Exploring self-care in children with and without motor impairments

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Submitted for the qualification of Doctor of Philosophy

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January 2024

Abstract

The ability to participate successfully in self-care, such as dressing, eating, toileting, and washing, is fundamental for a healthy life. It affects a child's daily functioning. It plays a crucial role in their balanced development and significantly impacts their health, well-being, and participation in society. Improving support for self-care is a priority for NHS improvement as set by families, providers, and decision-makers. However, there has been limited research into how self-care develops in childhood, what factors influence this, and how this is best supported.

This doctoral research identified: (i) personal and environmental factors influencing self-care in children and young people, (ii) intervention techniques for supporting self-care, and (iii) impacts of the COVID-19 pandemic restrictions on children's self-care and parents.

The research drew on Bronfenbrenner's Ecological Systems Theory, the World Health Organisation's International Classification of Function, Disability and Health, and the Discourse-Historical Approach. In the form of a mixed methods design, this research included a systematic evidence synthesis of self-care in children and young people (n=97 studies), two longitudinal cohort studies of children aged 2-5 years (n=24 children, n=299 children), a qualitative analysis of parents' (n=69) social media views on their children's self-care during the COVID-19 restrictions in the United Kingdom (UK), and an analysis of teachers' responses to a UK government survey on school readiness. Young people were involved in the research design.

A sequential synthesis was implemented from which the main overall messages were: 1) motor and cognitive ability are key predictors of self-care; 2) socioeconomic status may play a role in self-care development; 3) the COVID-19 pandemic significantly impacted children's self-care and consequent school readiness; and 4) children's self-care difficulties also significantly impact parents, and the relationship between children and parents.

Dedication

This thesis is dedicated to my daughter, Olivia Elizabeth Brewer. You just started reception when I started this PhD journey, and you have now finished primary school. We did this together.

Acknowledgements

I would like to thank my family for making my participation in this research programme possible. Without their support (financial and emotional), I would not have been able to do this. I would also like to thank the Elizabeth Casson Trust and the Royal College of Occupational Therapist Children, Young People and Families subgroup for their financial support and investment in me as a researcher.

I would also like to thank my supervisors, Dr Niina Kolehmainen, Professor Mark Pearce, Dr Emma Slack, and Dr Soudeh Ghaffari, for their generous support, particularly during the COVID-19 pandemic. They have developed my skills in several areas, and I am incredibly grateful for the opportunity to have learned so much from them. I am also grateful to my progress assessors, Dr Lindsay Pennington and Dr Bronia Arnott, who provided helpful insights and feedback over the years.

A heartfelt thank you to all the families who participated in the studies, whom this research would not have been possible without. I am also grateful for the support of my employers along the way and everyone who has encouraged and motivated me.

Finally, to all my friends and everyone who has helped me out in one way or another, through helping with childcare or picking up my daughter from school whilst I was busy with this PhD and have encouraged and supported me along the way. It takes a village!

Dissemination

Oral presentations

"The development of self-care in children (3-6 years) with and without motor impairments: a longitudinal mixed methods study" - Institute of Health and Society PGR Conference, Newcastle University, **June 2017**

"Supporting children's self-care through a programme of intervention research" – Royal College of Occupational Therapy Children and Young People Annual Conference, London, UK, **September 2019**

Poster presentations

"*The development of self-care in children (3-6 years) with and without motor impairments: a longitudinal mixed methods study*" - Institute of Health and Society PGR Conference, Newcastle University, **June 2017**

"A Research Protocol for a Longitudinal Study on Self-care in Young Children With and Without Motor Impairments"- Royal College of Occupational Therapy Children and Young People Annual Conference, Leeds, UK, **November 2017**

"The development of self-care in children with and without motor impairments: a systematic review" – Count Me In Conference, London, UK, **October 2018**

"Early Self-Care Development: A Systematic Review of the Factors Influencing Self-Care Participations in Young Children" – American Occupational Therapy Association Conference, New Orleans, USA, **April 2019**

"Early Self-Care Development: A Research Protocol for a Longitudinal Study in Three- to Six-Year-Old Children With and Without Motor Impairments" - American Occupational Therapy Association Conference, New Orleans, USA, **April 2019**

"*Early Self-Care Development: A Systematic Review of the Factors Influencing Self-Care Participations in Young Children"* - 13th International Conference on Developmental Coordination Disorder, at the University of Jyväskylä, Finland, **June 2019**

"*Research in the time of Corona – an altered research journey*" - Royal College of Occupational Therapy Children and Young People Annual Conference, Virtual Conference, **October 2020**

"The COVID-19 pandemic lockdown restrictions: a qualitative perspective of the impact on children's self-care" – European Academy of Childhood Disability Conference, Ljubljana, Slovenia, **May 2023**

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ADL	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
ASD	Autistic Spectrum Disorder
CASP	Critical Appraisal Skills Programme
CHAQ	Child Health Assessment Questionnaire
CI	Confidence Interval
CIMT	Constrained Induced Movement Therapy
CMC	Children with Medical Complexity
COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
CPQ	Children’s Participation Questionnaire
DCD	Developmental Coordination Disorder
DHA	Discourse-Historical Approach
EASIER	EArly Self-care In childrEn with and without motor impaiRments
EYFS	Early Years Foundation Stage
FOP	Fibrodysplasia Ossificans Progressiva
GMF	Gross Motor Function
GMFCS	Gross Motor Function Classification System
HABIT	Hand-arm bimanual intensive therapy
HRA	Health Research Authority
ICC	Intraclass correlation coefficient
ICF	International Classification of Functioning, Disability and Health
IMD	Indices of Multiple Deprivation
LSOA	Lower Layer Super Output Areas
MMAT	Mixed Methods Appraisal Tool for Children and Youth
MMC	Myelomeningocele
NDD	Neurodevelopmental Disorders
NHS	National Health Service
NIHR	National Institute of Health Research
OT	Occupational Therapy
PE	Physical Education
PT	Physical- or Physiotherapy
PEDI	Pediatric Evaluation of Disability Inventory
PEDI-CAT	Pediatric Evaluation of Disability Inventory Computer Adaptive Test
PEDI-FSS	Pediatric Evaluation of Disability Inventory Functional Skills Scale
PEM-CY	Participation and Environment Measure for Children and Youth
PPT OMS	Pediatric Physical Therapy Outcomes Management System
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PSS	Parental Stress Scales
RCT	Randomised Controlled Trials
REC	Research Ethics Committee
SEND	Special Educational Need or Disability
SES	Socio-economic Status
SLT	Speech and Language Therapy
SRD	Selective Dorsal Rhizotomy
SVMC	Selective Voluntary Motor Control
TD	Typically Developing
UCP	Unilateral Cerebral Palsy
UK	United Kingdom
VABS	Vineland Adaptive Behavior Scale
VABS-II	Vineland Adaptive Behavior Scale Second Edition
VLBW	Very Low Birth Weight
WeeFIM	Functional Independence Measure for Children
WFOT	World Federation of Occupational Therapists
WHO	World Health Organisation
YPAG	Young Person’s Advisory Group Young Person’s Advisory Group
YPAGne	Young Person’s Advisory Group North England

Chapter 1: Introduction

This doctoral programme of research investigated self-care in children with and without motor impairments, and the impact of the COVID-19 pandemic restrictions on children's self-care. In this opening chapter, I present the purpose and context of the research programme and define the importance of participation in self-care. Next, I provide a short overview of the concept of participation and the relationship between early childhood development and participation, especially in relation to self-care. At the end of the chapter, I discuss the contribution that this doctoral programme makes to the topic of self-care in children and outline the organisation of the thesis.

Throughout the thesis the key concepts that are referred to throughout the thesis are used as follows:

Self-care: This refers to doing everyday tasks relating to looking after oneself and making decisions about how these tasks are done.[1] For example, being able to feed oneself or getting dressed independently or having a say in our others assist you. In Chapters 5 and 6, self-care is measured through the Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) daily activities score, one of the subtests of the PEDI-CAT standardised assessment.

Motor impairments: This refers to impairments in neuromusculoskeletal and movement-related functions[2] (e.g., joint functions; muscle functions, including strength and tone; coordination of movements) or mobility limitations (e.g., changing and maintaining body position; carrying, moving, and handling objects; walking and moving). This includes, for example, DCD and CP.[3]

Participation: This refers to the World Health Organisation's definition (WHO)[2] as used in the International Classification of Functioning, Disability, and Health (ICF) where 'participation' is defined as a person's "involvement in a life situation" and represents the societal perspective of functioning.

1.1 The purpose and context of the research programme: What is self-care and why it matters?

The outcome, or phenomenon, of interest for this doctoral research was self-care. The ability to participate successfully in self-care, such as dressing, eating, toileting, and washing, affects a child's daily functioning, and plays a crucial role in their balanced development.[4] It also has a significant long-term impact on their health, well-being, and participation in society. In this PhD thesis, a definition that was used for self-care is one that was previously developed by young people and parents of young children. It defines self-care as covering the doing of everyday tasks relating to looking after oneself and the making of decisions about how these tasks are done.[1] Both of these dimensions are fundamental for a healthy life.

Self-care is considered essential to an individual's survival.[5] Participation in self-care affects a child's long-term health, for example their nutritional intake, and purposeful involvement in this domain contributes to their sense of well-being.[6] Purposeful participation in self-care also contributes to a child's sense of purpose and meaning in life and can influence their overall satisfaction with life.[7-9] Children's participation in self-care and the development of sensory-motor, cognitive and social skills are also closely interlinked.[2, 7] Whilst early involvement in self-care is crucial for life experience, developing the above-listed skills, in turn, affects children's ability to participate in self-care activities.[7, 9] This is discussed in more detail along with factors impacting children's development in the sections below.

1.2. The concept of participation in child health and development

Whilst the WHO's definition[2] of participation, which is a person's "involvement in a life situation" is used throughout this thesis, it is important to consider the wider context of this term beyond this definition. Participation is more than simply doing a task; a core feature is that it involves a sense of belonging and being in the world.[10] In turn, participation contributes to the evolvement of the sense of self.[11]

The involvement of children in daily activity settings also provides the contexts for their learning, development, and personal growth.[12] Further, participation is considered a health outcome and a fundamental human right.[9, 13, 14]

Two essential elements of participation have been identified by researchers as part of the family of participation-related constructs (fPRC) framework.[11] These elements are: 1) attendance and 2) involvement.[12] Attendance refers to the physical presence including where and with whom one participates whilst involvement captures the subjective aspect of participation, including experiencing enjoyment or frustration.[12] These elements play a role in the role of children's social emotional development, with a study[13] finding evidence to suggest that opportunities for choice and other conditions that optimise children's ability to participate in daily activities may contribute to children's sense of self-concept and acceptance.

According to the fPRC framework, participation experiences and outcomes are influenced by participation-related constructs, including intrinsic factors (i.e., the child's activity competence, sense of self, and preferences) and extrinsic factors (i.e., the environment or context).[11] In this doctoral research programme, which included participants with and without motor impairments, it is possible that children with more severe motor difficulties could have experienced less enjoyment in participation in daily activities, which in turn impacted on sense of self and preferences.[15] Further, children with motor impairments are often subjected to restrictions in their participation of daily activities.[16-18] For these children, parental knowledge and experiences along with the environment play an important role in facilitating their participation in daily activities, including self-care.[19] Early childhood development, environmental factors and its relationship to participation are discussed in more detail below.

1.3 Self-care, early development, and the environment

In this section I consider constructs related to children's early development and environmental factors and the role that this plays in the participation of daily activities, particularly in relation to self-care.

1.3.1 Early childhood development

Early childhood development is defined by some[20, 21] as a "maturational and interactive process, resulting in an ordered progression of perceptual, motor, cognitive, language, socio-emotional, and self-regulation skills". Developmental outcomes include the acquisition of developmental competencies in behavioural, socio-emotional, and academic domains.[22] This includes children's participation in self-care.[23]

The role of motor skill development in particular has often been investigated and discussed in the acquisition of developmental competencies and the facilitation of participation in daily activities in infants and children.[24-26] For example, the milestone of balancing the trunk and stabilising the head to use the arms and hands freely to self-feed, is one of the first examples of how motor skills can influence self-care.[27] This skill emerges between the ages of 5 and 10 months in typically developing infants.[25] Similarly, the development of fine motor skills in infants can directly influence their ability to handle tools and use items like spoons and cups to eat and drink.[27]

Another study[26] which investigated the longitudinal associations of age at achieving gross motor milestones and children's development found a correlation between the achievement of gross motor milestones and self-care. More specifically the study found that the age at which a child first stood predicted their self-care ability at the age of 4 years.[26] Beyond motor development, the association between cognitive and language development and participation in daily activities, including self-care has also been frequently investigated.[28-31] In an observational study[28] investigating toilet training in typically developing children, understanding and following instructions (cognitive development) had the most significant correlation with successful toilet training.

However, developmental health extends beyond the development of perceptual, motor, cognitive, language, socio-emotional, and self-regulation skills. Child development is also influenced by social circumstances in early life and other environmental factors.[31] Through global initiatives like UNICEF's sustainable development goals[32] to promote early child development, research is increasingly recognising the important impact that inadequate or deprived physical and social environments can have on developmental outcomes and participation.[32, 33] Many now recognise that child development and subsequently participation is a product of a child's continuing interactions with their physical, social and attitudinal environments for both typically developing children and those with impairments or disabilities.[20, 34] The impact of environmental factors on participation is discussed in more detail in the section below.

1.3.2. Environmental factors

The environment, more specifically a contextualised setting, plays an important role in participation.[11] A study[7] carried out with typically developing, preschool-aged children found that environmental factors along with child factors (including motor and cognitive skills) contributed to children's participation in everyday activities, which includes self-care. A previous study field[35], looking at the development of self-care in children, also found it helpful to differentiate the concepts of activities in the following constructs: (a) capacity (what a child is capable of doing in a standardised environment); (b) capability (what a child is capable of doing in a daily environment); and (c) performance (what a child actually does in a daily environment).

The ICF[2] emphasises the importance of understanding the influence of environmental factors when measuring participation, and assessing participation and environmental factors together can enhance our understanding of how specific settings might influence a young child's participation in everyday activities.[36] Environmental factors that impact on participation include three key areas: (1) the physical environment, (2) the social environment, including parental level of education, parental self-efficacy beliefs, parental stress, and social support, and (3) the attitudinal environment in which people live and conduct their lives.[2, 37, 38] It is important to consider the differences in the context, which is personal to an individual, and the external environment which refer to broader social and environmental structures.[11]

In this doctoral research programme, the impact of the physical environment on children's self-care is investigated, along with the social and attitudinal environment. This includes the associated environmental factors associated with the COVID-19 pandemic.

1.4 School readiness

Following the discussion of early childhood development in Section 1.3.1, school readiness is also considered an important developmental outcome.[39] It is also an important consideration for this doctoral research programme as the population of interest for this research was children who were soon to start formal schooling, or recent school starters. While self-care is important in its own right, it is also a crucial preparatory competency for school readiness. For example, there is an expectation that most children will be able to toilet, dress and eat with minimal supervision in the formal school setting.[8] As such, self-care abilities contribute to children’s capacity to perform in the school environment successfully, and difficulties in self-care can impact on their learning.

The early year foundation stage (EYFS) framework[40] defines school readiness as " the broad range of knowledge and skills that provide the right foundation for good future progress through school and life". Kindred Squared[41] refers to school readiness "as children being developmentally ready to access the learning and development opportunities available to them in the reception year, where this is not due to a previously identified Special Educational Need or Disability (SEND). It refers to the full range of developmental measures, not simply a narrow measure of ‘academic’ attainment".[41]

Along with learning and developing, there are activities during the school day that require children to be independent in self-care or activities of daily living. At school, children will need to be able to open their packed lunch or use a knife, fork, and spoon for school meals and to be able to eat during the school day.[42] Children will also be expected to: wear underwear to school and know when they need to use the toilet; go to the bathroom by themselves and wipe themselves; dress and undress themselves after going to the toilet or taking part in a P.E. or games lesson; and put their socks and shoes and coat on.[42] Dressing involves doing up zips or buttons, which requires age-appropriate fine motor skills, and similarly, challenges with fine motor skills will impact a child's ability to use eating utensils or open food containers independently.[43, 44]

1.5 What is the problem in supporting self-care?

The underpinning motivation for investigating this topic was to provide evidence for improving support for self-care for children and families. This is an agreed priority NHS improvement target for families, healthcare providers, and decision-makers.[1, 45-47] Specifically, within this, enabling self-care development in children most likely to find it difficult, e.g. children with motor impairments, is a core activity for children's healthcare professionals with participation in self-care being regarded as a core health outcome for all children. It is also a key area of focus for health care professionals working with children and young people with a neurodisability.[2, 48] For many children and young people, the presence of a neurodisability results in motor impairments of which the extent of this can vary.[49] Further, in another study[1], participants and researchers ranked self-care as the top priority for improvement when asked to rate participation outcomes in the order of importance for health improvement.

However in spite of this, there has been very little research to date to generate empirical evidence to guide improvements or health care professionals' practice.[1] Furthermore, little is known about self-care development in children with motor impairments compared to their typically developing peers.[35] Insight into children's performance in relation to their participation in self-care activities is essential for professionals designing optimal interventions.[50]

The population of focus for this doctoral research were young children (2-5 years) with and without motor impairments. Early childhood is a sensitive time for development, including self-care[51], and so understanding self-care during this period is of potentially significant value to professionals and families. Motor impairments were, in this doctoral research, understood as impairments in neuromusculoskeletal and movement related functions. Children with motor impairments include children with neurodisability, i.e., long-term conditions attributed to impairment of the brain and/or neuromuscular system, which represent the largest group of disabled children in the United Kingdom (UK), with an estimated prevalence of 3-4%.[52] They are at increased lifelong risk of multiple health and functioning problems, and their self-care problems are both significant and common.

Traditionally, in research with children, motor impairments have been operationalised through specific diagnostic conditions such as Cerebral Palsy (CP) and Developmental Coordination Disorder (DCD), which impact children's ability to move and maintain their posture and balance, amongst other factors. However, it has for some time now been accepted that the relationships between different childhood conditions are complex and that different conditions and related impairments often co-exist. In the case of children with motor impairments, I am looking at children with multiple long-term conditions, many of which are neurological in origin but also co-existing with other conditions e.g., cardiac conditions in the case of children with Down Syndrome (DS). While many children with motor impairments can achieve self-care levels similar to their typically developing peers this usually requires parent and therapy support (occupational therapy, physiotherapy, speech and language therapy). In the realities of front-line NHS practice, children present with diverse combinations of medical conditions, motor and other impairments, activity limitations, and participation restrictions. While some of the healthcare provided may focus on the management (or sometimes cure) of the medical conditions, the focus is increasingly often on the everyday activity limitations and participation restrictions and supporting the children and families to overcome these or live good quality lives with them. This is also the case when it comes to self-care, where the primary goal of the support and intervention is usually to improve the child's self-care activity and increase participation.[53]

In keeping with the underpinning motivation for this doctoral research, the results from this programme of research bring new insight into children's participation in self-care activities and the impact of the COVID-19 pandemic restrictions on children's self-care. The results are essential for healthcare professionals designing and implementing more effective interventions for these groups of children. Further, the results are relevant to parents, educators, and policymakers.

1.6 What is self-care support for children in the UK?

In the UK, children at birth typically receive a personal child health record[54] in the form of a 'Red Book'. Among other things, this also contains a space for parents to capture developmental milestones. These milestones are also intended to be checked on by health visitors through the universal healthy child programme.[55] Currently, most of this developmental focus is on basic abilities such as motor skills and speech. In comparison, there is little data[56] available on children's self-care to guide healthcare professionals on this critical area of participation. As a result, many healthcare professionals and parents are unclear as to how positive self-care development and participation looks like. This means that opportunities for early interventions can be missed, and self-care difficulties only flagged up when children's problems have become established.[57] For example, it is common for many children in the UK to be referred to occupational therapy for self-care support for the first time, by special educational needs coordinators (SENCOS),[58] when children's challenges with self-care impact on their ability to participate at school.

Further, for many children with motor impairments in the UK, access to early intervention, which is defined as the provision of support to ensure optimal child development during early childhood (i.e., 0-6 years), is also limited.[59] Early intervention can include specific therapy interventions and programs to improve child and family outcomes support, including difficulties with self-care. It was found that whilst many children have reasonable access to primary care, families found it harder to access more specialist support for children with motor impairments, and that children are often subject to lengthy waiting lists.[59] For children who can access therapy intervention for self-care, a UK study found that the most common interventions include providing techniques on how to learn a task (i.e. giving instructions and practicing a task), and modifications to children's physical and social environment.[60]

1.7 What does this programme of research add to existing knowledge?

This doctoral study programme initially set out to identify the trajectories, variations, and potential predictors of early self-care development in children with and without motor impairments, and to provide evidence for guiding self-care interventions in children. In response to changing circumstances, it later integrated research on the impact of the COVID-19 pandemic restrictions on children's self-care in the study programme. Now, at its completion, it provides new data on self-care to enable healthcare professionals to understand better factors influencing self-care, to inform interventions, and help therapists target the right children at the right time. This topic is in line with findings from a Delphi study[61] led by the World Federation of Occupational Therapists (WFOT) on international occupational therapy research priorities, which identified evidence-based practice and knowledge translation, and participation in everyday life (including self-care) as being within the top four research priorities for the profession worldwide.

This evidence will also be relevant to other healthcare professionals (e.g., speech and language therapists, physiotherapists, health visitors and paediatricians) working with young children experiencing challenges in self-care. It is anticipated that findings from this doctoral programme of study will also be relevant to those involved in early years education, as guidance from this study will help with the early identification of young children at risk of or who present with challenges in self-care participation. It is expected that early identification of challenges to support participation in self-care in young children will not only promote children's independence from an early age and improve their quality of life. It will also contribute to a more efficient use of occupational therapy resources and a more targeted intervention as therapists will have an increased understanding of factors influencing self-care development and participation and when the best time is to provide therapy input.

Planned data collection and recruitment for this study coincided with the COVID-19 pandemic, and as a result, the pandemic heavily influenced the direction of this doctoral programme of study. Instead of one large-scale longitudinal study, data were collected from a range of sources, including qualitative data gathered from parent forums on the impact of the COVID-19 pandemic restrictions on their children's self-care. As a result, it was not possible to identify trajectories of self-care in children with and without motor impairments as initially planned. Instead, findings related to factors influencing self-care in children with and without motor impairments. More specifically, chapter 4 provides new knowledge on factors and interventions that influence children and young people's self-care. Chapter 6 provides further insight into factors influencing self-care in children with and without motor impairments. Chapters 7 and 8 provides insight into how the COVID-19 pandemic impacted on children's self-care at both home and school.

1.8 Thesis organisation

This PhD thesis is split into ten chapters. Following this introductory chapter, in Chapter 2, I present the conceptual frameworks used to guide and make sense of the doctoral research.

In Chapter 3, I summarise the research question and aims, discuss the overall research design, and present the epistemological standpoint, alongside the PPIE (Patient and Public Involvement and Engagement) and a brief statement on the changes that had to be made to the planned research as a result of the COVID-19 pandemic.

In Chapter 4, I report the methods and results of the systematic review of factors influencing children's self-care. I also consider how the findings compare with the wider evidence on children's self-care.

In Chapter 5, I set out the methods for the longitudinal EASIER study and discuss the strengths and weaknesses of its design, execution and reflect on how the COVID-19 pandemic impacted this study.

In Chapter 6, I focus on self-care in children with motor impairments and reports on quantitative data on children's self-care from the ActiveCHILD study.

In Chapter 7, I focus on the impact of the COVID-19 lockdown restrictions on children's self-care and report the results of a qualitative, interpretive exploration of parents' discussions about their children's self-care during the lockdown on an online forum.

In Chapter 8, I discuss the impact of the COVID-19 pandemic on children's school readiness and self-care, based on document analysis, and the impact that challenges in self-care have on all children, teachers, and schools in general.

In Chapter 9, I bring together the quantitative and qualitative results for factors influencing children's self-care using a sequential synthesis design.

Finally, in Chapter 10, I summarise the main findings, highlight the strengths and weaknesses of the overall research programme, and consider the implications for key stakeholder groups, along with recommendations for future research.

Chapter 2: Conceptual Frameworks

The purpose of this doctoral research programme was to explore self-care in children with and without motor impairments. In the previous chapter, I presented the purpose and context of the research programme, defined the importance of participation in self-care for children, and the contribution that this doctoral research makes to the subject area, children's self-care. In this chapter, I present the conceptual frameworks used to guide and make sense of the doctoral research.

2.1 Ecological systems theory

I selected Bronfenbrenner's ecological model[62, 63] as the basis of the theoretical framework model for this doctoral research programme because it highlights the importance of environmental factors, personal characteristics, and contextual factors in shaping children's development.[64] I utilised it to investigate factors influencing children's self-care development and their participation in self-care.

As a considerable proportion of data collection for this doctoral programme took part during the COVID-19 pandemic, I recognised that there could be ecological influences as a result of the pandemic that would potentially impact on children's self-care.[65, 66] Using an ecological model as the theoretical framework was helpful here, for structuring the data collection and analysis.

