation or strain on relationships [72]. For instance, managing conflicting schedules for children's activities and maintaining social connections may become challenging, potentially limiting opportunities for personal downtime or relaxation [73].

The cultural context of families with typically developing children potentially plays a significant role in shaping parent QoL. Cultural values and norms may influence expectations around caregiving, family roles, and parental responsibilities, which can impact parental stress and satisfaction levels [74]. In cultures that emphasise collective family support, for example, parents may experience less pressure as caregiving responsibilities are often shared among extended family members [75]. Conversely, in more individualistic societies, parents may shoulder a larger share of childcare alone, which can contribute to increased stress and reduced QoL [75]. Furthermore, cultural attitudes toward parental roles can influence the level of societal support provided to parents, such as access to childcare facilities, parental leave policies, and community resources [76]. These cultural factors ultimately may shape the resources and social expectations that either alleviate or add to the demands of parenting.

Family composition may be another critical factor impacting parent QoL among families of typically developing children. Single parents may often face unique challenges, such as managing childcare and financial responsibilities without the support of a co-parent, which can increase stress and reduce parent QoL [77]. Similarly, multi-generational or extended family households, though providing additional support, may also lead to conflicting parenting styles or decision-making tensions that affect parent QoL [78]. Same-sex parent families may encounter societal stigma or a lack of support networks tailored to their needs, which can influence their experiences of parenthood [79]. Conversely, the presence of supportive family structures, such as extended family members or community support networks, may provide additional resources and emotional support, potentially enhancing QoL for parents in these family compositions [78].

Parents of young children prior to school age (zero to five years old) may also encounter distinctive challenges that can impact their QoL. During these formative years, children experience a period of profound dependency on their caregivers for basic needs such as safety, sustenance, and socialisation [80]. Parents therefore assume primary responsibility for tasks like feeding, bathing, and engaging with their young child [81]. This differs from caring for older children, who possess greater cognitive abilities and independence [82]. Financial challenges may arise as some parents opt to temporarily pause their careers to stay home and care for their child, while others may have to face the expense of enrolling them in daycare [83]. This situation can impact parent career progression and contribute to feelings of dissatisfaction or discontent for the stay-at-home parent [84]. Furthermore, the reliance on a single income can place additional financial strain on the family, potentially exacerbating stress and affecting overall family wellbeing [83]. Parents also carry the responsibility of monitoring their child's milestones during the early years, identifying and reporting any concerns about delays in the child’s development, managing any pain or dietary needs, and consulting with health practitioners as necessary [85].

1.2.3. The Relationship Between Parent QoL and Child Development

Age two marks a critical stage in early childhood development, characterised by rapid growth in developmental domains, which require heightened parental involvement and adaptation [86]. At this age, children often begin to assert autonomy which necessitates parents balancing safety and boundary-setting with their child’s growing independence [87]. Research highlights that developmental milestones such as language acquisition, motor skills, and social interactions, become especially significant during this stage [88] [89] [90]. These changes can place increased demands on parents’ time, energy, and emotional resilience, potentially affecting their QoL in distinct ways [42]. Examining parent QoL at this stage offers valuable insights into how these evolving developmental needs impact parental well-being and, by extension, family functioning.

Across all children, whether diagnosed with a condition or not, there exists a diversity of developmental needs and skills. Developmental delays are identified when infants or young children do not reach typical developmental milestones within the expected time window [91] [92]. These delays can manifest in one or more developmental domains including cognitive abilities, language skills, motor coordination, social-emotional development, and adaptive behaviours [93]. Cognitive abilities refer to a child's capacity to perceive, process, and understand information, encompassing skills such as attention, memory, problem-solving, and reasoning [93] [94]. Language skills involve the ability to comprehend and use spoken and written language, including vocabulary, grammar, and communication [93] [95]. Motor coordination pertains to the control and coordination of muscles and movement, including both gross motor skills (such as walking and running) and fine motor skills (such as grasping objects and writing) [93] [95]. Social-emotional development involves the child's ability to regulate emotions, form relationships, and interact with others in a socially appropriate manner [93] [96]. Finally, adaptive behaviours encompass a range of practical skills necessary for daily living, including self-care activities (such as eating and dressing), communication skills, and the ability to navigate various social situations independently [93] [97].

While some developmental delays may be transient and resolve over time, others persist and may signify underlying developmental disorders, such as autism, language disorders, or intellectual disabilities [98]. Even for children who do not receive formal diagnoses, developmental delays may pose ongoing difficulties as they progress through childhood and adolescence [99]. Children with developmental delays may experience difficulties in academic settings, social interactions, and independent living [100]. Without appropriate support and intervention, these challenges can persist into adolescence and adulthood, impacting individuals' QoL and limiting their opportunities for full participation in society.

Although studies suggest a connection between parent QoL and child outcomes, distinguishing clear predictors from outcomes remains challenging [101]. The reciprocal relationship between caregiver and child, as well as the impact of the parent-child relationship on parent QoL, may have relevance in the context of child developmental delays. When a child experiences developmental delays, it can necessitate increased caregiving responsibilities and alter the dynamics of the parent-child relationship [102]. Parents may face unique challenges in meeting the needs of their child with developmental delays, which can influence their own QoL.

Few studies have been conducted to determine the relationship between parent QoL and specific domains of child development at a young age. However, studies examining related concepts, such as parent wellbeing, life satisfaction, stress and mental health, can offer some insights. For instance, maternal life satisfaction has been found to be positively associated with typically developing children's verbal skills [103], self-regulation, prosocial behaviour and receptive language skills [104]. Studies by Button et al. [105] and Glenn et al. [106] have found that the level of cognitive impairment in children with cerebral palsy aged one to six years old significantly predicted caregiver stress. Similarly, Unsal-Delialioglu and colleagues [107] identified an association between speech issues in young children with cerebral palsy and maternal depression.

Of the limited studies specifically examining parent QoL with child development, parent QoL has been associated with the social-emotional skills of two- to six-year-old children with autism [108]. Further, Nuske and colleagues reported that parent QoL for parents of children with autism aged two to five years old decreased when children exhibited poor emotion regulation and externalising behaviours, such as child tantrums and aggression [109]. This highlights a potential association between parent QoL and child development, particularly in the social- emotional domain. However, these studies both focus on parents of children with autism. It remains unclear whether there is a relationship between parent QoL and child development within the general population.

1.3. Approaches to Assessment of Parent QoL

Approaches to assessing parent QoL may include quantitative and/or qualitative methodologies to comprehensively capture the multifaceted dimensions of the caregiving experience [110]. Quantitative assessments typically involve the administration of structured and standardised questionnaires, which provide numerical scores that facilitate comparisons and statistical analyses [111] [96]. Commonly used instruments in parent QoL research include the Short Form-36 (SF-

36) [112], which is the most widely applied measure for general QoL, providing a broad benchmark across physical, mental, and social domains [113] [114]. Another instrument, the CarerQoL-7D (127), aims to address caregiving-specific aspects of QoL, such as emotional burden and financial strain. Previous studies reported satisfactory psychometric properties of the CarerQoL-7D for caregivers of children with clinical conditions and adult dependents [115] [116] [117] [118]. These tools represent examples of how quantitative assessments can be tailored to different aspects of the caregiving experience, offering distinct perspectives within parent QoL research.

On the other hand, qualitative assessments such as interviews and focus groups delve further into the subjective experiences and perceptions of parents, allowing for an in-depth exploration of their lived experiences, coping strategies, and unmet needs [110]. Specific qualitative instruments for parent QoL are not typically standardised, as qualitative methods are often tailored to the unique responses and experiences of each participant, adapting flexibly to capture the complexity of individual caregiving contexts [110].

Additionally, mixed-method approaches integrate both quantitative and qualitative data, allowing for a more comprehensive understanding of parent QoL by triangulating findings from multiple sources [119]. An example of this is the Mother Generated Index [128], which asks mothers to identify and rate eight important areas of their life that have impacted their QoL since having a child, scoring these areas from best to worst to capture personalised dimensions of their caregiving experience. A scoping review on parent QoL with preterm infants [113] suggests that quantitative measurements are used more frequently, however parents noted that some of their concerns were not reflected by the quantitative assessments [120].

Selecting appropriate instruments for assessing parent QoL in the context of caregiving for children requires careful consideration of their psychometric properties. Reliability, validity, and responsiveness are key psychometric properties that ensure the accuracy and usefulness of these instruments [121]. Given QoL of parents of young children have received relatively little attention in the literature to date, it is not clear whether there are instruments available that have been adequately validated and proven to be reliable and responsive for this specific population.

1.4. Rationale for the Current Study

Understanding parent QoL and its interplay with child development is paramount, as these parents may face unique challenges. A parent's QoL may significantly influence their capacity to provide nurturing care, support their child's emotional and cognitive growth, and maintain family harmony [42] [113]. Moreover, the toddler years represent a pivotal developmental stage within the broader age range of zero to five, marked by significant milestones in language, motor skills, and the emergence of more complex social interactions [122] Toddlers also exhibit a blend of dependency and burgeoning independence [122], which may impact the parental experience. Balancing constant supervision and support with fostering their child's growing autonomy requires parents to swiftly adapt to changing abilities and exploratory desires [123]. This dynamic can influence parent stress levels, time management, and overall sense of control and fulfillment [123]. Despite these challenges, there is a noticeable gap in research on how parent QoL relates to specific aspects of child development during this critical age. As such, understanding this relationship can help identify the specific needs of these families, leading to better support and outcomes for both parents and young children.

Furthermore, the domains of parent QoL have not been well defined, and there is no gold standard instrument for the measurement of parent QoL. A comprehensive and systematic exploration of current approaches to assessing parent QoL in the literature may offer insights into core domains of parent QoL, while also highlighting gaps in current assessment approaches to be addressed in future research.

1.5. Theoretical Framework: Bronfenbrenner’s Ecological Systems Theory

This study is informed by Bronfenbrenner’s Ecological Systems Theory, which proposes that human development is shaped by interconnected environmental systems [124]. These systems encompass the microsystem (immediate environments like the family), mesosystem (interactions between microsystems), exosystem (external environments indirectly influencing development), and macrosystem (cultural and societal contexts) [124]. While traditionally applied to child development, Bronfenbrenner's theory has also been contextualised in studies involving adult caregivers of aging adults [125]. In our study, parent QoL is positioned centrally, with child development considered within the microsystem framework. By applying this framework, we explore how the interactions and dynamics within these systems impact parent QoL and the developmental outcomes of young children, while acknowledging the potential complex and multi-directional nature of these influences. Understanding these complex relationships can help clarify the broader factors that influence parent QoL and child development, especially during early childhood.

1.6. Aim and Objectives

The aim of the thesis is to better understand how parent QoL relates to early child development and evaluate how QoL for parents of young children has been assessed in the literature.

The objectives of this thesis are twofold: firstly, to investigate the relationship between parent QoL and child development at age two. The second objective is to identify and characterise current approaches to assessment of QoL of parents of young children aged five years and below through a scoping review of the literature.

1.7. Chapters

Chapter Two presents the first paper titled "The Relationship between Parent QoL and Child Development at Age Two." In this chapter, correlation and partial correlation analysis was used to examine whether there is a relationship between parent QoL and development in children aged two, after controlling for sociodemographic variables.

Chapter Three comprises the second paper titled "A Scoping Review on the Quality of Life of Parents of Young Children". This chapter presents a comprehensive scoping review that synthesises existing literature on approaches to assessment of QoL of parents with young children. This provides an overview of the instruments, psychometric properties and domains assessing parent QoL, and the implications for future research and practice.

Chapter Four offers a critical review and discussion of the findings from the preceding studies. This chapter aims to highlight key insights into the relationship between parent QoL and child developmental delays, identify gaps in the current literature, and propose avenues for further inquiry to advance knowledge in this vital area of research.

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Chapter Two: The Relationship between Parent QoL and Child Development at Age Two

Evelyn K.L. Toh^a, Professor Catherine Elliott^b, Dr. Caroline Alexander^c, Dr. Sarah Hall^d, and Dr. Ashleigh Thornton^e

^a Curtin University, Perth, Western Australia
^b Curtin University, Perth Children's Hospital, Perth, Western Australia
^c Curtin University, Perth Children's Hospital, Perth, Western Australia
^d Curtin University, Perth Children's Hospital, Perth, Western Australia
^e Curtin University, Perth Children's Hospital, Perth, Western Australia

2.1. Chapter Two Preamble

This chapter is a key component of a broader thesis that explores the complex interactions between parent QoL and child development during early childhood. It utilises data from the Early Moves project, a large birth cohort study (Elliott et al., 2021). In the Early Moves project, parent QoL was assessed using the CarerQoL-7D, a self-reported measure designed to capture the subjective burden experienced by informal caregivers (Brouwer., 2006). While there is no single gold standard for measuring parent QoL, the CarerQoL-7D (Brouwer., 2006) was selected due to its focus on caregiving-specific aspects of QoL, such as emotional burden and financial strain. Previous studies have also reported satisfactory psychometric properties of the CarerQoL-7D in assessing caregivers of children with clinical conditions and adult dependents (Hoefman et al., 2014; Payakachat et al., 2011; Fitzgerald et al., 2018; McCaffrey et al., 2020). Child development at age two was evaluated using the Bayley-4, which is widely recognised as the gold standard instrument for child developmental assessment (Bayley & Glen, 2019).

This study aims to provide a holistic understanding of child development domains and their intricate relationship with parent QoL during the crucial early childhood years.

2.2. Abstract

Purpose: This study aims to investigate the relationship between early child development and parent QoL in a general population-based cohort in Perth, Australia. Specifically, it explores how different domains of child development at age two, as measured by the Bayley-4 scales of infant development, correlate with parent QoL assessed by the CarerQoL-7D, accounting for sociodemographic variables.

Methods: Data were obtained for 412 mother-infant dyads participating in the Early Moves project within the ORIGINS project. Child development was assessed using the Bayley-4 scales covering cognition, language, motor skills, social-emotional development, and adaptive behaviours. Maternal QoL was measured using the CarerQoL-7D. Spearman’s rho correlation and partial correlation analyses, controlling for parent education and household income, were conducted to examine these relationships.

Results: Initial analyses revealed weak, negative associations between parent burden and child motor skills, social-emotional skills, and adaptive behaviours. After adjusting for sociodemographic factors, the negative association between the social-emotional domain and parent burden remained significant, though it was weak (r = -0.19, p = .01). This negative association corresponds to a positive relationship between the child’s social-emotional domain and parent QoL.

Conclusion: In this sample of predominantly typically developing children, social- emotional development at age two was found to be related to maternal QoL. Enhancing toddlers' social-emotional skills through early interventions may reduce parenting-related stress, supporting both child development and overall maternal QoL. Further research employing longitudinal designs and diverse caregiver perspectives is needed to understand possible bidirectional relationships between parent QoL and early child development.

Keywords: child development, parent quality of life, early intervention, Bayley-4, CarerQoL-7D

2.3. Introduction

Developmental delays comprise a range of difficulties faced by infants or young children in one or more of five developmental domains: cognitive, language, motor, social-emotional or adaptive behaviours (Bayley & Glen, 2019). Although some delays in the attainment of developmental milestones may be temporary, a subset of children with developmental delay identified in early childhood will later be diagnosed with a developmental disability, such as a language disorder, autism, or intellectual disability (Young et al., 2002). Even for children who do not go on to receive a formal diagnosis, developmental delays can be associated with a heightened risk of future learning difficulties, problems with emotional regulation, and functional impairments (Ogundele et al., 2018). Moreover, developmental delays are also linked to physical, psychological, and economic burdens for families and societies (Kim, 2022). As such, early identification of developmental delays is important for timely implementation of interventions that enhance health outcomes for these children (Baio, 2018) and potentially contribute to improved quality of life (QoL) for parents.

Parent QoL refers to the subjective assessment made by individuals who are caregivers or guardians for children regarding their overall life contentment, often derived from their perceptions of contentment across various life domains (WHO, 1998; Martin et al., 2019). Parent QoL is often linked to the burdens of caregiving, encompassing challenges such as time constraints, emotional strain, and financial pressures, which can contribute to parent burnout and significantly affect their overall wellbeing (Glozman, 2004).

While acknowledging the importance of both parents' QoL, this study focuses on maternal QoL, given the prevalence of maternal caregiving roles in child rearing (Holden, 2019). Results from the literature suggest that there is a reciprocal relationship between mother and child, and child factors, and the parent-child relationship may influence parent QoL (Paschall & Mastergeorge, 2016; Crnic & Low, 2002). For instance, parenting a child with complex needs such as autism can be associated with lower parent QoL (Vasilopoulou et al., 2016). Some mothers of children with ADHD (Cappe et al., 2017), cerebral palsy (Pousada et al., 2013) and autism (Vernhet et al., 2022) reported lower satisfaction with their own physical health, psychological wellbeing and financial resource, and felt less support from the community (Colic et al., 2022). Moreover, higher future anxieties and fear of anticipated failures were reported by mothers of children with developmental disabilities (autism, sensory disabilities, and intellectual disabilities), as compared to mothers with typically developing children (Bujnowska et al., 2019).

Research on the relationship between parent QoL and specific child developmental domains is limited. Emerging evidence highlights that maternal life satisfaction correlates positively with the verbal abilities of typically developing children in the two- to three-year age bracket (Berger & Spiel, 2011). Similarly, five- to seven-year- olds' social-emotional competencies are associated with improved maternal life satisfaction (Richter et al., 2011). For parents of young children with autism, aged two- to six- years, there is a notable link between lower QoL and their children's reduced social-emotional skills (Islam et al., 2021). Additionally, a decline in parent QoL is observed when these children (aged two to five) struggle with emotional regulation and exhibit externalising behaviours like tantrums and aggression (Nuske et al., 2018). This underscores the potential association between parent QoL and child's social-emotional domain.

While several studies have examined the relationship between child development and parent QoL (Vasilopoulou et al., 2016; Cappe et al., 2017; Pousada et al., 2013; Vernhet et al., 2022), studies typically focus on parents of children up to eighteen years old, which may overlook the unique challenges and experiences encountered by mothers during the early years of a child's life. In addition, most studies are conducted on parents with children with specific developmental disabilities QoL (Vasilopoulou et al., 2016; Cappe et al., 2017; Pousada et al., 2013). Research examining the relationship between parent QoL and children without diagnosis, including those with undiagnosed developmental delays, is scarce. Moreover, studies usually focus predominantly on one or two domains of child development when assessing the relationship with parent QoL (Nuske et al., 2018). This focus may overlook the interconnectedness of various developmental domains and may be unable to capture the holistic picture of child development and its relationship with parent QoL.

Therefore, the aim of this study was to investigate the correlation between early child development and maternal QoL within a general population-based cohort in Perth, Australia, aiming to fill an existing gap in the current literature. Specifically, the objective was to assess the relationship between child development, as measured by the Bayley-4 Scales of Infant Development at two years old for (i) cognition, (ii) language, (iii) motor skills, (iv) social-emotional, (v) adaptive behaviours, and parent QoL measured by the Carer QoL-7D, after controlling for sociodemographic variables. It is hypothesised that there will be a positive association between maternal QoL and child social-emotional skills.

2.4. Methods

2.4.1. Participants and Study Design

The present study is a cross-sectional study using existing data collected from the Early Moves project. Early Moves is a longitudinal cohort study of infant development until two years of age and is a subproject of The ORIGINS Project (Elliott et al., 2021). The Early Moves project recruited term and preterm babies between November 2019 to December 2023. Participation was open to all mothers of singletons attending antenatal clinics or on post-natal wards at Joondalup Health Campus or St John of God Public Hospital in Western Australia during the recruitment period. All participants who attended their two-year-old appointment from November 2019 until February 2024 and completed the CarerQoL-7D questionnaire and at least one domain of the Bayley-4 developmental assessment (Cognitive, Language or Motor) were included in the current cross-sectional sub-study. Fathers and twin infants were excluded from this sub-study. The final sample consisted of 412 mother-infant dyads and was expected to consist of typically developing children.

2.4.2. Sample Size

To determine the appropriate study size, a power analysis using G*Power was performed (Faul et al., 2007). Using an estimated effect size of 0.2 as suggested by Cohen and setting the significance level (alpha) at 0.05, the power analysis indicated that a minimum of 314 participants was required to achieve a power of 80%. This sample size would ensure that the study could reliably detect even modest associations between parent QoL and child development domains.

2.4.3. Measures

Demographics

Demographics, including infant gender, parent age at the infant's birth, marital status, and ethnicity, were attained from hospital records. Additional socioeconomic data, including mothers' educational attainment, pre-pregnancy employment and pre-pregnancy household income were obtained for participants enrolled in the ORIGINS Project who completed online questionnaires during pregnancy. The covariates of interest for the study were mother's highest level of education and annual household income (combined income for both parents).

Child development

Developmental assessments for the child were conducted at the study clinics by trained allied health clinicians using the Bayley Scales of Infant Development Fourth Edition (Bayley-4), which is recognised as the gold standard assessment to measure infant and toddler development (Bayley & Glen, 2019). The Bayley-4 is a comprehensive measure designed for infants and toddlers from 16 days to 42 months, encompassing cognitive, language, motor, social-emotional, and adaptive behaviours domains (Bayley & Glen, 2019). The cognitive, language, and motor domains were assessed through structured performance tasks administered to the child by a clinician who was masked to the child’s and family's history. In contrast, the social-emotional and adaptive behaviour domains were evaluated via questionnaires completed by the parent. Raw scores from the Bayley-4 were converted into standard scores (*M* = 100, *SD* = 15) for the five domains using Australian and New Zealand consensus norms (Bayley & Glen, 2019). Higher scores indicate development above age expectations relative to the normative sample, while lower scores indicate risk of developmental delay (Bayley & Glen, 2019). The Bayley-4 Scales have previously demonstrated robust internal reliability ranging from 0.93 to 0.95, and test-retest reliability ranging from 0.81 to 0.84 when assessing children with typical development or clinical diagnoses (Bayley & Glen, 2019). To assess validity, the Bayley-4 test developers analysed correlations between children's Bayley-4 performance and the Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition (WPPSI-IV) in a sample of 104 children aged 30-42 months. Results showed a 0.79 correlation between the Bayley-4 Cognitive scale and the WPPSI-IV Full-Scale IQ, a 0.70 correlation with the Language standard score, and a 0.64 correlation with the Fine Motor standard score, supporting evidence for the Bayley-4's validity (Bayley & Glen, 2019).

The first domain, cognitive, assesses abilities such as object manipulation, concept formation, memory, and initial stages of higher-order thinking. Tasks involve recalling names, classifying objects, or matching sizes. The second domain, language, comprises of receptive and expressive communication. Receptive communication evaluates both nonverbal and verbal communication skills, assessed through the child’s understanding of one-part directions and pronouns, plurals, and comparative terms. Expressive communication assesses vocabulary acquisition, syntactic structure, and morphological development, involving tasks such as identifying pictured objects, responding to yes or no questions, and speaking in sentences. Third, the motor skills domain consists of fine motor and gross motor. Fine motor evaluates perceptual-motor integration, motor planning, and speed, encompassing activities such as object manipulation and figure copying. Gross motor assesses locomotion, coordination, and balance, including tasks like kicking a ball and descending stairs independently. Fourth, the social-emotional domain evaluates a child's behaviour in social situations. Parents are asked to rate the child's response to social cues, ability to regulate emotions in different situations, and coping mechanisms in challenging scenarios. Lastly, the adaptive behaviours domain measures a child's ability to function independently in daily life. Parents are asked to rate the child's ability to dress themselves, communicate their needs effectively, and perform basic daily activities such as eating and grooming (Bayley & Glen, 2019).

Parent Quality of Life

Parent QoL was measured by the CarerQoL-7D, a caregiver self-reported measure that assesses subjective burden for informal caregivers (Brouwer et al., 2006), completed by the parent during their child's developmental assessment. It consists of seven items related to caregiver burden, comprising five negative dimensions and two positive dimensions, each offering three possible response options (no, some, a lot). The negative dimensions include fulfillment of caregiving, relational problems, mental health problems, problems with combining daily activities, and financial problems, while the positive dimensions include social support and physical health problems. The overall sum score, ranging from zero to fourteen, reflects the impact of informal caregiving on caregivers, with higher scores indicating greater burden and lower QoL when accounting for reversed item scores (Bayley & Glen, 2019).

The CarerQoL-7D instrument is commonly used in QoL assessments (Hoefman et al., 2011; Hoefman et al., 2014). Unlike typical QoL measures, which tend to be negatively skewed due to favourable self-reports, the CarerQoL-7D results exhibit a positive skew due to the focus on burden. It typically takes about five to ten minutes to complete the questionnaire. This timeframe can vary slightly depending on the individual caregiver's ability to reflect on their caregiving experiences and familiarity with the questions. Previous studies reported satisfactory psychometric properties of the CarerQoL-7D for caregivers of children with clinical conditions and adult dependents (Hoefman et al., 2014; Payakachat et al., 2011; Fitzgerald et al., 2018; McCaffrey et al., 2020). The CarerQoL-7D demonstrated moderate reliability with an internal consistency of $\alpha = .65$ (McCaffrey et al., 2020). Validity evidence includes correlations with other caregiving impact indicators, showing that higher fulfillment and support are associated with better caregiving quality of life, while increased burden (relational, mental health, daily activities, financial, and physical health problems) correlates with lower scores in a sample of caregivers with children of autism (Hoefman et al., 2014). Additionally, the instrument can differentiate between caregivers based on levels of fulfillment and support, indicating its convergent and discriminative validity in various caregiving contexts (Hoefman et al., 2014). The additional visual analogue scale (VAS) component of the CarerQoL-7D was not used in this study.