Ecological models, such as this one[63], interpret the various aspect impacting on human development through a holistic approach[67], an approach that would be important to understand how self-care develops in children and what the contributing factors are for children who develop differently in this area. Bronfenbrenner[63] particularly sought to identify important, underlying mechanisms that explain the reciprocal interaction between individuals and their environment, which is relevant in child health and development.[64, 67]

The ICF[68] framework from the WHO (World Health Organisation), which is both a multipurpose framework and classification system, also take environmental factors into account. However, Bronfenbrenner’s model suggests that there could different entry points according to his model that need to be considered when looking at factors influencing children’s self-care. Therefore, Bronfenbrenner’s[63] model was utilised in this doctoral research programme, along with the ICF framework in chapter 4.

Since its conceptualisation, Bronfenbrenner’s model[62, 63, 69] has evolved from its original ecological focus to a more comprehensive bioecological model, which now incorporates the dynamic interplay between biological, psychological, and environmental factors. This model consists of five interrelated systems: 1) microsystem, 2) mesosystem, 3) exosystem, 4) macrosystem, and 5) chronosystem.[67, 70]
These five systems are discussed below.

2.1.1 The microsystem

In the Bronfenbrenner model, the microsystem[62] refers to the immediate environment surrounding an individual[67], encompassing their daily interactions with others. In the case of children, this may include family members, peers, teachers, and others. For children who participated in this doctoral research programme, the microsystem typically included home and either nursery, school, or the home and people of a childminder. According to the framework, this level of the ecological model plays an essential role in shaping a child's development, as the microsystem accounts for direct experiences and relationships that influence behaviours, beliefs, and values.[67] The importance of the microsystem can be seen clearly in Chapter 7, where the impact of the COVID-19 pandemic lockdown restrictions on children’s self-care and their families are discussed.

Family dynamics, including family structure, and family relations, all play a vital role in the microsystem. For many children, the COVID-19 pandemic and the associated lockdown restrictions meant a significant disruption in family dynamics[70], with many children unable to see their extended family for a lengthy period of time and children losing loved ones and relatives.

At the microsystem level, personal characteristics, or body factors, including motor and cognitive abilities, can also significantly impact an individual's development and ability to participate in daily activities, which include self-care.[71] Additionally, environmental factors such as socioeconomic status, family resources, and community resources can significantly impact an individual's experiences within this level.[67] For example, it has been found that high-income families invest more time and resources into children’s cognitive and physical development than their lower-income counterparts.[72] Lower socio-economic status may also influence a child’s access to services through parental or neighbourhood factors.[73]

The findings from this programme of research on personal characteristics and environmental factors influencing children’s participation in self-care are discussed in detail in Chapters 4,5,6,7 and 8.

2.1.2. The mesosystem

The second layer, the mesosystem[62], relates to the connections and interactions between the microsystems in an individual's life.[67] This includes the relationships between family members, teachers, peers, and other social groups besides family that play a role in a child’s life. The mesosystem highlights the importance of understanding how different microsystems work together to influence an individual's development.[67] In this doctoral research programme, I anticipated that, as with the microsystem, the mesosystem for most of the study participants would have been disrupted due to the COVID-19 pandemic lockdown restrictions.

For example, many relationships that could usually impact on a child's development were of a different nature during the pandemic. Usual interactions between parents and children’s teachers were replaced by emails and online meetings.[74, 75] For most children in the UK, except those of key workers, regular face-to-face school attendance was replaced by online school.[76] This limited the interactions between a child and their peer group and the interactions between children’s peer groups and their families, which would have normally taken place before the lockdown restrictions. Children without siblings would also have had a different experience of the lockdown restrictions than those who had brothers and/or sisters to interact with.[77] Many children with developmental disabilities benefit from learning experiences with their peers[75], and only children without siblings[78] would not have had this opportunity or interaction with other children during the lockdown.

Identifying and understanding the complex relationships that play a role in a child's development are crucial in determining the contextual factors that contribute to a child's development[67, 70], and in the case of this doctoral research programme, the development of self-care.

2.1.3 The exosystem

The next layer, the exosystem[62], refers to the broader social and environmental contexts that indirectly influence an individual's development.[67] These contexts include factors such as community resources, government policies, and the availability of social services. In Chapter 4, one can see the impact that socioeconomic status and access to adaptive equipment has on self-care participation for children with Cerebral Palsy.

Children in low-income families often have less access to medical care, which includes developmental check-ups[79]which they need, as a result of being unable to afford to attend appointments. Some families in the UK have reported missing their child's medical appointments because of the financial costs of attending one due to travel, parking, food, childcare costs, and potential loss in earnings.[80]

Another study[81], carried out in the US, found that children from lower-income households are less likely to be diagnosed with Autism Spectrum Disorder (ASD) and receive the support they need. As a result, researchers[81] found significant differences in functional independence between children with ASD from higher and lower-income households, with children from higher-income families or households being more independent. For parents of children with medical complexity (CMC), accessibility barriers significantly impacted on care at home and the child's participation in family life.[16] This became even more difficult as children got older, and the study[16] highlighted the impact of CMC of not having access to a suitable, adapted living space on the whole family.

Even for children who do not have direct contact with these elements, they can still exert a considerable influence on their development. For example, children with limited access to playgrounds and opportunities for play could develop differently than those with access to these amenities.[82] Similarly, a child living in a neighbourhood with limited access to public transport, quality education or healthcare could face developmental challenges due to these environmental factors.[83]

For participants in this programme of research, children from different socio-economic backgrounds and those who live in different types of housing, with and without garden access, would also have had a different kind of lockdown experience[84] that shaped their development. A study[85] conducted in the North-East of England found that COVID-19 impacted young people from different backgrounds differently and concluded that the pandemic had widened existing inequalities for young people in the UK.

2.1.4 The macrosystem

The fourth layer, the macrosystem[62], encompasses the broader cultural, societal, and ideological forces that shape an individual's development.[67] This system accounts for the impact of cultural beliefs, values, customs, and social norms on a child’s development. Cultural contexts can play a significant role in influencing children’s behaviour and developmental outcomes.[86] For example, in a family or culture where children are encouraged to be independent, it is likely to see different outcomes in self-care compared to a culture where doing as much as possible for children is seen as a sign of affection.[87]

Another example of this is eating habits and the use of cutlery in different cultures.[88] In many countries, individuals use their hands to eat or could use other eating utensils such as chopsticks. It has been observed that child refugees often struggle with the Western expectation of eating with cutlery if they have not been exposed to using a knife or fork before.[89]

2.1.5 The chronosystem

The final level, the chronosystem[62], focuses on the role of time in shaping a child's development.[67] In this level, the influence of historical events, personal experiences, and major life transitions on developmental processes are considered. For participants in this doctoral research programme, the impact of the COVID-19 pandemic lockdown restrictions could have played a significant role in their development and participation in daily activities, including self-care, for years to come. In addition, data collection for the empirical studies in this doctoral research programme also coincided with the UK leaving the European Union[90], which could have impacted on family life for some participants.

As children progress through various stages of life and their development, they may also encounter a range of experiences that shape their development. For example, a child who experienced the loss of a close relative, an experience that many children had during the pandemic, may undergo significant changes in their family structure, which can impact their development in numerous ways. The COVID-19 pandemic has also exacerbated mental health conditions for many children.[76] Some of the mental strain caused by the pandemic is attributed to missed or delayed opportunities for celebrations and marking milestones; direct stress related to the virus, the stress of trying to avoid the virus and protect loved ones; and ongoing economic distress resulting from lockdown restrictions.[91, 92]

In addition to the mental health impact on children during and following the effects of the pandemic, Covid 19 also directly impacted children's physical health. Many parents of children with cerebral play indicated that they did not take their children to routine health appointments for fear of transmission of the virus.[93]

Figure 2.1 illustrates the ecological factors that could have impacted on children's development and self-care in the UK during the timeframe for this programme of research.

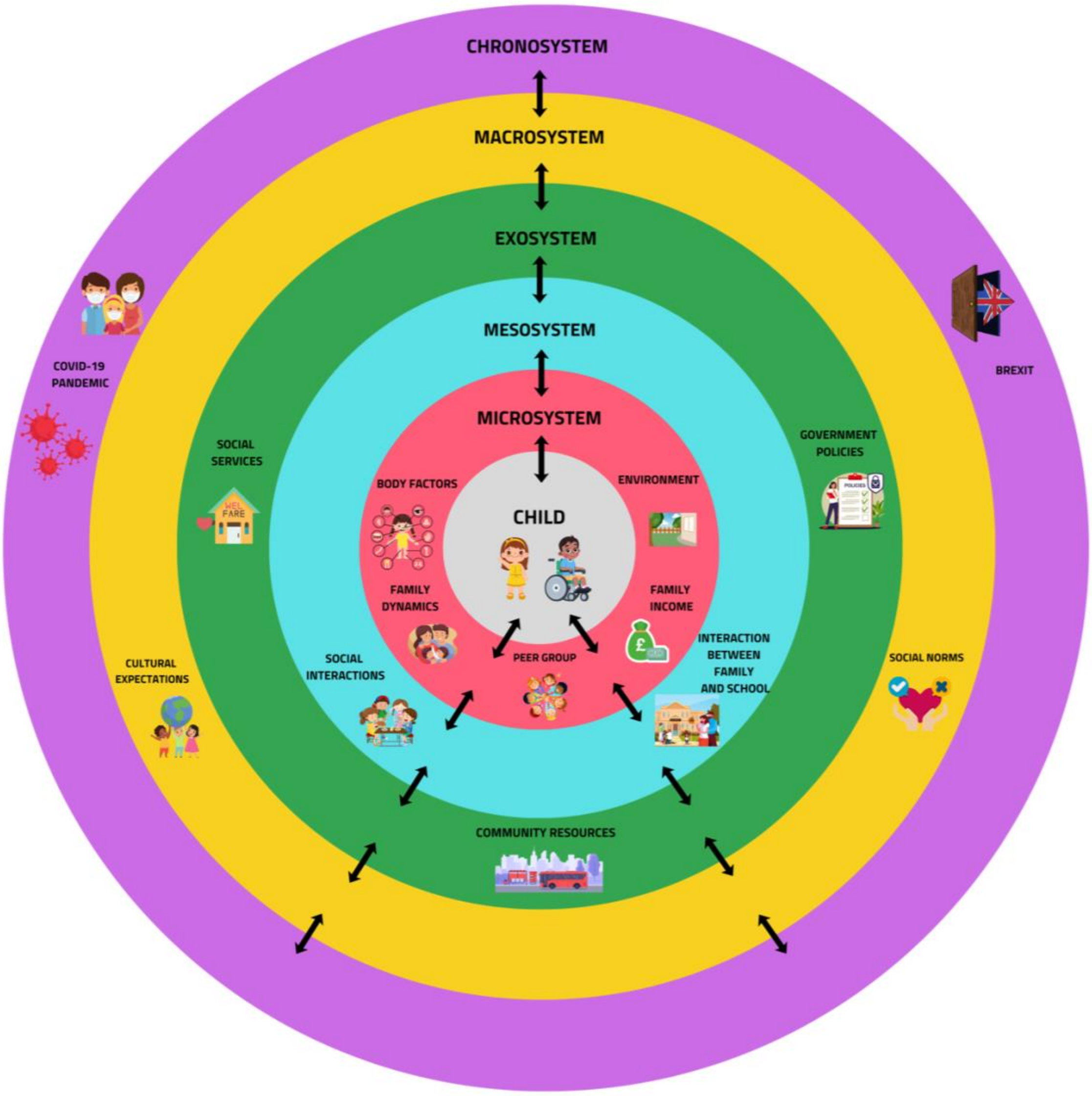


Figure 2.1 Bronfenbrenner's ecological systems theory and children's self-care in the UK, adapted from Bronfenbrenner's original model.

2.2 Logic model of factors influencing self-care

Prior to the start of the study, I constructed a logic model[94] showing factors that I anticipated would play a role in children’s self-care. Logic models are often constructed to hypothesise how an intervention could work, and then revisited and adjusted following measuring the output of the intervention.[95] I used this principle to construct a logic model of potential predictors of self-care, and was also informed by Bronfenbrenner's[63] ecological model discussed in section 2.1, to construct this model.

In the logic model shown in Figure 2.2, I proposed that child factors, including mobility and fine motor skills, are some of the key intervention elements, along with the provision of appropriate equipment and adaptations to provide children with motor impairments the opportunity to participate in self-care. I also proposed that potential difficulties in the areas outlined in the box, child factors could impact on parent self-efficacy, willingness to take risks, and parental stress levels. Overall, on a macrolevel outcome, I anticipated that the level of participation in self-care could affect children's long-term health, development, social integration, and school readiness. I anticipated that self-care outcomes could be moderated by children's intellectual ability, their level of disability, birth order in their family, ethnicity, complex medical needs and possibly birthweight. Further, I also considered that socioeconomic status, parental education levels, the physical environment, along with the time spent in and out of home environments could predict and influence the distal and macrolevel outcomes proposed in Figure 2.2.

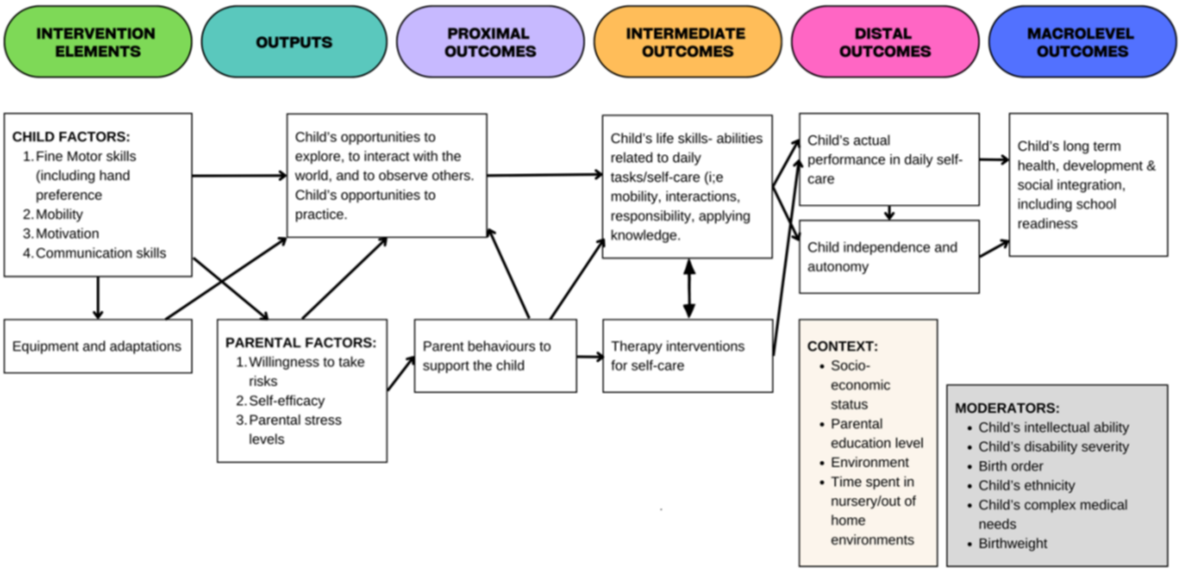


Figure 2.2 A proposed logic model of factors influencing children's self-care.

2.3 Summary

In summary, this chapter discussed the use of Bronfenbrenner's ecological systems theory model as a theoretical framework to make sense of and guide the research discussions in this PhD thesis. A logic model was also constructed and used to predict potential factors influencing children’s self-care. Both, the theoretical framework and the logic model are revisited in chapter 9, following the data analysis and synthesis.

Chapter 3: Overall Research Aims and Design

In this chapter, I present the overall aims and objectives, as well as the design and methodology, alongside epistemology. I also describe the study population on which the research programme focused, ethics and governance, patient and public involvement and the ways in which the outcome of self-care was operationalised and measured. Finally, this chapter discusses changes made to the doctoral programme because of the COVID-19 pandemic.

3.1 Research aims and objectives

The overall aim of this research programme was to generate new knowledge and evidence about factors influencing self-care in children with and without motor impairments.

The study objectives were the following:

1. To identify personal and environmental factors influencing self-care in children and young people.
2. To investigate intervention techniques for supporting self-care.

A later objective was added to adapt the research programme to the context of the COVID-19 pandemic and related restrictions on research.

3. To identify the impact of the COVID-19 pandemic restrictions on children's self-care and parents.

3.2 Broad approach and methodology

This doctoral programme of research took the form of a mixed methods design which was used to gain a better and deeper understanding of children's self-care by providing a fuller picture of factors influencing it.[96] It is important to consider that mixed methods research is more than simply utilising two different methods in the same study.[96] It is considered a research methodology in its own right with its own philosophical assumptions and methods of enquiry.[97] An important proposed strength of mixed methods[98] is the potential to provide particularly rich, multidimensional insights across quantitative and qualitative data, providing perspectives that cannot be fully comprehended by one type of data alone.

There are six, commonly referred to, justifications for using a mixed methods design in research.[98] The first of these is the opportunity to widen the inquiry and add to the depth and breadth of the study. Second it is a need for a particular holistic overview of a phenomenon, which is in the case of this doctoral study programme is self-care in children with and without motor impairments. Thirdly, it is to support researchers in accumulating a more in-depth and comprehensive understanding of the phenomenon investigated. Fourthly, a mixed method approach can support researchers to strengthen the rigor of their research and conclusions through triangulation of data across sources and data types. Fifthly the data triangulation can be used for validating results obtained from each of the quantitative and qualitative methods. The final justification for using a mixed methods approach is to develop refined conclusions as one method is used to inform or shape the use of the other one.[97, 98]

The overall design for this research programme was informed by the objectives of identifying factors influencing self-care in children with and without motor impairments and learning about the impact of the COVID-19 pandemic on children's self-care. Following the six points discussed above, I felt that a mixed method study would provide the most comprehensive overview of factors influencing children's self-care. The quantitative methods utilised in Chapters 5 and 6 were deemed relevant and important to collect statistically relevant information on factors influencing children's self-care. To complement this, the qualitative data collected in Chapters 7 and 8 provide more insight into the types of self-care difficulties that children experienced and the impact on others, including parents, teachers, and other pupils at school. Both the quantitative and qualitative research carried out in this research programme was informed and influenced by the mixed methods evidence synthesis discussed in Chapter 4.

When considering the methods selected in a mixed methods study there are some key considerations to take into account.[99] These include the priority of the approaches included in the study; the level of interaction between the component methods and data; and the timing of data collection and analysis of the quantitative and qualitative threads in the study.[97, 98, 100] Mixed methods can be combined in many different ways, including sequentially where findings from one strand informs the approach of the other, or concurrently where qualitative and quantitative date are collected in and analysed in parallel.[97, 101, 102] Within mixed methods research a convergent parallel mixed methods design, which mixes the qualitative and quantitative methods to triangulate the findings, or a sequential design can be followed.[97, 102]

I followed a sequential design which started with a mixed methods evidence synthesis followed by two quantitative longitudinal cohort studies. This was followed by a qualitative study of parent discourses, and a mixed-method analysis of existing data on children's self-care in school following the COVID-19 pandemic.

- The systematic review focused on the quantitative and qualitative evidence for factors influencing self-care. (Study objectives 1,2 and 3)
- The focus of the longitudinal survey study was to collect data on children's self-care on a six-monthly basis through a parent questionnaire to learn more about children's self-care development in relation to the demographic data collected from participants. (Study objective 1)
- The quantitative data analysis of existing longitudinal data investigated factors influencing self-care in children with motor impairments. (Study objective 1)
- The qualitative study collected data on parents' perspectives in an online forum on the impact of the COVID-19 pandemic lockdown restrictions on their child's self-care. (Study objective 3)
- The qualitative analysis of government documents on teacher's perspectives how the COVID-19 pandemic lockdown restrictions impacted on children's self-care in the school environment. (Study objective 3)

The findings of each individual study discussed in chapters four to seven informed and influenced the methodology for the subsequent chapter. Whilst mixed methods studies are often planned in advance, they can also take the form of an emergent design which arises during the course of the research programme.[97] In this doctoral research programme an emergent design evolved due to the circumstances around the originally planned quantitative data collection.

Shortly after ethics approval was obtained for the EASIER study, just before the first wave of data collection was due to commence, the study was interrupted by the arrival of the global COVID-19 pandemic. Besides the fact that the EASIER study was put on hold by the NHS, which delayed the data collection for this study, I also recognised that the COVID-19 pandemic was an event that would significantly impact on children's overall development and possibly self-care.

To explore the impact of the pandemic on children' self-care and capture the voices of parents on this topic, I carried out a qualitative study on the impact of the COVID-19 pandemic lockdown restrictions. This method considered that there were methodological constraints due to the COVID-19 pandemic. Studies involving children or direct contact with parents would have required NHS REC approval. During the pandemic, studies related to the treatment of COVID-19 (particularly pharmacological interventions) were prioritised for NHS REC approval. Due to these constraints, parent responses on Mumsnet and Netmums, parent internet forums[103, 104] of which answers are in the open domain, were analysed instead.

The internet-based qualitative study still allowed for meaningful views of parents about the impact of the lockdown restrictions on their children's self-care to be captured.[105] As parents were not directly contacted and existing data in the public domain was used, this methodology was deemed suitable by Newcastle University ethics and, therefore, possible to capture this information in a timely manner without NHS REC constraints.

To add to the data on the impact of the COVID-19 pandemic lockdown restrictions on children's self-care, teacher responses from YouGov reports[41, 106] were analysed along with other studies on how the lockdown impacts children in mainstream and special education schools. The exact methodology for each of the research streams in this PhD programme is specified below.

3.3 Epistemological standpoint

In this doctoral research, I took a pragmatist[107]stance. Whilst quantitative research is usually informed by positivism focussing on the objective reality, and qualitative research underpinned by interpretivism emphasising subjective meaning, mixed method research brings together these philosophies into what is referred to as a third research paradigm often influenced by pragmatism.[96, 108] The epistemic aim of this programme of research was to generate new knowledge on children's self-care that could inform healthcare professionals, parents, educators, and policymakers and guide expectations as to what children should be able to do for themselves. Pragmatism is underpinned by the belief knowledge is always based on experiences and that each person's knowledge is unique as it is created by their unique experiences.[109] It also a theory that is focused on improving practical understanding of real-world issues.[110] Besides generating new knowledge and understanding on the topic, I also thought it was important to identify the environmental and contextual factors that explain the variance in self-care across children from different backgrounds and with different health conditions.

3.4 Population of interest

Overall, the research programme focused on young children aged 2 to 5 years, with and without motor impairments. This age group was chosen as participation in self-care is a requirement for engaging in community activities from early on and especially so for children' school readiness.

The biggest diagnostic group included in children with motor impairments was CP. The prevalence of CP in the UK, where the research for this doctoral research programme took place, is 186 per 100 000 population[111], and further CP is a leading cause of physical disability in children in the developed world, which makes this research of interest for other child health providers in the rest of the world. Further, a primary goal of therapeutic intervention for this group of children is to increase participation in self-care activities, which makes them an important demographic group for this programme of research.

For the systematic review discussed in Chapter 4, studies were included with participants up to the age of 18 years, and in Chapter 7, qualitative data were collected from parents of nursery and primary school-aged children (approximately 1-11 years). This wider age group was selected to maximise the evidence in relation to self-care for these studies, as limiting the age group for both the systematic review and qualitative responses from parents during the COVID-19 pandemic lockdown would have significantly limited the research evidence obtained from these studies. Further, expanding beyond the 3-6-year age group provided me with a wider perspective of self-care difficulties and how it affects children and young people in different ways, and evidence-based interventions to address to challenges with self-care in this population.

3.5 Self-care as an outcome

The main health outcome for this doctoral research programme was children's self-care, defined in previous work with service users as a combination of (i) "making decisions about things that affect me" and (ii) "developing and learning to look after myself".[1] The definition covers tasks from basic self-care (e.g. dressing, personal hygiene, eating) to complex action sets (e.g. managing money and time, snack preparation and cooking, laundry and clothes care, cleaning, accessing resources, and managing and directing care providers). This is similar to the self-care definition adopted by the NHS[112] and occupational therapy paediatric practice.

In the EASIER and ActiveCHILD studies discussed in chapters 5 and 6, self-care was measured using the Daily Activities domain from the Pediatric Evaluation of Disability Inventory Computer Adaptive Testing (PEDI-CAT). This domain assesses the child's ability to participate in self-care and not the frequency of self-care participation. For the other studies in this doctoral programme, the outcome was guided by children's ability to participate in self-care as defined in the paragraph above.

3.6 Ethics and governance

I carried out this doctoral study programme in adherence with the NHS Research Governance Framework and the specific procedures agreed for the project in the Health

Research Authority (HRA) and Research Ethics Committee (REC) approvals. Specific details for each study are discussed in their respective chapters. For the qualitative research that used freely available online data (Chapter 7), I received Newcastle University ethical approval.

During the study I also had training and experience in conducting research with adherence to good clinical practice principles and legal requirements e.g., Good Clinical Practice (GCP), and General Data Protection Regulation (GDPR). I also completed NIHR training on communication and consent in paediatric research setting along with relevant research and mandatory training at the faculty of medical sciences at Newcastle University.