2.4.4. Data Analysis

Descriptive statistics, including frequencies and proportions, were used to describe parent and child characteristics. Spearman's rho correlation was used to determine the relationship between parent QoL and each domain of the Bayley-4 assessment (cognitive, motor skills, language, social-emotional, and adaptive behaviours). Due to the non-parametric nature of the data, Spearman's rho correlation coefficient was selected as it does not assume a linear relationship between variables and is robust against outliers (De Winter et al., 2016). Guidelines recommended by Dancey and colleagues (2007) were used to interpret the magnitude of correlation effects for Spearman's rho correlation. Partial correlation (Spearman's rho) was used to assess the relationship between parent QoL and Bayley-4 results after controlling for sociodemographic variables (parent education and household income). All analyses were conducted with IBM SPSS version 26.

2.5. Results

Sociodemographic data for the 412 participants are presented in Table One.

There was an approximately equal distribution of child gender, with 199 males (48.5%). The average age of the mothers was 32.47 years (SD = 4.65), and most mothers were married or in a de facto relationship (94.2%) and identified as Caucasian (86.1%). Educational attainment and household income data were available for 260 and 259 mothers respectively. A substantial proportion of mothers held a bachelor's degree (39.2%), and the majority had a family income of more than $150,000 per year (19.9%). The mean age of assessment for the Bayley-4 was 1.98 years ± 0.17 years.

Table One: Sociodemographic data for participants

Parent sociodemographic data	
Education, n (%)	*n = 260*
Less than Year 10	0 (0)
Year 10, 11 or equivalent	15 (6.1)
Year 12 or equivalent	37 (15)
Trade certificate/apprenticeship	48 (19.4)
Bachelor's degree	102 (41.3)
Postgraduate degree	45 (18.2)
Household income, n (%)	*n = 259*
Up to $25000 a year	9 (2.2)
$25001 to $50000 a year	12 (2.9)
$50001 to $75000 a year	25 (6.1)
$75001 to $100000 a year	44 (10.7)
$100001 to $150000 a year	78 (18.9)
More than $150000 a year	82 (19.9)

Descriptive statistics for the Bayley-4 and CarerQoL-7D are presented in Table Two. Bayley-4 results across all domains were normally distributed (refer to Supplementary Figure) and are presented as means and standard deviations. CarerQoL-7D results were positively skewed and are presented as median and interquartile range.

Table Two: Bayley-4 and CarerQoL-7D results

Variable	**N**	**Score**	**Range**	**Interquartile Range**
Bayley-4 Domains, *Mean (SD)*				
Cognition	411	98.31 (13.38)	65 to 145	15
Language	384	101.21 (15.53)	50 to 146	20
Motor Skill	361	98.88 (10.78)	67 to 130	15
Social-Emotional	386	103.87 (13.64)	55 to 130	20

Adaptive Behaviours	386	99.99 (16.76)	56 to 150	24
CarerQoL-7D, *Median (IQR)*				
CarerQoL-7D Total	412	2.0 (1.0 – 3.0)	0 to 9	2

The relationship between Bayley-4 domains and CarerQoL-7D assessed using Spearman's rho correlation is presented in Table Three. After conducting the analysis, a weak, negative correlation was noted between CarerQoL-7D scores and child motor skills, social-emotional skills, and adaptive behaviours, such that lower caregiver burden (higher parent QoL) was related to higher scores on these Bayley-4 domains. However, once parent education and household income were controlled for, this association remained only for social-emotional skills and CarerQoL-7D scores.

Table Three: Spearman's rho correlation between child development standard scores (Bayley-4) and caregiver burden (CarerQoL-7D).

	Cognitive	Language	Motor skills	Social-emotional	Adaptive behaviours
1. CarerQoL-7D	(n = 411) -0.03 (*p* = 0.58)	(n = 384) -0.07 (*p* = 0.20)	(n = 361) -0.13* (*p* = 0.01)	(n = 386) -0.21** (*p* < 0.001)	(n = 386) -0.13* (*p* = 0.02)
2. CarerQoL-7D (after controlling parent education and household income)	(n = 154) 0.09 (*p* = 0.19)	(n = 170) 0.02 (*p* = 0.78)	(n = 187) -0.05 (*p* = 0.47)	(n = 166) -0.19** (*p* = 0.01)	(n = 166) -0.09 (*p* = 0.16)

*$p < 0.05$ (two-tailed)

**$p < 0.01$ (two-tailed)

2.6. Discussion

The present study analysed the relationship between parent QoL and child development at age two in a non-clinical sample of mother-infant dyads. When controlling for parent education and household income, the results suggested a positive relationship between child social-emotional domain and parent QoL. While motor skills and adaptive behaviours domains showed initial relationships with parent QoL, these associations did not remain significant after controlling for parent education and household income in the partial correlation analysis. The positive relationship between the child social-emotional domain and parent QoL corresponds with Richter et al., (2018), Islam et al., (2021) and Nuske et al's (2018) studies, which underscore how parent QoL and child developmental outcomes are closely intertwined.

It is essential to acknowledge the potential complex nature of the relationship between parent QoL and child developmental domains. The study findings indicate a weak relationship between these factors; however, due to the correlational nature of the analyses, a specific directional influence cannot be inferred. This weak association may be influenced by Bayley-4 scores higher than clinical samples, indicating that the sample of children assessed may not represent a broader population with varied developmental needs.

Although limited predictive research exists on the direct effects of parent QoL on child development due to the young age of children, related constructs provide insightful inferences. For instance, parents' stress levels may shape the caregiving environment and the quality of interactions with their children (Hinshaw, 2005; Eaton et al., 2016). Parents experiencing high levels of stress or lowered QoL may have reduced capacity to engage in stimulating and nurturing activities, which can influence cognitive, language, and social-emotional development in children (Kinnear et al., 2016). Conversely, parents with elevated QoL levels may create nurturing environments conducive to optimal child development, as suggested in studies involving parents of children with cerebral palsy (Lincoln et al., 2017). Moreover, maternal depression during the sensitive period, spanning from birth to the child's first birthday, emerged as a significant predictor of subsequent internalising difficulties, such as anxiety, depression, and social withdrawal, in children aged 12 years and under (Gross et al., 2013). This suggests that parental mental health, which may be a critical component to parent QoL, may contribute to shaping child developmental trajectories characterised by behavioural and emotional challenges which may persist into later developmental stages. Furthermore, Lincoln reported that maternal behaviours during play and perceptions of their preschool child's regulatory abilities significantly predicted children's emotional responses like hostility and compliance (Britto et el., 2017). These findings align with the study results, suggesting that mothers who are more engaged and have positive perceptions of their child's abilities (suggesting better QoL) may be associated with children with better emotional regulation.

The association observed between parent QoL and child development may also be influenced by the development of emotional regulation skills in early childhood. Effective emotional regulation skills, crucial for promoting mental wellbeing from an early age, begin to develop in early childhood, starting from birth (Cummins & McMaster, 2006). These skills form an essential foundation for children's emotional development and their ability to manage and navigate their feelings as they grow (Cummins & McMaster, 2006). This foundational aspect of emotional regulation is closely intertwined with parent QoL, as parents play a pivotal role in supporting and nurturing their child's emotional development (Holland et al., 2017). A child's early acquisition of these skills not only enhances their own emotional resilience, but also contributes positively to parental wellbeing by reducing stress related to managing emotional outbursts and fostering a harmonious parent-child relationship (Frydenberg et al., 2019). Therefore, the social-emotional domain may serve as a foundational aspect in early childhood development, emphasising the critical role of nurturing emotional regulation skills from infancy onward. Additionally, it is essential to consider how variations in social-emotional development among toddlers impact parent experiences. Toddlers who exhibit delayed social-emotional skills may be prone to occasional behavioural challenges like tantrums, which can pose difficulties for parents to manage (Campbell et al., 2016). Conversely, toddlers with well-developed social-emotional skills that meet or exceed age expectations may experience fewer behavioural issues, potentially improving caregiver QoL (Frydenberg et al., 2019). This nuanced approach acknowledges that the developmental trajectory of social-emotional skills in toddlers may play a pivotal role in shaping parent QoL.

Methodological differences are also important to consider. The Bayley-4 cognitive, language and motor domains of children development were administered as behavioural assessments by a clinician, while the social-emotional and adaptive behaviours domain were assessed by parent questionnaires. Conducting comprehensive direct assessments of two-year-olds presents inherent challenges, particularly concerning engagement with the assessment process (Campbell et al., 2016). This age group is characterised by emerging autonomy and the exploration of boundaries, often resulting in resistance to certain aspects of assessments (Campbell et al., 2016). Moreover, factors such as fatigue and limited attention span may further impede the accuracy and reliability of direct assessment outcomes (Ahmed et al., 2022), therefore the child’s behaviour in a new setting may not be generalised to their natural behaviour (Schmuckler, 2001). Additionally, children within this age range may also be susceptible to demand characteristics, where they potentially change their behaviours or responses based on cues they perceive from the researcher or situation (McDonald, 2008). On the other hand, the child social- emotional domain was assessed through a self-reported parent proxy questionnaire. Parents completed the questionnaire based on their understanding of the child at the age of two, and their observations were potentially informed by their intimate knowledge of their child's personality, temperament, and developmental history. In addition, parents bring their own unique perspectives shaped by personal experiences, family dynamics, and cultural norms (Rubin, 2013) which can influence how they perceive and report their child's behaviours. It is therefore plausible that the child's experience may not be fully captured through clinical assessments alone, or parent self-reports alone.

Therefore, understanding the interplay between parent QoL and child development is crucial for comprehensively addressing the needs of both children and parents. This further highlights the importance in considering a complex relationship when developing interventions aimed at improving outcomes for both children and parents. Given the weak nature of the relationship identified in this study, it is essential to ensure that future research utilises valid and reliable measures to capture the intricacies of parent-child dynamics effectively. Enhancing parent QoL not only benefits parents but can also foster better developmental outcomes for children, creating a positive feedback loop that supports the overall QoL of the family. It is also important to acknowledge that variables may be influenced by interactions among multiple factors. This implies that the relationship between parent QoL and child outcomes, or vice versa, may not solely be attributed to one factor but rather to a complex interplay involving various other factors.

2.6.1. Limitations

One limitation of this study pertains to the predominantly homogeneous urban composition of the participant pool. The sample primarily comprises individuals of Caucasian ethnicity residing in urban areas, with a significant proportion holding bachelor's degrees and reporting household incomes of more than $150,000 annually. This homogeneity means the sample may not be fully representative of the broader population, potentially limiting the generalisability of the findings. Furthermore, this research focused on mothers of singletons within a population-based sample in metropolitan Australia. Therefore, while it provides valuable insights into the relationship between parent QoL and child development in the general population, the findings may not be applicable to other groups. Specifically, these results might not apply to children with significant medical or developmental conditions, fathers, or parents of multiples. Additionally, methodological differences, such as with the different assessment of domains with the Bayley-4, highlight the potential for variability in the measurement of child development. The presence of missing demographic data may have limited our power to detect correlations in the partial correlation analysis, introduced bias, and limited the generalisability of the findings. Next, due to the cross-sectional nature of this study, which involved the concurrent collection of data on parent QoL and developmental assessments, the analysis focused on examining associations rather than establishing predictive outcomes. As a result, causal relationships between variables could not be inferred from the current findings. Lastly, a potential limitation of using the CarerQoL-7D is that it may not fully capture the unique challenges faced by parents of typically developing young children. For example, one of the questions in the CarerQoL-7D is phrased as follows: “I have (no/some/a lot of) relational problems with the care receiver (e.g., he/she is very demanding or he/she behaves differently; we have communication problems).” This sentence structure suggests that the questions may not be specific enough to capture the unique challenges of caring for young children. As a result, parents may struggle to relate their experiences to the questions posed, potentially impacting the validity of the results in assessing their QoL.

2.6.2. Future Research

In future, longitudinal studies are recommended to explore the dynamic relationship between parent QoL and child development over time, providing insights into the trajectory of these constructs and potential causal pathways. In addition, further investigation into other potential confounding factors is warranted. Moreover, the current sample was limited to birth mothers. Future research would benefit from broadening the scope to encompass other parental figures, such as fathers or non- birth mothers, to capture a more diverse range of caregiving experiences and perspectives. Lastly, it would be beneficial to implement triangulation methodologies that combine objective assessments with parent self-report instruments and to conduct mixed methods studies that integrate both quantitative and qualitative approaches to better understand parents' QoL perspectives. This would create a more comprehensive dataset and enhance the overall validity of the findings by allowing the two types of data to inform and complement one another.

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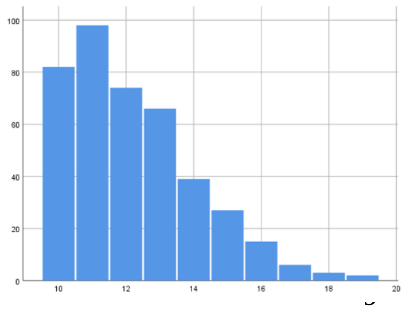
Supplementary Figure: Distribution of scores for CarerQoL-7D and Bayley-4



Carer QoL-7D
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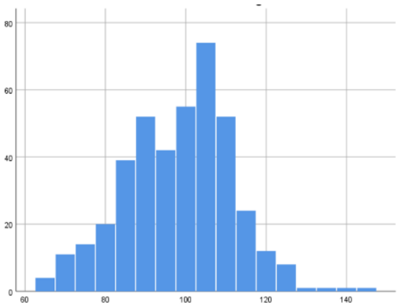

Bayley-4 (Cognitive)
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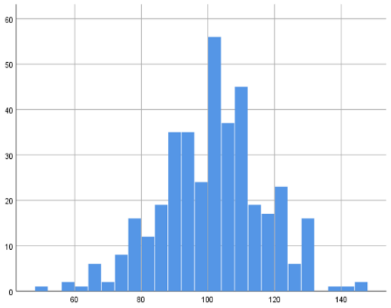

Bayley-4 (Language)
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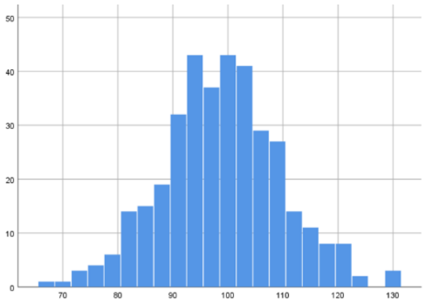

Bayley-4 (Motor)
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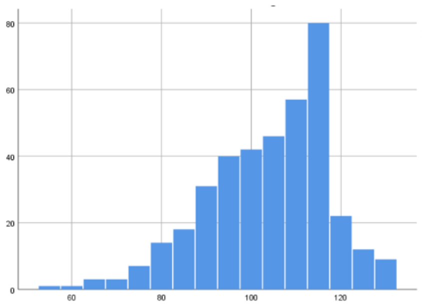
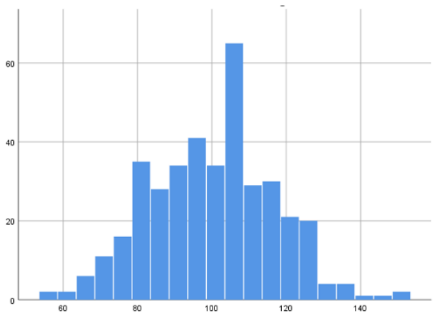


Bayley-4 (Social-Emotional)
N = 386



Bayley-4 (Adaptive Behaviours)
N = 386

Chapter Three: A Scoping Review on the Quality of Life of Parents of Young Children

3.1. Chapter Three Preamble

This chapter constitutes a crucial segment within a broader thesis dedicated to unravelling the intricate dynamics between parent QoL and child development during the formative years of early childhood.

The previous chapter utilised data from an existing dataset collected as part of a large birth cohort study. The study employed the CarerQoL-7D instrument to measure parent QoL, which is a caregiver self-reported measure that assesses subjective burden for informal caregivers [1]. The interchangeable usage of "burden" with "QoL" prompted us to question how parent QoL is being evaluated in the literature.

This scoping review is an exploration of the instruments assessing parent QoL in the current literature, for parents of young children aged zero to five years old. Given the absence of a gold standard instrument for assessing parent QoL, selecting appropriate measurement tools presents a challenge, particularly for parents of young children. Through an examination of QoL assessment methodologies tailored to parents of young children, this scoping review aspires to address methodological gaps and offer insights into the reported psychometric properties (following COSMIN guidelines [2]) and domains of the existing instruments.

3.2. Abstract

It is important to understand how parent quality of life (QoL) is defined and assessed in the literature to ensure accurate measurement and align research with parental needs. This scoping review assessed 83 articles and 35 instruments using PRISMA-ScR guidelines, focusing on parent QoL for children aged zero to five years. The databases searched included CINAHL, PsycINFO, and Medline, and the selection process involved title, abstract, and full-text review based on specific inclusion criteria. Inclusion criteria included empirical, peer-reviewed studies published in English that present an original or modified instrument assessing parent QoL for mothers and/or fathers, report the age range of children at the time of assessment, and involve children aged five years or younger. Studies focusing on parents' mental or physical health diagnoses, parents of bereaved children, or QoL instruments that are inaccessible (e.g., due to copyright), and grey literature were excluded. No restrictions on publication dates were imposed to provide a comprehensive overview of the topic. Instruments were analysed per COSMIN recommendations for psychometric properties, and item content was categorised into eight domains: physical, social, mental health, self-fulfilment, daily living, child symptoms, environment, and overall QoL. Commonly used tools like the SF-36 often emphasise health aspects, and many instruments lacked reported psychometric properties. Major domains included physical, mental health, social, and daily living, aligning with biopsychosocial models. The findings indicate that many QoL instruments may not fully capture the nuanced aspects of parent QoL, and there is insufficient evidence regarding the psychometric properties of parent QoL instruments. There is also a trend towards integrated QoL assessments for both parent and child conditions in single questionnaires. This review highlights the need for theoretical clarity and a specific conceptual model for parents of young children. Future systematic reviews should aim to assess psychometric properties of parent QoL instruments and address methodological limitations in studies focusing on parents of young children.

Keywords: parent quality of life, early childhood development, quality of life instruments, psychometric properties, quality of life domains

3.3. Introduction

Parent QoL refers to the subjective assessment made by individuals who serve as guardians for children regarding their overall life contentment, often drawn from their perceptions of contentment across various life domains [3]. A range of different instruments have been used to assess the QoL of parents across diverse contexts, including those with children diagnosed with rare diseases [4] and preterm infants [5]. However, differences in caregiving experiences based on the child's developmental or health status may necessitate the use of different items in parent QoL measures, which could be adapted depending on whether the focus is on typically developing children, those with chronic conditions, or children with complex disabilities. Across the literature, there is inconsistency in how parent QoL is defined and assessed. For example, a meta-analysis focusing on parents of children with asthma identified that parent QoL was primarily associated with physical and psychological functioning in some studies, while social functioning was emphasised in others [6]. A systematic review on parents of children with autism underscored the importance of physical and mental health domains [7], whereas another systematic review on parents of children with cerebral palsy highlighted physical health, psychological well-being, self-efficacy, and social support as key domains influencing parent QoL [8]. This suggests that parent QoL is a complex construct, and that universal agreement on the domains that comprise parent QoL is lacking, with variability depending on the parent and child's unique circumstances. While there are existing frameworks for the related constructs of family QoL, which assesses the perspective of all family members including parents and siblings [9], and caregiver QoL, which focuses on caregivers caring for individuals of any age including their spouse and older adults [10], these may not capture the unique experiences of parents as distinct from the broader family unit or caregiver roles.

The QoL of parents of young children prior to school age (zero to five years) is of particular interest, as parents of children in this age group may face unique challenges to QoL. Children undergo a period of "prolonged helplessness" during the first few years of their lives, such that they are completely reliant on the caretaker for safety, survival and socialisation [11]. At this stage, parents are responsible for tasks such as feeding, cleaning and playing with their young child [12]. In addition, mothers frequently bear the responsibility of providing full-time care for young children during the initial years, leading to many having no choice but to prioritise childcare over their careers, therefore affecting their career progress [13]. Financial difficulties may also be a challenge during this period, particularly for households relying on a single parent's income [13]. Therefore, parents may be at risk of diminished QoL due to the pressure of bearing responsibility and duty of care for the young child.

There is no gold standard instrument to assess parent QoL [10] and the selection of an appropriate tool for measuring QoL of parents of young children can be challenging. Established measures of QoL are commonly used but may not capture the additional demands that the parent's caregiving relationship places on QoL [14]. While some tools have been developed specifically to measure parent QoL [15], they may not have been validated with parents of young children under five. Moreover, many existing QoL instruments have been developed for health-related quality of life (HRQoL) purposes, focusing primarily on health-related aspects [16]. It remains uncertain whether these instruments are best suited for assessing the concept of QoL for parents. A comprehensive scoping review was chosen to understand the breadth of approaches to assessment of QoL for parents of young children, including evaluating the instruments and item contents, the reporting of psychometric properties, and domains assessed. This may be of value to guide future researchers seeking to assess QoL within this target group, to identify knowledge gaps and inform future theoretical and empirical research.

Therefore, the aim of this scoping review is to identify and characterise current approaches to assessment of QoL of parents of young children aged five years and below, whether typically developing or with health or developmental challenges. The specific review questions are as follows:

(a) What freely available instruments are being used to assess QoL for parents of children aged zero to five years in the literature?

(b) What psychometric properties are reported for instruments assessing parent QoL among parents of children aged zero to five years?

(c) Which domains of parent QoL are assessed for parents with children aged zero to five years?

3.4. Materials and Methods

The protocol for this scoping review was not registered but informed by the

Preferred Reporting Items for Systematic Reviews and Meta-Analysis – Extension for Scoping Reviews (PRISMA-ScR) [17].

3.4.1. Eligibility

3.4.2. Search Strategies

The inclusion eligibility criteria were as follows: (i) Articles are empirical, peer reviewed, and original full-length studies (excluding study protocols) published in English language; and only non-proprietary measures that are freely accessible or have unrestricted use were included to allow for comprehensive review and potential application in further research, (ii) Articles include at least one original or modified instrument or sub-scale assessing parent QoL (health-related and/or specific condition QoL and/or unspecified QoL) of mothers and/or fathers, (iii) Articles report the age range of children at the time of QoL assessment, and (iv) Articles assessed QoL in mothers and/or fathers with infants or babies or children who are aged five years and under at the time of assessment (upper age range of children does not exceed five years 364 days old). Exclusion criteria were: (i) Articles focus on parents' mental or physical health diagnosis, (ii) Articles focus on parents of bereaved children, and (iii) Articles included QoL instruments which were inaccessible (e.g., due to copyright permissions). Grey literature was not consulted in this review to maintain a focus on peer-reviewed literature, which suggest a higher standard of data quality, as these studies have undergone rigorous evaluation by experts in the field. A restriction on publication dates was not imposed to capture a comprehensive overview of the topic. Quality appraisal of the selected studies was also not conducted, as such an evaluation is not typically required for scoping reviews [25]. Systematic searches were conducted in December 2022 (last updated: June 2023) with the help of an experienced university librarian. The following databases were searched: Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Search terms were divided into four concepts. Concept one consisted of the terms "quality of life" or “qol” or "life quality" or “hrqol” or “health related quality of life” or “burden*” or “wellbeing” or "well being". Concept two included “parent*” or “mother*” or “mom” or “mum” or “father*” or “dad” or “guardian*” or “carer”* or “caregiver*” or "care giver*". Concept three comprised the terms: “baby” or “babies” or “infant*” or “toddler*” or ‘preschool*” or "pre school*" or “kindergarten” or “child*”. Lastly, concept four contained the words: “measure*” or “survey*” or “questionnaire*” or “tool” or “assessment”. The words for all four concepts were combined with “AND”, while concepts one and two were combined through proximity operators (within two words of each other). In addition to database searches, reference lists of included articles were screened to identify relevant studies.

3.4.3. Screening and Selection of Articles

All references identified through database searching were imported into the online review management software EndNote (version 20) [18] and the function “Find Duplicates” was used to remove duplicates. Screening of title and abstracts was conducted with assistance from Research Screener [19], a validated machine learning tool developed to enhance screening efficiency. Research Screener applies semi-automated abstract screening through an algorithm developed from machine learning methods to identify key words and concepts, and more information on the tool can be obtained from the article by Chai and colleagues [19]. If the articles were identified as potentially relevant based on title and abstract screening, the first team member then conducted a full-text review against eligibility criteria. Two other team members completed independent full-text reviews on a subset of these articles (20%) and consensus was reached through discussion regarding eligibility of the articles.

3.4.4. Data Extraction

Instruments identified as assessing parent QoL within eligible articles were sourced to facilitate review of item content and domains. The following data were extracted independently by the first team member from articles that met eligibility criteria: instrument used to assess parent QoL; author, year, and title of the original article regarding the development of instrument; author, year and title of the article which the instrument was cited in; and number of items in the QoL instrument.

Data on the approaches to assessment of parent QoL was extracted by analysing the wording of the instruments. The first author used manual coding to make a judgment on whether the wording of the instrument was suitable for a generic or parent population, e.g., where questions were phrased as: “In general, would you say your health is…” from the Short-Form 36 (SF-36) [20], as opposed to “I blame myself or my child’s other parent that my child has this hemangioma.” from the Infantile Hemangioma Quality of Life (IH-QoL) [21].

If the instrument wording was parent-specific, the author further evaluated whether the questions were related to a specific child’s condition or if they were applicable to a broader range of conditions. For instance, a question like “Because of your child’s glaucoma, how much do you experience bodily pain?” from the Caregiver’s Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) [22] is specific to the child’s condition. In contrast, a more generalisable question such as “The illness of our child means that I am often overtired and exhausted.” from the Impact on Family Scale (IoFS) [23] can apply to parents of children with various conditions.

This was then followed by the author’s judgment on whether the questions were phrased for young children based on the appropriateness of wording. An example question is: “How satisfied were you with your baby’s health?” in the Maternal Postpartum Quality of Life (MAPP-QOL) [24]. Another reviewer then assessed the data to ensure quality assurance.

3.4.5. Collating, Summarising, and Reporting the Results

Synthesis of the results included summarising the approaches to assessment of parent QoL, summarising the availability of psychometric properties for these instruments, and identifying common domains measured by included parent QoL instruments.

3.4.5.1. Psychometric Properties

Data on the psychometric properties of each QoL instrument were recorded in duplicate by two team members, in line with recommendations by COnsensus Standards for the selection of health Measurement Instruments (COSMIN) [2].

Reporting of psychometric properties of instruments were presented in line with the COSMIN framework, including reliability (internal consistency, reliability, measurement error), validity (content validity, criterion validity, structural validity, cross-cultural validity and hypothesis testing), and responsiveness [2]. When psychometric properties for an instrument were reported across multiple included articles, these were collated and presented together with all relevant citations listed. Categorising psychometric properties require methodological quality assessment and was beyond the scope of this scoping review. More information on the COSMIN framework is available in Appendix 1.

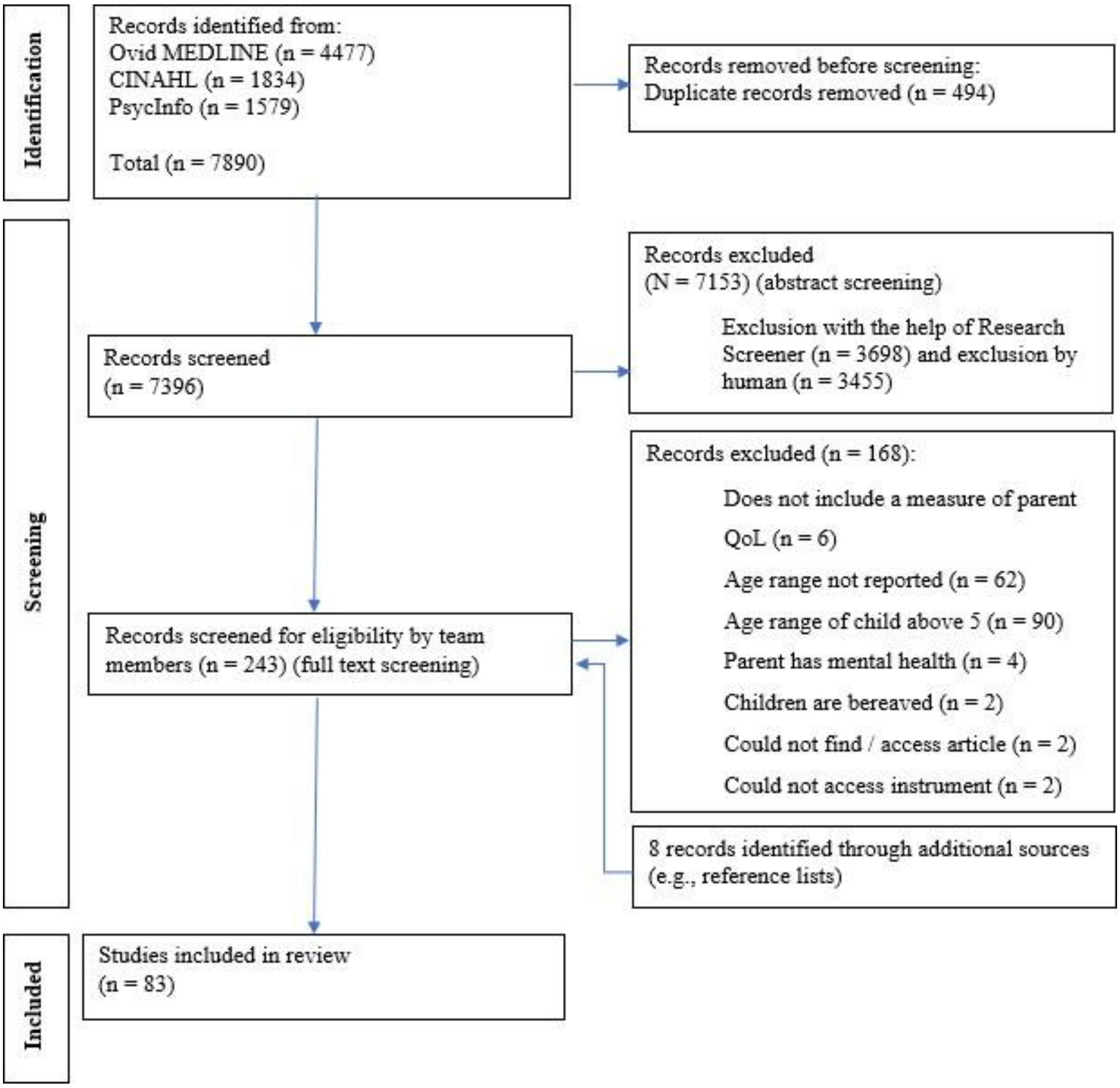
3.4.5.2. Domains of Parent QoL

To identify core domains of parent QoL assessed by the included instruments, we performed a basic qualitative content analysis [25] [26]. We familiarised ourselves with the data by thoroughly reading and understanding all included evidence sources to understand the relevance to our objectives and questions of the scoping review. After that, we used an inductive, qualitative approach to conduct open coding of the data. The process of open coding comprised of revisiting the evidence source to generate initial thoughts, potential categories, or notes that elucidate the occurrences within the data relevant to the objective and review questions. At this stage, the first team member listed various high-level categories and themes to identify core domains of parent QoL. After completing the open coding, the next step involved constructing the coding framework. This entailed consolidating the information gathered in the open coding stage to formulate a structured framework that facilitated the description and addressing of review questions, as well as organising the extracted data. At this stage, the first team member reviewed all individual items from included questionnaires and grouped the items into these common overarching themes according to item content. We opted to look at the individual item level to ensure consistency, rather than subdomain level, as not all instruments specified subdomains. The categorisation of items into domains was then repeated by two additional team members. The “critical friends” method was used, where each team member asked challenging questions to provide constructive criticism to offer an alternative point of view for the improvement of the work [27]. Discrepancies were resolved through multiple meetings and discussions, including referring to a fourth team member when required.

3.5. Results

A study selection flowchart is presented in Figure One, according to the Preferred Reporting Items for PRISMA guidelines [28]. Following de-duplication, screening and full-text review, a total of 83 articles were identified as eligible for inclusion.

Figure One: Study selection flowchart according to the Preferred Reporting Items for PRISMA guidelines (28)



3.5.1. Characteristics of the Studies Included in the Review

All 83 articles included were published between 1998 and 2023. Of the 83 articles, 40 were cross-sectional, 25 longitudinal, two both cross-sectional and longitudinal, 13 validation studies, and three longitudinal and validation. The sample size of studies ranged from seven to 86,724 participants. Majority of the studies were conducted in the USA, which consisted of 21 studies, followed by eight studies in Iran, and six studies in Taiwan. Regarding parent participants, 36 studies had collected data from either mothers or fathers; three had data from both parents, 28 had data from mothers only, one had data from fathers only, and 15 did not report whether parents were mothers or fathers. Seven papers had parent age range of 14 and above, 45 aged 20 and above, four aged 30 and above, and 27 papers did not report age of parents. Regarding the age of their children, most parents in the eligible studies had children in the early infancy stage, with 34 papers including parents of infants aged one year and below, 12 aged two years and below, 14 aged three years and below, 11 aged four years and below, and 12 aged five years and below. Of the articles identified, 26 focused on parents of health condition, five focused on parents with children with developmental delays, and 15 focused on parents with children from the general population.

Table One summarises all the scoping review papers assessed, including papers included, sample size, age range, condition, instrument used, study design, and country.

Table One: Scoping review papers assessed, sample sizes, age range, condition, instrument used, study design, and country

	Citation	*Sample size*	*Age range of children*	*Condition*	*Instrument used*	*Study design*	*Country*
1	[41]	190 participants first-time and multiparous mothers.	2, 6, 9 months	General	European Quality of Life 5 Dimensions 5 Level Version (EQ-5D-5L) (Japanese) [36]	Cross-sectional	Japan
2	[123]	Parents of 118 children, and 170 and caregivers as comparison group.	36 to 53 months	Very low birth weight	World Health Organization Questionnaire on Quality of Life: BREF (WHOQOL BREF) [115]	Cross-sectional	Taiwan
3	[84]	58 families led by adolescent mothers.	6 months to 5 years	General	Quality of Life Index [83]	Cross-sectional	Canada
4	[96]	473 women and children.	6 weeks to 12 weeks	General	Short-Form 12 survey (SF-12) [95]	Longitudinal	Australia
5	[29]	161 caretakers and children.	6-59 months	Acute otitis media (AOM)	AOM Questionnaire [29]	Validation	Canada
6	[99]	60 fathers & mothers of children.	1.6 to 5 years	Cerebral palsy	Short Form-36 (SF-36) [20]	Cross-sectional	India
7	[71]	381 parents of children aged matched with 381 children in the control group.	6 months–3 years	Influenza-like illness	a) PAR-ENT-QoL [70] b) SF-12 [95]	Longitudinal	Australia
8	[111]	35 parents with a child on active cancer therapy.	0 to 48 months	Cancer	SF-36 [20]	Cross-sectional	Canada
9	[107]	20 second-week postpartum, first-time mothers.	24 to 36 weeks	Low birth weight	SF-36 [20]	Cross-sectional	USA
10	[31]	55 children enrolled in the study and caregivers of children.	6 to 48 months	Influenza-like illness	Care Influenza Like Illness QoL (Care-ILI-QoL) [31]	Validation and Longitudinal	Australia
11	[90]	59 mothers and fathers of infants.	24 to 36 months	Very low birth weight	Quality of Life Scale [88]	Cross-sectional	Norway
12	[97]	78 mother-infant pairs.	Newborn infants	Colic	SF-36 [20]	Cross-sectional	Turkey
13	[100]	1747 postpartum women.	6 months	General	SF-36 (Taiwanese) [20]	Cross-sectional	Taiwan

14	[54]	96 postnatal women.	Postnatal	General	(a) Mother-Generated Index [52] (b) SF-36 [20]	Validation	Iran
15	[108]	114 parents of infant patients.	0 to 4 years	Congenital heart disease	SF-36 [20]	Cross-sectional	China
16	[124]	60 mothers with premature infants.	Infant	Premature	WHOQOL-BREF [115]	Longitudinal	Iran
17	[102]	56 mothers and children.	0 to 1 year	Congenital heart disease	SF-36 (Persian) [20]	Longitudinal	Iran
18	[24]	184 mothers of either a preterm, near-term, or term infant.	3 weeks postpartum	Preterm, near-term, or term infant.	Maternal Postpartum Quality of Life (MAPP-QOL)	Cross-sectional	USA
19	[94]	86,724 mothers and children.	Infants 37 weeks and below	General	Satisfaction with Life Scale [93]	Cross-sectional	Norway
20	[49]	1298 parents.	Baby under 3 years	Colic symptoms	Infant Colic Questionnaire [49]	Validation	France
21	[103]	141 mothers of infants.	Newborn	General	(a) EQ-5D-5L [38] (b) SF-36 [20]	Longitudinal	Netherlands
22	[67]	180 parents of infants admitted to NICU.	Infants 22 to 34 weeks	Admitted to NICU.	Paediatric Quality of Life PedsQL Family Impact Module (PedsQL- FIM) [61]	Cross-sectional	USA
23	[68]	194 parent–infant dyads admitted to a level IV NICU.	Infant	Admitted to NICU	PedsQL- FIM [61]	Longitudinal	USA
24	[112]	1,911 mothers.	3 to 45 months	General	SF-36 (Japanese) [20]	Cross-sectional	Japan
25	[98]	38 parental couples of infants.	6 months postpartum	Congenital heart disease	SF-36 [20]	Cross-sectional	Italy
26	[37]	36 couples.	1 or 6 months postpartum	Prenatally or postnatally diagnosed with a congenital anomality	European Health Interview Survey-Quality of Life (EUROHIS-QOL-8) (Portuguese) [36]	Longitudinal	Spain / Portugal
27	[104]	105 mothers.	Less than 37 weeks	Preterm infant (less than 37 weeks' gestation)	SF-36 (Persian) [20]	Cross-sectional	Iran

				experiencing feeding problems during the transition from gastric tube to oral feeding			
28	[127]	52 parents of 30 patients.	0-3 years	Biliary atresia	WHOQOL-BREF [15]	Cross-sectional	Netherlands
29	[43]	100 eligible patients and their parents.	28 – 42 weeks	Congenital anomalies	(a) Impact of a child with congenital anomalies on parents (ICCAP) [43] (b) SF-36 [20]	Validation	Netherlands
30	[121]	57 pairs of parents.	Between 30 and 37 weeks	Premature	WHOQOL-BREF (Persian) [15]	Longitudinal	Iran
31	[122]	72 mothers with premature infants.	Premature infants	Premature	WHOQOL-BREFW (Persian) [15]	Longitudinal	Iran
32	[22]	111 caregivers of children.	0 to 22.5 months	Primary congenital glaucoma	Caregiver’s Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) [22]	Validation	India
33	[30]	891 caregivers of children.	2.5 to 54.5 months	Congenital cataract, retinopathy of prematurity (ROP), and blinding corneal disorders.	CarCGQoL [22]	Validation	India
34	[109]	115 parents of infants.	0.5 to 5.3 years	Congenital heart disease (CHD)	SF-36 (Chinese) [20]	Cross-sectional	China
35	[72]	Parents of 79 children. A group of 34 parents to healthy children served as a control group.	<5 years	Obstructive Sleep-Disordered Breathing	Modified PAR-ENT-QoL questionnaire [70]	Longitudinal	Israel
36	[105]	59 women with Normal Vaginal Delivery, 39 with Caesarean Section and water birth delivery	Babies 2 months postpartum	General	SF-36 (Iranian) [20]	Cross-sectional	Iran
37	[87]	15 mothers at Phase I and 228 mothers at Phase II.	3 years and under	Developmental delays	Quality of Life Questionnaire for Families of Young Children with	Validation	USA

					Developmental Delays (QLQ-FYCDD) [87]		
38	[64]	101 parents of 18- to 36-month-old children.	18 to 36 months	Developmental delays	PedsQL-FIM [61]	Longitudinal	Taiwan
39	[120]	51 children and their mothers.	0 to 5 years	Esophageal atresia with or without tracheoesophageal fistula	WHOQOL BREF [115]	Cross-sectional	India
40	[128]	60 mothers with premature infants.	Infant	Preterm	WHOQOL BREF (Iranian) [115]	Longitudinal	Iran
41	[113]	135 mothers, whose newborn has completed 48 hours of NICU stay,	Newborn infant	Infants admitted to Neonatal Intensive Care Units (NICUs)	SF-36 [20]	Cross-sectional	India
42	[59]	149 children from low-income urban families.	0 to 4 years old	low income, 3 or more wheezing episodes	Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) [58]	Longitudinal	USA
43	[106]	55 mothers with a low-birth-weight, preterm infants.	Infant	LBW	SF-36 [20]	Cross-sectional	USA
44	[86]	169 caregivers enrolled in the study and completed the survey: 83 of 134 eligible caregivers of very low–birthweight infants and 84 of 187 caregivers of full-term infants identified as possible controls.	12 to 18 months old	Low birth weight	[85]	Cross-sectional	USA
45	[116]	77 caregivers of infants.	3 to 6 months	with cleft lip and palate	WHOQOL – BREF [115]	Cross-sectional	Brazil
46	[126]	30 mothers of children.	1.1 to 3.6 years	Congenital Zika Virus Syndrome	WHOQOL-BREF [115]	Cross-sectional	Brazil
47	[82]	71 caregivers and their children.	1 month to 36 months	Tracheostomy	Psychological General Well-Being Index (PGWBI) [81]	Cross-sectional	USA
48	[101]	1669 pairs of women and newborns.	Infant	General	SF-36 (Taiwanese) [20]	Cross-sectional	Taiwan
49	[78]	143 mothers and 72 fathers of	Infant	Hypoplastic left heart	Perceived Quality of Life (PQoL)	Longitudinal	USA

		children.		syndrome (HLHS)	Scale [77]		
50	[35]	143 mothers.	Infant	Skin problems, including infant eczema, diaper dermatitis (DD), and seborrheic dermatitis.	Dermatitis Family Impact (DFI) questionnaire (Japanese) [32]	Cross-sectional	Japan
51	[125]	400 women and infants.	4 months and 18 months	General	WHOQOL-BREF (Japanese) [115]	Cross-sectional	Japan
52	[114]	10 infants with hypoplastic left heart syndrome (n = 7) or other types of univentricular heart malformations (n = 3), and their parents (9 mother/father two-parent households, 1 single mother) were included.	Infant	Seven were diagnosed with HLHS, and three had a variant of Hypoplastic left heart syndrome (HLHS) with univentricular physiology with shunt-dependent pulmonary perfusion.	SF-36 (German) [20]	Longitudinal	Switzerland
53	[39]	187 caregivers participated.	1 to 36 months	General	European Quality of Life 5 Dimensions 3 Level Version (EQ-5D-3L) [38]	Cross-sectional	Africa
54	[39]	10 premature infants receiving Home Oxygen Therapy (HOT), 10 premature infants who were discharged from hospital on HOT but who no longer required it and 20 premature infants who had never required treatment with HOT and their caregivers.	Infants	Premature infant receiving home oxygen therapy	SF-36 [20]	Cross-sectional	Australia
55	[66]	153 preschool children and parents.	3 to 5 years	Sleep disordered breathing (SDB)	PedsQL – FIM [61]	Cross-sectional	Australia
56	[117]	7 patients with caregivers.	6 to 35 months	Intractable epilepsy	WHOQOL-BREF [115]	Longitudinal	Egypt
57	[70]	1214 parents of children.	6 months to 4 years old	Ear Nose and Throat infections	PAR-ENT-QoL [70]	Validation	France, Germany, Italy, Portugal and the Czech

							Republic
58	[76]	196 infants and their parents.	3 to 23 months	Mild to severe atopic eczema	QoL in Parents of Children with Atopic Dermatitis (PQoL–AD) [75]	Longitudinal	Germany
59	[73]	6250 children and parents.	0 to 71 months	Acute otitis media (AOM)	An AOM-specific self-administered questionnaire was developed based on the PAR-ENTQoL [29]	Validation	Germany, Italy, Spain, Sweden and the UK
60	[74]	110 patients and parents.	0.1 to 5.5 years	Acute otitis media	(a) PARAOM-QOL [73] (b) EQ-5D-5L [40]	Cross-sectional	Malaysia
61	[50]	Parents of 59 infants.	2 to 6 months	Infantile hemangioma	Infantile hemangioma-specific QoL-questionnaire IH-QoL) (Dutch) [21]	Cross-sectional	Netherlands
62	[46]	5211 of the general sample and 138 wheezing illness sample and their parents.	Child mean child age of 12 months interquartile range 10–40 months)	General and respiratory	Infant and Toddler Quality of Life Questionnaire–47 (ITQOL-SF47) [46]	Validation	Netherlands
63	[45]	94 subjects and their parents / caregivers.	1 to 48 months.	Born with non-syndromic cleft lip and/or palate and who needed surgical treatment to correct the defects	Impact on Family Scale (IOFS) [23]	Longitudinal	Nigeria
64	[33]	Parents of 203 infants.	0–4 years	Atopic dermatitis	Dermatitis Family Impact (DFI) [32]	Validation and Longitudinal	Scotland, UK
65	[92]	117 children and parents.	2 years and younger	Suspected and recurrent Respiratory syncytial virus (RSV) infection or acute lower respiratory infection (ALRI)	An ad hoc questionnaire was developed for the study (RSV questionnaire) [91]	Cross-sectional	Spain
66	[34]	80 parents and children.	4 months to 4 years of age	Atopic dermatitis	Dermatitis Family Impact questionnaire (DFI) [32]	Longitudinal	Spain

67	[91]	302 children and parents.	0 to 59 months	Acute rotavirus gastroenteritis (rotaviruspositive stool sample)	The questionnaire was developed from an initial 54-item pilot questionnaire, linguistically validated in Spanish, Polish and Italian [91]	Cross-sectional and Validation	Spain, Italy, Poland
68	[53]	124 women.	Postnatal	General	Mother-Generated Index [52]	Longitudinal	Switzerland and Germany
69	[57]	169 parents of preterm infants.	Preterm (< 37 weeks' gestation) infants up to 24 months corrected age	Preterm	Multicultural Quality of Life Index (MCQLI) [55]	Cross-sectional	USA
70	[118]	144 parent-infant dyads.	0 to 24 months	Seizures	WHOQOL-BREF [115]	Cross-sectional	USA
71	[80]	1208 children and their caregivers.	6 to 24 months	With and without a primary diagnosis of recurrent OM	(a) PedsQL Family Impact Module [61] (b) Patient-Reported Outcomes Measurement Information System (PROMIS) [79]	Cross-sectional	USA
72	[60]	211 children and their parents	2–5 years	Asthma	Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) [58]	Longitudinal	USA
73	[69]	186 preterm children with bronchopulmonary dysplasia (BPD)	2 years and below	Bronchopulmonary dysplasia (BPD)	PedsQL FIM [61]	Longitudinal and Cross-sectional	USA
74	[47]	121 patients and parents.	1.1 months - 9.6 months	Supraglottoplasty	Infant and Toddler Quality of Life Questionnaire–47 (ITQOL-SF47) [46]	Longitudinal	USA
75	[119]	Parents of 303 children.	2 years	Acute Neonatal Seizures	World Health Organization Quality of Life (WHOQOL-BREF) [115]	Longitudinal	USA

76	[56]	89 parents and children.	Up to 24 months corrected age	Preterm (<37 weeks gestation) infants	Multicultural Quality of Life Index (English and Spanish) [55]	Cross-sectional	USA
77	[42]	31 parents of children with various parent-reported types and degrees of hearing loss (HL; case) and parents of children who are typical hearing (TH) (control).	2.0 months to 3.5 years	Deaf of hard of hearing	(a) Hearing-Related Infant/Toddler and Parent Quality of Life (HIP-QL) [42] (b) PedsQL-FIM [61]	Validation	USA
78	[24]	184 mothers.	Newborn	General	MAPP-QOL [24]	Validation	USA
79	[21]	220 children and parents.	0.5 months to 19 months	Hemangioma	Infantile Hemangioma Quality-of-Life (IH-QoL) [21]	Validation	USA
80	[63]	32 children with developmental delays and their parents.	18 to 36 months	Developmental delays	(a) PedsQL-FIM [61] (b) WHOQOL-BREF [115]	Longitudinal	Taiwan
81	[65]	30 children with developmental delays and their parents as the study group and 57 age- and sex-matched children with typical development and their parents as the control group.	18 to 36 months	Developmental delays and typical development	PedsQL FIM [61]	Longitudinal	Taiwan
82	[23]	155 families with children.	Between 6 and 24 months of age	Non-syndromic orofacial cleft (OFC)	Impact on Family Scale (IOFS) [23]	Cross-sectional	Germany
83	[89]	31 parents of VLBW infants participating in a nutrition RCT and 31 parents of a reference group (non-participating)	Infant	Preterm	Quality of Life Scale [88]	Longitudinal	Norway

3.5.2. Instruments Assessing QoL for Parents with Children Aged Five Years and Below.

In total, 35 freely available instruments were identified as assessing parent QoL and are tabulated and summarised in Table Two. Thirty-four were quantitative instruments (self-report scales for the parent to complete) and one was a qualitative and quantitative instrument (semi-structured interview format, with quantitative scores).