All data collection adhered to NHS Research Ethics guidance as well as other best practice guidance (e.g., Nuffield Bioethics[113] recommendations for research with children). Data related to current self-care development were collected using rigorous quantitative techniques e.g., the used of a standardised computer adaptive test (PEDI-CAT) and guided by established practice in behavioural sciences to maintain valid and high-quality data. Further, all data met standards for replication. In relation to storage, data were managed and stored in accordance with University of Newcastle processes: https://research.ncl.ac.uk/rdm/working/. National Data Guardian standards and principles were adhered to for data security.

3.7 Patient and public involvement

The overall programme of self-care research (www.childresearch.co.uk/self-care-projects/) in which the EASIER project sat at the commencement of the research emerged from a formal involvement/engagement project with service users and providers in the North-East.[1] In that project, self-care and related interventions were prioritised and a plan for moving forward co-designed. The service user partners involved six young people and one young adult aged 11- 18 years from children's NHS services, and four parents from children's NHS services. The young people and parents prioritised the research topic and defined the outcome of self-care, identified problems with current self-care support, and co-designed a new intervention and a research study to evaluate it.

This specific doctoral study programme had input from the Young Person's Advisory Group North England (YPAGne), based at the Newcastle Hospitals in Newcastle upon Tyne. YPAGne are a group of young people who meet monthly to review research aimed at children and young people. The purpose of a Young Person's Advisory Group (YPAG)[114] is for children and young people to actively participate as partners and to advise researchers and their teams on a full range of activities in various clinical research projects and initiatives. The first YPAG group was formed in the UK in 2006, and this model for including children and young people in research has since been adopted across Europe. YPAGne members are between the age of 13 and 18 years, some of whom have experience of living with a long-term health condition or disability, others with experience of receiving care in a hospital setting, and others who joined the group because of a general interest in learning more about health and research. Members volunteer their time, but the NIHR covers the running costs of the group (catering and travel costs).

The overarching principle of YPAG[114] is that by participating in the group, children are transformed from research subjects to active contributors and partners in the research process. Some of the contributions that YPAG can make to research include: obtaining children's and young people's views about the research idea and sharing their opinions on the feasibility and the appropriateness of the study; sharing their views on the practical implications of the study, for example, the number of appointments required and the impact on this on other areas of participation; providing feedback on the participant information leaflet and it's level of appropriateness for children and young people; contributing to ethics applications by reviewing the lay summary; contributing to the interpretation of research findings; or contributing to the child and family-friendly feedback sent to the participants at the completion of the study.[114]

For the EASIER study, YPAGne contributed to the study description and shared feedback on the methods of the study. Following a presentation to the YPAGne group and other attendees at the meeting, young people at the meeting participated in a workshop activity in which they discussed the EASIER study. The young people provided feedback on how to explain the study to participants to engage them in the study, potential barriers to participants for inclusion in the study, and the method of data collection. These suggestions were taken on board and considered in the research protocol.

3.7 Changes to data collection because of the COVID-19 Pandemic

The time point of REC and HRA approval (February 2020) coincided with the arrival of the COVID-19 virus in the UK. When COVID-19 first took hold in the UK, the NIHR asked NHS Trusts, and other research organisations to prioritise studies and trials that would help support the global response to COVID-19. These studies were known as urgent public health studies[115] and as a result the trust who were hosting the EASIER study put the study on indefinite hold as it was not classed as an urgent public health study. According to the original ethics application, data was supposed to been collected during 2020, 2021 and 2022 at 6 monthly time points, and at that time point, there was no clear indication when non-urgent public health studies were to resume.

During this waiting, I engaged in other projects with the then CHILD research group in the Population Health Sciences Institute, which lead to the qualitative research work discussed in Chapter 7. It became clear that the proposed method of recruiting study participants face-to-face through health visitors and therapy appointments would be difficult as many staff working in these areas were redeployed[116] and a considerable proportion of children's health appointments moved to online consultations during the COVID-19 pandemic.[117] For example, it was reported for during the first wave of the pandemic that two-thirds of health visitors were having less than 10% of their contact with families face-to-face at in the home or a clinic.[79]

I decided to put forward a major amendment to the NHS REC and HRA to move recruitment of the study online (https://blogs.ncl.ac.uk/lbrewer2/). However, I had to wait for the ethics process for non-urgent studies to resume and finally received an approval to move the study recruitment online in December 2020. The aim was to recruit typically developing children and children with motor impairments online through sharing the study information on social media and with nursery schools. Children with motor impairments were still recruited through two NHS trusts in the North and in the Midlands of England after the study was portfolio adopted by the NIHR (National Institute of Health Research).

Although one of the original aims of finding out the trajectories of self-care in children with and without motor impairments were not achieved, I experienced a significant amount of personal learning in all stages of the study, from submitting the research proposal right up to the completion of the study.

The learning that I achieved from preparing the NHS ethics and portfolio application set the foundation for the research carried out throughout the rest of the doctoral study programme. Further, the difficulties that I experienced with recruiting participants for the EASIER study encouraged me to problem-solve creatively and to expand my research in order to meet the requirements for a PhD programme. I have reflected further on these challenges in chapter 9. In the process, I learned a variety of research methods including discourse analysis for qualitative research, which I would not have learned had the EASIER study gone as originally planned.

3.8 Conclusion

This chapter has outlined and discussed the methodology used in the programme of research to explore self-care in children, with and without motor impairments, and to investigate the impact of the COVID-19 pandemic lockdown restrictions on children's self-care. The following chapters present the mixed methods systematic review; the two quantitative studies, the EASIER and the ActiveCHILD, an analysis of parental discourses on how the pandemic impacted on their children's self-care, and teacher reports on children's self-care and levels of school readiness after the COVID-19 pandemic.

Chapter 4: A mixed methods systematic review of self-care in children and young people

The overall aim of this research programme was to investigate self-care in children with and without motor impairments. In the previous chapter (Chapter 3), I discussed the overall aims and objectives, as well as the design and methodology. I also described the study population on which the doctoral programme focused, ethics and governance, patient and public involvement and the ways in which the outcome of self-care was operationalised and measured. The present chapter is a mixed methods synthesis of factors influencing self-care in children and young people.

A rapid review of self-care interventions for children published in 2016[1] found limited evidence on self-care interventions to guide practice and policy. That review has not since been updated, and it was possible that new evidence has emerged that could inform interventions. Furthermore, that review[1] did not investigate factors influencing self-care that could be used to guide the development of interventions and was solely focused on interventions targeting children's self-care.

The review described in this chapter systematically reviewed published evidence on factors influencing self-care and interventions that might affect self-care in order to enhance the understanding of self-care development, difficulties, and interventions.

4.1 Methods

I used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines to report the evidence for this systematic review. A protocol was also published in the database of prospectively registered systematic reviews at www.crd.york.ac.uk (registration number CRD42017077366). The WHO International Classification of Functioning, Disability and Health (WHO ICF)[118] was used as an overarching framework for this systematic review. The ICF is the international, interdisciplinary consensus framework for describing functioning, health, and disability. Its main components are: 1) body structures and functions (also referred to as impairments), 2) activities and participation (also referred to as capacity and performance, or activity limitations and participation restrictions), and 3) personal and environmental factors. The review question was: what factors or interventions may influence self-care and self-care development in children aged 0-18 years?

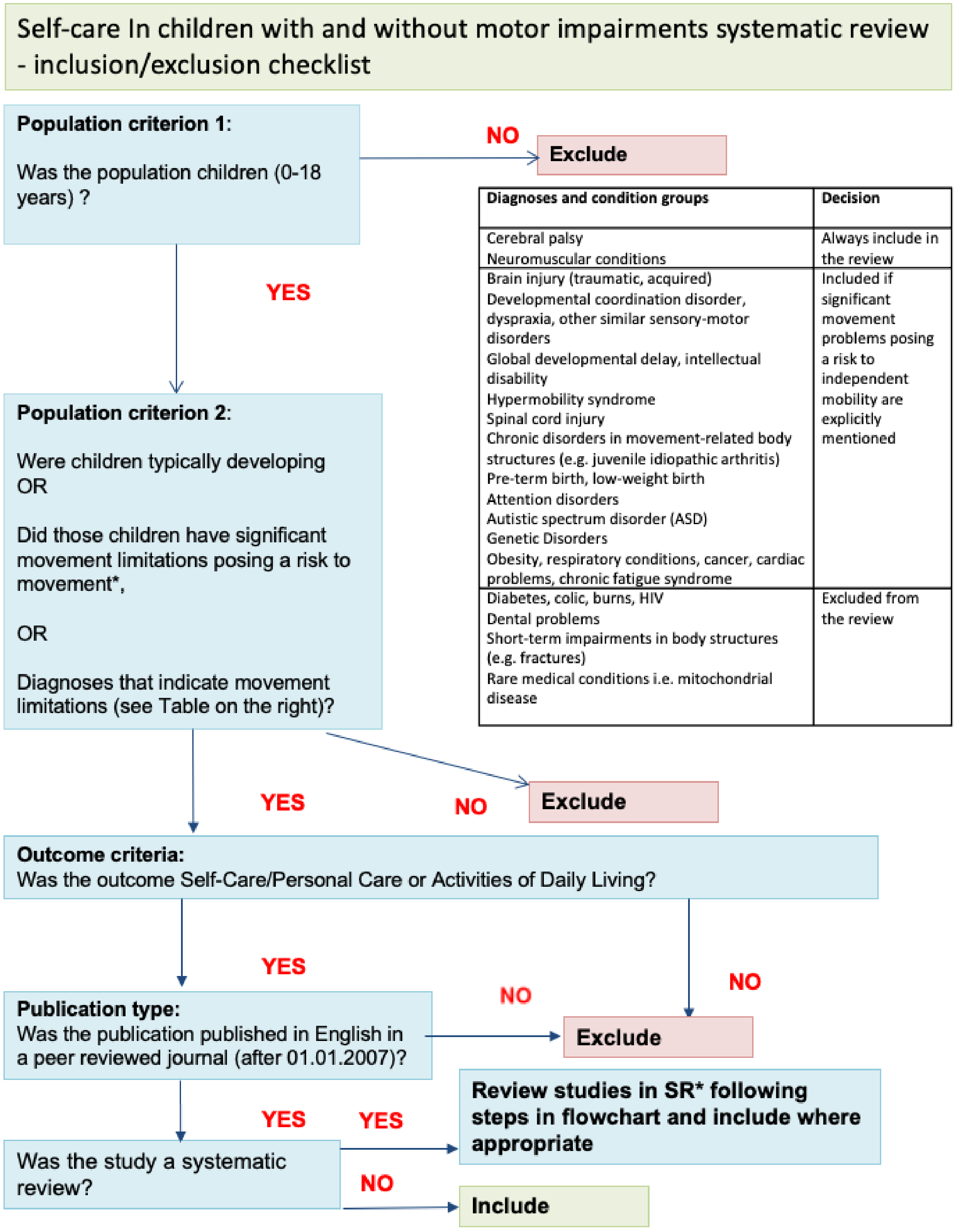
4.2 Search strategy and data sources

The search strategy was developed to locate papers reporting self-care in children and young people. It covered two facets, ‘children and young people’ and ‘self-care’, using free text terms and thesaurus-controlled standard terms (MeSH) where available. Terms within each facet were combined using the Boolean operator ‘OR’, and resulting sets of papers were combined using ‘AND’. The exact search strategy used in each of the electronic databases is reported in Appendix A. Two key databases were searched: MEDLINE (1946 – March 2019, via Ovid) and CINAHL (1981- March 2019, via EBSCO). The search was updated in November 2022, including MEDLINE (April 2019 – November 2022, via Ovid) and CINAHL (February 2019 – November 2022, via EBSCO).

Results were downloaded to EndNote, and duplicates were removed. All references were uploaded to the Rayyan QCRI systematic review web application[119], a tool designed to facilitate screening, abstraction, and review processes.

4.2.1. Inclusion criteria

I developed a Population, Intervention, Comparison, Outcome and Time (PICOT) inclusion and exclusion criteria (see figure 4.1) covering the following. The Population included children aged 0-18 years; and excluded dental conditions, diabetes, and short-term impairments in body structures (e.g., fractures). Any or no Interventions or exposures, as well as comparison groups, were included. The studies with the outcome as self-care, fitting within the broad definition of ‘doing everyday tasks related to looking after myself, and making decisions about how these tasks are done’[1] were included. Any type of study design published between 01.01.2007 and 15.11.2022 in English in a peer-reviewed journal was included.



Diagnoses and condition groups	Decision
Cerebral palsy Neuromuscular conditions	Always include in the review
Brain injury (traumatic, acquired) Developmental coordination disorder, dyspraxia, other similar sensory-motor disorders Global developmental delay, intellectual disability Hypermobility syndrome Spinal cord injury Chronic disorders in movement-related body structures (e.g. juvenile idiopathic arthritis) Pre-term birth, low-weight birth Attention disorders Autistic spectrum disorder (ASD) Genetic Disorders Obesity, respiratory conditions, cancer, cardiac problems, chronic fatigue syndrome	Included if significant movement problems posing a risk to independent mobility are explicitly mentioned
Diabetes, colic, burns, HIV Dental problems Short-term impairments in body structures (e.g. fractures) Rare medical conditions i.e. mitochondrial disease	Excluded from the review

*movement is defined as: moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation.

Figure 4.1 Flowchart of study selection criteria

4.2.2 Study Selection and Data Extraction.

A member of the supervisory team (NK) and me independently double-screened 200 abstracts using the inclusion criteria (above). As there was 100% agreement between us, I then screened all the remaining abstracts using those criteria. In the screening, specificity was prioritised, and papers that were unclear about meeting the inclusion criteria were excluded. This was particularly pertinent in screening for the population: papers were retained only when it was clear from the title or abstract that the focus was on self-care in children or adolescents. Studies identified as relevant based on title and abstract were obtained as full-texts and assessed for eligibility.
I then extracted key numeric and textual characteristics from all included studies.

A second reviewer reviewed and confirmed the extraction. Data were extracted by the first author; year of publication; study design; geographical location; the participants; outcome constructs and measures used; and exploratory variables considered. In addition, for intervention studies, intervention labels, as provided by the authors, were extracted. Key results were also extracted for all included studies, including any numeric data relevant to explaining variation in self-care outcomes.

4.3 Risk of bias assessment

All included studies were assessed for methodological strengths and limitations, with a focus on the risk of confounding in quantitative studies and risks to rigour in qualitative studies. It was anticipated that the majority of studies would be non-intervention observational studies which can be more susceptible to bias than experimental studies, and where it is recommended for the quality assessment to pay particular attention to participant selection and outcome detection.[120]

Version 2 of the Cochrane risk-of-bias tool for randomised trials (RoB 2)[121] was used to assess the risk of bias in randomised controlled trials. For non-randomised observational studies, selected items from the RTI bank[122] of signalling questions for assessing the risk of bias, confounding, and precision in observational studies of interventions and exposures were used (Table 4.1). This approach included common items related to sources of threats to validity and precision while allowing them to be used in a way that differentiated between the studies on quality, specifically considering confounding.

For qualitative studies, the Critical Appraisal Skills Programme (CASP) qualitative checklist was used. (https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf) This comprises ten questions addressing clarity of aims; appropriateness of qualitative methodology; research design; recruitment strategy and data collection method; consideration of reflexivity and ethical issues; rigour of analysis; clarity of findings; and the value of the research.

For mixed methods intervention studies, the Mixed Methods Appraisal Tool (MMAT) Version 2018 was used (http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf). The MMAT was selected as it allowed one tool to be used for concomitantly appraising the most common types of empirical studies. The risk of bias assessment was undertaken independently by me and a second reviewer. Disagreements that arose between us were resolved through discussion and with the assistance of a third reviewer where required.

4.4 Data analysis and synthesis

The International Classification of Functioning, Disability and Health (ICF)[2] was used as an overall organising framework for all data. Within this, data on the outcome and explanatory variables were first extracted and categorised (numeric data) and coded (qualitative data) according to the ICF. A tabulation approach[121] was then used to analyse and interpret semi-quantitative (data consisting of approximate instead of precise measurements) and numeric data, including the child’s function and contextual factors and how these related to self-care. The high levels of clinical, methodological, and statistical heterogeneity made data pooling inappropriate, and thus no metaanalysis was undertaken. A vote counting table[121] was used to assess relationships of the different factors on self-care based on the direction of effect to summarise and present the numeric data in relation to ICF categories and self-care.

4.5 Results

4.5.1 Study selection

The first electronic search of databases carried out in March 2019 returned 12,579 references, of which 2,049 were duplicates, resulting in 10,530 references. The search was updated in November 2022 and returned 5,108 references, of which 781 were duplicates, resulting in 4,327 references. In the initial title and abstract screen, 14,632 references were excluded, leaving 225 full texts to review. From these, 97 references (reporting on 97 studies) met the inclusion criteria and were retained for the review.

See Figure 4.2 for the PRISMA flow diagram of included and excluded papers.

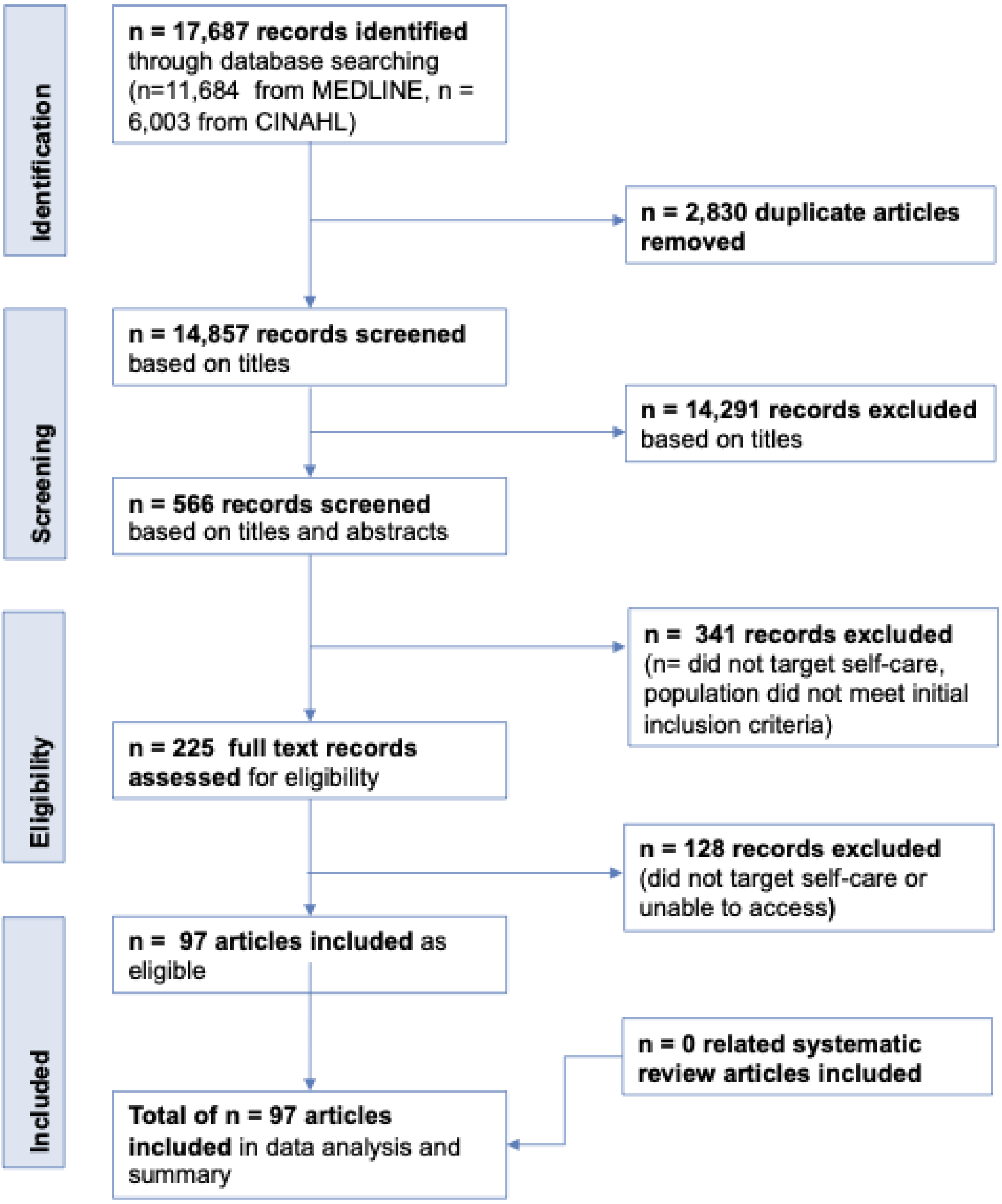


Figure 4.2 Prisma flowchart of included studies

4.5.2 Characteristics of included studies

The included studies (Table 4.2) comprised of eight randomised controlled trials (RCTs), four qualitative studies, and 85 studies of other designs, such as observational and non-randomized trials. Of the included studies, 21 were intervention studies. The included studies involved 12,575 participants, and the sample sizes ranged from 1 to 818 in individual studies, with a median of 59 participants. The largest two studies[123, 124] were in children and young people with cerebral palsy, with each reporting data for 818 children and young people.

In relation to data for specific age groups, 16 studies reported data for children aged ≤5 years, and 22 studies reported data on children >5years. Fifty-nine studies reported data for children across these age groups. The included studies featured participants with a range of diagnoses. Fifty-one studies included solely children with CP, and two studies[125, 126] included children who had a childhood stroke. Five studies[42, 50, 127-129] included children with DCD, thirteen studies[24, 130-141] included children with ASD, three studies[142-144] included children born preterm, and three studies[145-147] included children with Myelomeningocele (MMC). Two studies[4, 148] included children with DD, three[127, 149, 150] children with Attention Deficit Hyperactivity Disorder (ADHD), and one[151], children with Down Syndrome (DS). Two studies[152, 153] included children with arthrogryposis, one[154] with Juvenile Idiopathic Arthritis, one[155] with Spina Bifida, one[156] with Fibrodysplasia Ossificans Progressiva (FOP), and one[157] with Achondroplasia. Two studies[158, 159] included children with cancer. Two studies[7, 18] were carried out with typically developing children and in one of these studies[7], the focus was on children cared for in different settings. One study[160] was across diagnostic boundaries and compared self-care in children with ASD and intellectual disabilities.

Included studies were published in English between 2007 and 2022, with 89 studies from 2010 onwards. Twenty-five studies were published from 2020 onwards. Studies were carried out in Africa (n=2), Asia (n=23), Australia (n=7), Europe (n=31), North America (n=23), and South America (n=11).

4.5.3 Quality of included studies

For the intervention studies, the research questions were clear, and the data collected addressed the research question. Most of these studies also described the study populations and selection in sufficient detail. Whilst the randomisation process was appropriately performed for three RCTs[161-163], all eight out of eight studies were at risk of bias due to concerns about the randomisation process deviations from the intended intervention missing outcome data and measurement of the outcome. The agreement in the quality appraisal between the two reviewers was high (84%). The agreement was calculated by dividing the number of quality appraisal statements agreed on by the total number of statements.

For the eleven non-randomised intervention studies included, all outcome and exposure measurements used to assess the effectiveness of the interventions were appropriate; however, for two of the studies[164, 165] the outcome data were incomplete. In six[145, 154, 166-169] of the eleven studies, confounders were accounted for in the design and the analysis, whilst for one study[170], it was not accounted for, and for four others[139, 164, 165, 171], it was not clear whether this was the case. All intervention studies were included in the data synthesis. The agreement in the quality appraisal between the two reviewers was high (94%), and agreement was calculated in the same way as above.

For the four qualitative studies, the design and methodology were clear. For all four studies[42, 128, 138, 156], there was a threat to validity from a lack of clarity over whether the relationship between the researcher and participants had been adequately considered. For these four studies, there was 100% agreement between reviewers.

For all ninety-three quantitative studies, valid and reliable measures were used for exposures (Table 4.2), and the inclusion/exclusion criteria and recruitment strategies were clearly reported. Self-care outcomes were assessed using 29 measurement tools (Table 4.4), with the PEDI most frequently used. Outcomes considered self-care ability (the ability to participate in self-care) and self-care competence (the combination of the knowledge, ability, and skills to participate in self-care). Taking into account the individual studies' limitations, the findings were considered partially credible in 40 of the observational studies.[122] Nevertheless, no study was excluded from data synthesis. The agreement in the quality appraisal between the two researchers was high (95%).

4.6 Findings

The results below included findings for non-intervention and intervention studies. For non-intervention studies, evidence was found in relation to body functions, environmental factors, and personal factors. The impact of the COVID-19 pandemic and the associated lockdown restriction on children's self-care was investigated in three studies.[137, 172, 173] This is discussed under environmental factors, as these studies referred to the impact of the associated lockdown restrictions, not the actual coronavirus.

4.6.1 Body functions

Within body functions, movement functions, including those of the lower and upper extremities, were studied most frequently and showed the most consistent association with self-care (Table 4.5). Mental functions were frequently associated with self-care, with lower cognitive and executive functions predicting poorer self-care. Three studies[4, 143, 174] investigated the association between children's birthweight and self-care with no association found. In one study[155], an association was found between the weight of adolescents with spina bifida and their self-care independence, with adolescents who were overweight demonstrating more difficulties with self-care.

The impact of pain was investigated in two studies[123, 175], and four studies[136, 140, 176, 177], considered the impact of sensory functions on self-care; in these, sensory processing and pain were associated with self-care. One study[178] investigated the association between attention and participation in self-care and found that children with ADHD participated in self-care less compared to peers without ADHD.

Children with ASD also presented with lower levels of self-care in comparison to peers without ASD; in Table 5.5, these findings are grouped under mental functions of language. The ICF refers to ASD as a group of conditions that are characterized by impairments of reciprocal social interaction, verbal and non-verbal communication, as well as a preference for repetitive, stereotyped activities, behaviours, and interests. Based on this, children with ASD were grouped in Table 5.5 under the association between language and self-care, as limited other information was provided by the respective authors of these papers.

Two studies[158, 159] investigated the occurrence of self-care difficulties in children with cancer. This group of children often present with higher levels of fatigue and pain, and previous research[179] has found high levels of upper limb impairments, including poor grip strength and poor bilateral coordination in this population, which impacts on participation in self-care. One study[159] showed a positive association between challenges with self-care and lymphoma, whereas another study[158] did not find a correlation between self-care difficulties and a cancer diagnosis.

4.6.2 Contextual factors: environmental and personal

The impact of environmental factors on self-care was considered in fourteen studies. Five studies[134, 146, 180-182] found an association between children's age and self-care ability (Table 4.5); three studies found an association between the physical environment and self-care[123, 183, 184] and one[185] found an association between socio-economic status and children's self-care. Two studies investigated cultural factors in relation to children's self-care. One[148] of these studies found significant differences in self-care between American and Taiwanese children, and the other study[186], which investigated self-care performance in Dutch and Spanish children, found that Dutch participants demonstrated a higher level of self-care ability. Regarding family factors, two studies[124, 134] found positive associations between increased parental stress and family ecology and difficulty with self-care in children.

The COVID-19 pandemic and associated lockdown measures were a factor that played a significant role in children and young people's well-being across the world between 2020 when the virus was first discovered, and 2022 when some of the last worldwide Covid restrictions were implemented. Three studies[137, 149, 172] included in this review investigated the impact of the COVID-19 pandemic and the associated lockdown measures on children's self-care. Two studies[137, 172] found a decrease in children's ability to perform activities of daily living independently, whereas in another study[149], parents reported that their children demonstrated an increased engagement with personal care activities.

4.6.3 Qualitative findings

Four qualitative studies were included in this review. Two qualitative studies[42, 128] investigated children and young people's experience of DCD and difficulties with self-care through parent interviews. Both studies found that children and young people with DCD presented with challenges in self-care and were felt to be reliant on their parents to participate in self-care. The other two studies investigated self-care in children with ASD[138], and children with FOP.[156] Parents of children with ASD reported that eating independently was one of the most challenging areas of self-care for their children, whilst toileting was less of a challenge. Children with FOP, and their parents, reported that FOP had a significant impact on children's ability to participate in self-care and dressing and toileting. As with children with DCD, participants from the other two studies also required a high level of parental assistance with self-care.

4.6.4 Interventions for self-care

The interventions utilised in the 21 intervention studies (Table 4.6) varied from physical intervention to environmental adaptations. The most frequent intervention studied was the use of CIMT for children and young people with CP. All of the three studies[164, 187, 188] found a positive association between CIMT and improved functional independence (Tables 4.3 and 4.6). HABIT was also associated with greater improvement in self-care in children with CP.[163]

Conductive education was associated with improved self-care competence for children and young people with CP[166], and a visual perception intervention[171] also demonstrated a positive correlation with increased self-care performance. For children with spastic diplegia, there was a strong association between task-orientated training and high variability practice and improved functional independence.[189] One study[170] of children with CP, found a significant positive correlation between the frequency of allied health therapies and PEDI scores. Similarly, another study[40], found significant gains in self-care in children with CP when selective dorsal rhizotomy was followed with intensive Occupational Therapy sessions. Another study[145] found a significant positive correlation between intensive goal-directed therapy and PEDI scores, with children receiving the intervention presenting with higher scores. For children with CP, there was also a positive association between sit-to-stand training and self-care independence.[162]

Other interventions associated with improved PEDI scores for self-care post-intervention included hippotherapy and educational programmes for primary caregivers.[161, 190] Adaptive seating was associated with increased self-care participation when used.[168] No evidence was found of the impact of kinesio-taping on functional independence.[191] For children with MCC, goal-setting training was associated with more significant improvements in toilet independence compared to traditional training or rehabilitation support.[145] For children with ASD, video-based interventions[139] were associated with improvements in self-care.

In relation to surgical interventions, children with CP showed a significant improvement in functional self-care performance after selective dorsal rhizotomy.[165] A pharmaceutical intervention Etanercept for children with juvenile idiopathic arthritis was associated with improved functional ability.[154]

4.7 Discussion

This review summarised the available evidence on factors associated with self-care in children and young people aged between birth and 18 years and related interventions, and 97 peer-reviewed papers focussing on factors that influence self-care in children and young people were analysed.

Of body function and structure factors investigated, movement-related upper and lower extremity structures and functions, and cognitive and executive function, were consistently associated with self-care. Of environmental factors, age and physical environment were consistently associated with self-care. Of intervention factors, adaptive seating, goal setting, educational programmes for primary caregivers, and constrained induced movement therapy were found to have shown promise in influencing self-care.

Although a diversity of diagnostic populations was represented, the overall evidence was heavily weighted towards children with CP, with evidence in other groups considerably thinner.

4.8 Strengths and weaknesses of the study

The main limitations of the present review were that: the included publications were limited to work published in English; the majority of included studies were cross-sectional designs, which limits causal inferences; RCT's were of low quality; studies in children with CP were vastly overrepresented compared to other populations; and it was not possible to undertake further quantitative synthesis due to the heterogeneity of the measurement tools and study designs. Key strengths were the robust use of evidence synthesis methods throughout and the broad population inclusion criterion that allowed focus on children across diagnostic categories as well as those without known health or development problems.

4.9 Strengths and weaknesses in relation to other studies

This review updates and substantially expands previously summarised information on self-care in children and young people broadly and identifies new factors that should be taken into account when considering self-care development and support in children and young people across a range of abilities and health states.

The present study applied wide inclusion criteria, which generated results for a broad population, including results for typically developing children and children with a range of diagnostic categories, and summarised evidence about environmental factors alongside the more commonly considered movement and cognitive functions.

From this, there was an early suggestion of a dynamic relationship between the child's environment, capacity, and self-care. For example, typically developing children who attended nursery presented with greater self-care skills compared to children being cared for at home[184]; children with CP had a better self-care performance with a more accessible physical environment[123]; and children with severe CP and low SES (socioeconomic status) presented a worse performance in self-care[185] compared to children with severe CP and average to high SES.

Overall, due to the heterogeneity of the present literature, the variance that different types of factors explain remains difficult to establish, and further research is needed to unpack how environments impact on children's self-care.

4.10 Implications for clinicians and policymakers

Out of the intervention studies included in this review, CIMT and task-oriented training were associated with good outcomes in relation to improving self-care in children and young people with CP, whilst goal-setting training showed better outcomes for children and young people with MMC compared to traditional therapy support. However, the findings are limited by the heterogeneity of the study populations, the interventions, the quality of the evidence, and the outcome measures utilised, and careful consideration will continue to be required before and during the use of these interventions. There is an urgent need for clinicians and researchers to collaborate to develop studies to evaluate these and other existing self-care interventions with designs and populations that reflect clinical realities and the characteristics of the populations served. In particular, this needs to involve expanding studies to populations beyond CP and DCD.

4.11 Recommendations for future research

From this review, there are three clear future directions for studies of self-care. First, further exploratory studies to investigate how physical and social (including cultural) environmental factors influence self-care, including how they may interact with health conditions, body functions, and personal factors in the context of children's self-care.

Second, pain and sensory processing should be investigated further as both these factors demonstrated associations with self-care, but further large-scale evidence is needed to understand and test the relationships.

Third, and perhaps more urgently, future studies are needed to evaluate formally, at a large scale, the range of self-care interventions in practice and in later stages of development to produce summative conclusions and inform guidelines about which self-care interventions to use when and with whom. While some intervention studies were identified, overall, the evidence base about the effectiveness of interventions on children's self-care is very limited. This is especially concerning when considering the high prevalence of self-care problems observed in practice. The findings from the present review provide proof that, in principle, self-care interventions for children can be formally evaluated.

4.12 Conclusion

Whilst body functions show strong associations with self-care, there is also preliminary evidence to suggest that environmental factors are also important. Research about effective interventions is limited and skewed towards one diagnostic condition, and further research is recommended to investigate interventions applicable to a wider range of children and young people. In the next chapter, chapter 5, I discuss the EASIER study which investigated factors influencing self-care in children, with and without motor impairments.

Table 4.1 Quality appraisal items from the RTI bank used for non-randomised observational studies.

QA Category	**Rationale**	**Proposed items**
detection bias	Based on the included studies it is anticipated that this is to be an important bias category for differentiating quality of studies	(Q5) Was the assessor blinded to the outcome, exposure, or intervention status of the participants? (Q6) Were valid and reliable measures implemented consistently across all study participants used to assess: (6.1) inclusion/exclusion criteria; (6.2) intervention/exposure; and (6.3) participant health benefits and harms? *(Q0) Was attrition/retention reported?*
selection bias	Based on the sample sizes and the study designs, these items are deemed appropriate to report on selection bias.	(Q1,2 modified) Are the inclusion/exclusion criteria and recruitment strategy clearly reported? (Q6) as above
confounding	It is anticipated that confounding will be an issue for most studies because of the study designs – especially the studies without controls/comparisons.	*(*Q0), (Q2) and (Q6) as above Q6 (modified) Were valid and reliable measures implemented consistently across all study participants used to assess confounding? (Q12) Any attempt to balance the allocation between the groups or match groups (e.g., through stratification, matching, propensity scores)*?*

[1] The Q0 is not from RTI but was added by the authors. The RTI has items on how attrition was handled but based on previous experience, we anticipate that attrition data in the papers will be limited so added this item to further differentiate quality.

Table 4.2 Study Characteristics

Author/s	**Year**	**Design as reported by authors**	**Participants**	**Description of Population**	**Age Group**	**Outcome Measure**
Adler C. et al.	2015	Nonrandomized, Cross-sectional Study	18	With and without Mirror Movements	6-16 years	Questionnaire developed by authors comparing 33 bimanual ADL's
Adler C. et al.	2014	Nonrandomized, Cross-sectional Study	20	Hemiparesis	6-12 years	AMPS
Alaniz ML et al.	2015	Nonrandomized, Cross-sectional Study	51	With and without Autistic Spectrum Disorder	4-10 years	Questionnaire developed by authors comparing 27 items in 4 domains
Alemdar D, Polat S	2014	Descriptive, Comparative Study	255	Children cared for in different settings	3-6 years	Self-Care Skills Control List
Alemdaroğlu-Gürbüz I, Karakuş AB	2019	Cross-sectional Study	100	Cerebral Palsy	5-15 years	Barthel Index
Assis-Madeira EA, Carvalho SG & Blascovi-Assis SM	2013	Cross-sectional Study	49	Cerebral Palsy	3-7 years	PEDI (Brazilian Version)
Babik I et al.	2019	Cross-sectional Study	38	Arthrogryposis	1-5 years	Observation of Feeding Behaviours (non-standardised)
Bartlett DJ et al.	2014	Longitudinal Study	429	Cerebral Palsy	1-5 years	Self-care domain of Child Engagement in Daily Life Measure

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Blanco Martinez N et al.	2020	Cross-sectional Study	40	Neurodevelopmental Disorder	5-12 years	CASP
Blank R et al.	2008	Individual Cohort study (B-A-B design)	64	Cerebral Palsy	3-6 years	Measurement of Activities of Daily Living (M-ADL)
Burgess A et al.	2019	Longitudinal Study	290	Cerebral Palsy	1-5 years	PEDI
Burgess A et al.	2020	Longitudinal Study	71	Cerebral Palsy	2-12 years	PEDI-CAT
Burgess A et al.	2021	Cross-sectional Study	74	Cerebral Palsy	8-12 years	PEDI-CAT
Chaovalit S, Dodd KJ, Taylor NF	2021	Randomised Control Study	42	Cerebral Palsy	4-12 years	WeeFIM
Chen KL et al.	2010	Comparative Study	604	With and without DD	0-12 years	PEDI-C
Chi IJ, Lin LY	2021	Comparative Study	132	Autistic Spectrum Disorder	4-6 years	PEDI-C
Chi IJ, Lin LY	2022	Cross-sectional Study	60	Autistic Spectrum Disorder	4-5 years	PEDI-C, AMPS
Chiarello LA et al.	2014	Multi-site prospective cohort study	539	With and without CP	1-4 years	Child Engagement in Daily Life; PPT-OMS
Chien CW et al.	2014	Nonrandomized, Cross-sectional Study	253	With and without DD	2-12 years	VABS
Cho M, Kim DJ, Yang Y	2015	Pre/post test	56	Cerebral Palsy	4-7 years	WeeFIM
Colver A et al.	2012	Cross-sectional Study	818	Cerebral Palsy	8-12 years	Assessment of Life Habits
Cooper An et al.	2019	Longitudinal Study	33	Arterial Ischemic Stroke	9-10 years	VABS-II

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Dang VM	2015	Longitudinal Study	818	Cerebral Palsy	8-12 years	Assessment of Life Habits
De Brito Brandao M et al.	2010	Single Blinded RCT	16	Hemiplegic CP	5-7 years	PEDI
De Brito M, Gordon AM, Mancini MC	2012	Randomised Control Study	16	Cerebral Palsy	3-10 years	PEDI; COPM
Delgado-Lobete L et al.	2020	Cross-sectional study	300	Typically Developing	5-8 years	DCDDailyQ
Delgado-Lobete L et al.	2022	Descriptive Study	370	With and without DCD	5-10 years	DCDDailyQ
Di Rezze B et al.	2019	Longitudinal Study	421	Autistic Spectrum Disorder	3-9 years	VABS-II
Dogruoz Karatekin BD et al.	2021	Cross-sectional Study	110	Cerebral Palsy	1-18 years	WeeFIM
Dolva AS, Kleiven J	2021	Longitudinal Study	43	Down Syndrome	5-14 years	PEDI
Donlau M, Mattison S, Glad-Mattison G	2013	Pilot Study	22	Myelomeningocele (MMC)	3-17 years	GAS; COPM
Ferreira FR et al.	2018	Observational Transversal Study	15	Myelomeningocele (MMC)	1-4 years	PEDI
Figueiredo PR et al.	2020	Randomised Control Study	41	Cerebral Palsy	4-16 years	PEDI
Fisher A et al.	2018	Nonrandomised, Cross-sectional Study	52	Autistic Spectrum Disorder	6-17 years	VABS-II
Forst H et al.	2022	Cohort Study	73	Cerebral Palsy	4-17 years	PEDI-CAT, WeeFIM
Gaser D et al.	2022	Cross-sectional Study	41	Leukemia/Non-Hodgins Lymphoma	4-18 years	AskP

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Green SA, Carter AS	2014	Longitudinal Study	162	Autistic Spectrum Disorder	1-2 years	VABS
Halbig M, Horneff G	2009	Longitudinal Study	114	Juvenile Ideopathic Arthritis	7-16 years	CHAQ
Hamer Rohrer U, Smit N, Burger M	2012	Single System (A-B-A-B-A) Study	1	Cerebral Palsy	4 years 9 months	PEDI
Holloway JM et al.	2021	Cross Sectional Study	22	Autism Spectrum Disorder	4-5 years	Preschool ACS
Ireland PJ et al.	2011	Cross Sectional Study	44	Achondroplasia	3-7 years	WeeFIM
Irwin LN et al.	2021	Cross Sectional Study	141	ADHD	8-13 years	BASC 2/3
James S et al.	2015	Randomized, Cross-Sectional Study	101	Cerebral Palsy	8-17 years	AMPS
Jasmin E et al.	2009	Descriptive Study	35	Autistic Spectrum Disorder	3-4 years	WeeFIM; VABS II
Josenby AL et al.	2015	Follow up Study	24	Cerebral Palsy	4-16 years	PEDI
Joubert F, Franzen D	2016	Nonrandomized, Cross-Sectional Study	19	Arthrogryposis	0-7 years	PEDI
Jovellar-Isiegas P et al.	2020	Cross-sectional Study	53	Cerebral Palsy	6-15 years	PEDI-CAT
Kara OK et al.	2021	Cohort Study	55	ADHD	6-11 years	PEM CY
Kaur R et al.	2022	Comparative Study	30	Autistic Spectrum Disorder	4-14 years	Questionnaire developed by authors
Keller JW et al.	2021	Cross-sectional Study	31	Upper Motor Neuron Lesion	6-18 years	WeeFIM
Ketelaar M et al.	2015	Longitudinal Study	100	Cerebral Palsy	1-4 years	PEDI-FSS

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Kilincaslan A et al.	2019	Cross-sectional study	102	Autism Spectrum Disorder, Intellectual Disability	6-18 years	Waisman Activities of Daily Living Scale, Basic Daily Living Skills (BDLS) Questionnaire
Ko EJ et al.	2019	Randomised Control Study	18	Cerebral Palsy	4-7 years	PEDI
Kruisen Terpstra AJA et al.	2015	Longitudinal Study	92	Cerebral Palsy	1-4 years	PEDI-FSS
Kuijper MA et al.	2010	Cross-sectional Study	61	Cerebral Palsy	5-14 years	PEDI-NL
Kusumoto Y et al.	2021	Cross-sectional Study	76	Cerebral Palsy	5-18 years	PEDI
Kwon HY, Ahn SY	2016	Randomised Control Study	7	Spastic Diplegia	4-7 years	WeeFIM
Lopes O et al.	2022	Cross-sectional Study	33	Cancer	2-18 years	PEDI-CAT
Majnemer A et al.	2010	Cross-sectional Study	95	Cerebral Palsy	6-12 years	VABS
Markowitz JT et al.	2022	Qualitative, Phenomenological Approach	17	Fibrodysplasia Ossificans Progressiva (FOP)	4-7 years	N/A (parent interview)
Missiuna C et al.	2007	Qualitative, Phenomenological Approach	13	Developmental Coordination Disorder (DCD)	6-14 years	N/A (parent interview)
Montes-Montes R et al.	2021	Case Control Study	60	ADHD	5-15 years	DCDDailyQ
Mota LAT et al.	2022	Cohort Study	14	Stroke	2-6 years	PEDI (Brazilian Version)
Naik SJ, Vajarattkar PV	2019	Qualitative, Phenomenological Approach	20	Autism Spectrum Disorder	5-9 years	N/A (parent interview)
Orvahl AM et al.	2010	Cross-Sectional Study	195	Cerebral Palsy	3-15 years	PEDI (Swedish Version)

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Palisano RJ et al.	2019	Multi-site Prospective Cohort Study	708	Cerebral Palsy	1-11 years	Child Engagement in Daily Life
Park ES	2014	Nonrandomized Control Study	34	Cerebral Palsy	3-12 years	PEDI-FSS
Park EY	2018	Longitudinal Study	222	Cerebral Palsy	3-18 years	PEDI
Park EY, Kim EJ	2018	Longitudinal Study	162	Cerebral Palsy	3-15 years	PEDI
Park H et al.	2021	Cross-sectional Study	59	Cerebral Palsy	2-14 years	PEDI-CAT
Parkes J, McCullough N, Madden A	2010	Nonrandomized, Cross-Sectional Study	102	Cerebral Palsy	8-12 years	Life-H
Pavao SL et al.	2014	Cross Sectional Study	10	Cerebral Palsy	5-12 years	PEDI
Pavao SL et al.	2021	Cross Sectional Study	28	Cerebral Palsy	5-15 years	PEDI
Richard PR, Noell GH	2018	Experimental Study	3	Autism Spectrum Disorder	5 years	Task Analysis
Rigby PJ, Ryan SE, Campbell KA	2009	Baseline-intervention-baseline study.	30	Cerebral Palsy	2-6 years	COPM; Home Activity Log Interview
Rosenberg L	2015	Cross-Sectional Study	60	Typically developing	6-9 years	CPQ
Saquetto MB et al.	2018	Randomized Control Study	63	Cerebral Palsy	1-12 years	PEDI
Simsek TT et al.	2011	Randomized Control Study	30	Cerebral Palsy	1-12 years	WeeFIM
Simsek TT, Turkucuoglu B, Tezcan C	2015	Cross-Sectional Study	116	Spina Bifida	5-18 years	WeeFIM
Smits DW et al.	2011	Longitudinal Study	116	Cerebral Palsy	5-7 years	PEDI-NL
Snider L et al.	2009	Longitudinal Study	100	Children born preterm	0-1 year	VABS

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Song CS	2013	Cross-Sectional Study	68	Cerebral Palsy	1-3 years	WeeFIM
Sorsdahl AB et al.	2010	Repeated measures design	22	Cerebral Palsy	2-9 years	PEDI
Steinhart S et al.	2018	Nonrandomized, Cross-Sectional Study	113	Myelomeningocele (MMC)	3-18 years	PEDI
Sullivan MC & Msall ME	2007	Nonrandomized, Cross-Sectional Study	155	Children born preterm	4 years	WeeFIM
Summers J, Larkin D, Dewey D	2008	Qualitative, phenomenological approach	87	With and without DCD	6-9 years	N/A (parent interview)
Travers BG et al.	2022	Descriptive study	101	With and without Autistic Spectrum Disorder	6-10 years	VABS-II
Tseng MH et al.	2011	Nonrandomised, Cross-sectional Study	216	Cerebral Palsy	4-15 years	PEDI-C
Van der Linde BW et al.	2015	Nonrandomised, Cross-sectional Study	50	Developmental Coordination Disorder (DCD)	5-8 years	DCDDailyQ
Van Eck M et al.	2010	Nonrandomised, Cross-sectional Study	94	Cerebral Palsy	12-16 years	VABS-II
Verkerk G et al.	2013	Longitudinal Study	143	VLBW children without CP	0-3 years	PEDI-NL
Viera MT, Da Silva J, Fronio da Silva J	2017	Nonrandomised, Cross-Sectional Study	26	Children born preterm	1-3 years	PEDI
Vos RC	2013	Longitudinal Study	497	Cerebral Palsy	1-16 years*	VABS
Voulgarakis HM et al.	2021	Observational Transversal Study	657	Autistic Spectrum Disorder	7-11 years	VABS-II

Author/s	Year	Design as reported by authors	Participants	Description of Population	Age Group	Outcome Measure
Wang TN et al.	2009	Nonrandomised, Cross-Sectional Study	104	Children with and without DCD	7-8 years	VABS-C
Wu WC et al.	2013	Quasi-experimental, one-group pre- intervention–postintervention and follow-up trial	7	Hemiplegic CP	5-11 years	PEDI
Yela-Gonzales N et al.	2021	Cross-sectional Study	40	Autistic Spectrum Disorder	4-10 years	PEDI
		Total participants:	**12575**			

Table 4.3 Key results from the primary studies extracted for each included study.