Table Two: Instruments assessing parent QoL for young children and original study cited, articles included in scoping review, number of items of instrument, whether the instrument is phrased for parent-specific QoL, whether the instrument is phrased for specific symptoms of children, whether the instrument is worded for young children, and domains of measure for parent QoL instrument

No	Instrument used (original instrument citation)	Article/s included in review	Number of items	Parent-specific QoL	Questions phrased for specific symptoms of children	Questions phrased for young children	Domains of measures
1	Acute Otitis Media (AOM) questionnaire [29]	[29]	6	Yes	Yes	No	1. Sleeping 2. Changing daily activities 3. Cancelling of family activities 4. Caregiver emotional distress 5. Caregiver concerns
2	Caregiver's Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) [22]	[22], [30]	20	Yes	Yes	No	No subscales specified. Broadly, the items target the caregiver's social aspects, emotional well-being, economic, and physical functioning.
3	Care Influenza Like Illness QoL (Care-ILI-QoL) [31]	[31]	16	Yes	Yes	No	1. Daily life disturbance 2. Social functioning 3. Satisfaction 4. Worry
4	Dermatitis Family Impact (DFI) questionnaire [32]	[33], [34], [35]	10	Yes	Yes	No	1. Housework 2. Food preparation and feeding 3. Sleep of other family members 4. Family leisure activities 5. Time spent shopping for the family 6. Expenditure 7. Causing tiredness and exhaustion of parents/caregivers 8. Causing emotional distress of parents / caregivers 9. Relationships between the main caregiver and partner or

							other children 10. The main caregiver’s life.
5	European Health Interview Survey-Quality of Life (EUROHIS- QOL-8) [36]	[37]	8	No	No	No	1. Physical 2. Psychological 3. Environmental 4. Social
6	European Quality of Life 5 Dimensions 5 Level Version EuroQol (EQ-5D-5L) [40]	[41]	25	No	No	No	1. Mobility 2. Self-care 3. Usual activities 4. Pain/discomfort 5. Anxiety/depression
7	European Quality of Life 5 Dimensions 3 Level Version (EQ-5D-3L) [38]	[39]	15	No	No	No	1. Mobility 2. Self-care 3. Usual activities 4. Pain/discomfort 5. Anxiety/depression
8	Hearing-Related Infant/Toddler and Parent Quality of Life (HIP- QL) [42]	[42]	17	Yes	Yes	Yes	1. Child auditory/communication behaviour 2. Child temperament 3. Parent management 4. Parent directed factors
9	Impact of a Child with Congenital Anomalies on Parents (ICCAP) [43]	[43]	36	Yes	Yes	Yes	1. Contact with caregivers 2. Social network 3. Partner relationship 4. State of mind 5. Child acceptance 6. Fears and anxiety
10	Impact of Child Gastroenteritis on Parents questionnaire [44]	[44]	44	Yes	Yes	No	1. Symptom Severity 2. Child’s Behaviour 3. Parents’ Worries due to Symptoms 4. Parents’ Distress 5. Impact on Parents’ Daily Activities
11	Impact on Family Scale (IoFS) [23]	[23], [45]	33	Yes	No	No	1. Financial impacts 2. Social relationships 3. Personal impacts

							4. Coping strategies 5. Concerns of siblings (if present)
12	Infant and Toddler Quality of Life Questionnaire–47 (ITQOL- SF47) [46]	[47], [48]	47	Yes	No	Yes	1. Physical function, 2. Growth and development 3. Bodily pain 4. Temperament and moods 5. Behaviour 6. General health perceptions.
13	Infant Colic Questionnaire (ColiQ) [49]	[49]	16	Yes	Yes	Yes	Symptom module 1. Quantitative description of crying 2. Qualitative description of crying 3. Associated symptoms 4. Perceived pain related to crying and digestive discomfort 5. Infant behaviour Impact module 1. Psychological impact 2. Impact on life as a couple 3. Impact on parent's general state 4. Impact on daily life 5. Overall impact
14	Infantile Hemangioma Quality of Life (IH-QoL) [21]	[21], [50]	29	Yes	Yes	Yes	1. Child physical symptoms 2. Child social interactions 3. Parent emotional Functioning 4. Parent psychosocial functioning
15	Maternal Postpartum Quality of Life (MAPP-QOL) [24]	[24], [51]	16	Yes	No	Yes	1. Psychological/baby 2. Socioeconomic 3. Relational/spouse-partner 4. Relational/family-friends 5. Health and functioning
16	Mother Generated Index [52]	[53], [54]	3	No	No	No	None
17	Multicultural Quality of Life Index (MCQLI) [55]	[56], [57]	10	No	No	No	1. Physical well-being 2. Psychological/Emotional well-

							being 3. Self-care and independent functioning 4. Occupational functioning 5. Interpersonal functioning 6. Social emotional support 7. Community and services support 8. Personal fulfillment 9. Spiritual fulfillment 10. Overall Quality of Life
18	Paediatric Asthma Caregiver’s Quality of Life Questionnaire (PACQLQ) [58]	[59], [60]	13	Yes	Yes	No	1. Activity limitations 2. Emotional function
19	Paediatric Quality of Life - Family Impact Module (PedsQL- FIM) [61]	[62], [63], [64], [65], [66], [67], [68], [69]	36	Yes	No	No	1. Physical 2. Emotional 3. Social 4. Cognitive functioning 5. Communication 6. Worry 7. Daily activities 8. Family relationships
20	Parental Acute Otitis Media Quality of Life (PARAOM-QOL) [73]	[73], [74]	15	Yes	Yes	No	1. Emotional 2. Daily disturbance
21	PAR-Ear, Nose and Throat- Quality of Life (PAR-ENT-QoL) [70]	[70], [71]	15	Yes	Yes	No	1. Emotional 2. Daily disturbance
22	PAR-ENT-QoL (Modified) [70]	[72]	18	Yes	Yes	No	1. Emotional 2. Daily disturbance
23	Parent QoL of Children with Atopic Dermatitis (PQoL–AD) [75]	[76]	26	Yes	Yes	No	1. Psychosomatic well-being 2. Effects on social life 3. Confidence in medical treatment 4. Emotional coping 5. Acceptance of the disease
24	Patient-Reported Outcomes Measurement Information System (PROMIS) [79]	[80]	10	No	No	No	1. Anxiety 2. Fatigue 3. Depression 4. Satisfaction
25	Perceived Quality of Life Scale (PQoL) [77]	[78]	20	No	No	No	1. Physical 2. Social

							3. Cognitive functioning.
26	Psychological General Well-Being Index (PGWBI) [81]	[82]	22	No	No	No	1. Anxiety 2. Depressed mood 3. Positive well-being 4. Self-control 5. General health 6. Vitality.
27	Quality of Life Index (QLI) [83]	[84]	33	No	No	No	1. Health and Functioning 2. Social and Economic 3. Psychological and Spiritual 4. Family
28	Quality of Life Inventory [85]	[86]	32	No	No	No	1. Health 2. Self-esteem 3. Goals and Values 4. Creativity 5. Learning 6. Money 7. Work 8. Play 9. Helping 10. Love 11. Relationship with friends 12. Family 13. Children 14. Satisfaction with home 15. Neighbourhood 16. Community
29	Quality of Life Questionnaire for Families of Young Children with Developmental Delays (QLQ- FYCDD) [87]	[87]	28	Yes	Yes	Yes	1. Behaviour Problem 2. Developmental Level 3. Family Psychiatric History 4. Satisfaction/Support
30	Quality of Life Scale (QoLS) [88]	[89], [90]	18	No	No	No	1. Material and physical well-being 2. Relationships with others 3. Social, community, and civic activities 4. Personal development and

							fulfillment 5. Recreation 6. Independence
31	Respiratory Syncytial Virus (RSV) scale [91]	[92]	38	Yes	Yes	No	1. Child's symptoms 2. Child's behaviour 3. Parent's concerns 4. Parents' emotions 5. Impact of the infection on family activities
32	Satisfaction With Life Scale (SWLS) [93]	[94]	5	No	No	No	Overall satisfaction with life
33	Short-Form-12 (SF-12) [95]	[96]	12	No	No	No	1. Physical 2. Mental
34	Short-Form-36 (SF-36) [20]	[97], [98], [99], [100], [101], [102], [103], [104], [105], [106], [107], [108], [109], [110], [111], [112], [113], [114]	36	No	No	No	1. General health 2. Physical performance 3. Limitation in role performance due to physical reasons 4. Limitation in role performance due to emotional reasons 5. Physical pain 6. Mental health 7. Fatigue or exhilaration 8. Social function.
35	World Health Organisation Questionnaire on Quality of Life: BREF (WHOQOL-BREF) [115]	[116], [117], [118], [119], [120], [121], [122], [123], [124], [125], [126], [127], [128]	24	No	No	No	1. Somatic 2. Psychological 3. Social 4. Life status

The questionnaires in these studies were derived from the parent paper in which the tools were originally developed for a different sample population. Specifically, the tools may have been designed for parents of children outside the age range of 0-5 years old, which differs from the eligibility criteria set for this scoping review.

The most frequently used QoL instrument was the Short-Form Health survey-36 (SF-36), which was used in 18 articles. The second most used instrument was the World Health Organisation Quality of Life Brief Assessment (WHOQOL-BREF), which was used in 13 articles. The third most used instrument was the Paediatric Quality of Life - Family Impact Module (PedsQL-FIM) [61], used in eight articles. Fifteen of the identified instruments were used in multiple articles, while there were 20 individual instruments that were used only once across all eligible articles.

The instruments also included several modified versions. For example, the PAR-ENT-QoL [70] was originally developed to assess conditions of parents with children with ear, nose and throat infections. Two modified versions of this instrument were identified, assessing acute otitis media [73] and obstructive sleep apnoea [72]. We decided to include condensed versions of several original instruments, examined separately due to different psychometric properties assessed and domains assessed. Examples were the European Quality of Life-5 Dimensions-3 Level Version (EQ-5D-3L) [38] and European Quality of Life-5 Dimensions-5 Level Version (EQ-5D-5L) [40], the Short Form-12 (SF-12) [95] and SF-36 [20], and the European Health Interview Survey-Quality of Life (EUROHIS-QOL-8) [36] and WHOQOL-BREF [115]. Lastly, our scoping review examined the Mother Generated Index (MGI), a unique instrument incorporating both quantitative and qualitative elements [52].

Several instruments identified through this review were generic QoL measures, where questions were phrased from an overall or general perspective. We decided to term these “generic QoL instruments”. This is compared to other measures which attribute QoL to parent-related factors. We termed these “parent-specific QoL instruments”. In total, 15 generic QoL instruments and 20 parent-specific impact instruments were collated.

For studies focusing on parents of children with specific symptoms (e.g., chronic health condition such as cancer), 34 papers used a generic QoL assessment to assess parent QoL and 23 used a parent-specific QoL assessment. Of these 23 parent-specific QoL assessments, 11 were not phrased for specific child symptoms (e.g., parents with children with sleep disordered breathing were assessed with the PedsQL-FIM [61]), which have questions phrased for children with any health conditions [66]). The other papers reported children from a general population and used a generic QoL assessment to assess parent QoL. Generic QoL instruments were commonly used in the earlier years, e.g., 2000-2011. From 2018 onwards, there was a rise in the development and use of parent-specific QoL instruments.

Several instruments were specific for parents of young children (aged birth to 5 years old), while others were suitable for children of all ages. In total, seven questionnaires were specifically catered for young children, while 29 instruments were designed for a broader age range of children, including preschool-aged children or those with specific health conditions. For example, the Maternal Postpartum Quality of Life Scale [24] includes items such as “How satisfied are you with... your ability to feed your new baby?” which is aimed at parents of very young infants. In contrast, the Caregiver’s Congenital Glaucoma Quality of Life (CarCGQoL) [22] includes more generalised items, such as, “Because of your child’s glaucoma, how much do you experience the following... Powerless in facing child’s disease?” which does not specify an age and can apply to caregivers of older children as well. Questionnaires with items phrased for young children began to be used more frequently in 2018-2022. In addition, there is a rise in developing questionnaires which are age appropriate (e.g., for young infants) from the year 2014 onwards, such as the Hearing-Related Infant/Toddler and Parent Quality of Life (HIP-QL) [42], Infant and Toddler Quality of Life Questionnaire–47 (ITQOL-SF47) [46], and Infantile hemangioma Quality of Life (IH-QoL) [21].

3.5.3. Psychometric Properties Reported

Psychometric properties of the instruments were reported per COSMIN recommendations in Table Three [2].

Table Three: Instruments and psychometric properties (as measured by COSMIN) reported.

No	*Instrument*	*Reliability*			*Validity*					
		Internal consistency	*Reliability*	*Measurement error*	*Content validity*	*Criterion validity*	*Construct validity*			*Responsiveness*
							Structural validity	*Cross-cultural validity/ Measurement invariance*	*Hypothesis testing for construct validity*	
1	Acute Otitis Media (AOM) questionnaire [29]	✓ [29]			✓ [29]				✓ [29]	
2	Caregiver's Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) [22]	✓ [22], [30]			✓ [22], [30]		✓ [22], [30]	✓ [22], [30]		
3	Care Influenza Like Illness QoL (Care-ILI-QoL) [31]	✓ [31]			✓ [31]		✓ [31]		✓ [31]	✓ [31]
4	Dermatitis Family Impact (DFI) questionnaire [32]								✓ [33]	
5	European Health Interview Survey-Quality of Life (EUROHIS-QOL-8) [36]	✓ [37]								
6	Hearing-Related Infant/Toddler and Parent Quality of Life (HIP-QL) [42]	✓ [42]	✓ [42]		✓ [42]		✓ [42]	✓ [42]	✓ [42]	
7	Impact of a Child with Congenital Anomalies on Parents (ICCAP) [43]	✓ [43]	✓ [43]		✓ [43]		✓ [43]		✓ [43]	✓ [43]
8	Impact of Child Gastroenteritis on Parents questionnaire [44]	✓ [91]						✓ [91]	✓ [91]	
9	Infant and Toddler Quality of Life Questionnaire–47 (ITQOL-SF47) [46]	✓ [46]					✓ [46]	✓ [46]	✓ [46]	

10	Infant Colic Questionnaire (ColiQ) [49]	✓ [49]	✓ [49]	✓ [49]			✓ [49]	✓ [49]
11	Infantile Hemangioma Quality of Life (IH-QoL) [21]	✓ [21]	✓ [21]	✓ [21]	✓ [21]		✓ [21]	
12	Maternal Postpartum Quality of Life (MAPP-QOL) [24]	✓ [24]	✓ [24]	✓ [24]	✓ [24]		✓ [24]	
13	Mother Generated Index [52]			✓ [54]		✓ [54]	✓ [54]	
14	Parental Acute Otitis Media Quality of Life (PAR-AOM-QOL) [73]	✓ [73]		✓ [73]		✓ [73]	✓ [73], [74]	
15	PAR-ENT-QoL [70]	✓ [70]		✓ [70]	✓ [70]		✓ [70]	
16	PAR-ENT-QoL (Modified) [72]	✓ [72]	✓ [72]		✓ [72]	✓ [72]	✓ [72]	
17	Psychological General Well-Being Index (PGWBI) [81]	✓ [82]					✓ [82]	
18	Quality of Life Index (QLI) [83]	✓ [84]						
19	Quality of Life Inventory [85]	✓ [86]						
20	Quality of Life Questionnaire for Families of Young Children with Developmental Delays (QLQ- FYCDD) [87]	✓ [87]	✓ [87]	✓ [87]	✓ [87]			
21	Quality of Life Scale (QoLS) [88]	✓ [89]						
22	Satisfaction With Life Scale (SWLS) [93]	✓ [94]						

23	Short-Form-36 (SF-36) [20]	✓ [102], [103], [106]		✓ [104], [106], [109], [112], [113]
24	World Health Organisation Questionnaire on Quality of Life: BREF (WHOQOL-BREF) [115]	✓ [121], [124]	✓ [124]	✓ [123], [116], [127]

In total, psychometric properties were reported for 24 of 35 instruments. Internal consistency was the most frequently reported, in 22 instruments. In addition, majority of papers which reported internal consistency were published from the year 2010 onwards. The second most reported psychometric property was hypothesis testing for construct validity, which was assessed in 17 instruments. Pearson's and Spearman's correlation were used to assess the construct validity with other related variables for most of these articles. Next, content validity was assessed in 13 instruments, through pilot testing, focus groups, interviews, and/or literature review. Structural validity was assessed in 10 instruments with Rasch analysis, factor analysis, goodness of fit, structured equation modelling, and/or the Akaike Information Criterion (AIC).

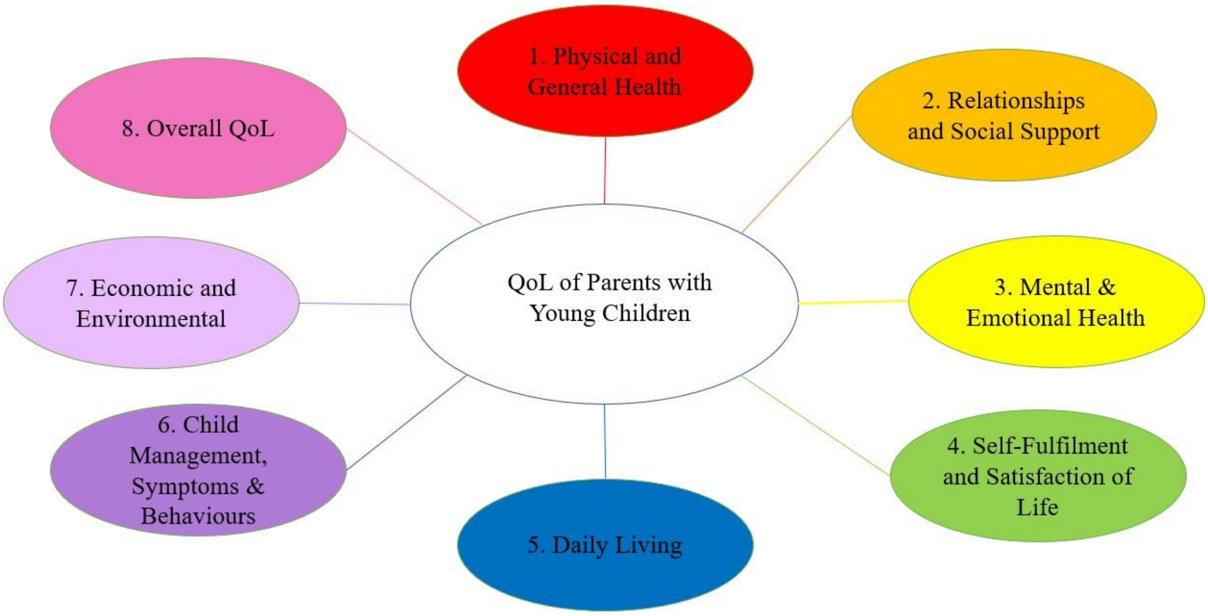
The scoping review consisted of articles from 25 countries, and cross-cultural validity was reported for seven instruments. Cross-cultural validity/measurement invariance was assessed for the Indian version of the CarCGQoL [22]; English of the HIP-QL [42]; Spanish, Italian and Polish for the Impact of Child Gastroenteritis on Parents questionnaire [44]; Iranian for the Mother Generated Index [52]; Italian, German, Czech and Portuguese for the PAR-ENT-QOL [70]; German, Italian, Spain and Sweden for the PAR-AOM-QOL [73]; and Hebrew for the PAR-ENT-QOL (modified) [72].

Seven instruments assessed reliability, which was demonstrated by intraclass correlation coefficient (ICC), test-retest, or Person Separation Index (PSI). Responsiveness, where authors compared the changes in time for the instruments, was measured in only three studies. Measurement error and criterion validity were not assessed in any included studies. Nineteen of the 84 papers reported at least one aspect of reliability and validity, and majority of these sample participants were recruited from a clinic or hospital setting. Lastly, none of the 39 instruments had been evaluated for all nine psychometric properties as recommended by COSMIN.

3.5.4. Domains of QoL Assessed for Parents

The results from the thematic content analysis were summarised into eight core domains (shown in Figure Two).

Figure Two: Visual depiction of domains identified using an inductive thematic analysis of instruments assessing parent QoL of young children.



Further details on the domains assessed by each instrument can be found in Table Four. As the Mother Generated Index did not specify the domains assessing parent QoL (as participants were asked to fill it in when answering the questionnaire) [52], this instrument was not included for domain analysis.

Table Four: Domains assessed by instruments measuring parent QoL

		Physical and General Health	Relationships and Social Support	Mental and Emotional Health	Self-Fulfilment & Satisfaction of Life	Daily Living	Child Symptoms and Behaviours	Economic and Environmental	Overall quality of life
1	Acute Otitis Media (AOM) questionnaire [29]	✓		✓		✓	✓		✓
2	Caregiver's Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) [22]	✓		✓	✓	✓			
3	Care Influenza Like Illness QoL (Care-ILI-QoL) [31]	✓	✓	✓		✓			
4	Dermatitis Family Impact (DFI) questionnaire [32]	✓	✓	✓		✓		✓	
5	European Health Interview Survey-Quality of Life (EUROHIS-QOL-8) [36]	✓	✓		✓	✓		✓	✓
6	European Quality of Life 5 Dimensions 3 Level Version (EQ-5D-3L) [38]	✓		✓		✓			
7	European Quality of Life 5 Dimensions 5 Level Version EuroQol (EQ-5D-5L) [40]	✓		✓		✓			
8	Hearing-Related Infant/Toddler and Parent Quality of Life (HIP-QL) [42]		✓				✓	✓	
9	Impact of a Child with Congenital Anomalies on Parents (ICCAP) [43]		✓	✓			✓		
10	Impact of Child Gastroenteritis on Parents questionnaire [44]	✓	✓	✓		✓	✓	✓	
11	Impact on Family Scale (IoFS) [23]	✓	✓	✓		✓		✓	
12	Infant and Toddler Quality of Life Questionnaire–47 (ITQOL-SF47) [46]		✓	✓		✓	✓		
13	Infant Colic Questionnaire (ColiQ) [49]	✓	✓	✓		✓	✓		✓
14	Infantile Hemangioma Quality of Life (IH-QoL) [21]	✓	✓	✓		✓	✓		
15	Maternal Postpartum Quality of Life (MAPP-QOL) [24]	✓	✓	✓	✓	✓	✓	✓	
16	Mother Generated Index [52]								
17	Multicultural Quality of Life Index (MCQLI) [55]	✓	✓	✓	✓	✓		✓	✓
18	Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) [58]		✓	✓		✓			
19	Paediatric Quality of Life - Family Impact Module (PedsQL-FIM) [61]	✓	✓	✓		✓			
20	Parental Acute Otitis Media Quality of Life (PARAOM-QOL) [73]	✓	✓	✓		✓		✓	✓
21	PAR-ENT-QoL [70]		✓	✓		✓	✓	✓	
22	PAR-ENT-QoL (Modified) [70]	✓	✓	✓		✓		✓	✓
23	Parent QoL of Children with Atopic Dermatitis (PQoL–AD) [75]	✓	✓	✓		✓		✓	
24	Perceived Quality of Life Scale (PQoL) [77]	✓	✓	✓	✓	✓		✓	
25	PROMIS [79]	✓	✓	✓		✓			✓
26	Psychological General Well-Being Index (PGWBI) [81]	✓		✓		✓			
27	Quality of Life Index (QLI) [83]	✓	✓	✓	✓	✓		✓	✓

28	Quality of Life Inventory [85]	✓	✓			✓		✓	
29	Quality of Life Questionnaire for Families of Young Children with Developmental Delays (QLQ- FYCDD) [87]		✓	✓		✓	✓		✓
30	Quality of Life Scale (QoLS) [88]	✓	✓		✓	✓		✓	
31	Respiratory Syncytial Virus (RSV) scale [91]	✓	✓	✓		✓	✓		
32	Satisfaction With Life Scale (SWLS) [93]				✓				
33	Short-Form-12 (SF-12) [95]	✓	✓	✓		✓			
34	Short-Form-36 (SF-36) [20]	✓	✓	✓		✓			
35	World Health Organisation Questionnaire on Quality of Life: BREF (WHOQOL-BREF) [115]	✓	✓	✓	✓	✓		✓	

3.5.4.1. “Physical and General Health” Domain

The “Physical and General Health” domain comprises items assessing physical health, physical pain, energy and discomfort, and general health. An example question in this domain is: “How dissatisfied or satisfied are you with your physical health (the health of your body)?” from the Perceived Quality of Life (PQoL) Scale [77]. In addition, pain and discomfort, where the individual is asked about the presence and severity of physical pain experienced, include questions on the frequency, duration and impact of pain. An example question is from the WHOQOL-BREF: “To what extent do you feel that (physical) pain prevents you from doing what you need to do?” [115]. This includes physical sickness and neglecting one’s own health. In addition, energy and fatigue consist of self-evaluations of an individual’s energy levels including tiredness, pep, exhaustion, appetite, and sleep. Example is from the Dermatitis Family Impact (DFI) Questionnaire: “Over the last week, how much effect has your child having eczema had on causing tiredness or exhaustion in your child’s parents/carers.” [32]. Lastly, general health is categorised here as well, as physical health is often described as one’s perception of their overall health status as well as any chronic health condition or illness. An example question is from the PROMIS: “In general, would you say your health is…?” where participants could choose the options of “Excellent”, “Very Good”, “Good”, “Fair”, and “Poor” [79].

3.5.4.2. “Relationships and Social Support” Domain

The “Relationships and Social Support” domain captures items assessing the quality and extent of the parent’s social relationships and support. An individual’s social network can comprise of friends, family (including children), romantic partners, clinicians and teachers. Individuals often turn to their social support system for emotional support, practical assistance, and instrumental support [129]. Questions related to one’s satisfaction of the quality and frequency of social interactions and social support in one’s life is often included as well. An example question is “How satisfied were you about the practical support you had from your family?” from the Care-ILI-QoL [31] and “I am satisfied about my contact with doctors.” from the Impact of a Child with Congenital Anomalies on Parents (ICCAP) [43]. Furthermore, questions can also relate to the impact of social factors on the parent, which may lead to feelings of loneliness and isolation [130]. This includes inquiries about the individual’s sense of belonging and connectedness with others [130]. “I have trouble getting support from others” from the PedsQL-FIM [61] is an example. Included in the category of impact of social situations on parents’ QoL is stigma and discrimination towards the child’s health condition [131]. Example question: “Neighbours treat us in a different way because of the disease of our child.” from the Impact on Family Scale (IoFS) [132].