Authors	Year	Key result(s)	Intervention
Adler C et al.	2015	Mirror movements have a negative impact on bimanual performance and time needed to complete self-care (p=0.24)	No intervention
Adler C et al.	2014	The motor skills scale of the AMPS correlated with motor competence, and the process skills scale of the AMPS correlated with cognitive abilities when measuring self-care	No intervention
Alaniz ML et al.	2015	Grip and pinch strength correlated with independence in self-care in children with autism and typically developing children.	No intervention
Alemdar D, Polat, S	2014	Significantly higher scores on “Dressing,” “Personal Care” skills of the Self-Care Skills Control List for children attending nursery in comparison to children being cared for by their mothers and by baby-sitters	No intervention
Alemdaroğlu-Gürbüz I, Karakuş AB	2019	A strong correlation was found between mobility, motor function and self-care independence as measure on the Barthel Index in children with CP.	No intervention
Assis-Madeira EA, Carvalho SG, & Blascovi-Assis SM	2013	Children with severe CP with low SES presented worse performance in self-care skills	No intervention
Babik I et al.	2019	Children with movement impairments demonstrated different feeding behaviours from typically developing children. This included spending less time lifting spoons from the table, placing food in spoons and transporting food to their mouths.	No intervention
Bartlett, DJ et al.	2014	Higher motor function, fewer health conditions and higher levels of adaptive behaviour is associated with greater self-care participation	No intervention
Blanco Martinez N et al.	2020	Children with NDD presented with moderate or severe participation limitation in ADL in comparison to TD children. (p<001)	No intervention

Authors	Year	Key result(s)	Intervention
Blank R et al.	2008	Conductive education increased self-care competence compared with no significant improvement under special education.	Conductive Education
Burgess A et al.	2019	Self-care development achieved by 60 months was negatively associated with the severity of manual ability impairment.	No intervention
Burgess A et al.	2020	Children classified in MACS levels I to IV showed progress in self-care development between the ages of 5 and 12 years; Children in MACS level V showed a decline in self-care.	No intervention
Burgess A et al.	2021	Strong association between self-care and bimanual performance in children with CP.	No intervention
Chaovalit S, Dodd KJ, Taylor NF	2021	Sit-to-stand training improved independence and mobility for children with CP.	Sit-to-stand training
Chen KL et al.	2010	Taiwanese children in study needed more assistance with self-care than the American Children	No intervention
Chi IJ, Lin LY	2021	Young children with ASD obtained significantly lower scores for self-care performance and visual perception compared to TD children. Study found positive correlation between self-care performance and visual motor integration in children with ASD.	No intervention
Chi IJ, Lin LY	2022	Children with ASD present with poor self-care performance and needed assistance in comparison to TD children.	No intervention
Chiarello LA et al.	2014	Self-care varied by age and motor ability	No intervention
Chien CW et al.	2014	Hand skill performance followed by children's age, disability status, cultural context most significant predictors of self-care function	No intervention
Cho M, Kim DJ, Yang Y	2015	WeeFIM scores and self-care performance improved for all children who participated in the study	Visual Perceptual Intervention
Colver A et al.	2012	Higher participation in self-care was significantly associated with a better physical environment at home (p<0.1)	No intervention

Authors	Year	Key result(s)	Intervention
Cooper AN et al.	2019	At 5 years after a stroke, children presented with significantly poorer activities of daily living than age expectations.	No intervention
Dang VM et al.	2015	Impairment predicted participation in self-care (p<0.001); Pain predicted participation in self-care (<0.001) except for mealtimes	No intervention
De Brito Brandao M et al.	2010	Higher gains were observed in the intervention group for functional skills and independence post intervention (functional skills p=0.013, independence p=.0001) and follow-up (functional skills p=0.004; independence p=0.0016	CIMT
De Brito Brandao, M. Gordon AM, Mancini MC	2012	Both groups showed significant improvements on functional measures. Group · Assessment interaction in COPM performance revealed greater improvements for the HABIT group after intervention (p = .04).	CIMT/ Bimanual training
Delgado-Lobete L et al.	2020	Differences in self-care observed in boys and girls in Spanish participants whereas as both Dutch boys and girls performed self-care at the same level. Dutch children performed better than Spanish children in self-care as reported by parents.	No intervention
Delgado-Lobete L et al.	2022	Motor performance had a direct effect on daily participation and the delayed learning of ADL in children with and without DCD.	No intervention
Di Rezze B et al.	2019	Improvement in Daily Living Skills (DLS) domain score from Vineland Adaptive associated with lower and improving ASD severity.	No intervention
Dogruoz Karatekin BD et al.	2021	Children with CP presented with significantly worse spasticity and reduced scores on the WeeFIM self-care subscale following the COVID-19 pandemic lockdown restrictions.	No intervention
Dolva AS, Kleiven J	2021	PEDI scores in self-care for children with DS was lower for TD children however for children with DS improvement in self-care score was observed until the age of 14 years.	No intervention
Donlau M et al.	2013	Goalsetting showed a better outcome for improving toilet independence than traditionally performed training or rehabilitation support.	Goalsetting training

Authors	Year	Key result(s)	Intervention
Ferreira FR et al.	2018	PEDI scores in self-care varied according to the age and level of participants	No intervention
Fiqueiredo PR et al.	2020	Children in HABIT group showed greater improvement in functional and self-care skills compared to children who received usual care.	Hand-arm bimanual intensive therapy (HABIT)
Fisher A et al.	2018	Positive association between balance and daily living skills specific to youths with below average IQ (p<.001)	No intervention
Forst H et al.	2022	Children who received OT intervention after selective dorsal rhizotomy showed significant improvements in upper and lower body dressing skills.	OT after SDR
Gaser D et al.	2022	Multifunctional impairments in self-reported ADLs (Activities of Daily Living), motor performance and physical activity observed in children shortly after a diagnosis of leukaemia or non-Hodgkin lymphoma.	No intervention
Green SA, Carter AS	2014	Self-care associated with parental stress levels. Children with lower IQ and more severe symptoms showed lower gains in self-care	No intervention
Halbig, M. and Horneff, G.	2009	All functional areas of the CHAQ improved significantly during therapy with etanercept (P < 0.0001)	Etanercept
Hamer-Roher et al.	2012	Intervention associated with increased scores in functional skills (FS) on the PEDI.	Constrained Induced Movement Therapy
Holloway JM et al.	2021	Children with ASD who had greater gross motor skills demonstrated greater participation in self-care	No intervention
Ireland PJ et al.	2011	Functioning improved in children with achondroplasia between the ages of 3 and 5 years (p<0.001) but not subsequently (p=0.4)	No intervention

Authors	Year	Key result(s)	Intervention
Irwin LN et al.	2021	Participants with ADHD presented with significant more difficulties in activities of daily living (ADL) in comparison to participants without ADHD (p<.005). Study results indicated that lower working memory in ADHD group predicted lower performance in ADL.	No intervention
James S et al.	2015	The AHA and JTTHF dominant upper limb score together explained 57% of the variance in AMPS motor scale scores. TVPS-3 Visual Sequential Memory, TVPS-3 Visual Closure, and JTTHF dominant upper limb score together explained 35% of the variance in AMPS process scale scores.	No intervention
Jasmin E et al.	2009	Significant correlation between sensory avoiding behaviour (p=0.4); fine motor quotient (p=0.3) and self-care for children in autism group	No intervention
Josenby AL et al.	2015	All scores improved significantly (p<0.01) during the first 5 years in patients assigned to GMFCS levels I–III and IV–V. Between 5 years and 10 years, changes were seen in GMFCS levels I–III in the functional skills(p=0.04), caregiver assistance self-care (p=0.03), GMFCS levels IV–V showed small changes between 5 years and 10 years after surgery.	Selective Dorsal Rhizotomy
Joubert F, Franzsen D	2016	The infant and toddler group performed above expected levels in the self-care domain, whereas the preschool and school-aged group performed below the expected level. Correlation between the amount of caregiver assistance needed and the participants' level of independence (p=0.73)	No intervention
Jovellar-Isiegas P et al.	2020	A significant relationship (p<.001) was found between sensory processing difference, particularly proprioception, and poor performance in ADL in children with UCP.	No intervention
Kara OK et al.	2021	Parents of children with ADHD reported that children showed a higher level of personal care during the COVID-19 pandemic.	No intervention
Kaur R et al.	2022	A drastic regression in the mean values of pre and post lockdown ADL score observed in study participants.	No intervention
Keller JW et al.	2021	Trunk control, followed by upper extremity SVMC, spasticity and strength explained most oof the variance in self-care independence in children with upper motor neuron lesions.	No intervention
Ketelaar M et al.	2014	Despite large variations among individuals in the development of mobility and self-care capabilities in young children with cerebral palsy, distinct developmental trajectories were found for children in different GMFCS levels.	No intervention

Authors	Year	Key result(s)	Intervention
Kilincaslan A et al.	2019	ASD group scored significantly lower in daily living skills (DLS) compared to the ID group. Age, intellectual level, speech level, autism severity, and monthly household income identified as independent correlates of DLS.	No intervention
Ko EJ et al.	2019	No significant improvement in self-care as measured on the PEDI-CAT observed in the intervention group.	Task oriented training
Kruijsen-Terpstra AJA et al.	2015	PEDI-FSS self-care scores increased over time ($p < .001$) Significant differences in self-care development (i.e., significant interaction with time) for GMFCS level, type of CP, intellectual capacity, and epilepsy.	No intervention
Kuijper MA et al.	2010	The Spearman correlation coefficient between the MACS and the self-care domain of the PEDI Caregiver Assistance Scale was high and statistically significant ($r =.72$)	No intervention
Kusumoto Y et al.	2021	PEDI functional skills scale scores correlated with the Box and Block test in the dominant hand and GMFCS ($r^2=0.71$)	No intervention
Kwon HY, Ahn SY	2016	There were statistically significant differences in the amount of change before and after the training among the three intervention groups for the gross motor performance measure and functional independence measure. ($p<0.05$)	Task orientated training and High variability practice
Lopes O et al.	2022	Children with cancer presented with lower mobility scores on the PEDI-CAT than healthy peers but PEDI-CAT daily activities score was in the average expected.	No intervention
Majnemer A et al.	2010	Functional limitations were more likely for children with quadriplegia ($P < .0001$), but not diplegia or hemiplegia, and for children in level IV-V, but similar for level I and level II-III.	No intervention
Markowitz JT et al.	2022	Children and parents reported that FOP has a significant impact on children's ability to participate in ALD, in particularly dressing and toileting.	No intervention
Missiuna C et al.	2007	Nearly all parents identified performance in functional tasks such as feeding and dressing as somewhat or very delayed.	No intervention

Authors	Year	Key result(s)	Intervention
Montes-Montes R et al.	2021	Children with ADHD demonstrated poorer motor performance and less participation in ADL compared to TD children. (p<.01)	No intervention
Mota LAT et al.	2022	Preschool children showed age-appropriate functional outcomes on self-care domains on the PEDI after stroke.	No intervention
Naik SJ, Vajarattkar PV	2019	Parents of children with ASD reported that their children had the most difficulties with eating, followed by brushing and grooming, and least for toileting.	No intervention
Öhrvall AM et al.	2010	Children classified as MACS and GMFCS levels I or II scored higher than children in MACS and GMFCS levels III to V on both the self-care and mobility domains of the PEDI, with significant differences between all classification levels (p<0.001)	No intervention
Palisano RJ et al.	2019	Children with GMF levels IV or V have limited self-care independence compared to levels I, II, or III.	No intervention
Park ES et al.	2014	Significant improvement in PEDI FSS scores after hippotherapy intervention	Hippotherapy
Park EY	2018	Higher initial values of gross motor function correlated with higher initial values of ADL performance (p<.001). Correlation between improvement in gross motor function and gradual improvement in ADL performance (p=0.004). Initial high score of gross motor function correlated with a high growth rate for ADL performance (p<.001)	No intervention
Park EY, Kim EJ	2018	Correlation (p<0.01) between frequency of Occupational Therapy and improvement of PEDI FSS.	Occupational- and Physiotherapy
Park H et al.	2021	Range, accuracy, and fluency dimension of Melbourne Assessment of Unilateral Upper Limb Function Version 2, and the Upper Limb Physician's Rating Scale correlated moderately with the daily activity domain of the PEDI-CAT.	No intervention
Parkes J, McCullough N, Madden A	2010	Children with cerebral palsy and severe co-impairments were significantly less likely to experience higher levels of participation in most areas of everyday life when compared to children with cerebral palsy and no severe co-impairments.	No intervention

Authors	Year	Key result(s)	Intervention
Pavão SL et al.	2014	Significant relationship (p<0.05) between postural control and functional abilities.	No intervention
Pavão SL et al.	2021	Behavioural outcome of sensory processing (as tested on sensory profile) a significant predictor (p<0.05) of functioning for self-care in children with CP.	No intervention
Richard PR, Noell GH	2018	A Video-Based Intervention (VBI), video prompting combined with backward chaining was effective in teaching children with ASD to tie their shoes	Video prompt models and backward chaining
Rigby PJ, Ryan SE, Campbell KA	2009	Significant improved participation and improvement with self-care when children used the adaptive seating devices.	Adaptive seating
Rosenberg, L.	2015	Executive function found to predict self-care independence	No intervention
Saquetto, MB et al.	2018	The addition of an education programme to supplement therapy demonstrated a significantly greater benefit in the self-care domain on the FSS	Educational Programme
Simsek TT et al.	2011	No direct effects of KT observed on gross motor function and functional independence.	Kinesio taping (KT)
Simsek, TT, Turkucuoglu B, Tezcan S	2015	A relationship was found between weight and self-care in both girls and boys	No intervention
Smits DW et al.	2011	Self-care predicted by level of gross motor function and intellectual capacity	No intervention
Snider L et al.	2009	Delays in functional performance for infants assessed at 1year who were born preterm	No intervention
Song CS	2013	Self-care significantly affected by CP type but not by age or standing independence	No intervention

Authors	Year	Key result(s)	Intervention
Sorsdahl AB et al.	2010	Change scores in the Pediatric Evaluation of Disability Inventory (PEDI) ranged 2.0-6.7, p < 0.01 in the Self-care domain of the Functional Skills dimension, and the Self-care and Mobility domains of the Caregiver Assistance dimension	Intensive goal directed physiotherapy
Steinhart S et al.	2018	The presence of hydrocephalus was the most significant determinant of dependence in self-care activities in this study	No intervention
Sullivan MC, Msall ME	2007	Neonatal illness, socioeconomic status, preschool health, and motor predictors explained 44% of the variance in functional performance.	No intervention
Summers J, Larkin D, Dewey D.	2008	Parents of children with DCD reported that coordination difficulties impacted on all areas of self-care for children in the study	No intervention
Travers BG et al.	2022	Strong relationship (p=.02) between motor difficulties and all domains of daily living skills. Combined results for motor and sensory functioning a stronger predictor of difficulties in daily living skills than motor or sensory functioning alone. (p<.001)	No intervention
Tseng MH et al.	2011	Correlation between increase in GMFCS level and daily function (p<.0001)	No intervention
Van der Linde BW et al.	2015	Compared with their peers, children with DCD showed poor performance of self-care and less frequent participation in self-care	No intervention
van Eck M et al.	2010	MACS and ABILHAND-Kids were both strongly associated with personal daily activities (explained variance 77% and 84%, respectively)	No intervention
Verkerk, G et al.	2013	Higher frequency of disability in self-care in VLBW pre-schoolers compared to term born peers	No intervention
Vieira MT, da Silva J, Frônio da Silva J	2017	Day care centres seem to positively affect self-care independence in premature children between 18 and 42 months	No intervention
Vos RC et al.	2013	Significant relationship between intellectual disability and the developmental trajectory for performance of self-care (p<.001)	No intervention

Authors	Year	Key result(s)	Intervention
Voulgarakis HM et al.	2021	Significant correlation (p=.004) between gastrointestinal (GI) symptoms and daily living skills in autistic children.	No intervention
Wang, TN et al.	2009	The functional performance of children with DCD was statistically significantly lower than those without DCD (p's<0.05).	No intervention
Wu WC et al.	2013	Significant improvement in PEDI scores after intervention	Group CIMT
Yela-Gonzales N et al.	2021	A correlation was found between sensory processing differences and performance of activities of daily in living in autistic children (P<0.0001)	No intervention

Table 4.4 Self-care Measures and Outcomes in the Included Studies

Outcome measures (n=29) (no. studies using measure)	**Outcomes (n=97) (study references)**
Assessment of life habits (2/97)	Self-care [123, 124]
Assessment of motor and process skills (AMPS) (3/97)	Self-care [131, 192, 193]
Ask Performance version (1/97)	Self-care[159]
Barthel Index (1/97)	Self-care[194]
Basic Daily Living Skills (BDLS) Questionnaire (1/97)	Self-care[160]
Behavioural Assessment for Children (BASC 2/3) (1/97)	Self-care[150]
Canadian Occupational Performance Measure (COPM) (3/97)	Self-care [145, 168, 188]
Child and Adolescent Scale of Participation (CASP) (1/97)	Participation in self-care[18]
Child Health Assessment Questionnaire (CHAQ) (1/97)	Self-care [154]
Child Engagement in Daily Life (3/97)	Self-care [51, 181, 195]
Children's Participation Questionnaire (CPQ) (1/97)	Self-care[196]
DCD Daily Q (4/97)	Performance of Self-care [127, 178, 186, 197]
Functional Independence Measure (Weefim) (12/97)	Self-care [40, 136, 143, 155, 157, 162, 171, 172, 182, 189, 191, 198]
Home Activity Log interview (1/97)	Self-care [168]
Life habits questionnaire (Life H) (1/97)	Self-care [199]
Measurement of Activities of Daily living (M-ADL) (1/97)	Self-care[166]
Modified version of Pediatric Physical Therapy Outcomes Management System (PPT OMS) (1/97)	Self-care [181]
Observations of feeding behaviours (non-standardised) (1/97)	Self-care[152]
Parent interview (4/97)	Self-care [42, 128, 138, 156]
Participation and Environment Measure for Children and Youth (PEM-CY) (1/97)	Self-care[149]
Pediatric Evaluation of Disability Inventory (PEDI) (Including PEDI Brazilian version; PEDI-NL; PEDI Swedish; PEDI-C Versions) (31/97)	Self-care [24, 35, 65, 66, 126, 129, 131, 146-148, 151, 153, 161, 164, 165, 167, 169, 170, 174, 177, 180, 183, 185, 187, 188, 200-207]

Outcome measures (n=29) (no. studies using measure)	**Outcomes (n=97) (study references)**
Pediatric Evaluation of Disability Inventory Functional Skills Scale (PEDI-FSS) (3/97)	Self-care [190, 208, 209]
Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) (6/97)	Self-care[40, 158, 176, 210-212]
Preschool Activity Sort Card (Preschool ACS) (1/97)	Self-care[135]
Study questionnaire developed by authors (1/97)	Self-care [213]
Self-care skills control list (1/97)	Self-care [214]
Task Analysis (1/97)	Self-care[139]
Vineland Adaptive Behavior Scale (VABS) (6/97)	Self-care [4, 129, 134, 142, 215, 216]
Vineland Adaptive Behavior Scale 2nd Edition (VABS-II) (7/97)	Self-care [125, 132, 133, 136, 140, 141, 217]
Waisman Activities of Daily Living Scale (W-ADL) (1/97)	Self-care[160]

Table 4.5 Summary of factors associated with self-care and their associations.

		Related to self-care		**Not related to self-care**	**Coding**	
	Nr of studies	**Nr of studies**	**Direction of association**	**Nr of studies**	**% of studies supporting Association**	**Association**
Body functions						
Mental functions						
Executive function	1	1	+		100	+
Cognitive function	9	8	+	1	89	++
Mental functions of language	4	3	+	1		++
Attention functions	1	1	+			
Functions of the joints and bones						
Arthrogryposis	1	1	+		100	+
Achondroplasia	1	1	+		100	+
Fibrodysplasia Ossificans Progressiva (FOP)	1	1	+		100	+
Level of spinal cord lesion	1	1	+		100	+
Movement functions						
Functions of lower extremity structures	30	28	+	2	93	++
Functions of upper extremity structures	20	19	+	1	95	++
Sensory functions and pain						
Sensory functions unspecified	4	4	+		100	++
Pain	2	2	+		100	+
Seeing and related functions, other specified and unspecified	1	1	+		100	+
Functions of the digestive, metabolic and endocrine systems						
Weight	1	1	+		100	+

		Related to self-care		Not related to self-care	Coding	
	Nr of studies	Nr of studies	Direction of association	Nr of studies	% of studies supporting Association	Association
Birthweight	3	0	-	3		--
Environmental Factors						
Individual						
Socio-economic status	4	1	-	3	25	-
Physical environment	4	3	+	1		++
Cultural	2	2	+		100	+
COVID-19 lockdown restrictions	3	2	+		66	+
Personal factors						
Individual						
Child Mental Health	1		-	1		-
Child Behaviour	1		-	1		-
Health Status	1	1	+		100	+
Birth order	1		-	1		-
Educational placement	1	1	+		100	+
Developmental level	1	1	+		100	+
Age	5	5	+		100	++
Family factors						
Parental Stress	5	1	-	4	25	-
Caregiver Mental Health	1		-	1		-
Family ecology	1	1	+		100	+
Parental coping style	1		-	1		-
Number of children in family	1		-	1		-

(The number of studies refer to the number of studies that examined the association of the factors above with self-care. Double summary codes (e.g. ++ were applied when 3 or more studies showed an association. Code '+/-" was applied when studies differed in respect to the established association.)

Table 4.6 Summary of interventions associated with self-care and their associations.

		Related to improvement in self-care		Not related to improvement in self-care	Coding	
	Nr of studies	**Nr of studies**	**Direction of association**	**Nr of studies**	**% of studies supporting Ass**	**Association**
Interventions						
Therapy Interventions						
Constrained Induced Movement Therapy	3	3	+		100	++
Education Programme for Caregivers	1	1	+		100	+
Intensive Goal Directed Physiotherapy	1	1	+		100	+
Goalsetting training	1	1	+		100	+
Conductive Education	1	1	+		100	+
Hand-arm bimanual intensive therapy	1	1	+		100	+
Adaptive Seating	1	1	+		100	+
Sit-to-stand training	1	1	+		100	+
Task-Oriented Training	1	1	+		100	+
Increased frequency Occupational Therapy and Physiotherapy	1	1	+		100	+
Hippotherapy	1	1	+		100	+
Visual Perceptual Training	1	1	+		100	+
Video prompt modelling	1	1	+		100	+
Kinesiotaping	1			1		-
Surgical Interventions						
Selective Dorsal Rhizotomy	2	2	+		100	+
Pharmaceutical Interventions						

	Nr of studies	Related to improvement in self-care		Not related to improvement in self-care	Coding	
		Nr of studies	Direction of association	Nr of studies	% of studies supporting Ass	Association
Etanercept	1	1	+		100	+

(The number of studies refer to the number of studies that examined the association of the factors above with self-care. Double summary codes (e.g. ++ were applied when 3 or more studies showed an association. Code '+/-" was applied when studies differed in respect to the established association.)

Chapter 5: EASIER – Study of early self-care development

5.1 Background

The primary aim of this chapter is to describe the EASIER (Early Self-care in Children with and without Motor Impairments) study which formed the original basis for this doctoral research programme. The EASIER study originally aimed to investigate the levels and trajectories (path of development) of self-care in children aged 3-6 years old with and without motor impairments and the importance of demographic factors in explaining levels of self-care participation and path of development, including interactions with the level of motor impairment, at different time points. Questionnaires and assessments were selected based on evidence of parental and environmental factors influencing self-care, as discussed in Chapter 4, a systematic review of self-care in children and young people. This chapter focusses on the background, process followed, a descriptive analysis of the data obtained, and conclusions drawn.

5.2 Study design

The EASIER study was designed as a longitudinal cohort study, of which the overall aim was to generate new knowledge and evidence by identifying the trajectories, variation, and potential predictors of early self-care development in children with and without motor impairments, to provide evidence for guiding self-care interventions in children. The plan was for participants to be followed up every six months for three years from the point of participant's third birthday. As the data collection was discontinued after two rounds of follow up, due to a lack of participants, it was not possible to follow the original study design.

5.3 Sampling and recruitment

For this longitudinal study, the aim was to recruit two groups of children, n=100 children each. One group that consisted of children aged three years who had impairments in neuromusculoskeletal and movement related functions or mobility limitations; had a least some independent movement using skeletal muscles; and whose parents agreed to participate. A second group that consisted of children aged three years of where there were no concerns about development; no known impairments; and whose parents agreed to their participation in the study. The study looked to recruit children from a range of sociodemographic backgrounds and with a range of health statuses.

Pre-prepared recruitment packs for the study were designed, which consisted of information sheets for both parents and children. Packs were to be handed out to the parents of eligible children. It was anticipated that children with motor impairments would have been identified by therapy providers whilst typically developing 3-year-olds would have been presented with recruitment packs from the health visiting team.

As with most observational studies, the key parameters for a sample size calculation for the EASIER study were unknown until the study was completed. Therefore, instead of a formal size calculation, I used an estimate for a number of children likely to be needed to capture important, significant relationships in the study in relation to factors influencing self-care.

This age group was selected as limited information was available on the development of self-care in children aged 3-6 years old at the commence of this PhD project. Further, this age group was selected as an area for focus as children in England typically enter formal education (reception) in the year they turn 5 years old, and this is a time where children are often referred to occupational therapy due to challenges with participation in self-care. The study would add to the body of the knowledge to increase understanding of children's readiness and ability to participate in the formal school environment, as well as in the wider society.

5.4 Ethics

The study had favourable opinions from the NHS Research Ethics Committee and Health Regulation Authority (Reference IRAS 246896, 19-EM-0310).

The research project did not present any major ethical issues beyond the general issues related to non-invasive research with children and parents. Within these general issues, two are of specific importance: 1) children's right to contribute and 2) children's right to be safe from harm.

A report[113] by the Nuffield Council on Bioethics recommended that the best way of ensuring that children do not become vulnerable in research is to involve children and/or their parents in designing the studies and to ensure that they are enabled to make informed decisions throughout the research process.[113] The report also recommended that the nature of child and parent involvement and enablement depends on the population of children (e.g., their capabilities and interests) and the nature of the research. The EASIER study focused on young children who were unlikely to be able to make fully informed choices about their participation in research and who were likely to have limited attention spans and understanding for contributing directly to the research design.

It is recommended that in these circumstances, the children’s parents are usually best placed to inform the research and make decisions on their children’s behalf.[113] However, the children should also have opportunities to be involved in ways that suit them. Throughout the project:

- Good relationships and trust were proactively built with parents to facilitate open communication and reduce any worry about the research.
- Parents were provided with clear information about the study before they were asked to take part to enable them to make the best choice for their children. (Appendix B or web version https://blogs.ncl.ac.uk/lbrewer2/2020/09/20/information-for-parents-and-carers-on-the-easier-study/)
- Potential participants were offered opportunities to discuss the studies appropriately and sensitively so that they were able to make free and informed choices about whether to take part.
- Children were given as much control over their participation as possible. A special participation information sheet was created for children and this information used visuals to explain what the study was about. (Appendix C or

web version https://blogs.ncl.ac.uk/lbrewer2/2020/09/20/study-information-for-children/) Parents were encouraged to show the information sheet to children and discuss their willingness to participate in the study. Sensitivity was shown to their preferences not to participate (ongoing 'assent').

- The context of any data collection with children was carefully considered.

Ethical approval from the NHS Research Ethics Committee (REC) and Health Research Authority (HRA) specified that the study would be hosted in an NHS trust in the North of England and that the service providers would be able to identify eligible children against a prior selection criterion explained to them.