3.5.4.3. “Mental and Emotional Health” Domain

Items assessing mental and emotional health, and the presence of mental health symptoms, were categorised as “Mental and Emotional Health.” Common elements relating to one’s emotional health ask about one’s feelings, moods, and emotional stability, such as: “While your child was having rhinopharyngitis and/or ear infections, did that affect your mood?” from the PAR-ENT-QoL [70]. Furthermore, one’s own thoughts and mental cognition about a particular situation was also categorised here, such as “Sometimes I wonder if I should treat my child in a different way from a normal child” from the IoFS [132]. This domain also included items which assessed the presence of mental health symptoms or conditions, or elevated psychological distress. This includes the individual’s history of a mental health diagnosis, treatments, medical use, and family history. An example question is: “Rate how much of a problem anxiety disorders are in your family history (e.g., your immediate family and those relatives who live in your home)” from the Quality of Life Questionnaire for Families of Young Children with Developmental Delays (QLQ-FYCDD) [87].

3.5.4.4. “Self-Fulfilment and Satisfaction of Life” Domain

Items under this domain include one’s thoughts on the purpose of life, personal growth and spirituality. Terms associated with this domain are also related to the self, which include “self-esteem” and “self-control”. With regards to the purpose of life, this relates to a higher cognitive thinking which questions the meaning of circumstances. An example question for this is “How dissatisfied or satisfied are you with the meaning and purpose of your life?” from the PQoL [77]. Items that assess an individual’s sense of personal growth and development were also categorised under this domain. An example of this is from the Quality of Life

Inventory which assesses one’s thoughts regarding their “creativity” and “learning” [85]. Other elements may influence one’s personal growth and development, self-improvement and acquisition of new skills and knowledge, such as spirituality and religion as a sense of connection to a higher purpose which leads to a sense of fulfilment. Examples of this include determining how “Faith in God” and “Peace of Mind” affect one’s QoL, as assessed in the Quality of Life Index [83].

3.5.4.5. “Daily Living” Domain

The “Daily Living” domain comprises of specific daily activities including self-care tasks, household chores necessary for daily life, or time for oneself. Example questions include: “I have slight problems washing or dressing myself,” from the EQ-5D-3L [38]. Other categories under this domain include work, such as the question from the Caregiver’s Congenital Glaucoma Quality of Life Questionnaire (CarCGQoL) [22]: “Because of your child's glaucoma, how much do you experience… reduced efficiency in doing work”; eating habits, with the example: “How dissatisfied or satisfied are you with the kind and amount of food you eat?” from the PQoL [77]; sleep, “How often were you awakened during the night because of your child’s asthma?” from the Paediatric Asthma Caregivers Quality of Life Questionnaire [58]; shopping, the example from the DFI: “Time spent shopping for the family” [32], and sexual activity: “How dissatisfied or satisfied are you with your level of sexual activity or lack of sexual activity?” from the PQoL [77]. Personal leisure activities were also classified under here: “To what extent do you have the opportunity for leisure activities?” from the WHOQOL-BREF [115].

3.5.4.6. “Child Management, Symptoms, and Behaviours” Domain

For this domain, questions assessed the parents’ perception of their child’s behaviours, the nature and severity of the child’s health condition or disability, comparison of the child’s condition with others, and the parents’ perception of how to manage the situation. Some questions were related to the child’s problems (as rated by the parent), such as: “Rate how often your child has problems falling asleep.” from the QLQ-FYCDD [87]. Specific child behaviours were also highlighted, such as the child “sleeping more than usual”, “has less desire to play”, and “has been less attentive” from the Respiratory Syncytial Virus scale (RSV) [91];

and specific symptoms and outcomes [44]. For the presence of the child's health conditions, an example listed in this domain is: "My child seems sickly or prone to illness because of the hemangioma" from the IH-QoL [21]. Some questions in this domain asked parents to compare their child against other children. Example questions include: "Compared with other children the same age, my child has difficulty expressing themselves." from the HIP-QL [42]. Lastly, parent management of specific child symptoms and behaviours were also listed here, such as assessing the parent's "ability to feed your new baby" from the Maternal Postpartum Quality of Life (MAPP-QOL) [24].

3.5.4.7. "Economic and Environmental" Domain

Questions related to parents' socioeconomic status, education and employment status, housing and neighbourhood, and access to healthcare were categorised under this domain. Income and socioeconomic status are examples, as are financial stress and limitation to resources to provide for basic needs. "Have you enough money to meet your needs?" is an example from the EUROHIS-QOL-8 [36]. Parental education and employment status is also another important factor, as it is linked to earning potential and job security. Examples of this include satisfaction with one's "economic or financial capacity" and "employment work" from the MAPP-QOL [24]. Housing instability, unsafe neighbourhoods, limited access to transport and exposure to environmental hazards can also negatively affect QoL [133]. Questions may relate to satisfaction with the "home/apartment/place where you live" – an example from the MAPP-QOL [24]. Additionally, access to healthcare also plays an important role – as barriers such as the lack of health insurance or limited healthcare facilities can lead to unmet healthcare needs [134]. An example for this is "How satisfied are you with your access to health services?" from the WHOQOL-BREF [115].

3.5.4.8. "Overall Quality of Life" Domain

The last domain included questions which encompassed an overall perspective of QoL, which did not ask about specific components of QoL. An example item includes: "Would you say your QoL has been affected?" from the Parental Acute Otitis Media Quality of Life (PARAOM-QOL) [73].

3.6. Discussion

This scoping review describes the instruments, psychometric properties, and domains of QoL of parents with young children under five years of age. Thirty-five freely available instruments were identified through the literature, which assessed parent QoL across eight domains.

Across the instruments analysed, items categorised as belonging to the "Daily Living" domain were most frequently identified, while items pertaining to "Self-Fulfillment" and "Overall Quality of Life" were least frequently reported. Many questionnaires provided multiple examples of “Daily Living” activities, reflecting the broad scope of activities encompassed by this domain. For instance, the DFI [32] consisted of items assessing “housework”, “food preparation and feeding”, and “time spent shopping for family”. Previous studies have linked aspects of QoL to Maslow's Hierarchy of Needs [135], which posits five levels: "Physiological Needs", "Safety Needs", "Love and Belonging", "Esteem", and "Self-Actualisation" [136]. Many of the items observed in the “Daily Activities” domain fit into the first level of Maslow’s Hierarchy of Needs – for individuals to obtain “Physiological Needs” such as food, water, shelter, and hygiene [137]. According to Maslow's theory, fulfilling these basic needs is essential before individuals can pursue higher-level needs [136]. Therefore, by engaging in these daily activities, parents contribute to fulfilling not only their own physiological needs but also those of their young children.

With regards to “Self-Fulfilment”, items in this domain map to the top level of Maslow’s Hierarchy of Needs – “Self-Actualisation”, which is described as achieving one’s full potential [136]. Assessing “Self-Fulfillment” involves a more subjective and complex construct compared to other domains, as it encompasses perceptions based on personal values, beliefs, life circumstances, and culture. In the context of parenting young children, there is often a necessity to prioritise the immediate needs of the child, such as caregiving responsibilities, managing daily routines, and addressing child-related challenges [138]. This focus is likely reflected in the design of many QoL instruments, which are frequently developed to capture the practical and day-to-day experiences of parenting. Consequently, these instruments tend to emphasise observable and immediate challenges, making domains like "Daily Living" and "Physical Health" more prominent. Therefore, questionnaires including items on “Self-Fulfilment” may provide valuable insights by acknowledging and addressing the complex interplay between daily parenting demands and long-term personal growth and satisfaction.

The limited inclusion of “Overall QoL” questions in many instruments may be attributed to the inherently multidimensional and subjective nature of QoL. Capturing the broad spectrum of QoL with a single question is challenging. Instead, subdomains that address specific aspects of QoL, such as physical health, emotional health, and social relationships are most frequently used in QoL instruments [139]. Aggregating the scores from these subdomains provides a comprehensive assessment of overall QoL, which can be more informative and nuanced than a single-item measure. Additionally, single questions tend to have lower reliability in psychometric evaluations, as they do not capture the complexity of constructs as effectively as multi-item scales [140]. Thus, using detailed subdomains allows for a more reliable and in-depth understanding of QoL without depending solely on a single question.

Among the instruments analysed, the Maternal Postpartum Quality of Life (MAPP-QOL) [24], the Multicultural Quality of Life Index (MCQLI) [55], and the Quality of Life Index (QLI) [83] each covered seven out of eight QoL domains, addressing various needs related to caregiving.

The MAPP-QOL was designed specifically for parents, particularly mothers in the postpartum period, and thus includes items focused on the unique aspects of maternal and parenting QoL, such as recovery from childbirth and the challenges of balancing infant care with self-care [24]. In contrast, the MCQLI [55] and QLI [83] were developed as general QoL measures applicable to a broader population, making them suitable for use across diverse contexts and cultural settings. While this general applicability allows these instruments to be versatile, they may lack the specificity of the MAPP-QOL in capturing parenting-related experiences and challenges.

Relating to psychometric properties, the SF-36 [20] was identified as the most commonly used instrument with the most psychometric properties reported. While it is well-supported in terms of reliability and validity, the SF-36’s [20] focus remains largely on health-related QoL aspects, potentially limiting its sensitivity to specific parenting-related concerns. The importance of validated outcome measures should be discussed, especially to highlight the impact of using tools with robust psychometric properties on the reliability of research outcomes. This gap in addressing the nuanced needs of parents, along with the lack of reported psychometric properties for several other instruments, highlights the need for further research on tools tailored to parents of young children.

The lack of reported psychometric properties for the included instruments highlights the need for further research on instrument development for parents of young children. Additionally, researchers may encounter challenges in obtaining certain psychometric properties. For instance, there is an absence of established gold standard instruments for measuring parent QoL [141]. As a result, assessing criterion validity becomes problematic in the absence of benchmark instruments against which to validate the chosen measures. These factors collectively contribute to the complexity and limitations surrounding the assessment of psychometric properties in studies examining parent QoL.

The most frequently used instrument in papers included in the current review of parents with young children was the SF-36 [20], which mirrored the findings in the systematic scoping review by Brekke [142] measuring parent QoL during the pre- and post-natal period. The SF-36 measures domains related to “Physical Health”, “Relationships”, and “Emotional Health”, with many papers reporting internal consistency and hypothesis testing for construct validity. It is noted that the SF-36 was constructed through a “patient-centred lens”, which is useful for medically unwell individuals. However, most of the instruments constructed through this lens focus on HRQoL, which prioritise health metrics and health indicators, such as symptoms, treatment adherence and physical functioning [16]. As such, these instruments may not be suitable for parents who do not have a medical condition. Moreover, while there is evidence that the SF-36 can be used for the general and clinical population [143], questions in the SF-36 are formulated in a manner that is not tailored specifically to parents.

It was also observed that most articles in this review used a generic QoL instrument to assess parent QoL in studies of children with a specific condition (e.g., cancer or cerebral palsy). Generic QoL instruments included questions in the “Physical Health”, “Mental and Emotional health”, and “Relationships” domains, but did not have any items reported for the “Child Symptoms, Behaviours, and Management” domain. The generic instruments in this review also often reported internal consistency, but did not report reliability, structural validity, and responsiveness. While it is possible to use generic QoL instruments to assess QoL, it may be challenging to accurately interpret parent QoL scores or identify areas of concern for intervention without tailored items or subscales related to the child's condition. For example, a generic QoL instrument may not include items that specifically address the challenges of raising a child with cancer, such as dealing with the child's diagnosis and handling the child psychological maladjustment [144]. As a result, the instrument may not accurately measure the impact of these challenges on the parent's overall QoL.

Parent-specific QoL instruments often reported "Physical Health", "Daily Living", "Mental and Emotional health", and "Relationships" domains. These findings are consistent with many parent QoL studies, which identify "Emotional," "Physical," and "Social" as fundamental domains [7]. Regarding the "Daily Activities" domain, it is noteworthy that several generic QoL instruments, like the WHOQOL-BREF [115], combine "Physical Health" and "Daily Living" into one category. Conversely, parent-specific QoL instruments such as the Care-ILI-QoL [31] distinguish between "Physical Health" and "Daily Activities". This distinction suggests that the "Daily Living" domain may be particularly important to parent QoL, as daily routines and caregiving responsibilities linked to children may impact parental stress levels, time management, emotional resilience, and overall satisfaction with life [145]. Parent-specific instruments were also more likely to report items in the "Child Symptoms, Behaviours, and Management" domain. This indicates a focused effort to understand how parental perceptions of their child's health and behaviours contribute to overall parent QoL assessments. Moreover, internal consistency and hypothesis testing for construct validity was also commonly reported for parent-specific questionnaires.

It is worth noting a rise in development of specific QoL instruments which assess both parent and child conditions in one questionnaire, as opposed to two separate questionnaires. For instance, the Paediatric Quality of Life Inventory (PedsQL) questionnaire was first designed to measure QoL of children and adolescents; and the PedsQL-FIM was developed later as a standalone, independent measurement of parent QoL used to complement the PedsQL [61]. In contrast, the more recently developed HIP-QL instrument consists of domains addressing QoL for both child (parent observed conditions of the child's auditory/communication behaviour, temperament) and parent (how the parent is coping/managing) [42] in the same questionnaire. This further acknowledges the complex interaction between parent and child wellbeing.

3.6.1. Strengths and Limitations

While this review provides insights regarding how parent QoL for young children is measured within the literature, there are several strengths and limitations. Firstly, a primary strength is by using a bottom-up approach to conduct a content analysis in the absence of a predefined theoretical framework. Doing so allowed for the inclusion of diverse and emerging perspectives on parent QoL, making it more adaptable to the specific challenges faced by this group. This flexibility, however, may limit the review's ability to systematically explore predefined categories and themes [146]. Additionally, the search criteria, which limited studies to those assessing parent QoL for children aged zero to five, ensured that results remained relevant to early childhood but constrained generalisability to families, with older children (up to eighteen years old). Next, a methodological strength of this review was the use of COSMIN's classification framework [2], ensuring a consistent and rigorous categorisation of psychometric properties. However, this approach could vary if alternative frameworks were used. The choice of categorisation for psychometric properties can impact recommendations and interpretations. Furthermore, the review focused on whether psychometric properties were investigated in the included studies, without assessing the robustness or reliability of these properties. A more rigorous assessment would facilitate a clearer identification of which instruments demonstrate psychometric validity and reliability, and which do not. Lastly, we focused on freely available instruments, where some instruments were excluded from the review because they were inaccessible due to copyright or licensing restrictions. Therefore, this review highlights practical and accessible tools, but may not capture the full range of proprietary assessments available in the field.

3.6.2. Future Research

The current review findings suggest that there are various instruments employed in the literature for assessing parent QoL, encompassing items from diverse domains, although psychometric properties were not reported in many studies within this specific age range. It would therefore be useful to foster theoretical clarification on the components of parent QoL. The current review findings also indicate that “Daily Living” and “Child Symptoms, Management and Behaviours” may be particularly important domains to consider in this development of a theoretical framework specifically for parents of young children. This can help guide the selection of appropriate parent QoL assessments by providing a comprehensive understanding of factors comprising parent QoL, thereby contributing to the determination of a gold standard parent QoL instrument. In addition, future research could also explore family-oriented QoL measures that include perspectives beyond the parents, such as the sibling’s viewpoint or broader family dynamics. These instruments, which are often used in family assessments, were not included in the current review as the focus was specifically on parent QoL. Moreover, this review identified that structured, quantitative instruments are typically used to assess parent QoL for parents with young children. Incorporating qualitative assessments could provide richer, nuanced insights into the lived experiences and specific challenges faced by these families and deepen the understanding of how various factors uniquely impact parent QoL [148]. Finally, a rigorous systematic review on psychometric properties of parent QoL instruments with quality assessment should be conducted to ensure the robustness of the review findings.

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Chapter Four: General Discussion

The primary aim of this thesis was to better understand the assessment of QoL in parents of young children and how it relates to early child development. This aim was explored through two studies: a quantitative cross-sectional analysis assessing the relationship between parent QoL and child development at age two, and a scoping review examining the nature, psychometric properties, and domains of instruments typically used to assess QoL in parents of young children aged five years and below. Our study draws upon Bronfenbrenner's Ecological Systems Theory [1], which posits that human development is shaped by interactions across multiple environmental systems. Our findings underscore the relevance of this framework in understanding the dynamics between parent QoL and child development during early childhood.

The first study demonstrated a relationship between a child's social-emotional functioning and parent QoL, such that higher social-emotional scores were associated with better parent QoL, even after controlling for covariates such as parental education and household income. While this finding was statistically significant, the relationship was weak in strength, indicating that the association, although present, is modest. This finding corresponds with studies by Richter and colleagues [2], Islam and colleagues [3], and Nuske and colleagues [4], which highlight the interconnected nature of parent QoL and child developmental outcomes. This underscores the importance of early childhood interventions that not only target the child's development but also consider the QoL of the parents, thereby fostering a supportive environment that benefits the entire family unit. This also aligns with Bronfenbrenner's microsystem concept, highlighting the complex association between the immediate family environment (child development) and parent QoL [1].

The second study, a scoping review, revealed that many generic HRQoL tools, such as the SF-36 [5], are commonly used to assess parent QoL. However, these tools were developed with an emphasis on health, and were not specifically designed for parents of young children. In addition, the review found that none of these instruments have been thoroughly evaluated for all nine psychometric properties recommended by COSMIN. Without comprehensive evaluation across all psychometric properties, there is a risk that these instruments may not accurately capture the nuances of parent QoL in the context of young children. Moreover, through a basic qualitative content analysis, we identified eight domains that are typically captured in assessment tools of parent QoL. This finding is important as it highlights the multidimensional nature of parent QoL, which can allow researchers to gain insight into the comprehensive range of factors that potentially contribute to parent QoL. These domains also reflect the complex interplay within Bronfenbrenner's ecological systems—from the microsystem (individual parent experiences) to the exosystem (external environments indirectly influencing development) [1]. For example, parent QoL may be influenced by interactions between parental mental health (microsystem) and their economic circumstances (exosystem).

4.1. Challenges in the Assessment of Parent QoL

Assessing the QoL of parents presents unique challenges, particularly in capturing the nuanced experiences of those with young children. The widespread use of generic QoL instruments suggests that tools may be chosen due to their availability, cost-effectiveness or prevalence in prior research rather than their suitability for the target population [6]. The generic nature of these instruments means they may not adequately capture the unique experiences and challenges faced by parents of young children. For example, generic QoL instruments may lack the specificity required to address the stresses and responsibilities associated with parenting, thereby providing an incomplete picture of parent QoL [7]. As such, parent-specific QoL questionnaires may include questions that are better suited to assess the unique QoL needs of parents. If researchers choose parent-specific QoL questionnaires, it is also advised to consider the specific characteristics of the children in their sample which may emphasise symptoms specific to those conditions. For instance, questionnaires may include items that assess the challenges parents face related to communication difficulties, sensory sensitivities, and behavioural issues commonly experienced by children with autism [8]. In such instances, generic QoL instruments or parent-specific QoL instruments with general health measures for children may not aptly capture challenges related to the child's particular condition. This underscores the necessity for developing parent-specific and child-specific QoL instruments tailored to the unique needs of this population, encompassing the specific challenges related to managing children's development.

Furthermore, many existing instruments are not age-specific, which may be unable to capture the developmental nuances of early childhood. The early years of a child's life are marked by rapid and significant developmental changes [9]. For instance, delays in meeting milestones such as the child learning to walk, talk, and develop fine motor skills may present unique challenges and stressors for parents, potentially impacting on emotional wellbeing and stress levels [10]. Hence, age-specific assessment tools may help to accurately reflect the experiences and challenges faced by parents during this period. Such tools would provide deeper insights into how early childhood development relate to parent QoL, allowing for more targeted and effective interventions. Therefore, it is suggested that researchers consider both parent-specific with child-specific aspects and age-specific factors when choosing suitable parent QoL assessment instruments. This necessitates exploring existing tools that may have been specifically developed for the target population. Additionally, conducting a systematic review would help in enabling more informed recommendations for clinicians and researchers regarding the selection of the most suitable instrument for their sample.

There is a growing acknowledgment of the importance of employing qualitative methodologies in evaluating parent QoL, driven by the need for deeper insights and the exploratory essence of family QoL research [11]. This approach may help to prevent overly broad generalisations of findings by capturing the diverse and nuanced experiences of families. While qualitative instruments allow parents to provide personalised insights by focusing on the life aspects most impacted by caregiving, they are often used to supplement quantitative assessments rather than serve as primary QoL measures [36]. Through methods such as interviews and focus groups, qualitative data can reveal caregiving-specific challenges and priorities, which quantitative instruments might miss [11]. By analysing these responses, researchers can identify common themes and inform the development or adaptation of quantitative tools, making them more responsive to the real-life experiences of parents [11]. This approach not only highlights specific areas of concern but may also reveal the interplay between different QoL domains, offering a holistic understanding essential for developing tailored interventions. Implementing qualitative instruments may ensure comprehensive data collection, allowing for the identification and validation of key QoL domains [13]. Furthermore, integrating qualitative findings into quantitative QoL assessments may enhance the instruments' adaptability, ensure they reflect subjective experiences, and provide comprehensive data collection. This can lead to more accurate and effective tools for supporting the QoL of parents of young children, allowing for the identification and validation of key QoL domains [12].

4.2. Terminology and Inconsistency in the Literature

Findings from the scoping review indicated that many existing instruments assessing parent QoL predominantly focus on health-related quality of life (HRQoL). Historically, QoL instruments were constructed with a strong emphasis on health due to input from health professionals, medically unwell patients, and control groups of healthy individuals [14]. These instruments have been particularly useful in clinical settings where the primary concern is the health status and medical outcomes of patients. However, while these instruments are appropriate for evaluating the QoL of patients receiving medical care, they may not be ideal for parents who are not experiencing health issues such as illness or disability.

The emphasis on health and disagreements about what the domains of QoL should comprise can also lead to ambiguity. As there is no established framework for parent QoL, examining the theoretical evolution of the QoL concept can help us understand how it has been used in the literature. The theoretical foundation models by Wilson & Cleary [15] and Ferrans [16] provide valuable insights into the interconnected domains of QoL, emphasising the roles of health such as biological and psychological factors. However, the findings from this thesis suggest that the unique challenges and experiences faced by parents may extend beyond health considerations, encompassing self-fulfilment, economic, and child symptoms dimensions. The multidimensional nature of QoL is therefore recognised and advocated for a holistic approach to assessing parent QoL. Moreover, Wilson and Cleary's model, for instance, highlights the indirect influence of individual and environmental characteristics on HRQoL, suggesting that factors beyond traditional health measures contribute to overall QoL [15]. Ferrans's model, while applicable across various healthcare disciplines, may overlook the importance of "nonmedical factors" such as socioeconomic status in shaping parent QoL [16]. Therefore, findings from this thesis emphasise the need to expand the scope of QoL assessments to include a broader range of factors in assessing parent QoL, aligning with the diverse realities of parenting experiences. By considering a broader range of factors, a more comprehensive understanding of parent QoL can be gained, tailoring interventions and support services more effectively to address the multifaceted needs of parents and families.

Additionally, the use of multiple terms such as "QoL," "wellbeing [17]" and “burden” [18] to describe similar constructs highlights a lack of clarity and consistency in the literature. This variation poses challenges in accurately assessing and addressing the needs of individuals and comparing findings across different studies. For instance, “wellbeing" is often used in studies involving both general and clinical populations, capturing a wider range of life experiences and subjective assessments of overall happiness and contentment. Additionally, the term "burden" is frequently employed in the health economics literature, particularly in the assessment of costs associated with a disease. This inconsistency in terminology can lead to difficulties in synthesising research findings, and the lack of standardisation can also obscure the true nature of what is being measured. For instance, a study examining "wellbeing” in parents of children with disabilities might highlight coping mechanisms and overall resilience, while a study focusing on "burden" in the same group might explore high levels of anxiety and emotional strain. Without clear definitions and consistent usage, it becomes challenging to draw accurate conclusions and develop targeted support strategies for parents.

4.3. Analysis of CarerQoL-7D

For the assessment of the relationship between child development and parent QoL in Chapter Two, an existing dataset was used where parent QoL was measured using the CarerQoL-7D instrument [19], which equates the term “burden” to “QoL”. While the CarerQoL-7D effectively captures challenges and strains inherent in caregiving situations, it also encompasses broader aspects that contribute to overall QoL and satisfaction across various life domains [20]. It is noted that the CarerQoL-7D did not appear in my scoping review search results. Two papers utilising the CarerQoL-7D [20] [21] were identified in the initial abstract search, specifically Hoefman's study [20] which focused on children with autism aged 4-17 years, and

Fitzgerald's study [21] which examined children with cystic fibrosis aged 3-83 months. However, the upper age limit of the children in the samples exceeded the zero to five-year age range; therefore, the CarerQoL-7D was excluded from the final review.

To address this gap, the CarerQoL-7D domains were compared to my content analysis of parent QoL domains. It is important to note that the CarerQoL-7D was originally designed for adult informal caregivers [19], therefore it was not specifically developed for assessing the QoL of parents. Based on item content, the CarerQoL-7D assesses six out of the eight parent QoL domains identified in Chapter Three’s scoping review, excluding "Child Management, Symptoms, and Behaviours" and “Overall QoL”. In comparison to other instruments reviewed, most tools mapped onto fewer domains. Notably, the "Self-Fulfilment" domain emerged as significantly underrepresented in my scoping review table results across other instruments, which was addressed by the CarerQoL-7D. Even the most used instrument in the literature, the SF-36 [5], mapped onto only four domains and did not include "Self-Fulfilment" items. This breadth suggests the CarerQoL-7D's comprehensive approach to capturing various aspects of QoL, emphasising its utility in assessing a wide range of domains relevant to caregiving experiences.

The absence of the "Child Management, Symptoms, and Behaviours" domain in the CarerQoL-7D highlights potential limitations in thoroughly assessing parent QoL. Managing and addressing children's symptoms and behaviours are critical aspects of parenting responsibilities, contributing significantly to parental stress and emotional burden [22]. This includes disruptions in daily routines, chronic stress, and anxiety stemming from frequent medical appointments and adherence to treatment regimens for children requiring special care [22].

Furthermore, managing children's behaviours like tantrums or sleep disturbances can lead to feelings of helplessness, frustration, and exhaustion, which may compromise parents' mental health and overall caregiving capacity [23]. The time and effort involved in managing these needs can also restrict parents' opportunities for self-care, social interactions, and professional development, further diminishing their overall QoL [24]. Including this domain in parent assessments could acknowledge the holistic nature of parenting, offering a more comprehensive understanding of parent QoL, especially among those caring for children with chronic conditions or disabilities, and potentially enhancing support interventions. Moreover, researchers have recently placed greater emphasis on highlighting the potential influence of child conditions on parent QoL. For example, many newly developed instruments incorporate domains that address both child outcomes and parent QoL within a single questionnaire assessing parent QoL, rather than using two separate questionnaires [25] [26].

While the CarerQoL-7D excludes questions assessing "Child Management, Symptoms, and Behaviours," this was not a limitation in Chapter Two of my thesis, as child development domains were measured using the Bayley-4 [27]. By utilising the Bayley-4, the study was able to capture detailed information about the child's development, thereby addressing some components of the "Child Management, Symptoms, and Behaviours" domain through rigorous, validated developmental measures. However, it is important to acknowledge that the Bayley-4 primarily provides an objective developmental assessment and may not fully capture how parents respond to managing their child's behaviours and symptoms. Therefore, including measures to assess child conditions when measuring parent QoL may be worth considering for future research settings. Integrating the "Child Management, Symptoms, and Behaviours" domain may be especially important in clinical populations where children are likely to experience particularly challenging symptoms or behaviours. This approach not only provides a more holistic view of parent QoL but also highlights the significant impact that child development can have on parents.

The absence of the "Overall Quality of Life" domain in the CarerQoL-7D may restrict parents from expressing their broader perspectives on their QoL. For instance, Spilker's hierarchical QoL model posits that overall QoL assessment, broader QoL domains, and specific aspects within these domains are connected but distinct units [28]. This model highlights that while each specific QoL domain provides valuable information, they do not individually offer a comprehensive picture of an individual's overall QoL. Instead, individuals integrate the importance of various domains into a general value judgment, reflecting their overall sense of wellbeing [29]. For example, a child's challenging behaviours might negatively impact a parent's social life, which may be a specific domain of QoL. However, QoL is a subjective experience, and parents may find positivity in other domains, such as self-fulfilment, thereby adjusting to changing circumstances to maintain a consistent overall state of QoL [30]. This suggests that the absence of an “Overall Quality of Life” domain in existing instruments may result in an incomplete understanding of parent QoL. Parents might weigh various life domains differently and integrate them into an overarching perception of their QoL, which may not be adequately captured by instruments lacking this comprehensive domain. This discrepancy also suggests that parents' perceptions of their overall QoL may be influenced by a combination of factors, and any assessment tool should consider these nuanced perspectives to provide a holistic understanding.

4.4. Theoretical Implications

This thesis emphasises the need to refine theoretical models of parent QoL to encompass a broader spectrum of factors influencing QoL and to establish a universal agreement on the domains assessing parent QoL. While models by Wilson and Cleary [15], Ferrans [16], the WHO’s definition of health [31] and Engel’s biopsychosocial model [32] provide useful frameworks for understanding HRQoL, the ongoing discourse surrounding the importance of prioritising health as the central focus when evaluating parent QoL raises fundamental questions regarding the comprehensive understanding of parent QoL. This debate necessitates a thorough examination of whether factors beyond health exert significant influence on parent QoL and merit equal consideration in measurement frameworks.

In addition, the terms used synonymously and together with “QoL” present challenges. To address this issue, rather than advocating for the universal adoption of a single term such as "QoL," it may be more beneficial to recognise the complementary nature of these concepts and consider integrating them within a broader framework of parent QoL. This involves acknowledging the multifaceted nature of parent QoL, which may encompass various dimensions including “wellbeing”, “burden”, and other related terms. By acknowledging the nuanced differences between these terms and understanding how they intersect with parent QoL, researchers can develop more comprehensive assessments and targeted support strategies tailored to the diverse needs of parents.

The prevalence of generic instruments like the SF-36 [5] also underscores the necessity for a more nuanced approach to conceptualising parent QoL. These instruments, primarily designed through a patient-centred lens, prioritise health-related metrics and may not adequately capture the diverse experiences of parents who do not have medical conditions. Additionally, the absence of items specifically tailored to address the challenges of parenting children with specific conditions further highlights the limitations of generic QoL instruments in accurately assessing parent QoL in these contexts. The emergence of specific QoL instruments designed to evaluate both parent and child conditions in a single questionnaire represents a promising development in the field. These instruments recognise the complex interaction between parent and child QoL and provide a more comprehensive understanding of the challenges and stressors faced by parents of children with specific conditions.

The current findings also underscore the importance of broadening theoretical models of parent QoL beyond health-related metrics. By acknowledging the multidimensional nature of parent QoL and the intricate interplay between parent and child conditions, theoretical frameworks can more effectively capture the lived experiences of parents. This, in turn, informs the development of more comprehensive measurement tools and targeted interventions tailored to the diverse needs of parents, addressing the complexity of their situations more effectively.

Furthermore, considering the potential influence of the child's condition on the parent's QoL enriches theoretical understandings of QoL dynamics within the context of caregiving. This can provide a more accurate and nuanced understanding of QoL, facilitating the development of more comprehensive measurement tools. Additionally, it prompts researchers to explore the complex interactions within the parent-child dyad, fostering the creation of more robust and inclusive theories that better capture the lived experiences of diverse populations. This theoretical evolution also encourages scholars to explore the role of familial relationships and societal support structures in shaping parent QoL. Integrating these dimensions into theoretical frameworks not only enhances our understanding of QoL dynamics but also underscores the interconnectedness of individual QoL within broader social contexts. This holistic approach may enhance the validity and applicability of QoL research across different contexts and improve its relevance to real-world settings.

4.5. Clinical Implications

Building on these theoretical perspectives, clinicians can develop more comprehensive care plans that address not only the physical and mental health of parents but also other domains such as their social and economic needs. This approach can lead to more personalised and effective interventions, ultimately improving the overall QoL for parents caring for children with various conditions. Furthermore, recognising the distinct stressors and challenges faced by parents can help healthcare providers offer targeted resources and support systems, thereby enhancing both parental and child outcomes.

Addressing both child and parent needs holistically is also crucial, especially considering the potential relationship between child development and parent QoL identified in the results of Chapter Two. It is important to consider how different aspects of child development may influence parent QoL. While the findings in Chapter Two suggest a possible link between social-emotional development and parent QoL, this relationship may be bidirectional or influenced by other factors. Early interventions that promote overall family functioning can be beneficial, addressing both the child's developmental needs and the parent's QoL.

Understanding how different aspects of child development influence parent QoL may allow for the design of effective support programs that address both the child's and the parent's needs, fostering a more supportive and nurturing family environment. Policies aimed at improving early childhood development may also incorporate components that support parent QoL, such as access to affordable childcare, parental leave policies, and parenting support programs. Additionally, funding for the development and validation of parent-specific QoL instruments including child-related symptoms and age-appropriate questions should be prioritised to ensure that assessments and interventions are based on accurate and comprehensive measurements.

4.6. Limitations and Future Directions

Despite the insights gained from the studies, there are notable limitations that must be acknowledged. For the quantitative study in Chapter Two, the generalisability of results is restricted to mothers, as all participants were female. This limits the ability to draw comprehensive conclusions about parent QoL, as fathers and other caregivers may experience different challenges and perspectives. In contrast, the scoping review in Chapter Three did not place restrictions based on gender in its eligibility criteria, allowing for a broader examination of the approaches to parent QoL assessment. However, it is important to note that many of the assessment tools identified in the review were developed in consultation with or trialled predominantly among mothers [33] [34]. This reflects a broader trend in the literature, where the perspectives of fathers and other caregivers are underrepresented. As a result, the existing assessment tools may not fully capture the diverse experiences and needs of all parents.

It is therefore imperative to ensure a representative sampling of parents and other caregivers to enhance the broader applicability of the findings. This methodological approach would enable researchers to capture a more comprehensive understanding of parent QoL across diverse demographic groups, encompassing fathers, additional family members, or other caregivers. Moreover, given the potential variance in experiences and viewpoints among different caregiver cohorts, qualitative inquiries focusing specifically on these groups could provide valuable insights. These qualitative studies might utilise methodologies such as in-depth interviews or focus group discussions to delve into the unique perspectives of these groups regarding parent QoL, thereby elucidating the salient aspects from their vantage points. Notably, the identification of mother-specific measures such as the Mother Generated Index [35] in the scoping review underscores the necessity of developing similar instruments tailored specifically for fathers or other caregivers. Such qualitative investigations would complement quantitative research efforts by furnishing nuanced insights into the multifaceted experiences of caregivers and their perceptions of parent QoL. Additionally, this approach provides a platform for groups such as fathers to share their unique experiences, ensuring a more inclusive representation of diverse perspectives within parent QoL research.

Future research should also consider longitudinal studies that examine predictor-outcome relationships over time. These studies could explore various domains of child development, considering both the impact of child development on parent QoL and the potential influence of parent QoL on child outcomes. By adopting a more comprehensive and nuanced approach, future research can better elucidate the complex interplay between parent QoL and child development, ultimately informing more effective interventions and support strategies for families.

The development of a theoretical framework that integrates the complex interplay between parent and child factors is also crucial. Such a framework would provide a conceptual basis for understanding how various factors, including “Child Management, Behaviours, and Symptoms”, contribute to parent QoL. This theoretical model could guide future research efforts and inform the design of interventions aimed at improving parent QoL. Empirical studies examining the specific impact of child factors on parent QoL are also needed. These studies would involve collecting data from diverse populations of parents and children, using validated measures to assess parent QoL, and analysing the relationships between child-related variables and parent QoL. By quantifying these relationships, researchers can identify modifiable factors that contribute to poor parent QoL and develop targeted interventions to address them.

Guidelines for selecting appropriate assessment instruments would also be beneficial, helping researchers and practitioners choose the most suitable tools for their specific populations and research questions. A systematic review of clinimetric properties, which focus on assessing the quality of measurements in medical research, may also be helpful for guiding clinicians in selecting the most valid and reliable instruments for assessing parent QoL in clinical settings. Lastly, there is a need for further psychometric studies and potential modifications of existing measures to ensure valid and reliable QoL measures for parents of young children.

4.7. Conclusion

In conclusion, this thesis underscores the need for a standardised and comprehensive framework to assess parent QoL. While the quantitative paper (Chapter Two) reveals a potential relationship between parent QoL and the social-emotional development of two-year-old children, it emphasises the intricate interplay between parent QoL and early child development. Additionally, the scoping review (Chapter Three) uncovers discrepancies in how parent QoL is conceptualised and measured, indicating a lack of consensus on the domains encompassed within parent QoL assessments. This highlights the importance for a more holistic approach to parent QoL assessment, one that accounts for the multifaceted nature of parental experiences.

The prevalence of generic QoL instruments in assessing parent QoL raises concerns. Many of these instruments are not specifically tailored for parents of young children and may not adequately capture their unique challenges and experiences. Additionally, the lack of comprehensive evaluation across all psychometric properties underscores the need for further research to ensure the accuracy and appropriateness of existing assessment tools for this population. Moreover, longitudinal studies are recommended to explore the direction of effects in the relationship between parent QoL and child development, providing insights into the dynamic interplay between these factors over time.

Addressing these research gaps and advancing the understanding of parent QoL in the context of early child development may inform the development of more effective family-centred interventions and support services. This holistic approach has the potential to foster healthier parent-child relationships and promote positive outcomes for families, ultimately contributing to the wellbeing of society.

4.8. References

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APPENDIX 1: COSMIN Guidelines for Evaluating Psychometric Properties of Instruments

Guidelines to evaluate the psychometric properties of instruments are important for a systematic method to help in standardisation, where researchers and clinicians may draw meaningful conclusions when comparing results across different studies or populations [1]. COSMIN categorises psychometric properties into three domains, comprising a total of nine recommended properties [2]. The first domain is reliability, which includes internal consistency, reliability, and measurement error. Internal consistency refers to the degree of interrelatedness of the items; and reliability refers to the proportion of total variance in the measurements due to differences between patients. Measurement error refers to the systematic and random errors of a patient’s score that is not attributed to changes in the construct to be measured [2].

The second domain, validity, encompasses content validity, criterion validity, and three aspects of construct validity – structural validity, cross-cultural validity, and hypotheses-testing. Content validity refers to the degree to which the content of an instrument is an adequate reflection of the construct to be measured. Next, criterion validity refers to the degree to which the scores of an instrument are an adequate reflection of a “gold standard”. Structural validity refers to the degree to which the scores of an instrument are an adequate reflection of the dimensionality of the construct to be measured. Lastly, cross-cultural validity refers to the degree to which the performance of the items on a translated or culturally adapted instrument are an adequate reflection of the performance of the items of the original instrument [2].

The third domain, responsiveness, focuses on the psychometric property of responsiveness, which is the ability of an instrument to detect change over time in the construct to be measured. It is worth noting that COSMIN also highlights the importance of interpretability, which relates to the understanding of the scores obtained from an instrument. Interpretability is not considered as psychometric property as it focuses on the meaning of scores rather than evaluating the instrument's quality, therefore it was not included in Chapter Three of our scoping review.

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1. Prinsen CA, Mokkink LB, Bouter LM, Alonso J, Patrick DL, De Vet HC, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. Qual Life Res. 2018;27:1147-57.
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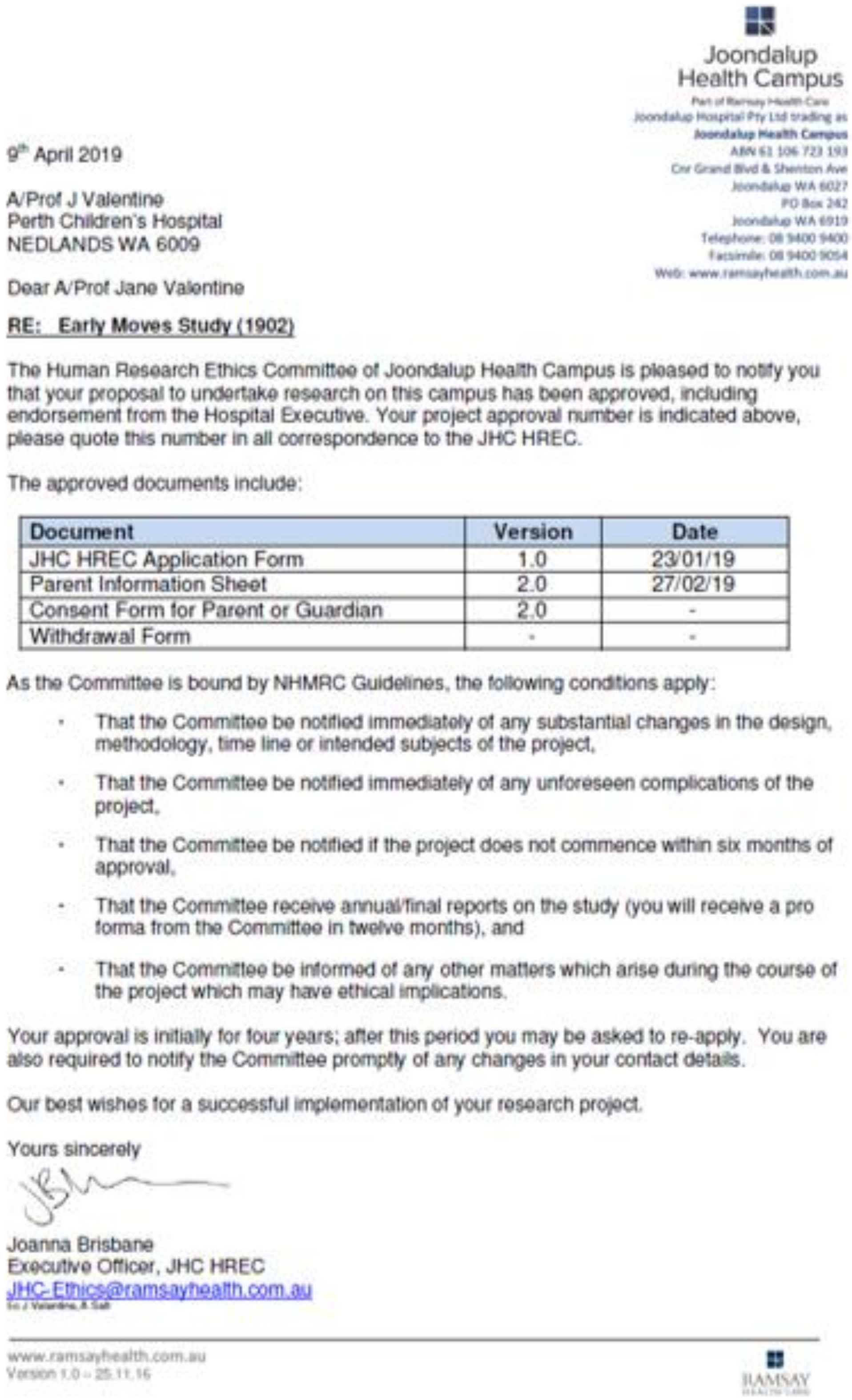
APPENDIX 2: Ethics forms

Joondalup Health Campus ethics form



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Cnr Grand Blvd & Shenton Ave
Joondalup WA 6027
PO Box 242
Joondalup WA 6919
Telephone: 08 9400 9400
Facsimile: 08 9400 9054
Web: www.ramsayhealth.com.au

9th April 2019

A/Prof J Valentine
Perth Children's Hospital
NEDLANDS WA 6009

Dear A/Prof Jane Valentine

RE: Early Moves Study (1902)

The Human Research Ethics Committee of Joondalup Health Campus is pleased to notify you that your proposal to undertake research on this campus has been approved, including endorsement from the Hospital Executive. Your project approval number is indicated above, please quote this number in all correspondence to the JHC HREC.

The approved documents include:

Document	Version	Date
JHC HREC Application Form	1.0	23/01/19
Parent Information Sheet	2.0	27/02/19
Consent Form for Parent or Guardian	2.0	-
Withdrawal Form	-	-

As the Committee is bound by NHMRC Guidelines, the following conditions apply:

- That the Committee be notified immediately of any substantial changes in the design, methodology, time line or intended subjects of the project,
- That the Committee be notified immediately of any unforeseen complications of the project,
- That the Committee be notified if the project does not commence within six months of approval,
- That the Committee receive annual/final reports on the study (you will receive a pro forma from the Committee in twelve months), and
- That the Committee be informed of any other matters which arise during the course of the project which may have ethical implications.

Your approval is initially for four years; after this period you may be asked to re-apply. You are also required to notify the Committee promptly of any changes in your contact details.

Our best wishes for a successful implementation of your research project.

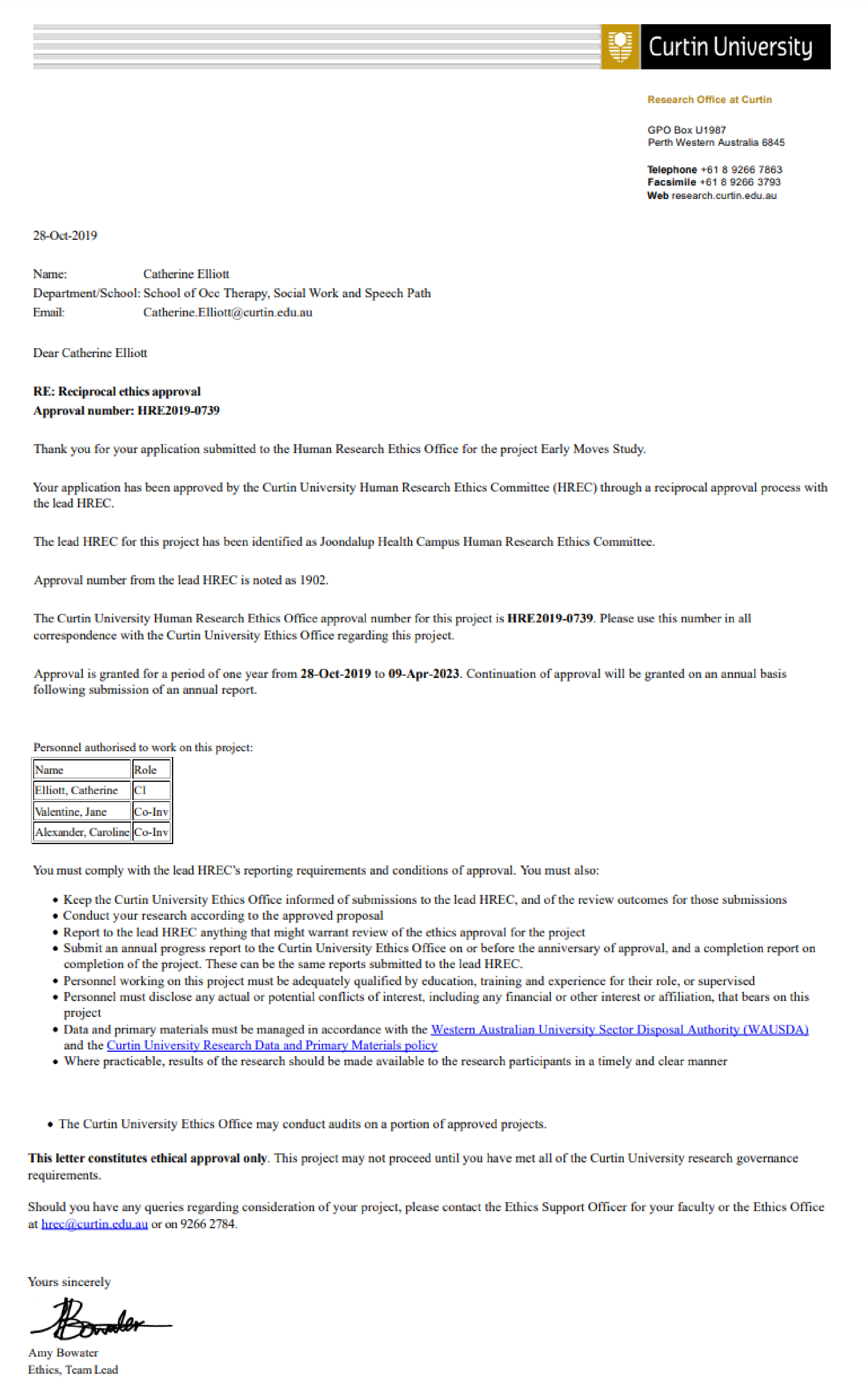
Yours sincerely

Joanna Brisbane
Executive Officer, JHC HREC
JHC-Ethics@ramsayhealth.com.au

www.ramsayhealth.com.au
Version 1.0 – 25.11.16

RAMSAY

Curtin University reciprocal ethics form



Curtin University

Research Office at Curtin

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863
Facsimile +61 8 9266 3793
Web research.curtin.edu.au

28-Oct-2019

Name: Catherine Elliott
Department/School: School of Occ Therapy, Social Work and Speech Path
Email: Catherine.Elliott@curtin.edu.au

Dear Catherine Elliott

RE: Reciprocal ethics approval
Approval number: HRE2019-0739

Thank you for your application submitted to the Human Research Ethics Office for the project Early Moves Study.

Your application has been approved by the Curtin University Human Research Ethics Committee (HREC) through a reciprocal approval process with the lead HREC.

The lead HREC for this project has been identified as Joondalup Health Campus Human Research Ethics Committee.

Approval number from the lead HREC is noted as 1902.

The Curtin University Human Research Ethics Office approval number for this project is **HRE2019-0739**. Please use this number in all correspondence with the Curtin University Ethics Office regarding this project.

Approval is granted for a period of one year from **28-Oct-2019** to **09-Apr-2023**. Continuation of approval will be granted on an annual basis following submission of an annual report.