5.5 Data collection

The primary outcome, children's self-care, was set out to be measured using the daily activities domain on the PEDI-CAT. Children's mobility and cognitive skills were set to be measured using the PEDI-CAT Mobility and Social/Cognitive domain on the PEDI-CAT. Demographic information to be collected included: the postcode and main carer's educational level through an initial background questionnaire at baseline, along with details of whether the child attends nursery or preschool, and whether they have siblings and if so what ages.

The final measures for data collection included a background questionnaire (Table 5.1) designed for the study, the Parental Stress Scale (PSS)[218] and the Pediatric Evaluation of Disability Computer Adaptive Test (PEDI-CAT).[219] An important consideration for all assessment tools was that they needed to be succinct, as parents have limited time to spend on completing research questionnaires, and that they should be relatively easy to access and complete.

5.5.1 Sociodemographic and background details

Sociodemographic and background information were collected for all participations in the form of the EASIER study questionnaire (Table 5.1) using an electronic form on Qualtrics. By completing the electronic form, participants indicated that they consented to the study and a copy of the response was sent to participants by email upon completion. The questionnaire contained 12 questions related to demographics and participants' characteristics.

The purpose of these questions was to identify whether parents had concerns about their child's development prior to participating in the study. For example, question three, "Does your child handle objects easily" referred to children's ability to carry out fine motor tasks. The question was included due to the number of studies in Chapter 4 that referred to the impact of poor fine motor skills on children's self-care, particularly in relation to dressing themselves.

Although one can argue that these questions are subjective, the questions provided parents with the opportunity to voice their opinions or concerns about their children's development and fine motor skills without the additional stressor of another, possibly time-consuming, standardised assessment to complete. Some researchers[220] also take the view that parents know their children best and that researchers should value their contributions in this respect.

For questions related to family members, I investigated the association between family factors and independent participation in self-care. Parental working hours were included in the background questionnaire as previous research[221] has examined the impact of parental non-standard work schedules on a wide range of child outcomes. Positive associations were between parental working hours and child cognitive ability[222-224], one of the domains that is measured by the PEDI-CAT. I also wanted to investigate the impact of parental education on self-care and hypothesised based on previous research[225, 226], that parents who were educated to a higher level might have a better understanding of their child's developmental needs and how to best support them.

Following the studies discussed in Chapter 4, I also aimed to better understand the role that the family environment and ecology play in influencing children's development and participation in self-care. For example, researchers[227, 228] found that working parents in the UK report that grandparents are the most common source of informal childcare in their families. Sometimes grandparents can have different expectations from children, or rules in the house that impact on children's behaviour and development. For example, a recent study[229] found that grandparents are more likely than the child's parents to restrict participation in physical activities and outside play. In terms of family, other data that was deemed useful to obtain was whether the child had siblings, and if they were older or younger than the child.

The question regarding time spent at nursery followed on the from the results from one of the studies[144] included in the systematic review in Chapter 4. This study indicated that children who attended nursery or day-care settings, often referred to as childminders in the UK, had better self-care outcomes than children who did not attend nursery. I was interested to learn more about this phenomenon, particularly in the context of the high fees for childcare in the UK.[230] A study[231] reported that the UK has some of the most expensive child-care costs compared to other Western countries. Had I been able to demonstrate a clear link between nursery attendance and children's self-care development from the EASIER study discussed in this chapter, this research could have contributed to the evidence base advocating for more government subsidised child-care.

Finally, the intent of question seven was to ascertain from the response whether there might be cultural barriers to answering some of the questions in the study. Post codes of participants were asked for the in the questionnaire with the intention to sort them into indices of multiple deprivation (IMD) deciles. Previous research[232] has indicated that neighbourhood deprivation can impact on children's health and behavioural outcomes.

The questions included in the background questionnaire are included in table 5.1.

Table 5.1 Background Questionnaire for EASIER study

Question:		**Response Option:**
1.	Is your child?	a. A boy
		b. A girl
2.	What is your child's date of birth?*	
3.	Do you have concerns about your child's development?	a. Yes
		b. No
4.	Does your child handle objects easily?	a. Yes
		b. No
5.	Does your child have any siblings?	a. Yes – If yes, how many are older than your child?
		b. No
6.	Does your child attend nursery/go to a childminder?	a. Yes
		b. No
7.	What language does your child speak at home?*	
8.	Who is your child's main carer?	a. Mother
		b. Father
		c. Grandparent
		d. Other
9.	What is the main carer's highest qualification?*	
10.	On average, how many hours does the main carer work outside home per week?	a. Less than 10 hours
		b. 10-20 hours
		c. 21-30 hours
		d. 31-40 hours
		e. More than 40 hours
11.	What postcode does your child live in?*	
12.	Where did you hear about the study?*	

*open-ended questions

5.5.2. Parental Stress Scale (PSS)

The PSS[218] was created in 1995 as a shorter alternative to other parental stress measures such as the parenting stress index (PSI) which is a lengthier and more invasive test than the PSS.[233] It was designed to assess both stressful and rewarding components of parenting and consists of 4 domains: parental rewards, parental stressors, lack of control, and parental satisfaction. This 18-item questionnaire was selected as the questionnaire demonstrated evidence of excellent content validity[234] and was also available as a free tool online. It has also been used in studies similar to the EASIER.[235, 236]

The 18 questions for the PSS are:

1. I am happy in my role as a parent.
2. There is little or nothing I wouldn’t do for my child(ren) if it were necessary.
3. Caring for my child(ren) sometimes takes more time and energy than I have to give.
4. I sometimes worry whether I am doing enough for my child(ren).
5. I feel close to my child(ren).
6. I enjoy spending time with my child(ren).
7. My child(ren) is an important source of affection for me.
8. Having child(ren) gives me a more certain and optimistic view for the future.
9. The major source of stress in my life is my child(ren).
10. Having child(ren) leaves little time and flexibility in my life.
11. Having child(ren) has been a financial burden.
12. It is difficult to balance different responsibilities because of my child(ren).
13. The behaviour of my child(ren) is often embarrassing or stressful to me.
14. If I had to do it over again, I might decide not to have child(ren).
15. I feel overwhelmed by the responsibility of being a parent.
16. Having child(ren) has meant too few choices and too little control over my life.
17. I am satisfied as a parent.
18. I find my child(ren) enjoyable.

The scoring for this test consisted of a 5-point scale. Response options included strongly disagree, disagree, undecided, agree and strongly agree.

5.5.3 Pediatric Inventory of Disability Inventory-Computer Adaptive Test (PEDI-CAT)

The PEDI-CAT was selected as an outcome measure for children's self-care as it is an established, widely used and psychometrically sound instrument.[237, 238] As seen in Chapter 4, a systematic review on children's self-care, it is also a tool used frequently in other research studies[40, 211] investigating children's self-care. An advantage of the PEDI-CAT is that it is not as time-consuming as other standardised tests for this population due to the nature of the computerised adaptive testing, which only selects test items relevant for each participant. It is also reported that the approximate administration time per child is twelve to fifteen minutes which made this a realistic tool to consider for a large study timewise. Further, the ability to carry out the test remotely makes it a useful assessment tool for researchers.

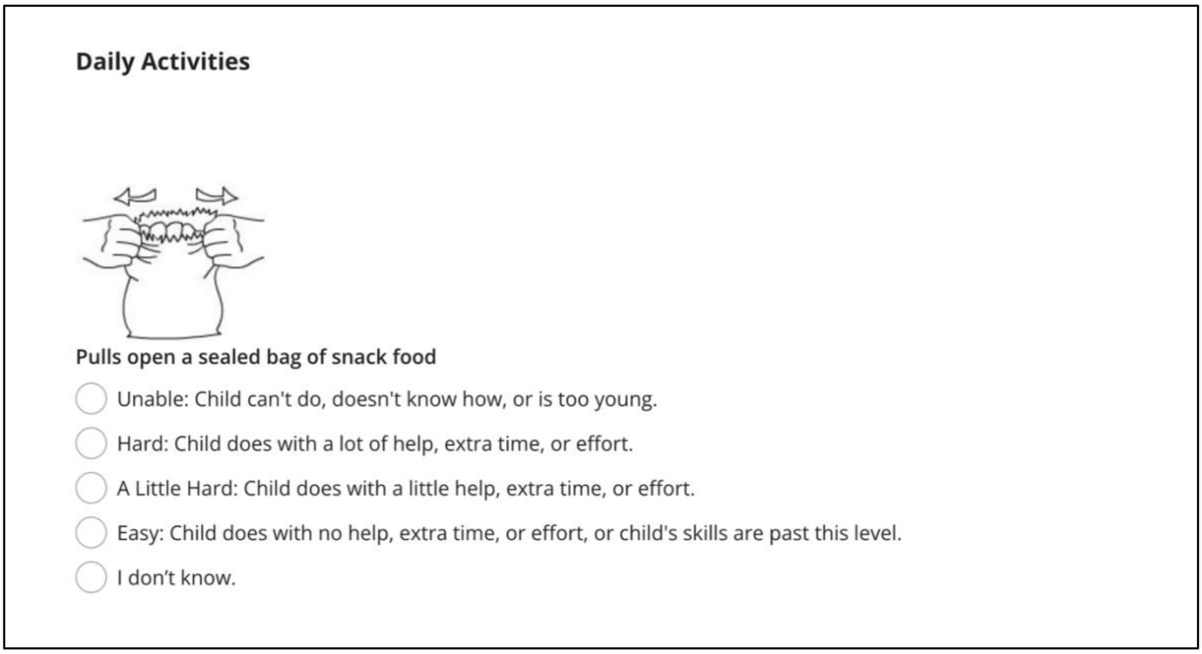
The PEDI-CAT is a norm referenced[239] standardised test, a type of test which yields an estimate of the individual being tested in comparison to others from a predefined population in relation to a specific trait being measured. It consists of a caregiver questionnaire and comprises of a comprehensive item bank of 276 functional activities acquired through early childhood up till adulthood in four domains: 1) Daily Activities, 2) Mobility, 3) Social/Cognitive and 4) Responsibility.

1) Daily activities: These include 68 items in daily activities which include items like getting dressed, keeping clean, and eating & mealtime.
   Sample daily activities questions (in the exact wording of the PEDI-CAT) include:

- Pulls open a sealed bag of snack food
- Puts on and fastens pants
- Tucks in shirt or blouse
- Puts on a T-shirt
- Pours liquid from a large carton into a glass
- Cuts vegetables or meat with a fork and table knife
- Wipes self with toilet paper after a bowel movement

An example of the format in which questions are presented can be seen in Box 5.1.

Box 5.1 Example of PEDI-CAT question.



Daily Activities

Pulls open a sealed bag of snack food

○ Unable: Child can't do, doesn't know how, or is too young.

○ Hard: Child does with a lot of help, extra time, or effort.

○ A Little Hard: Child does with a little help, extra time, or effort.

○ Easy: Child does with no help, extra time, or effort, or child's skills are past this level.

○ I don't know.

2) Mobility: The Mobility domain consists of 75 items in four content areas, including basic movement and transfers, standing and walking, steps, and inclines, and running & playing. There are also an additional 10 items specifically for children who use mobility devices such as walking aids (canes, crutches, walkers) and a wheelchair subdomain with 12 items. Parents were asked at the start of the test to indicate whether their child used mobility devices, and appropriate test questions were selected based on the parent's response to that question. Researchers[240] have found that the PEDI-CAT is reliable in discriminating between ambulatory and non-ambulatory, as well as manually independent (i.e., children who are able to self-propel a wheelchair) and dependent (children who use a power wheelchair) children.

Sample Mobility questions include:

- Walks down a flight of stairs holding onto handrail. Please do not consider use of walking aids.
- Gets in and out of van, truck or four-wheel drive. Please do not consider use of walking aids.

- Pumps legs and swings on playground swing
- Stands whilst holding on in a moving vehicle (i.e. bus or ferry)

3) Social/Cognitive: The Social/Cognitive domain includes 60 items in four content areas of interaction, communication, everyday cognition, and self-management. Sample social/cognitive test questions include:

- Recognises numbers such as on a clock or phone
- Provides own address and telephone number when asked
- Understands signs in the community such as Restrooms or EXIT
- Uses the words yesterday/tomorrow/today correctly
- Recognises his/her printed name

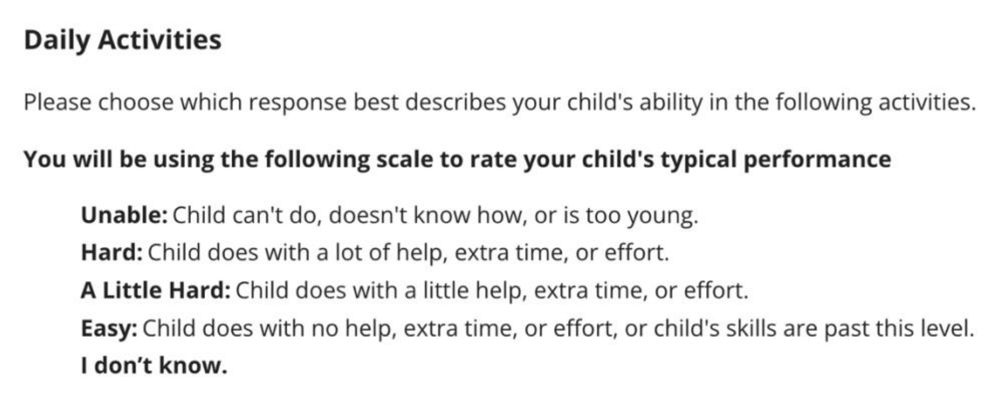
4) Responsibility: The Responsibility domain includes 51 items that assess the extent to which a child or young person is managing life tasks that enable independent living in four content areas of organisation and planning, taking care of daily needs, health management, and staying safe.
   Sample responsibility test questions include:

- Having all items that will be needed before leaving home for the day
- Selecting clothing that is appropriate given the weather, daily schedule, and activities.
- Staying safe in a familiar location that is known to be safe such as a friend's home or park.
- Putting items and objects away after use

The test utilises a computer algorithm to select appropriate questions based on previous responses thereby ensuring that only relevant questions are asked based on the level of ability of the child.[238] All PEDI-CAT respondents start the test with the same item in all domains in the middle range of difficulty. Based on the response to the first question, a harder or easier question will be asked next. Answering the questions required parents or caregivers to select the most relevant answer from a choice of 4 or 5 options. For the three functional skills domains of Daily Activities, Mobility, and Social/Cognitive, children’s ability is rated on a 4-point difficulty scale with responses ranging from “Unable” to “Easy.” Responses in between include “Hard” and “A Little Hard”.

The Responsibility domain has its own 5-point responsibility scale with responses ranging from ‘Adult/caregiver has full responsibility if the child does not take any responsibility’ to ‘Child takes full responsibility without any direction, supervision or guidance from an adult/caregiver’. Other response options in between include ‘Adult/caregiver has most responsibility and child takes a little responsibility’, ‘Adult/caregiver and child share responsibility about equally’ and ‘child has most responsibility with a little direction, supervision or guidance from an adult/caregiver’. For all domains there was also the option to enter ‘I don’t know’. Box 5.2 contains an example of the instructions provided to parents completing the test.

Box 5.2 Example of PEDI-CAT instructions for parents or caregivers.



Daily Activities

Please choose which response best describes your child's ability in the following activities.

You will be using the following scale to rate your child's typical performance

Unable: Child can't do, doesn't know how, or is too young.
Hard: Child does with a lot of help, extra time, or effort.
A Little Hard: Child does with a little help, extra time, or effort.
Easy: Child does with no help, extra time, or effort, or child's skills are past this level.
I don’t know.

The purpose of the PEDI-CAT is to assist clinicians with formulating an accurate description of a child’s current functional status or the child’s development in relation to acquisition of functional skills required for daily activities.[241] For the EASIER study, the ‘Daily Activities’ section was used as the outcome for self-care whilst the other three sections were used to collate information on participants’ motor skills and cognitive skills, supplemented by answers from the background information questionnaire.

Adequate test-retest reliability for the PEDI-CAT has been reported for children and young people children 3 through 20 years of age with and without disabilities.[219] Test–retest reliability estimates are high for all four domains of the PEDI-CAT. The intraclass correlation coefficient (ICC) is lowest for the responsibility domain (ICC = 0.96, 95% confidence interval (CI) = 0.91–0.98) and highest for the daily activities (ICC = 0.99, 95% CI = 0.99–1.00) and mobility domains (ICC = 0.99, 95% CI = 0.97–0.99), with the social/cognitive domain in the middle (ICC = 0.98, 95% CI = 0.95–0.99).[242]

In comparison to other assessments, another study[243] found a statistically significant correlation ($p<0.001$) between the PEDI-CAT mobility domain and GMFM-66 scores in children with CP. Both tests were able to pick up the same level of motor difficulties in this group of children. A comparison between the Vineland third edition (VABS-III) and the PEDI-CAT daily activities domain for the purpose of assessing young children was less favourable, with the PEDI-CAT being less sensitive to find out whether nursery aged children present with functional difficulties.[244] However, in another study[245], scores for the PEDI-CAT Daily Activities, Mobility, Social/Cognitive and Responsibility domains all significantly correlated with most of the VABS-III domains for children with fragile X syndrome.

Two options were available for the PEDI-CAT, Content-Balanced and Speedy-CAT. For the data collection, the Speedy CAT option was selected as it is quicker and reduces the possibility of irrelevant questions. It also felt inappropriate to ask parents of children with disabilities and complex needs irrelevant questions related to their child's functional abilities. A study[246] which investigated the use of the Content-Balanced and Speedy version found a strong agreement between the results obtained in the scaled scores for all domains of both versions of PEDI-CAT. This demonstrates that the two versions are comparable and can provide similar information on children's performance for researchers and clinicians.

Overall, the PEDI-CAT was deemed a good option for the EASIER study as the test consists of four domains, of which all four are areas that I was interested in to investigate in this study. It has also been described as including all the activity and participation components of the ICF[2, 247], the framework that was used to structure the findings of the systematic review discussed in the previous chapter. In comparison to the VABS-III, the PEDI-CAT speedy version is better suited to research studies as it can take up to forty minutes to administer the VABS-III.[248]

Upon completion of the study, my only criticism of the PEDI-CAT relates to the use of language in the test, which I perceive as a potential barrier to using this test in the UK. The test is written in US English, and I believe there is a risk of phrases such as: “Puts on and fastens pants” or “Pours liquid from a large carton into a glass” being misunderstood or being misinterpreted. Even more so in the case of participants where English is not their first language. As the PEDI-CAT is a standardised test, it was not possible to make changes to the wording of the online test however this should be taken into account in the analysis of responses.

5.6 Method of data collection

Information about the study was shared to participants in the form of study information packs by participating NHS trusts, and flyers with the study details on social media. Information packs and flyers contained the email address for the principal researcher. Interested study participants were asked to contact the author and principal researcher, myself, by email to express their interest. Upon receipt of their email, an email detailing the data collection procedure, which also contained the Qualtrics links for the background information questionnaire and the Parental Stress Scale, was sent to participants. Upon receipt of the notification for the completed background questionnaire, which also indicated that participants consented to the study terms and conditions, a study profile was created for them on the Q-global Pearson assessment website. Q-global is a web-based platform for test administration, scoring and reporting. It houses assessment tools for a range of health care professionals and is accessible from any computer which is connected to the internet. To create a test profile, researchers need to provide verification of their professional status and, where relevant professional registration details in order to ensure the appropriate use and administration of assessments.

This assessment profile sat within my test profile for the publisher and required two-factor authentication to log into the publisher's website. From here, a link for the PEDI-CAT was generated for participants based on the information in their profile, including the date of birth and sex of children in the study.

The link for the PEDI-CAT was sent to parents by email and a follow up email was sent for parents who did not complete the assessment on the link for the first time. Participants were informed at the start of the study that it would entail completing the PEDI-CAT at the start of the study and then repeating it every six months from commencing the study for a duration of three years in total.

Once a parent completed the online form a notification was sent to me to complete the automatic online scoring report, which was generated by Pearson Q-global. The completed scoring reports were then downloaded and saved anonymously with the participant number in a secure file stored on the Newcastle University server which is only accessible by two factor authentication.

Further data management included, entering the PEDI-CAT T-scores for all participants in an excel spreadsheet, which was then entered into STATA. This was stored on the Newcastle University server along with the PSS and questionnaire data collected on Qualtrics. No cleaning of data was required as the scores were in the format required for descriptive data analysis in STATA.

5.7 Description of dataset

Despite being on the NIHR portfolio and extensive social media posts along with letters to parents distributed by nursery headteachers, there was a poor uptake of participants for the study. Initially 32 participants expressed interested in the study and contacted the principal researcher to participate. Of these participants, 24 completed the PSS and the PEDI-CAT assessment for the first wave of data collection.

As this number of participants were too low to draw significant conclusions from responses from an ongoing attempt was made to recruit more participants to the study. Unfortunately, this attempt was not successful and for the second wave of data collection respondents dropped down to 16 participants.

A breakdown of participants for the first wave and the second wave of data collection can be seen in table 5.2 below.

Table 5.2 EASIER participants characteristics

Sex	**Developmental Concerns**	
	Yes	**No**
Male (wave 1)	4	9
Male (wave 2)	3	6
Female (wave 1)	2	9
Female (wave 2)	2	5

From the graph in Figure 5.1 below it can be observed that there was a higher frequency of parents of boys expressing concerns about their child's development.

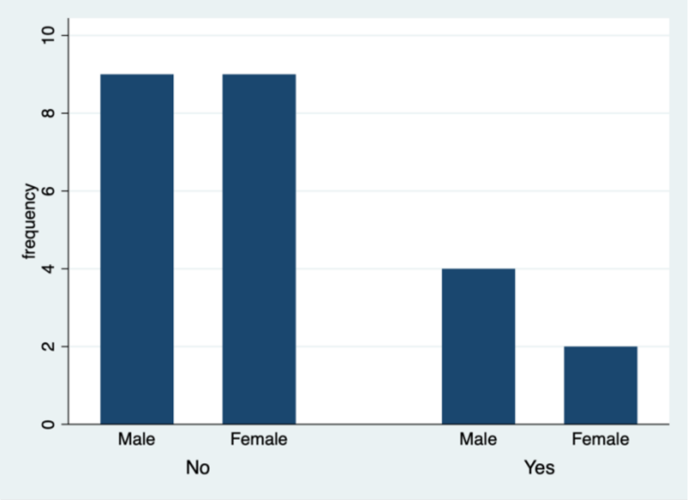


Figure 5.1 Frequency of developmental concerns as expressed by parents of study participants.

The data set for participants include interval-level scaled scores for all PEDI-CAT domains for two waves of data collection. This was analysed and is reported, along with questionnaire data using descriptive statistics, further on in this chapter. It was not possible to conduct statistical tests for significance of study results as the sample size was too small. Data collection for the EASIER study was also discontinued after the second wave of data collection as it was felt that it would be unethical to continue to collect data from children and families that would be void in a statistical analysis.

5.8 Data analysis

To analyse which of the child, family or environmental determinants are related to the development of self-care the aim was to use random co-efficient analysis or multilevel analysis. This analysis method[249] allows for consideration of the dependency of repeated measures within the same children in the study and a difference in regression coefficients between subjects. Following this, the initial goal was to construct a multivariable model to identify which determinants are most significantly linked to the development of self-care. However, as the sample size for the final data collection was too small to draw significant conclusions this process was not followed, and data entered in Stata 17 is discussed below.

Demographic characteristics for study participants were summarised using descriptive statistics. Normative or T-scores for all the four PEDI-CAT domains for all participants were entered into Stata. The T-scores were obtained from the electronically generated report for each participant. Data for each of these domains were summarised using means and standard deviations (SDs) and is shown in table 5.4. For T-scores, the mean for each age group is 50, with a standard deviation of 10 (the same format used for normative scores in the original PEDI). Typically, T-scores between 30 and 70 (i.e., mean ± 2 standard deviations) are considered within the expected range for a child in comparison to others in their age group.[219]. Normative scores below 30 indicate decreased functional ability compared to what is typically expected for that age range. In contrast, normative scores above 70 indicate scores above what is typically expected for that age range. (PEDICAT website https://www.pedicat.com/faq/)

The PEDI-CAT has no total score which is the sum for test items across all domains. Instead, children's normative scores are used to describe their overall performance in comparison to other children in their age group. Normative PEDI-CAT scores were derived from the standardisation of 2,205 typically developing children and this process was carried out in the United States. Therefore PEDI-CAT normative scores are reflective of the general US paediatric population, which should be considered when using this test in countries with different norms and expectations. The mean T-score for every age group is 50, and for each age group the pattern of items completed with no difficulty with this mean score will vary considerably.

5.9 Results

5.9.1 Demographic information

Participants were from the North, South and Midlands of England. All parents (n=24) who completed the study questionnaire as main carers of their children indicated that they were working parents.

The hours that parents worked varied across participants with the majority (75%) indicating that they worked more than 21 hours per week. These data are summarised in Table 5.3. For the main carers, 23 out 24 (96%) indicated that they had completed a university education, and of these responses, five (21.74%) included postgraduate degrees.

Table 5.3 Summary of hours worked by the main carer per week.

Number of participants	**Hours worked by main carer**
4 (16.67%)	Less than 10 hours
2 (8.33%)	10-20 hours
6 (25%)	21-30 hours
12 (50%)	31- 40 hours

All children in the study attended nursery, or went to a child minder, during the daytime. Parents indicated that 19 out of 24 (79,17%) children had siblings, of which 11 were older than study participants.