Personnel authorised to work on this project:

Name	Role
Elliott, Catherine	CI
Valentine, Jane	Co-Inv
Alexander, Caroline	Co-Inv

You must comply with the lead HREC's reporting requirements and conditions of approval. You must also:

- Keep the Curtin University Ethics Office informed of submissions to the lead HREC, and of the review outcomes for those submissions
- Conduct your research according to the approved proposal
- Report to the lead HREC anything that might warrant review of the ethics approval for the project
- Submit an annual progress report to the Curtin University Ethics Office on or before the anniversary of approval, and a completion report on completion of the project. These can be the same reports submitted to the lead HREC.
- Personnel working on this project must be adequately qualified by education, training and experience for their role, or supervised
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, that bears on this project
- Data and primary materials must be managed in accordance with the Western Australian University Sector Disposal Authority (WAUSDA) and the Curtin University Research Data and Primary Materials policy
- Where practicable, results of the research should be made available to the research participants in a timely and clear manner

- The Curtin University Ethics Office may conduct audits on a portion of approved projects.

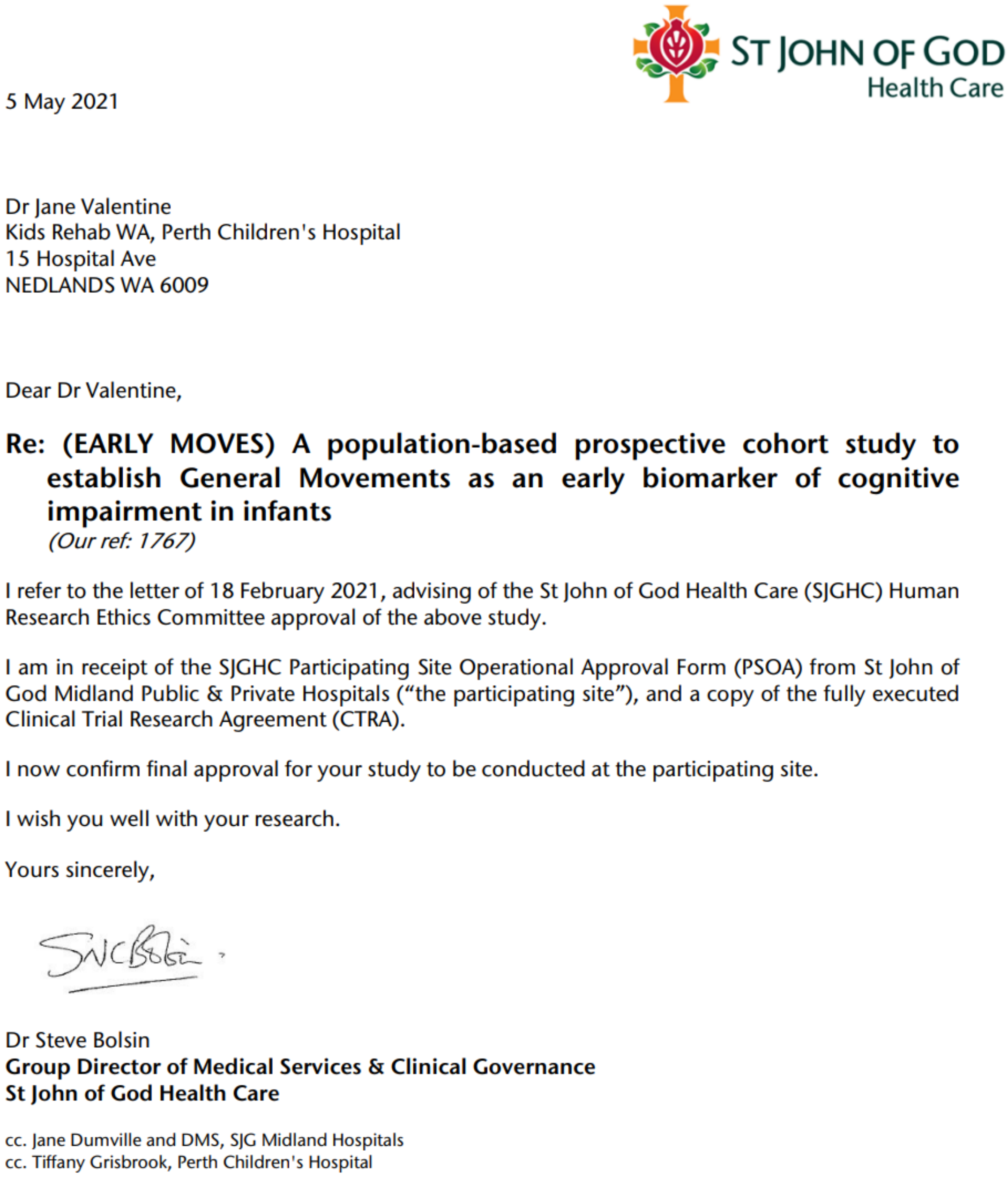
This letter constitutes ethical approval only. This project may not proceed until you have met all of the Curtin University research governance requirements.

Should you have any queries regarding consideration of your project, please contact the Ethics Support Officer for your faculty or the Ethics Office at hrec@curtin.edu.au or on 9266 2784.

Yours sincerely

Amy Bowater
Ethics, Team Lead

St John of God ethics form



ST JOHN OF GOD
Health Care

5 May 2021

Dr Jane Valentine
Kids Rehab WA, Perth Children's Hospital
15 Hospital Ave
NEDLANDS WA 6009

Dear Dr Valentine,

Re: (EARLY MOVES) A population-based prospective cohort study to establish General Movements as an early biomarker of cognitive impairment in infants
(Our ref: 1767)

I refer to the letter of 18 February 2021, advising of the St John of God Health Care (SJGHC) Human Research Ethics Committee approval of the above study.

I am in receipt of the SJGHC Participating Site Operational Approval Form (PSOA) from St John of God Midland Public & Private Hospitals (“the participating site”), and a copy of the fully executed Clinical Trial Research Agreement (CTRA).

I now confirm final approval for your study to be conducted at the participating site.

I wish you well with your research.

Yours sincerely,

Dr Steve Bolsin
Group Director of Medical Services & Clinical Governance
St John of God Health Care

cc. Jane Dumville and DMS, SJG Midland Hospitals
cc. Tiffany Grisbrook, Perth Children's Hospital

APPENDIX 3: Participant information forms

WHO IS CARRYING OUT THE STUDY?

The *Early Moves* study is being led by Dr Jane Valentine and Prof Catherine Elliott from the Kids Rehabilitation Department at Perth Children's Hospital. The study also involves ORIGINS Project investigators Prof Susan Prescott and Prof Desiree Silva from the Telethon Kids Institute, Joondalup Health Campus, Curtin University, Deaking University, the University of Western Australia and the Australasian Cerebral Palsy Clinical Trials Network Centre for Research Excellence.

ETHICAL INFORMATION

The ethical aspects of this study have been approved by the Ramsay Health Care WA | SA Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in a research project, please contact Joondalup Health Campus Executive Office on (08) 9400 9404. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

THE ORIGINS PROJECT

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

Joondalup Health Campus
Part of Ramsay Health Care

THE EARLY MOVES STUDY

ANY QUESTIONS?

If you would like further information about this study, please do not hesitate to contact **Dr Caroline Alexander on 0434 938 571 or email** earlymoves@health.wa.gov.au.

Information can also be found on our website: originsproject.telethonkids.org.au/sub-projects.

early moves

HOME VIDEOS ARE BEING USED TO DETECT IF A CHILD HAS DEVELOPMENTAL DIFFICULTIES IN THIS WORLD-FIRST RESEARCH PROJECT.

Early Moves PIB v3 Oct20

WHAT IS EARLY MOVES?

The *Early Moves* study, a sub-project of The ORIGINS Project, is investigating whether a baby's early movements can predict learning difficulties later in childhood.

WHY ARE WE DOING THIS STUDY?

This study will help us to better understand how to recognise developmental difficulties early enough to provide support and intervention when babies' brains are most able to benefit in the first year of life, a critical period of brain development.

We think that the movement pattern in very young babies may help us predict learning difficulties. Babies' early movements develop in a very particular way, and this changing pattern of movements shows that the brain and nervous system are developing well. Sometimes, however, the brain and nervous system don't develop normally, and this can indicate they baby may be at risk of developmental disorders.

We are currently unable to reliably identify difficulties at such a young age. Predicting learning difficulties early means we can give the babies the best possible start to life by offering early intervention and support when their brain is developing rapidly.

WE INVITE YOU TO TAKE PART

We are inviting you to consider taking part in this research study because you have agreed to be part of The ORIGINS Project. We are aiming to involve 3000 ORIGINS babies in this study.

- Before you decide whether to take part, it is important for you to understand why the research is being undertaken and what is involved for participants in the Early Moves Study.
- Please read this information carefully. Talk with your friends and relatives if you wish.
- Ask questions about anything that you don't understand or want to know more about.
- You are free to decide whether or not to take part in this study. Regardless of your decision, your family's health care will not be affected in any way.

WHAT DOES MY PARTICIPATION INVOLVE?

If you choose to take part in this study, we will follow your baby's development until they turn two years old. We know that life can be busy when you have young children, and life with a newborn is a very unique and special time, so we have tried to make participating in this research simple and easy for you. A lot of it you can do from home, in your own time.

Installation of a smartphone app on your mobile device

Before you leave the hospital after having your baby, a researcher will pay you a quick visit to help you install our specialised smartphone app, Baby Moves. This app was developed to allow you to collect videos of your baby at home, and send them to us for assessment.

Recording your baby

So we can assess your baby's movements, you will be asked to take short, three-minute videos of your baby using the Baby Moves app and upload them directly to our secure database. You will be asked to take these videos at 1, 3, 12 and 14 weeks post-term age (baby's age calculated based on their due date, not birth date). The app will send you notifications to remind you it is time to take the video.

Remote assessment of your baby's movements

We will conduct a specialist assessment of your baby's movements using the videos you upload to the secure database, so there is nothing further for you to do. Our assessors are highly trained and experienced in these assessments, but even then it takes some time to complete. To reduce the time and costs of the assessment, in the hope it will one day be available to every child in Australia, we will be developing an automated scoring system using machine learning and advanced image recognition techniques.

Developmental assessment

The developmental assessment is the final activity for this research project and takes place when your child turns two years old. This standardised play-based assessment measures your baby's language and cognitive development, among other things. It normally takes no more than one hour, and often less, and an appointment at JHC will be arranged to conduct the assessment.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Participants will receive an early screening for risk of cerebral palsy through the 12 -14 week video assessment, and a full developmental assessment of your baby when he/she is two years old. Should any concerns be identified at either assessment, you will receive the best care and support to address these concerns. By being part of this study, you and your child could also be involved in an important scientific advance.

WHAT ABOUT PRIVACY?

The videos you record through the app are uploaded directly to the research centre by you. This is a secure process, and the videos can only be accessed by authorised researchers on the *Early Moves* team. The information we collect from the videos, questionnaires and assessments is kept strictly confidential. As soon as you join the study, you and your child will be allocated a code number, so no identifying details will be stored with your study information. We will never publish your images or identifying information.

WHAT IF I CHANGE MY MIND?

Even if you consent to take part, and change your mind later, that is OK. You can withdraw from the *Early Moves* study at any time, and you don't have to explain why. Withdrawal will not affect your involvement in ORIGINS, or the care you receive. If you withdraw, the information we collected may still be used.

WHAT HAPPENS TO THE RESULTS OF THE STUDY?

At the end of the study we will send you a project summary booklet that gives results of our research. We also plan to publish our findings in scientific journals, and the results may appear in the media. Under no circumstances will you be identified in any publications.

Who is carrying out the study?

The Early Moves study is an ORIGINS subproject being led by Professor Jane Valentine (Perth Children's Hospital) and Professor Catherine Elliott (Curtin University).

Ethical information

The ethical aspects of this study have been approved by the Ramsay Health Care WA | SA Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in a research project, please contact Joondalup Health Campus Executive Office on (08) 9400 9404. Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Questions?

If you would like further information about these additional assessments, please do not hesitate to contact Caroline Alexander by phone or email:

0434 938 571 | earlymoves@health.wa.gov.au

Implementing partners

Funding partners

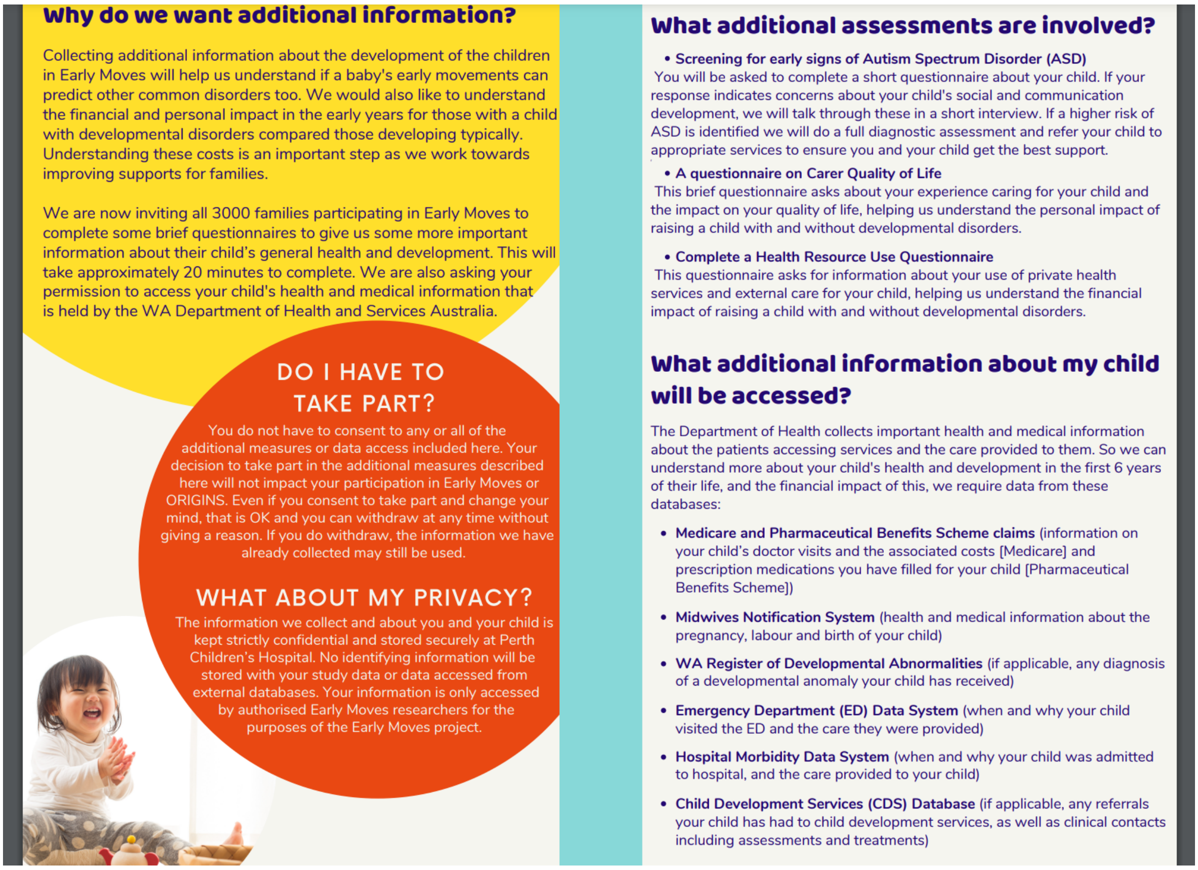
Research partners

early moves

Invitation for additional assessments and data linkage

Thank you for participating in the Early Moves project. Your participation to date has been incredibly valuable. By completing the developmental assessment at 2-years, we hope to learn how to identify babies at risk of learning difficulties at a very young age, so we can, in the future, make sure they get intervention to offer them the best start to life.

This information booklet contains information about additional assessments and data linkage you are invited to participate in, so we can better understand some other important issues.



Why do we want additional information?

Collecting additional information about the development of the children in Early Moves will help us understand if a baby's early movements can predict other common disorders too. We would also like to understand the financial and personal impact in the early years for those with a child with developmental disorders compared those developing typically. Understanding these costs is an important step as we work towards improving supports for families.

We are now inviting all 3000 families participating in Early Moves to complete some brief questionnaires to give us some more important information about their child's general health and development. This will take approximately 20 minutes to complete. We are also asking your permission to access your child's health and medical information that is held by the WA Department of Health and Services Australia.

DO I HAVE TO TAKE PART?

You do not have to consent to any or all of the additional measures or data access included here. Your decision to take part in the additional measures described here will not impact your participation in Early Moves or ORIGINS. Even if you consent to take part and change your mind, that is OK and you can withdraw at any time without giving a reason. If you do withdraw, the information we have already collected may still be used.

WHAT ABOUT MY PRIVACY?

The information we collect and about you and your child is kept strictly confidential and stored securely at Perth Children's Hospital. No identifying information will be stored with your study data or data accessed from external databases. Your information is only accessed by authorised Early Moves researchers for the purposes of the Early Moves project.

What additional assessments are involved?

- **Screening for early signs of Autism Spectrum Disorder (ASD)**

You will be asked to complete a short questionnaire about your child. If your response indicates concerns about your child's social and communication development, we will talk through these in a short interview. If a higher risk of ASD is identified we will do a full diagnostic assessment and refer your child to appropriate services to ensure you and your child get the best support.

- **A questionnaire on Carer Quality of Life**

This brief questionnaire asks about your experience caring for your child and the impact on your quality of life, helping us understand the personal impact of raising a child with and without developmental disorders.

- **Complete a Health Resource Use Questionnaire**

This questionnaire asks for information about your use of private health services and external care for your child, helping us understand the financial impact of raising a child with and without developmental disorders.

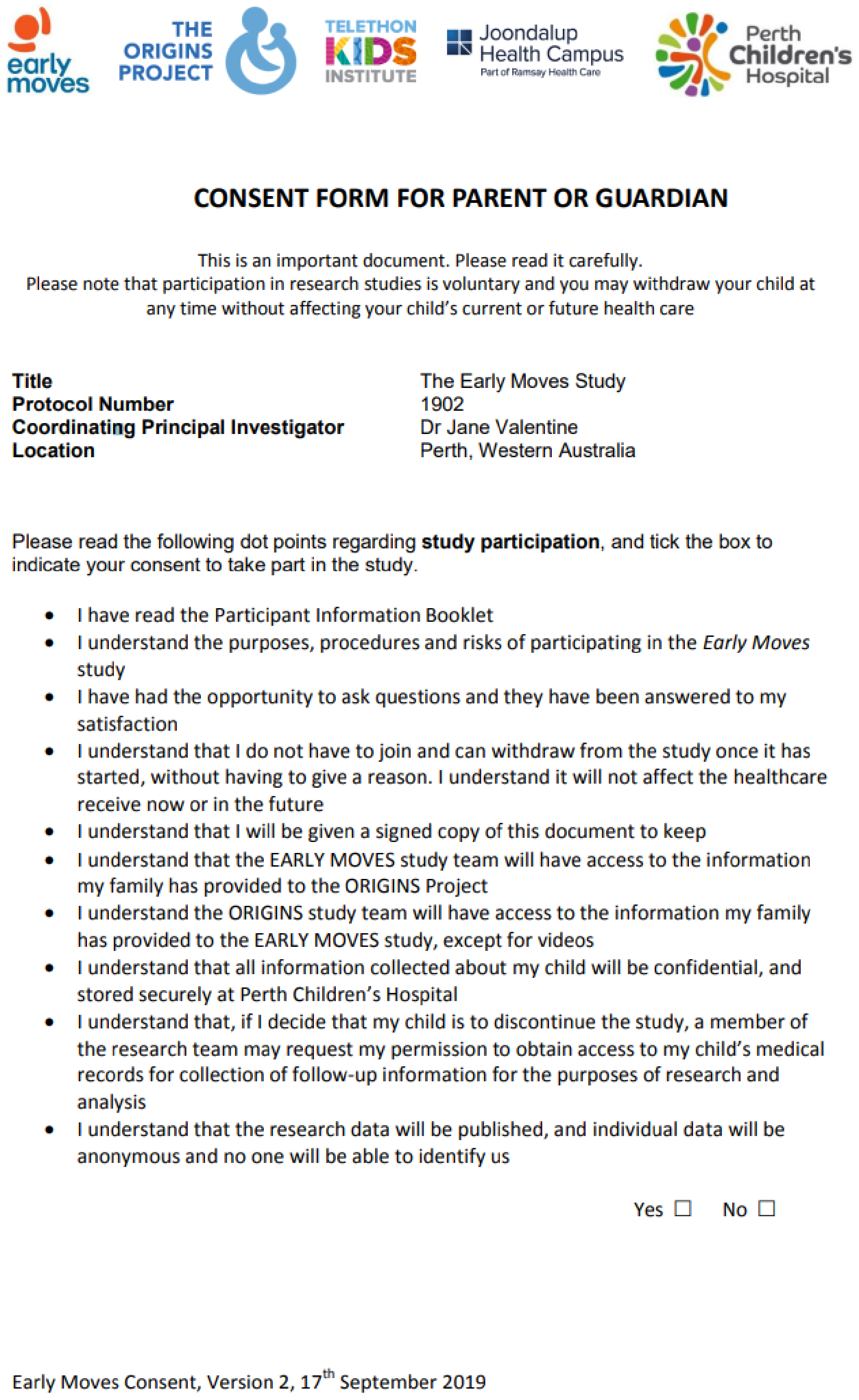
What additional information about my child will be accessed?

The Department of Health collects important health and medical information about the patients accessing services and the care provided to them. So we can understand more about your child's health and development in the first 6 years of their life, and the financial impact of this, we require data from these databases:

- **Medicare and Pharmaceutical Benefits Scheme claims** (information on your child's doctor visits and the associated costs [Medicare] and prescription medications you have filled for your child [Pharmaceutical Benefits Scheme])
- **Midwives Notification System** (health and medical information about the pregnancy, labour and birth of your child)
- **WA Register of Developmental Abnormalities** (if applicable, any diagnosis of a developmental anomaly your child has received)
- **Emergency Department (ED) Data System** (when and why your child visited the ED and the care they were provided)
- **Hospital Morbidity Data System** (when and why your child was admitted to hospital, and the care provided to your child)
- **Child Development Services (CDS) Database** (if applicable, any referrals your child has had to child development services, as well as clinical contacts including assessments and treatments)

APPENDIX 4: Participant consent forms

Early Moves Consent form



CONSENT FORM FOR PARENT OR GUARDIAN

This is an important document. Please read it carefully.
Please note that participation in research studies is voluntary and you may withdraw your child at any time without affecting your child's current or future health care

Title	The Early Moves Study
Protocol Number	1902
Coordinating Principal Investigator	Dr Jane Valentine
Location	Perth, Western Australia

Please read the following dot points regarding **study participation**, and tick the box to indicate your consent to take part in the study.

- I have read the Participant Information Booklet
- I understand the purposes, procedures and risks of participating in the *Early Moves* study
- I have had the opportunity to ask questions and they have been answered to my satisfaction
- I understand that I do not have to join and can withdraw from the study once it has started, without having to give a reason. I understand it will not affect the healthcare receive now or in the future
- I understand that I will be given a signed copy of this document to keep
- I understand that the EARLY MOVES study team will have access to the information my family has provided to the ORIGINS Project
- I understand the ORIGINS study team will have access to the information my family has provided to the EARLY MOVES study, except for videos
- I understand that all information collected about my child will be confidential, and stored securely at Perth Children's Hospital
- I understand that, if I decide that my child is to discontinue the study, a member of the research team may request my permission to obtain access to my child's medical records for collection of follow-up information for the purposes of research and analysis
- I understand that the research data will be published, and individual data will be anonymous and no one will be able to identify us

Yes ☐ No ☐

Early Moves Consent, Version 2, 17th September 2019

Data Collection

Please read the following points regarding **data collection,** and tick the box to indicate your consent for data to be collected as part of this study:

- I understand the study will involve me using a specialised smart phone app to video my child's movement
- I understand this video will be uploaded to a secure database to be reviewed by a trained assessor
- I understand my video will be used to develop automated scoring system using machine learning
- I consent for the study researchers to perform a play-based child development assessment on my child at age 2 years

Yes ☐ No ☐

Name of Parent/Guardian (please print) ______________________________

Signature: ______________________________ Date: ______________

Declaration by Senior Researcher

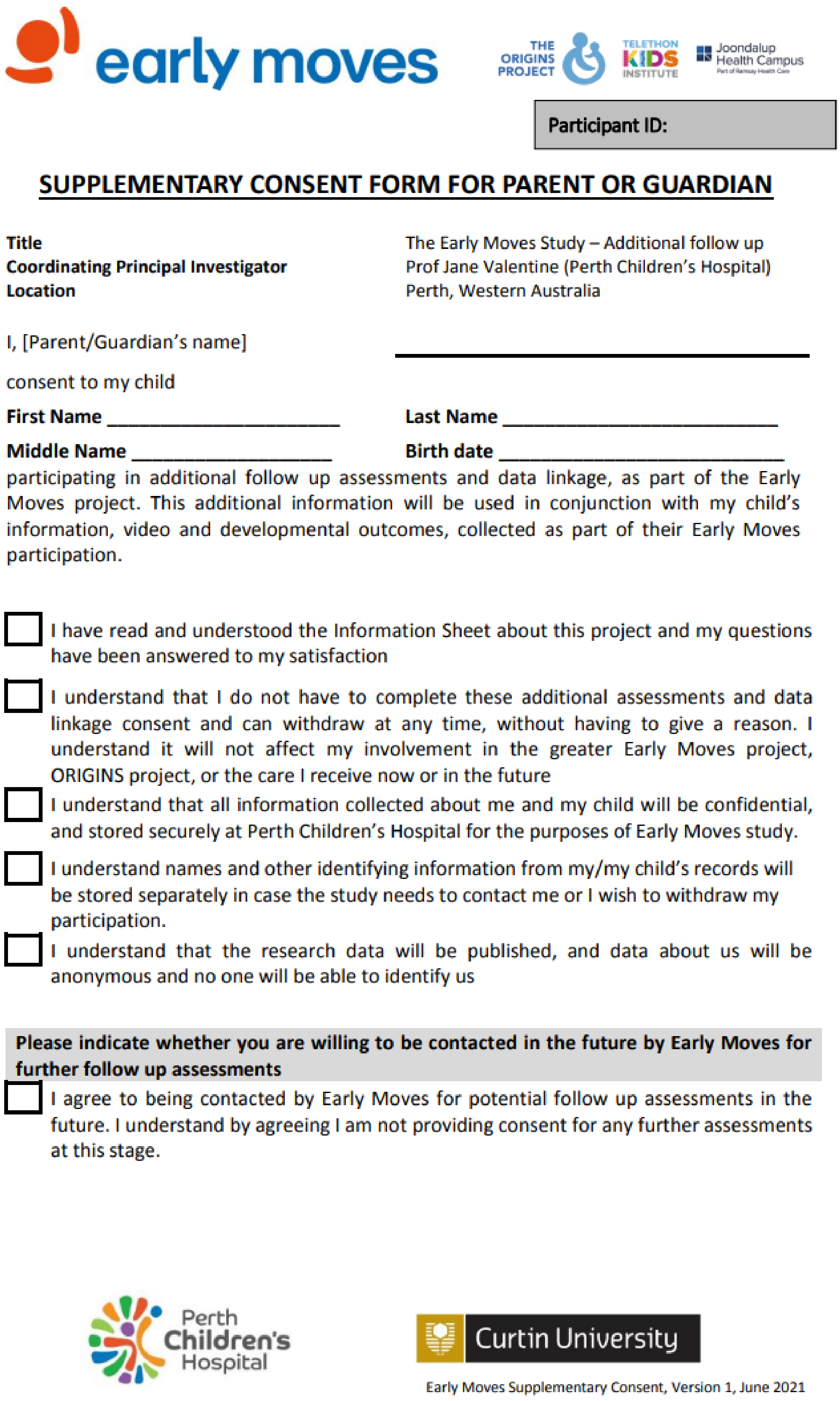
I have provided the Participation Information Booklet to the participant's parent / guardian and have provided an opportunity for the parent / guardian to ask questions and I have answered those questions to the best of my ability.

I have given a verbal explanation of the EARLY MOVES study, its procedures and risks and I believe that the parent/guardian has understood that explanation.

Name of Senior Researcher (please print) ______________________________

Signature: ______________________________ Date: ______________

Early Moves supplementary consent form



Participant ID:

SUPPLEMENTARY CONSENT FORM FOR PARENT OR GUARDIAN

Title	The Early Moves Study – Additional follow up
Coordinating Principal Investigator	Prof Jane Valentine (Perth Children's Hospital)
Location	Perth, Western Australia

I, [Parent/Guardian's name] ________________________________

consent to my child

First Name ______________________ **Last Name** __________________________

Middle Name ___________________ **Birth date** ___________________________

participating in additional follow up assessments and data linkage, as part of the Early Moves project. This additional information will be used in conjunction with my child's information, video and developmental outcomes, collected as part of their Early Moves participation.

☐ I have read and understood the Information Sheet about this project and my questions have been answered to my satisfaction

☐ I understand that I do not have to complete these additional assessments and data linkage consent and can withdraw at any time, without having to give a reason. I understand it will not affect my involvement in the greater Early Moves project, ORIGINS project, or the care I receive now or in the future

☐ I understand that all information collected about me and my child will be confidential, and stored securely at Perth Children's Hospital for the purposes of Early Moves study.

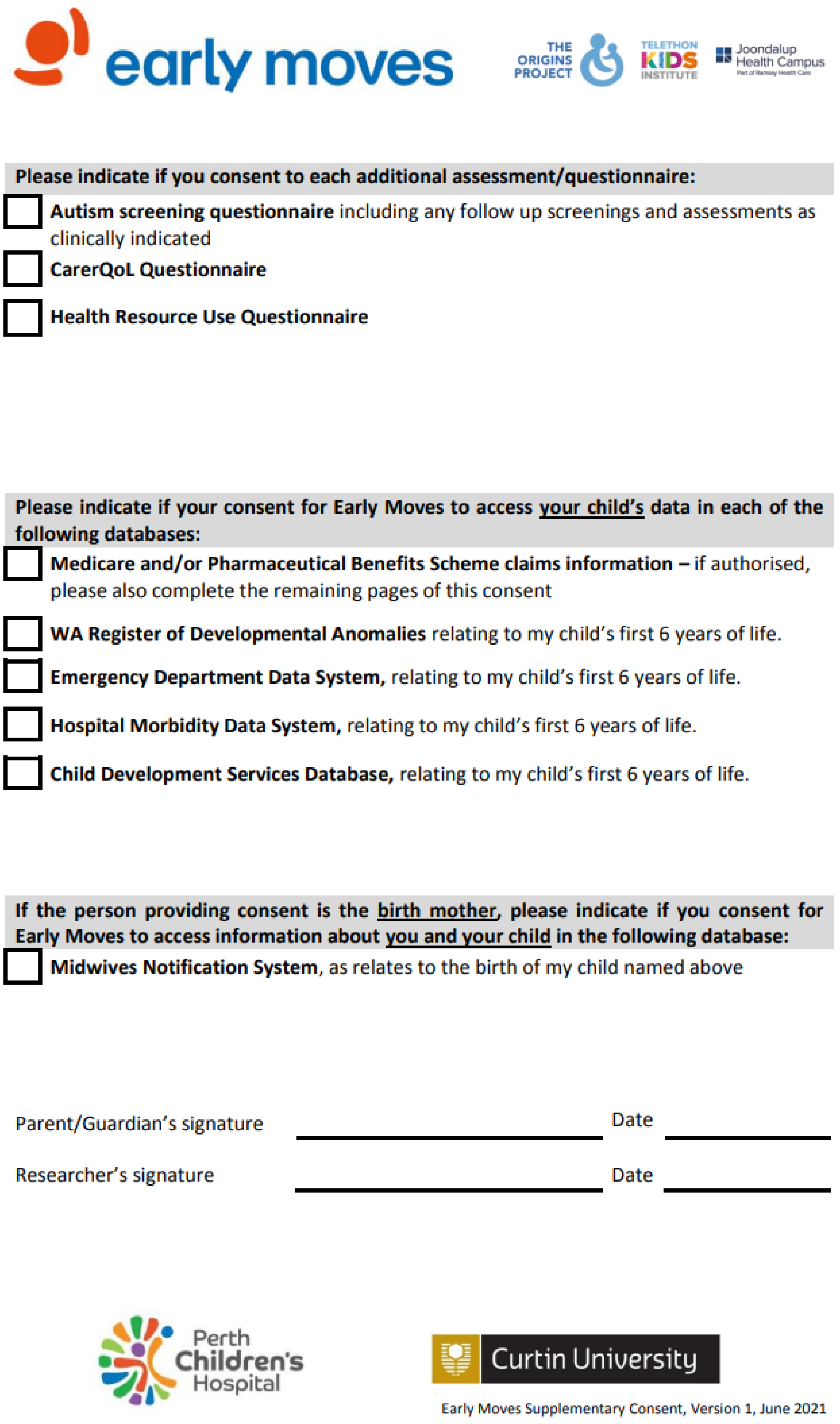
☐ I understand names and other identifying information from my/my child's records will be stored separately in case the study needs to contact me or I wish to withdraw my participation.

☐ I understand that the research data will be published, and data about us will be anonymous and no one will be able to identify us

Please indicate whether you are willing to be contacted in the future by Early Moves for further follow up assessments

☐ I agree to being contacted by Early Moves for potential follow up assessments in the future. I understand by agreeing I am not providing consent for any further assessments at this stage.

Early Moves Supplementary Consent, Version 1, June 2021



Please indicate if you consent to each additional assessment/questionnaire:

☐ **Autism screening questionnaire** including any follow up screenings and assessments as clinically indicated

☐ **CarerQoL Questionnaire**

☐ **Health Resource Use Questionnaire**

Please indicate if your consent for Early Moves to access your child's data in each of the following databases:

☐ **Medicare and/or Pharmaceutical Benefits Scheme claims information** – if authorised, please also complete the remaining pages of this consent

☐ **WA Register of Developmental Anomalies** relating to my child's first 6 years of life.

☐ **Emergency Department Data System,** relating to my child's first 6 years of life.

☐ **Hospital Morbidity Data System,** relating to my child's first 6 years of life.

☐ **Child Development Services Database,** relating to my child's first 6 years of life.

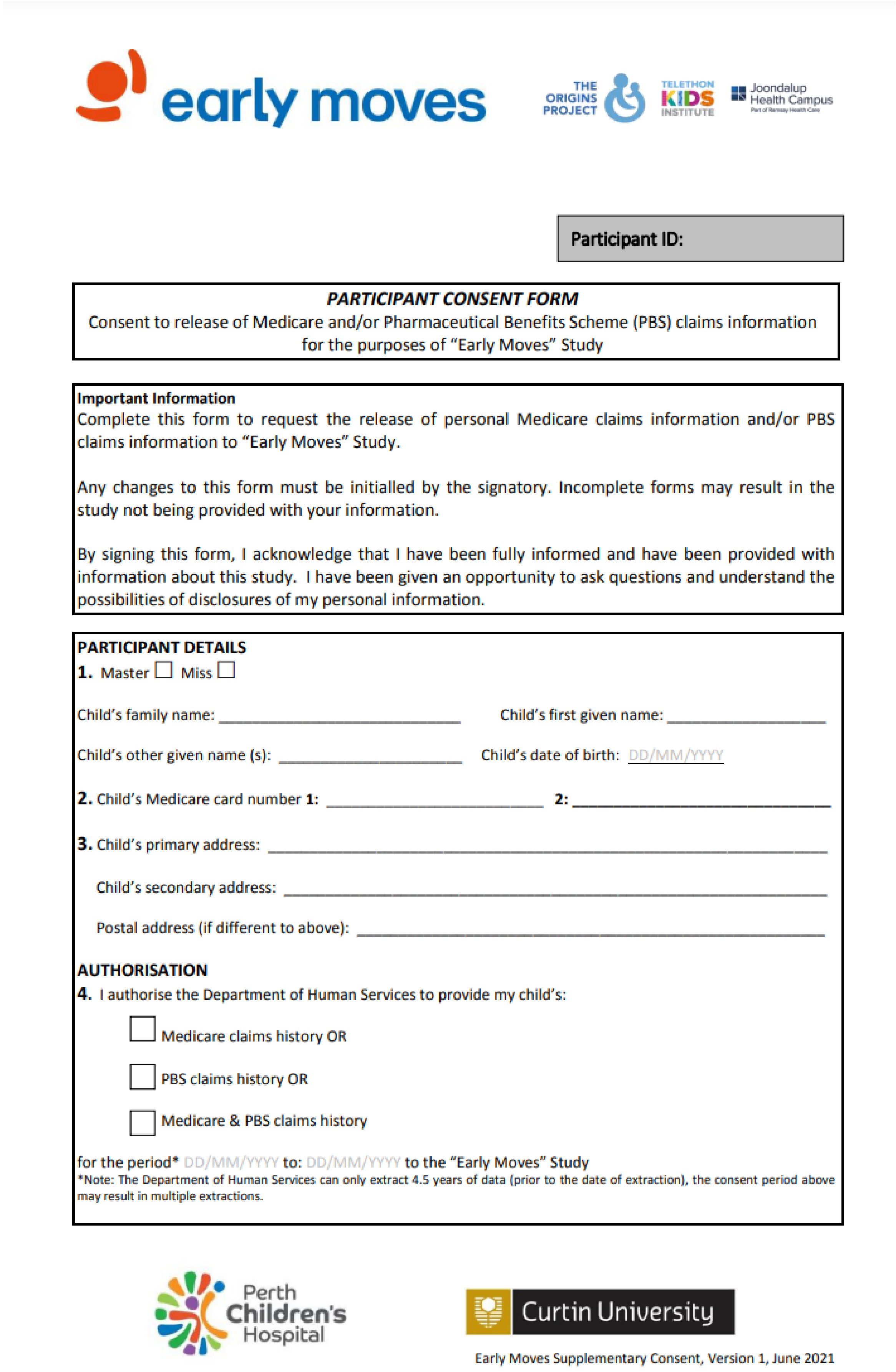
If the person providing consent is the birth mother, please indicate if you consent for Early Moves to access information about you and your child in the following database:

☐ **Midwives Notification System**, as relates to the birth of my child named above

Parent/Guardian's signature ______________________ Date ____________

Researcher's signature ______________________ Date ____________

Early Moves Supplementary Consent, Version 1, June 2021



early moves

THE ORIGINS PROJECT

TELETHON KIDS INSTITUTE

Joondalup Health Campus
Part of Ramsay Health Care

Participant ID:

PARTICIPANT CONSENT FORM

Consent to release of Medicare and/or Pharmaceutical Benefits Scheme (PBS) claims information for the purposes of "Early Moves" Study

Important Information

Complete this form to request the release of personal Medicare claims information and/or PBS claims information to "Early Moves" Study.

Any changes to this form must be initialled by the signatory. Incomplete forms may result in the study not being provided with your information.

By signing this form, I acknowledge that I have been fully informed and have been provided with information about this study. I have been given an opportunity to ask questions and understand the possibilities of disclosures of my personal information.

PARTICIPANT DETAILS

1. Master ☐ Miss ☐

Child's family name: ______________________ Child's first given name: ______________

Child's other given name (s): ________________ Child's date of birth: DD/MM/YYYY

2. Child's Medicare card number **1:** ____________________ **2:** ________________________

3. Child's primary address: ____

Child's secondary address: ____

Postal address (if different to above): ______________________________________

AUTHORISATION

4. I authorise the Department of Human Services to provide my child's:

☐ Medicare claims history OR

☐ PBS claims history OR

☐ Medicare & PBS claims history

for the period* DD/MM/YYYY to: DD/MM/YYYY to the "Early Moves" Study

*Note: The Department of Human Services can only extract 4.5 years of data (prior to the date of extraction), the consent period above may result in multiple extractions.

Perth Children's Hospital

Curtin University

Early Moves Supplementary Consent, Version 1, June 2021

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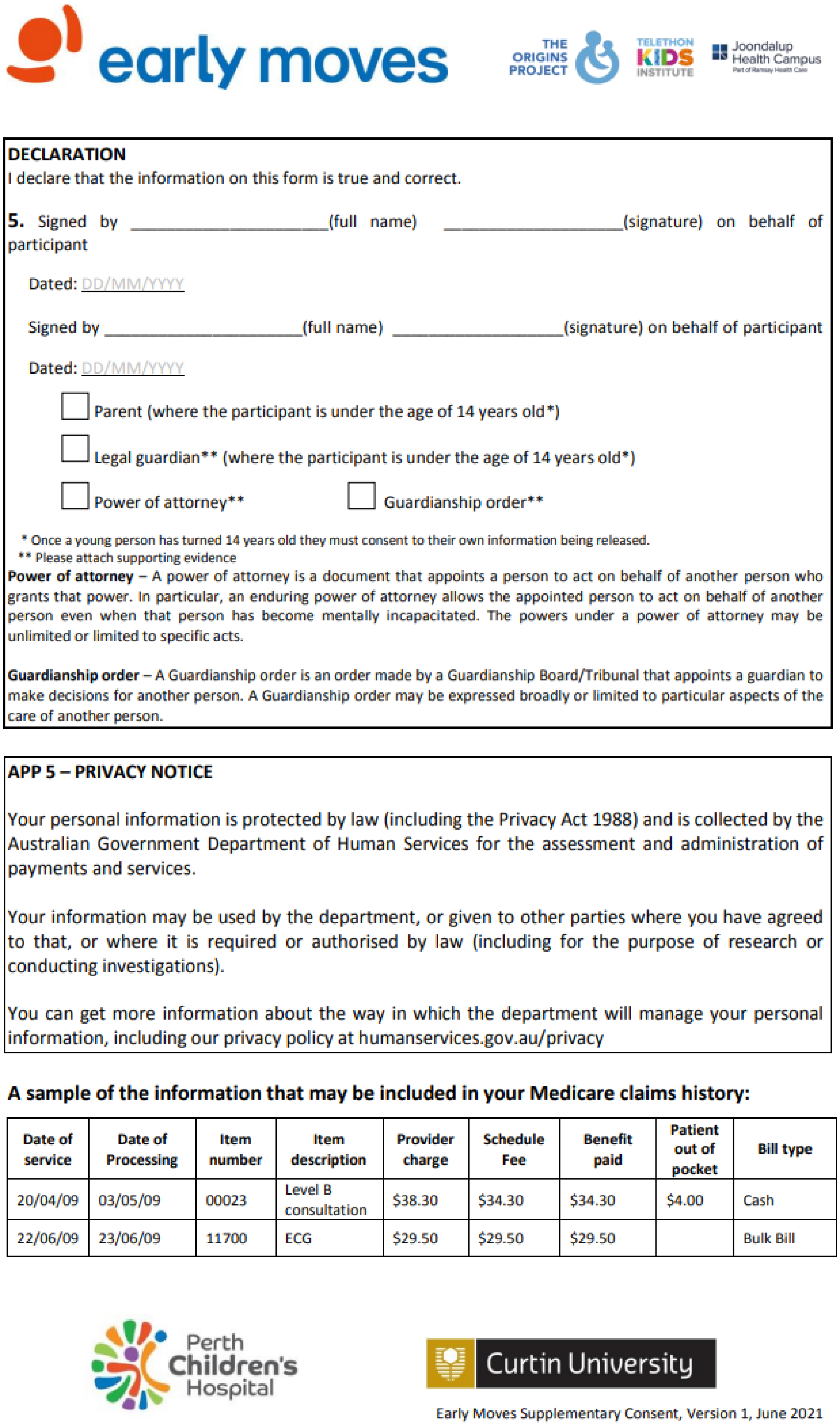


DECLARATION

I declare that the information on this form is true and correct.

5. Signed by ______________________(full name) ____________________(signature) on behalf of participant

Dated: DD/MM/YYYY

Signed by ______________________(full name) ____________________(signature) on behalf of participant

Dated: DD/MM/YYYY

☐ Parent (where the participant is under the age of 14 years old*)

☐ Legal guardian** (where the participant is under the age of 14 years old*)

☐ Power of attorney** ☐ Guardianship order**

* Once a young person has turned 14 years old they must consent to their own information being released.
** Please attach supporting evidence

Power of attorney – A power of attorney is a document that appoints a person to act on behalf of another person who grants that power. In particular, an enduring power of attorney allows the appointed person to act on behalf of another person even when that person has become mentally incapacitated. The powers under a power of attorney may be unlimited or limited to specific acts.

Guardianship order – A Guardianship order is an order made by a Guardianship Board/Tribunal that appoints a guardian to make decisions for another person. A Guardianship order may be expressed broadly or limited to particular aspects of the care of another person.

APP 5 – PRIVACY NOTICE

Your personal information is protected by law (including the Privacy Act 1988) and is collected by the Australian Government Department of Human Services for the assessment and administration of payments and services.

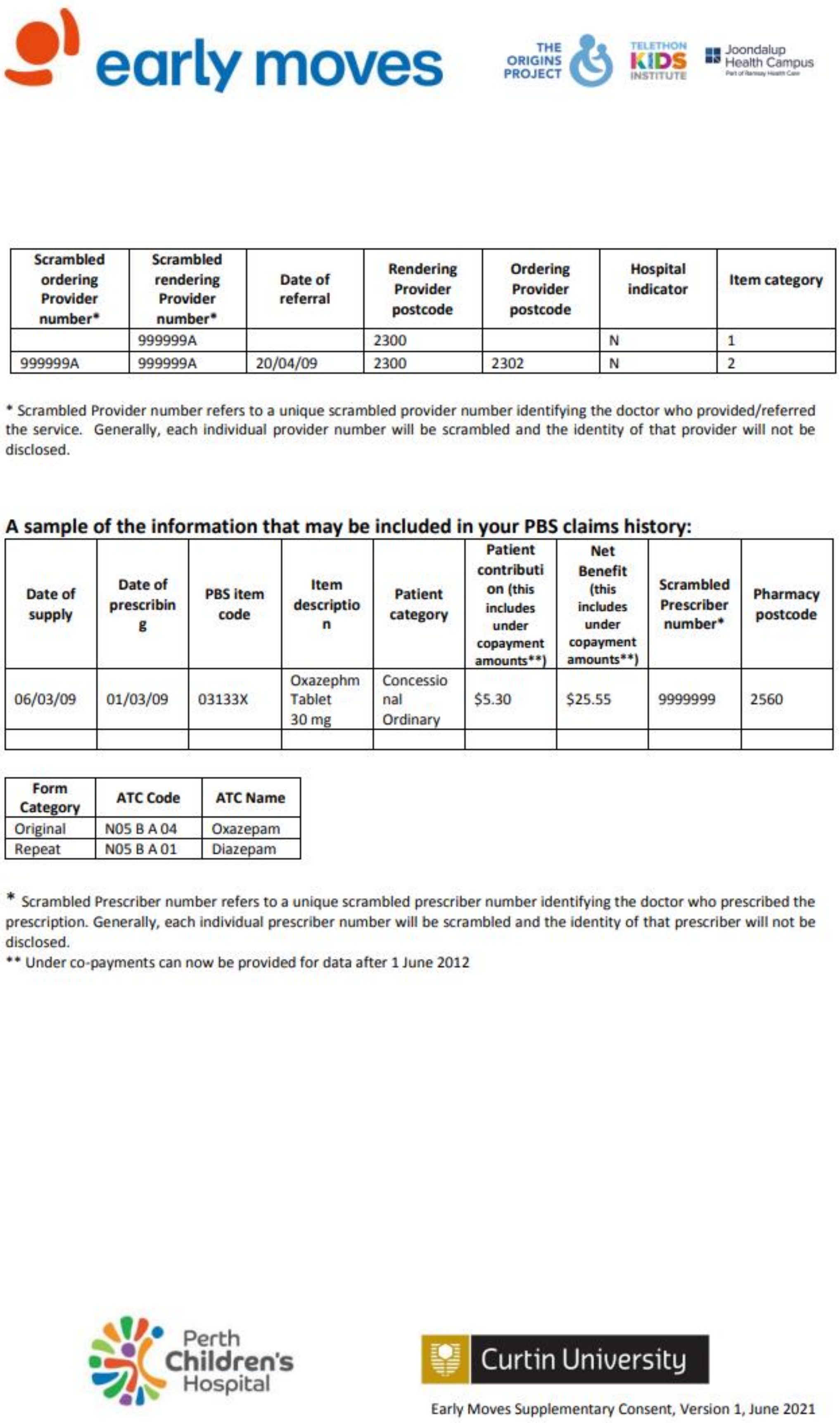
Your information may be used by the department, or given to other parties where you have agreed to that, or where it is required or authorised by law (including for the purpose of research or conducting investigations).

You can get more information about the way in which the department will manage your personal information, including our privacy policy at humanservices.gov.au/privacy

A sample of the information that may be included in your Medicare claims history:

Date of service	Date of Processing	Item number	Item description	Provider charge	Schedule Fee	Benefit paid	Patient out of pocket	Bill type
20/04/09	03/05/09	00023	Level B consultation	$38.30	$34.30	$34.30	$4.00	Cash
22/06/09	23/06/09	11700	ECG	$29.50	$29.50	$29.50		Bulk Bill

Early Moves Supplementary Consent, Version 1, June 2021



Scrambled ordering Provider number*	Scrambled rendering Provider number*	Date of referral	Rendering Provider postcode	Ordering Provider postcode	Hospital indicator	Item category
	999999A		2300		N	1
999999A	999999A	20/04/09	2300	2302	N	2

* Scrambled Provider number refers to a unique scrambled provider number identifying the doctor who provided/referred the service. Generally, each individual provider number will be scrambled and the identity of that provider will not be disclosed.

A sample of the information that may be included in your PBS claims history:

Date of supply	Date of prescribing	PBS item code	Item description	Patient category	Patient contribution (this includes under copayment amounts**)	Net Benefit (this includes under copayment amounts**)	Scrambled Prescriber number*	Pharmacy postcode
06/03/09	01/03/09	03133X	Oxazephm Tablet 30 mg	Concessional Ordinary	$5.30	$25.55	9999999	2560

Form Category	ATC Code	ATC Name
Original	N05 B A 04	Oxazepam
Repeat	N05 B A 01	Diazepam

* Scrambled Prescriber number refers to a unique scrambled prescriber number identifying the doctor who prescribed the prescription. Generally, each individual prescriber number will be scrambled and the identity of that prescriber will not be disclosed.

** Under co-payments can now be provided for data after 1 June 2012