5.9.2 Daily Activities (Self-Care)

For the first wave of data collection, (n=24), the mean normative score for daily activities was 47.88, with the minimum score being 16 and the maximum score being 59. The maximum score and the mean scores were both in the average score range, which is 30 to 70. The standard deviation for this first wave of data collection was 9.48. Of the 24 participants, only 1 participant scored below 30 (score of 16) which indicated difficulty with self-care.

For the second wave of the data collection, (n=16), there was a small increase in the mean score to 48.06 and the standard deviation decreased from 9.48 to 7.10 which indicated that the values of scores tended to be closer to the mean for this data set. For this dataset, the minimum score was 28 with the maximum being 59. Again only 1 participant presented with a T-score below 30 and showed difficulties with self-care, and the score of 28 was closer to the average range of 30-70 compared to the first wave of data collection. PEDI-CAT scores for all domains, for both the first and second wave of data collection are included in Table 5.4.

5.9.3 Explanatory variables

Mobility, Social/Cognitive and Responsibility PEDI-CAT scores for both waves of data collection were considered as explanatory variables. The scores for all PEDI-CAT domains are included in table 5.4.

Table 5.4 Descriptive summary of PEDI-CAT Scores

Variable	**Obs (n)**	**Mean**	**Std. dev.**	**Min**	**Max**
Daily activities Wave 1	24	47.88	9.48	16	59
Daily activities Wave 2	16	48.06	7.10	28	58
Mobility Wave 1	24	49.54	8.96	21	57
Mobility Wave 2	16	48.94	7.20	29	57
Social/Cognitive Wave 1	24	49	6.78	26	56
Social/Cognitive Wave 2	16	50.19	2.74	29	55
Responsibility Wave 1	23	54.22	11.93	16	69
Responsibility Wave 2	16	56.63	4.76	46	64

After the daily activities scores, the second lowest PEDI-CAT scores were for mobility, however only a small number of participants had difficulties in this area. For the first wave of data collection, (n=24), the mean T-score for Mobility was 49.54 with the minimum score being 21 and the maximum score being 61. Of the 24 participants only 2 participants scored below 30 (scores of 21 and 29), which indicated difficulty with mobility. For the second wave of the data collection, (n=16), there was a slight decrease in the mean T-score to 48.94, and the standard deviation decreased from 8.96 to 7.20, which indicated that the values of scores tended to be closer to the mean for this data set. For this dataset, the minimum T-score was 29, with the maximum being 57. For the mobility subtests on the second wave of data collection, only one participant showed difficulties with mobility, and the score of 29 was closer to the average range of 30-70 compared to the lower score for the first wave of the data collection.

For the domain, Social/Cognitive most of the participants presented with T-scores in the range expected for their age group. For the first wave of data collection, (n=24), the mean T-score for Social/Cognitive was 49, with the minimum score being 26 and the maximum score being 56. Of the 24 participants, only 1 participant scored below 30 (score of 26) which indicated difficulties in this domain. For the second wave of the data collection, (n=16), there was a slight increase in the mean T-score to 50.19 and the standard deviation decreased from 6.79 to 2.74 which indicated that the values of scores tended to be closer to the mean for this dataset. For this dataset, the minimum score was 45, with the maximum being 55. For the second wave, all remaining participants scores in this domain were within the average expected for their age group.

Similarly, for the domain Responsibility, I observed few difficulties in this domain. For the first wave of data collection, (n=24), the mean T-score for Responsibility was 54.22 with the minimum score being 16 and the maximum score being 69. This subtest was completed by 23 participants, of which one scored below the average range expected for their age group. For the second wave of the data collection, (N=16), there was a slight increase in the mean score to 56.63 and the standard deviation decreased from 11.93 to 4.76 which indicated that the values of scores tended to be close to the mean for this dataset. For this dataset the minimum score was 46 with the maximum being 64. For the second wave all participants' T-scores in this domain were within the higher end of the average expected for their age group.

As all the mean scores for the PEDI-CAT domains discussed above are in the average range expected for participants' age group, it was not possible for me to make any definite conclusions as to how these three variables interacted with participants' ability to participate in self-care.

5.9.4 Parental stress

Data on parental stress were collected at the start of the study for participants, and in total, 23 participants completed the PSS. Scoring for the PSS ranges from 18 to 90, with a lower score indicating a low amount of parental stress and a higher score a high amount of parental stress.

Scores for the PSS in this study ranged from 52 to 83 with a median of 63 and a standard deviation of 7.36. This suggests that participants were experiencing moderate to high levels of parental stress at the time of completion of the PSS.

5.10 Bias

For this study it is important to consider attrition bias, bias due to differences in the two study groups for wave 1 and wave 2 because of differences in participant numbers and the way participants are lost from the study. This could have been influenced by the timing and circumstances of the study. It is possible that the stressors of the COVID-19 pandemic contributed to the low uptake of participants for the study[250]. It was observed in a few cases after the data collection was completed that where parents achieved a higher score for parental stress that they also did not complete the data required for the second wave of the data collection. For participants who completed both waves of the study the average PSS score was 61.8 whilst for participants who dropped out after the first wave of data collection the average PSS score was 67.9. Beyond the differences in PSS scores there were no other demographic differences between participants who participated in both waves of data collections and those who dropped out after the first wave.

5.11 Discussion of results

Due to the small sample size, it was not possible to make any real inference from the study results obtained. Further, the majority of participants scored within the average range expected for their age group on the Daily Activities subtest indicating that most participants in the study were participating in self-care at the level expected for their age group. In fact, whilst six parents indicated that they were concerned about their child's development only one child actually scored below the average range for their age group in the Daily Activities subtest on the PEDI-CAT. A similar pattern was seen in the other three PEDI-CAT subtests: Mobility; Social/Cognitive; and Responsibility.

It was observed that all parents in the study presented with moderate to high scores for parental stress. As these data were collected during the second lockdown (December 2020) of the COVID-19 pandemic it is more than likely that these scores were related to the stressors of raising children during the pandemic, rather than being worried about children's development. Particularly as all respondents were working parents. A study[251] carried out in 2020 found a significantly higher rate of parental stress than before the pandemic and found that some of the stressors included changes in children's routines, worry about the pandemic and online school demands. As almost all children presented with self-care within the average range for their age group, no association was observed between parental stress and children having difficulty with self-care. This is in contrast with the findings of the literature discussed in Chapter 4 which found a positive correlation between parental stress and children's self-care difficulties.[134] However, it is not possible to make definite conclusions about the association between parental stress and children's self-care in this chapter due to the limited sample size of the EASIER study.

In some cases, it could have been possible for children with older siblings that their parents expected them to perform at a higher developmental level than was appropriate for their age group. As a result, parents could have assumed that their younger child had difficulties with self-care in comparison to their older siblings and this was the concern that was passed onto the researcher. However, due to the small sample size this is a speculation and not a confirmed association.

5.12 Conclusion

In summary, this chapter described the rationale, methods, and description of data for the EASIER study. The study was significantly impacted on by the COVID-19 pandemic, and several changes had to be made to the study throughout the research process. There was a poor uptake for the study and the sample size was limited as a result, potentially at least in part explained by increased stress of the pandemic on an already high-stress population of parents with young children. Therefore, in this chapter, it is not possible to make associations and predictions regarding the self-care of children with and without motor impairments. In the next chapter, Chapter 6, I will discuss self-care in another longitudinal study, the ActiveCHILD study, which consists of a significantly larger sample size.

Chapter 6: ActiveCHILD - Data analysis of self-care from a longitudinal study

6.1 Background

In this chapter I describe the development of self-care, and factors influencing self-care, in a representative sample of children aged 1 to 5 years, with and without physical limitations, from a selection of thirteen sites in England. The data analysed in this chapter originate from the ActiveCHILD study[252, 253], a National Institute of Health Research, HEE/NIHR Integrated Clinical Academic Senior Clinical Lecturer funded study (NIHR ICA-SCL-2015-01-00). The ActiveCHILD study was originally led by one supervisor (NK), and another (MP) was a co-applicant.

The ActiveCHILD study aimed to advance interventions for physical activity for young children across abilities. As part of this, it also collected data on children's self-care at two waves.[254] This chapter uses data related to self-care for a secondary analysis, to explore how self-care interacted with other variables in the study.

In this chapter, I consider explanatory measures influencing self-care, discuss the data set used, the descriptive secondary analysis of the data obtained, and conclusions drawn from this. My contribution to the study solely consisted of contributing to the data collection for the second wave of the study and analysing data in relation to participants' self-care.

6.2 Design

I conducted a quantitative secondary analysis on selected data from the ActiveCHILD longitudinal study. The primary study[254] focused on generating evidence about children's participation in physical activity and its relationship with physical limitations, social and behavioural factors, and health in children with and without physical limitations. Detailed methods for the primary study are available to access in the ActiveCHILD study protocol.[253] In the primary study[254], children 1-5 years across developmental and health states, including children who had impairments in neuromusculoskeletal and movement-related functions or mobility limitations, as well as children with no known impairments, and their parents were recruited. The primary study[254] used purposive sampling across health pathways and sociodemographic factors. Children and parents had been recruited through routine contact with health visitors and other child health professionals, who identified eligible children for the study. Eligible participants had been sent a recruitment pack, and families who returned the consent form were contacted for data collection. Data collection for the PEDI-CAT took place by phone or in person depending on parent preference.[254] The primary study had the relevant NHS Research Ethics Committee (REC) and Health Research Authority (HRA) approval, and as the data were anonymised no further approval was required for the secondary data analysis discussed in this chapter.

6.3 Outcome variable: Self-care

The main outcome for the secondary data analysis in this chapter was self-care. One of the measurement tools that was used to collect data for the ActiveCHILD study, the Paediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDICAT)[237], contained a domain for daily activities, which was used to measure self-care in study participants.

The PEDI-CAT[219, 237] is a norm-referenced standardised test, which consists of a caregiver questionnaire. The test utilises a computer algorithm to select appropriate questions based on previous responses, thereby ensuring that only relevant questions are asked based on the level of ability of the child.[238] In total, the PEDI-CAT item banks, which measure function in 4 domains: (1) Daily Activities, (2) Mobility, (3) Social/Cognitive, and (4) Responsibility, consist of 276 test items. I shared examples of these test items in the previous chapter, Chapter 5.

The purpose of the PEDI-CAT is to assist clinicians with formulating an accurate description of a child’s current functional status or the child’s development in relation to the acquisition of functional skills required for daily activities. The PEDI-CAT results, which were collected in two waves over a period of 2-3 years for all willing study participants, form part of the dataset used for the data analysis discussed in this chapter.

6.4 Explanatory variables

In this chapter, I was seeking to investigate the variables influencing children's self-care. Scores from the PEDICAT domains, Mobility, Social/Cognitive and Responsibility were considered as explanatory variables influencing participants’ self-care. Other data taken into account for the secondary analysis to explain self-care included the following: the child’s date of birth and sex, the child’s cognitive and mobility level as reported by their NHS provider, the recruitment pathway, and Indices of multiple deprivation (IMD) deciles previously derived from the child’s postcode by the ActiveCHILD researchers. All of the variables considered are listed in table 6.1. For self-care at waves one and two, I used univariate and multivariable linear regression to explore potential explanatory factors influencing participants’ T-scores for daily activities. This method measured the strength of the association between T-scores for daily activities and the independent variables which were age, sex, NHS Cognitive levels, Mobility T-scores, Social Cognitive T-scores, and Responsibility T-scores. I also used the adjusted r^2 to assess the percentage variance in outcome explained by the variables in the regression model.

Parents who consented to their children participating in the study were asked to complete and return a baseline demographic questionnaire, which included their postcode which was used to identify IMD deciles. Deciles are calculated by ranking lower-layer super output areas (LSOAs) in England according to levels of social deprivation. Areas in decile 1 fall within the most deprived 10% of LSOAs in England, whereas areas in decile 10 fall in the 10% of least deprived LSOAs nationally.

Data on NHS cognitive levels and NHS mobility levels were collected through a form completed by either the health visitor in the case of the first recruitment pathway or the physio or occupational therapist in the case of children recruited through the second recruitment pathway. Response options for NHS cognitive levels for the primary study consisted of four options which were: 1) There are no concerns about the child’s development; 2) I am not able to comment; 3) The child has a global delay; and 4) There are concerns about the child's development. For mobility levels, the primary study considered three levels of mobility as indicated by NHS providers. These three levels were: 1) the child moves around using his/her body (e.g crawling, shuffling); 2) the child moves around using aids/equipment/human help; and 3) the child walks on his/her own (including cruising along furniture). However, the NHS mobility levels were excluded from the secondary data analysis as these were similar to the PEDI-CAT mobility questions, which provided more details about children's mobility and motor skills. The PEDI-CAT data was collected by team members from the primary study, following the standardised test instructions.

Table 6.1 Explanatory variables considered in secondary data analysis

Variable	**Measurement/Assessment**	**Type of Variable**
NHS Cognitive	4 Response options reported by NHS provider	Categorical
Date of Birth (Age)	Recorded by research team	Continuous
Sex	Recorded by research team	Ordinal
IMD Decile	Derived from participant's postcode by research team	Categorical
Mobility (PEDICAT) (T-score)	Caregiver questionnaire	Categorical
Social Cognitive (PEDICAT) (T-score)	Caregiver questionnaire	Categorical
Responsibility (PEDICAT T-score)	Caregiver questionnaire	Categorical

To represent the relationships between explanatory variables influencing self-care, and possible confounders in this dataset, I created DAGs (directed acyclic graphs).[255] A DAG is a specific type of graph that consists of nodes that are directionally related to each other and do not form a directional closed loop. DAGs are a useful addition to statistical analysis in health research to add transparency to identifying confounding variables that require conditioning to estimate causal effects.[256]

The DAGs in this section show the proposed causal relationships affecting self-care, and the arrows represent the proposed causal relationships pointing from cause to affect. In this figure, self-care (measured through the PEDI-CAT daily living normative or T-scores) is the outcome represented in the DAG. An important point to consider about DAGs is that causal relationships between the variables are always unidirectional, and therefore there are no feedback loops. As a result, the two variables cannot influence each other. Instead, two variables can be joined by what is defined as a path. In open paths, there is a statistical correlation between the variables at either side of the arrow, whereas in closed paths, this correlation is lacking.

There are three main types of paths in DAGS. These are: 1) directed paths; 2) backdoor paths; and 3) closed paths. In directed paths, the association between variables are the result of a causal relationship, and in the graph, all arrows are showing in the same direction. In backdoor paths, two variables are influenced by the same cause even though there is no relationship between these two variables. In this case, the cause which is referred to as the backdoor path, is representative of the confounder in the results. In the case of closed paths, two different variables have the same effect even though there are no associations between these two variables. The effect is referred to as a collider.

In this chapter, I anticipated that the recruitment pathway for the primary study would influence self-care outcomes for children, with those recruited from the specialist pathways – more likely to present with developmental problems - showing more challenges with self-care compared to those recruited through health visiting appointments. In this case, the recruitment pathway is shown as the mediator in Figure 6.1, whilst children's mobility as measured through the T-score for Mobility on the PEDI-CAT, are the exposure affecting children’s self-care.

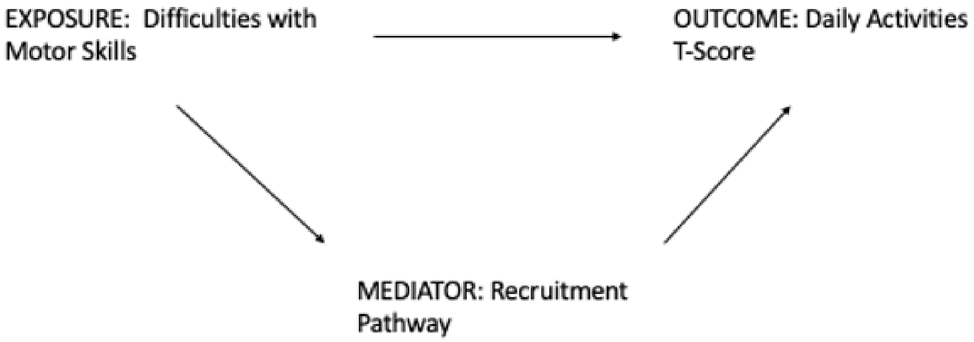


Figure 6.1 DAG showing recruitment pathway as a mediator in relation to Daily Activities/Self-care outcomes

Further, I predicted IMD Deciles as a confounder in this study. Whilst there was a strong correlation between IMD Deciles and self-care (p<0.01 for the first wave for participants who participated in both waves and p=0.12 for the second wave), there was a higher percentage of children recruited through the specialist pathway who were well in the most deprived LSOAs compared to children recruited through regular health visiting appointments. Through this pathway illustrated in Figure 6.2, IMD Deciles impacted on the PEDI-CAT Daily Activities T-scores.

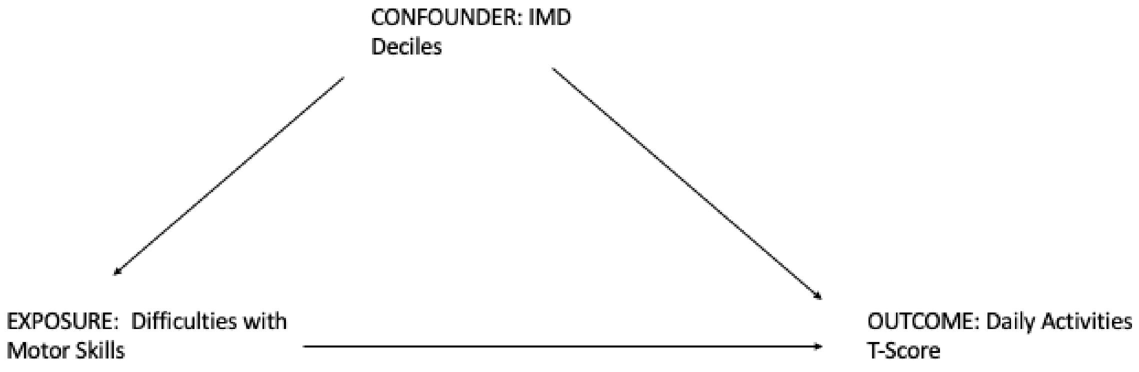


Figure 6.2 DAG showing IMD Deciles as a confounder in relation to Daily Activities/Self-care

6.5 Description of dataset

The analysis in this chapter draws on data from 299 children, born between 02/2015 and 07/ 2018, who provided eligible data, collected from 07/2017 to 08/2021. The dataset consists of 299 participants for the first wave of data collection and 153 participants for the second wave. For both waves of data collection, there were significantly more female than male participants (149 and 111 for the first wave, respectively, and 82 compared with 68 for the second wave, respectively).

Demographic characteristics for participants in the primary study[254] are shown in Table 6.2. Participants were patients from the NHS trust in the North-West and North-East or Midlands of England and participants came from one of two recruitment paths. Details of the recruitment pathway, along with a breakdown of age and sex of participants, for both waves of data collection can be seen in Table 6.2.

Table 6.2 Breakdown of participants according to age, sex, and recruitment pathway

	Wave 1 **(n=299)**	**Wave 2** **(n=153)**
Age, month: mean (25th, 75th centiles) n	21.9 (14,28) 260*	55.62 (49, 61) 150**
Sample size at each age point		
- **Females, *n(%)***	149 (57)	82 (55)
- **Males, *n(%)***	111 (43)	68 (45)
Recruitment Pathway ***		
- **one, n(%)**	147 (56)	81 (54)
- **two, n(%)**	115 (44)	70 (46)

*260/299 participants

** 150/153 participants

***For both time points there are participants where data was not provided in relation to the pathway of recruitment. For time point one, 262/299 provided this data and for time point two, 151/153

For the first wave of data collection, data on NHS cognitive levels were obtained for 245/299 (82%) participants (Table 6.3). For these participants, it was indicated that 4% of participants presented with a cognitive delay, and for another 28% of participants, it was noted that there are concerns about their cognitive development—the second cohort of participants presented with similar numbers. Information about cognitive levels was provided for 139/153 (90%) participants. In the second cohort, one participant presented with a global developmental delay and concerns were expressed about the cognitive development of 43 other participants.

A breakdown of NHS cognitive levels provided for study participants at the two different waves can be seen in Table 6.3.

Table 6.3 NHS cognitive levels for study participants

NHS cognitive levels	Wave 1	Wave 2
There are no concerns about the child's development, n(%)	130 (53)	79 (57)
I am not able to comment, n(%)	37 (15)	16 (12)
The child has a global delay, n(%)	9 (4)	1 (1)
There are concerns about the child's development, n(%)	69 (28)	43 (31)
Total	245*	139**

*245/299 participants

*139/153 participants

NHS mobility levels at wave 1 and wave 2 are tabulated in Table 6.4.

Table 6.4 NHS Mobility levels for study participants

NHS Mobility Levels	Wave 1	Wave 2
The child moves around using aids/equipment/human help, n(%)	19 (10)	8 (7)
The child moves around using his/her body, n(%)	20 (11)	11 (10)
The child walks on his/her own, n(%)	150 (79)	88 (82)
Total	189*	108**

*189/299 participants (63%)

**108/153 participants (70%)

The dataset included indices of multiple deprivation (IMD) deciles[161] for study participants from the primary study. There was a spread of participants across deciles 1 to 10 for both waves of data collection, with a similar number of participants in decile 1 (most deprived; 14% for wave 1 and 13% for wave 2) and decile 10 (least deprived; 12% for both wave 1 and 2). However, it is important to note that 18% more of children recruited through specialist services (indicating that they had additional needs) were in the bottom 20% of the deprivation index (deciles one and two) compared to children recruited through regular health visiting check-ups. For children recruited through health visitors, 26/162 participants (16%) fell in the bottom 20% of the deprivation index. This means that these participants were from some of the most deprived LSOAs in the UK. For children recruited through the specialist pathway, this figure was 34% (45/132 participants). This finding is similar to another UK study[257] which found that there is a higher rate of children with disabilities living in deprivation and poverty, in comparison to children without disabilities. For children from the least deprived LSOAs, there were 58/162 participants (35%) who fell in the top 20% of the deprivation index (deciles 9 and 10), and for children recruited through the specialist pathway, the representation for these deciles were 18/132 participants (14%).

6.6 Data analysis

Mobility, Social/Cognitive and Responsibility T-scores on the PEDI-CAT were assessed as potential predictors of participants' self-care, along with the variables age, sex, IMDDecile, and NHS cognitive levels using linear regression. Univariate linear regression was first used to determine the relationship between these variables and the outcome, self-care, which was measured through the PEDI-CAT daily living T-scores. Following this, a multivariable model[258] was constructed to identify which determinants were most significantly associated with the development of self-care. The multivariable linear regression also took into account confounding variables.

The dataset was cleaned by the research team on the primary study who took the necessary steps to ensure the validity of quantitative data and the accuracy of all findings in the study. The analysis therefore consisted of relevant, accurate data which already had been entered in the computer programme used, Stata 17 by Stata Corp, and the data set included both the scaled and the T-scores for the PEDI-CAT. Participant data was anonymised before any statistical analysis and the significance was set at $P<0.05$.

Demographic characteristics for study participants were also summarised using descriptive statistics in Stata 17. The scaled scores for the four PEDI-CAT domains which were included in the dataset were first calculated according to instructions from the

PEDI-CAT manual. Data for each of these domains were then summarised using means and standard deviations (SDs) as they were normally distributed. Scaled scores for the PEDI-CAT test represent a child's status along a continuum of functional ability represented by the test items. An increase in scaled scores indicate an increase in the child's ability to perform tasks from one of the test domains.

For each of the 4 domains, in addition to scaled scores, normative standard scores (provided as T-scores and age percentiles) were calculated. Normative scores describe the child’s performance in comparison to other children of the same age (in one-year intervals). For T-scores, the mean for each age group is 50, with a standard deviation of 10 (the same format used for normative scores in the original PEDI). Typically, T-scores between 30 and 70 (i.e., mean ± 2 standard deviations) are considered within the expected range for age. Scores below 30 indicate decreased functional ability compared to what is typically expected for that age range. Scores above 70 indicate scores above what is typically expected for that age range. (PEDICAT website https://www.pedicat.com/faq/)

Although the scaled scores were calculated first for all participants, they are not included in this data set as they are more useful to refer to the performance of one specific child, whereas the T-scores provided information on children's performance in comparison to other participants. It was therefore thought that it would be more clinically relevant to discuss the T-scores, for participants in the study, in this chapter.

6.7 Results

The results for this chapter included the PEDI-CAT scores and other explanatory variables shown in Table 6.1 for 140 participants who participated in both waves of the primary study. Overall, there were no key major differences in the key characteristics, which included age, sex, recruitment pathway and IMD Decile, for this sample in comparison to the main sample of the primary study.

6.7.1 Descriptive characteristics

In this section I describe the PEDI-CAT T-scores for wave 1 and 2, and report on the differences and similarities between the two waves of data collection. PEDI-CAT scores for both waves of data collection are summarised in Table 6.5. T-scores ranging from 30-70 are in the typical range, and T-scores below 30 indicate difficulties with tasks in a domain.

Table 6.5 Descriptive summary of PEDI-CAT scores

	Wave 1 N=140			**Wave 2 N=140**			**P value**
	Mean	**SD**	**(Min, Max)**	**Mean**	**SD**	**(Min, Max)**	
Daily activities	50.65	10.46	7,77	50.21	12.69	14,79	0.65
Mobility	48.89	15.17	-6,75	47.20	17.75	-53,70	0.13
Social/cognitive	50.74	8.54	27,66	47.40	10.18	3,61	<0.01
Responsibility	48.17	11.65	11,70	51.96	10.41	13,69	<0.01

Overall, there was a small increase in the number of participants who presented with difficulties with self-care in the second wave of data collection in comparison to the first wave. I observed that for self-care, measured through the daily activities PEDI-CAT T-Scores, that there was a minimal decrease in the mean score from 50.65 for the first wave to 50.21 for the second wave. Both the minimum and maximum scores for Daily Activities shown in Table 6.5 increased for the second wave of data collection. However, the standard deviation increased from 10.46 to 12.69 which indicated that the Daily Activities T-scores for the second data were more varied.

The distribution of Daily Activity scores for both waves of data collections (n=140) are shown in figure 6.3. For the first wave of data collection, 5 out 140 participants (3.5%) achieved a T-score below 30 which indicates difficulties in the Daily Activities domain, and for the second wave this number was 12 out 140 participants (8.6 %). This demonstrates an increase of 5.1% in the number of participants who presented with difficulties with self-care in the second wave of data collection in comparison to the first wave.

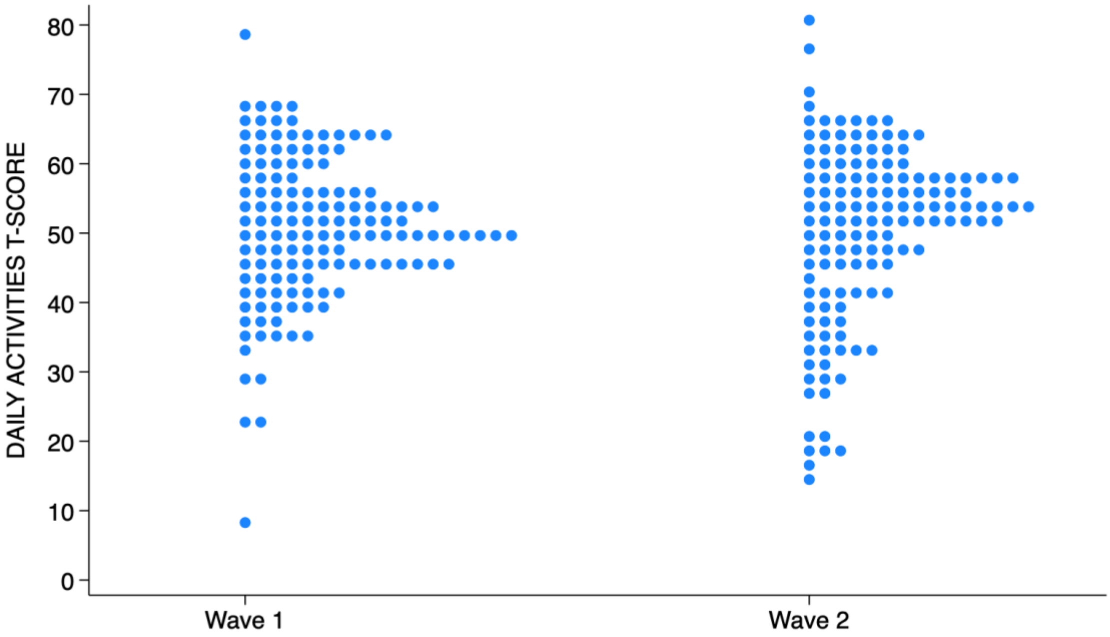


Figure 6.3 Distribution of PEDI-CAT T-scores for Daily Activities for waves 1 and 2

For mobility, I also found a minimal increase (0.71%) in the number of participants who presented with difficulties in the PEDI-CAT Mobility subtest in the second wave in comparison to the first wave of data collection. In the first wave, 15/140 (10.71%) of participants had a T-score below 30 for this subtest, and for the second wave this number was 16/140 (11.42%). I also observed a decrease in the mean score from 48.89 for the first wave to 47.20 for the second wave of data collection. For the first wave of data collection (n=140), the lowest T-score for mobility was -6 with the highest T-score being 78. (M=48.89, SD=15.17). For the second wave of the data collection (n=140) the lowest T-score was -53 with the highest being 70. (M=47.20, SD=17,75). This demonstrates an increase from 15.17 to 17.75 in the standard deviation of the T-score for participants, who participated both in the first and second wave of data collection. This is similar to the daily activities T-scores where T-scores for the second wave showed greater variation.

The distribution of mobility T-scores for both waves of data collections (n=140) are shown in Figure 6.4. The results in Figure 6.4 show that a high number of participants presented with challenges with mobility. For the first wave of data collection 15 out 140 participants (10.71%) achieved a T-score below 30 which indicates difficulties in this domain and for the second wave this number was 16 out 140 participants (11.42%).

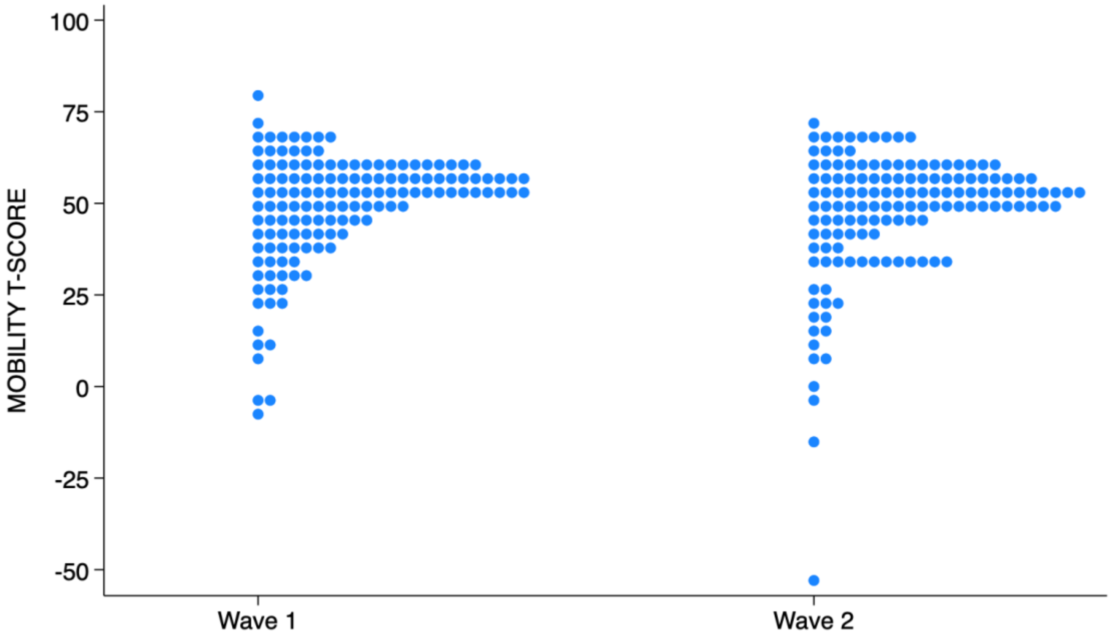


Figure 6.4 Distribution of PEDI-CAT T-scores for mobility for waves 1 and 2

Next, I found a 5.7% increase in the number of participants who showed difficulties with social/cognitive from the first to the second wave of data collection. For social/cognitive, the lowest T-score for the first wave of data collection (n=140) was 27 and the highest, 66. (M= 50.74, SD=8.54). For the second wave of data collection (n=140) the lowest T-score was 3 with the highest being 61. (M=47.30, SD=10.18).

In Figure 6.5 one can observe the higher number of participants in the second wave with a T-score of below 30 which indicates difficulties in this area. For the first wave of data collection, two out of 140 participants (1.43%) achieved a T-score below 30 which indicates difficulties in this domain and for the second wave, this number was 10 out of 140 participants (7.14 %).

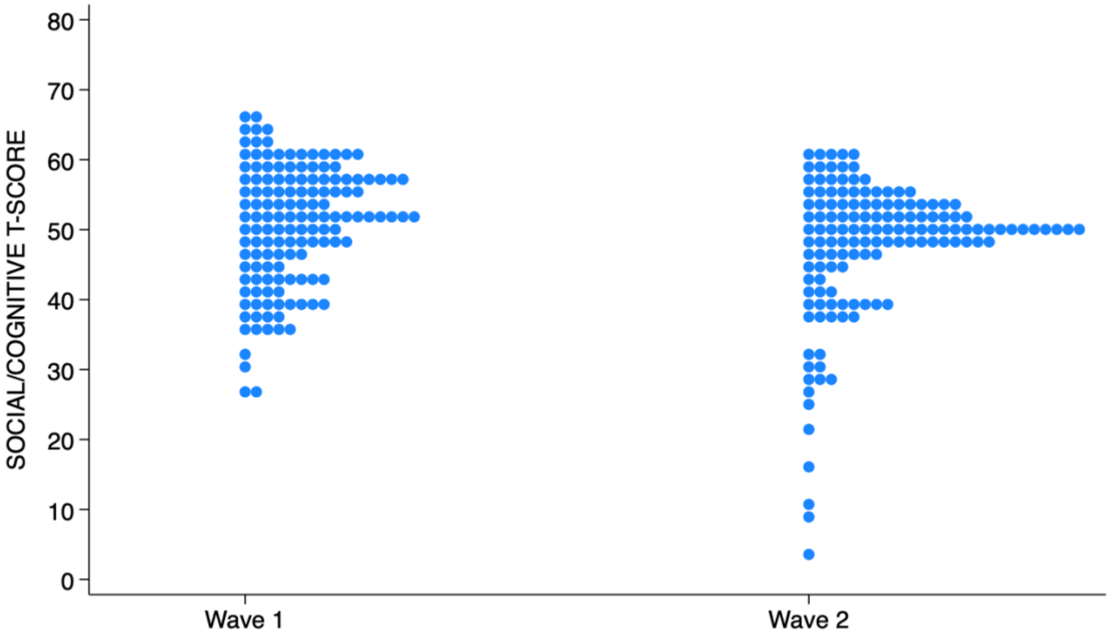


Figure 6.5 Distribution of PEDI-CAT T-scores for Social/Cognitive for waves 1 and 2

For the last of the four PEDI-CAT domains, Responsibility, I also observed a small increase in the number of participants who presented with lower T-scores for this domain in the second wave of data collection. For Responsibility, the lowest T-score for the first wave of data collection (n=140) was 24 and the highest, 75. (M=48.17, SD=11.65) For the second wave of the data collection, the lowest T-score was 13 and the highest, 69. (M=51.96, SD=10.41). Figure 6.6 shows that T-scores for this domain were more evenly distributed for the second wave of data collection. For the first wave of data collection, seven out of 140 participants (5%) achieved a T-score below 30 which indicates difficulties in this domain and for the second wave, this number increased slightly to eight out of 140 participants (5.8%) as shown in Figure 6.6. This increase could be indicative of the PEDI-CAT questions making higher demands of responsibility skills at the second time point of data collection, which made the difficulties experienced by participants more pronounced than at the first time point of data collection.

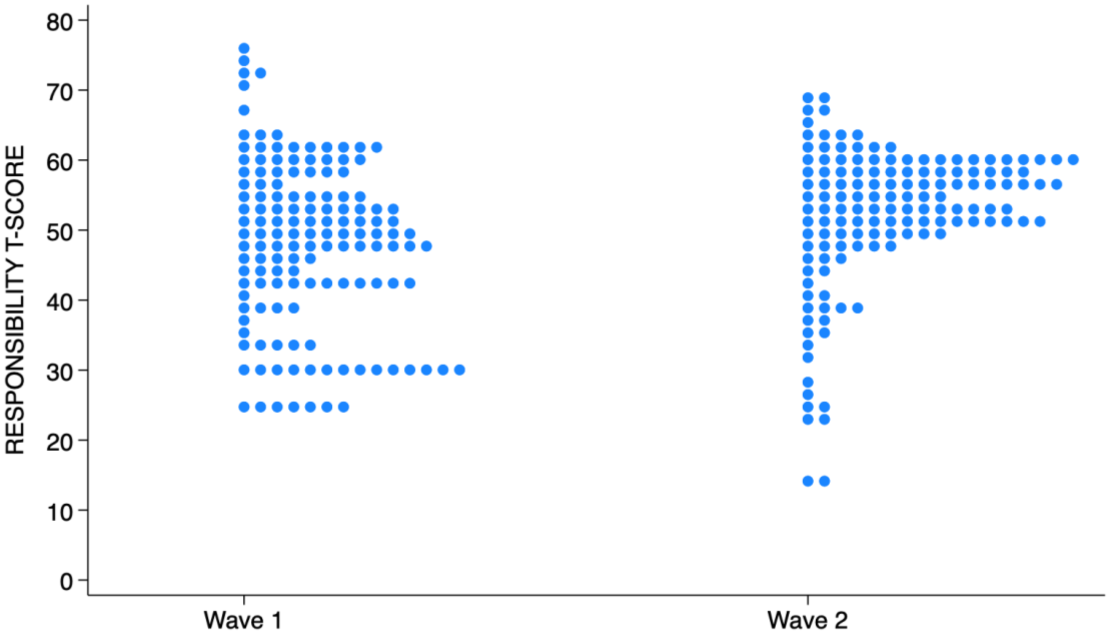


Figure 6.6 Distribution of PEDI-CAT T-scores for Responsibility for waves 1 and 2

6.7.2 Univariate analysis

As seen in section 6.7.1 above, 3.5% of children in the first wave of this secondary dataset presented with difficulties with self-care as measured through the PEDI-CAT daily activities domain. For the second wave of data collection, this number was 8.6%.

For the univariate analysis of potential explanatory variables influencing children in the dataset's self-care, I included the following variables as potential predictors: age, sex, and NHS cognitive levels. Recruitment pathway as a mediator was not included in the univariate analysis, and the analysis adjusted for IMD Decile as a confounder. The results of the univariate analyses of waves 1 and 2 are shown in Tables 6.6 and 6.7.

Table 6.6 Univariate Analysis of potential predictors for self-care (Wave 1)

Variable	**Coefficient**	**95% CI**	**P-Value**
Age	0.03	-0.21 to 0.28	0.78
Sex	-4.02	-7.48, to 0.57	0.02
NHS Cognitive Level	-0.97	-2.16 to 0.23	0.11
Mobility (PEDI-CAT) (T-Scores)	0.51	0.43 to 0.59	<0.001
Social/Cognitive (PEDI-CAT) (T-scores)	0.98	0.86 to 1.10	<0.001
Responsibility (PEDI-CAT) (T-scores)	0.48	0.35 to 0.60	<0.001

Table 6.7 Univariate Analysis of potential predictors for self-care (Wave 2)

Variable	**Coefficient**	**95% CI**	**P-Value**
Age	0.03	-0.19 to 0.26	0.77
Sex	-6.30	-10.45 to -2.16	0.003
NHS Cognitive Level	-1.68	-3.28 to -0.14	0.03
Mobility (PEDI-CAT) (T-Scores)	0.57	0.50 to 0.64	<0.001
Social/Cognitive (PEDI-CAT) (T-scores)	0.99	0.86 to 1.11	<0.001
Responsibility (PEDI-CAT) (T-scores)	0.91	0.77 to 1.04	<0.001

From the univariate analysis for wave 1, I found that sex (p=0.03), along with PEDI-CAT T-scores for Mobility (p<0.001), Social/Cognitive (p<0.001) and Responsibility (p<0.001) showed strong associations with PEDI-CAT T-scores for Daily Activities. Similarly, from the univariate analysis from wave 2, I found that I found that sex (p=0.0.001), along with

PEDI-CAT T-scores for Mobility (p<0.001), Social/Cognitive (p<0.001) and Responsibility (p<0.001) showed strong associations with PEDI-CAT T-scores for Daily Activities. The association between sex and the Daily Activities T-score is unclear as the data included for the secondary analysis showed a similar distribution between boys and girls from the two recruitment pathways for both waves of data collection.

6.7.3 Multivariate analysis

To establish which factors influenced participants' score for Daily Activities (the outcome measure for self-care) a multivariable linear regression analysis was carried out to investigate explanatory factors influencing the outcome variable, self-care (Daily Activity T-score), at waves one and two.

The multivariable analysis consisted of a multiple linear regression model with the variables above indicates as predictors. Recruitment pathway, as a mediator, was excluded from the regression models. The regression model also adjusted for IMD Deciles, which is a potentially confounding variable. The regression model for the first wave had complete data for 112 children and the regression model for the second wave had complete data for 121 children. Coefficients, confidence intervals, and p-values from the multivariable analysis are reported in the regression results which are recorded in Tables 6.8 and 6.9.

Table 6.8 Multivariable linear regression model of variables influencing participant's self-care at wave one.

Variable	**Results of linear regression with IMD Deciles (adjusted)**		
	Coefficient	**95%CI**	**P-value**
Age (months)	-0.10	-0.22 to 0.02	0.09
Sex (M)	-0.48	-2.36 to 1.39	0.61
NHS Cognitive	0.24	-0.45 to 0.93	0.50
Mobility (PEDI-CAT) (T-Scores)	0.17	0.08 to 0.26	<0.001
Social Cognitive (PEDI-CAT) (T-scores)	0.74	0.57 to 0.90	<0.001
Responsibility (PEDI-CAT) (T-scores)	0.002	-0.10 to 0.10	0.97
IMDDecile	-0.11	-0.41 to 0.19	0.46

* Number of observations = 112

Table 6.9 Multivariable linear regression model of variables influencing participant's self-care at wave two.

Independent Variable	**Results of linear regression with IMD Deciles (adjusted)**		
	Coefficient	**95%CI**	**P-value**
Age (months)	-0.01	-0.11 to 0.10	0.88
Sex (M)	-2.39	-4.48 to -0.29	0.03
NHS Cognitive	-0.55	-1.31 to 0.22	0.17
Mobility (PEDI-CAT) (T-Scores)	0.48	0.38 to 0.57	<0.001
Social Cognitive (PEDI-CAT) (T-scores)	0.28	0.05 to 0.46	0.02
Responsibility (PEDI-CAT) (T-scores)	0.26	0.10 to 0.43	0.003
IMDDecile	-0.26	-0.60 to 0.09	0.14

* Number of observations = 121

Overall, the predictors in the multivariable models accounted in total for 74% of the variance in daily activities T-scores at the first wave of data collection and 80% of the variance at the second time point of data collection. I found significant positive associations between self-care and the PEDI-CAT Mobility T-scores ($p<0.01$), and between self-care and PEDI-CAT Social Cognitive T-scores ($p<0.01$ and $p=0.02$) for the first wave and second wave of data collection. Lower scores for the PEDI-CAT domains, Mobility and Social Cognitive, therefore accounted for lower scores in the PEDI-CAT Daily Living domain. For the second wave of data collection, I also found a positive relationship between self-care and the PEDI-CAT Responsibility T-scores (p<0.01), where lower scores correlated with difficulties with self-care.

6.8 Discussion

This secondary date analysis set out to investigate how children's self-care develops over time, as measured by the PEDI-CAT, and to contribute to the evidence base for factors that contribute to self-care over time. PEDI-CAT Social/Cognitive T-scores (p<0.01 and p=0.01) and PEDI-CAT Mobility T-scores (p<0.01) emerged as key positive predictors of self-care aged 1-5 years in this secondary data analysis.

In this secondary data analysis, I observed a small increase (5.1%) in the percentage of participants who presented with self-care difficulties from baseline to follow up. As seen in section 6.6 the predictors in the multivariable models showed a high level of correlation and accounted in total for 74% of the variance in Daily Activities T-scores for the first wave of data collection and 80% of the variance for the second wave of data collection. Of the predictors included in the model, PEDI-CAT Mobility T-scores and PEDI-CAT Social/Cognitive T-scores showed the highest correlation followed by PEDI-CAT Responsibility T-Scores for participants in the second wave of data collection. The influence of age on Daily Activities T-scores was found not to be significant. In the multivariable analysis I observed that the sex of participants was not significant in predicting Daily Activities T-scores in the first wave of data collection, but in the second wave of date collection boys presented with higher levels of difficulty with Daily Activities (P=0.03).

Another study[259] carried out on children aged 4-7 years with CP also found that the PEDI-CAT Mobility T-Score was a significant predictor of the Daily Activities T-Score. In this secondary data analysis, 10.71% (15/140) of the dataset presented with Mobility T-Scores below 30 which indicates difficulty with this domain for the first wave of data collection. For the second wave of data collection this percentage was 11.42% (16/140) of the dataset. The lowest scores for waves 1 and 2 were -6 and -53 respectively which indicated that these participants presented with significant mobility difficulties. A previous study[260] investigating mother-child interactions in children with disabilities found that in some circumstances, the parents of children with reduced mobility assisted their child with self-care activities regardless of whether the child required assistance. As the PEDI-CAT is a caregiver questionnaire, it would be useful to also investigate the correlation between mobility and self-care in other ways, which include qualitative views from children on what aspects of self-care they find challenging themselves.

These findings have implications for health care providers addressing self-care concerns in young children as it indicates that these areas need to be considered in conjunction with self-care. In this secondary analysis there was insufficient evidence to suggest that any of the other variables including socio-economic status, as indicated by areas of deprivation, or the recruitment pathway directly played a role in children's ability to participate in self-care. The results of this secondary data analysis align with the findings in Chapter 4 which showed cognitive skills and motor skills (including mobility) as predictors of self-care.

6.9 Comparison of the ActiveCHILD and EASIER datasets.

There were a number of similarities between the primary study where the data for this secondary analysis was obtained from, and the EASIER study described in Chapter 5. Most of the similarities relate to the methodology, as both studies were longitudinal studies and with a similar target population.

Firstly, the study recruited children from a range of sociodemographic backgrounds and with a range of health statuses, similar to the selection criteria of the EASIER study discussed in Chapter 5. The only difference in the selection criteria was the age range, as the EASIER study collected data on children aged three years and over. However, the sample discussed in this chapter consisted of data for 140 participants for two waves whereas the number of participants in the EASIER study were significantly less.

Secondly, as with the EASIER study, the primary study in this chapter did not present any major ethics issues, beyond the general issues related to non-invasive research with children and parents. To recap, within these general issues, two are of specific importance: 1) children's right to contribute and 2) children's right to be safe from harm. Just as in the EASIER study, the ActiveCHILD study involved young children who were unlikely to be able to make informed choices about their participation in the study and possibly lacked the understanding to actively contribute to the research design of the study. Recommendations from a report[113] by the Nuffield Council on Bioethics, state that the nature of child and parent involvement and enablement depends on the population of children (e.g. their capabilities and interests) and the nature of the research were also considered in this study. Therefore, in the ActiveCHILD study, parents were asked to make decisions on their children’s behalf, and parents’ views were drawn upon to inform the research.

Thirdly, as with the EASIER study discussed in Chapter 5, the PEDI-CAT[237] was used to measure participation in self-care for study participants in the ActiveCHILD study. The PEDI-CAT, a parent questionnaire, was completed by parents and caregivers in two waves. Whilst the PEDI-CAT was used in both the EASIER and ActiveCHILD studies, a significant difference in the method compared to the previous chapter is that the PEDI-CAT was completed by research assistants over the phone or by interviewing parents in person. In the EASIER study discussed in Chapter 5 parents of participating children were sent a link to complete the PEDI-CAT on their own devices, in their own time. The online version of the PEDI-CAT which enable researchers to send links to participants launched a couple of years after the first wave of data collection for the ActiveCHILD study which is why this version was not used for the ActiveCHILD study. The PEDI-CAT data discussed in this chapter was collected by the research team by telephone. PEDI-CAT profiles were set up for each participant on a study account, and the test profile for each participant was anonymised with a study participation number allocated to it. Unlike the web version, Q-global, used for data collection in Chapter 5, there was no automated scoring and report generation for this manual version of the test. This version did also not present the option for parents to open the questionnaire by Weblink and only had the option to be administered by a member of the research team. Questions were read out over the phone by a member of the research team, and the answers were completed by the same individual whilst talking to the parent over the phone. During the first wave of data collection, before the COVID-19 pandemic, parents were also presented with the option to complete the PEDI-CAT in person with a member of the research team. However, this option was not possible for the second wave of data collection due to social distancing and lockdown restrictions in the UK.

6.10 Strengths and limitations of the study process and results

A strength of the data in this chapter was the high sample (n=140) of data on children's self-care for two waves of data collection. Data were collected on children from a range of socio-economic circumstances and two different recruitment pathways. This provided a balanced representation of children at approximately two years of development.

Limitations relate to the administration of the PEDI-CAT. For the second round of PEDI-CAT data collection, all interviews took place by phone, as opposed to the additional option of in-person data collection for the first round of data collection. Due to the lockdown restrictions associated with the Covid19 pandemic, and the fact that many individuals with health conditions were shielding[261] during the pandemic, it was not possible to offer the option for collecting PEDI-CAT in person for the follow-up data collection. This meant that the research team had to contact parents by telephone to arrange for the PEDI-CAT data collection and rely on telephone numbers provided at the start of the study for this. The pandemic itself also possibly influenced attrition due to children or their parents being unwell with the virus, or participants being unable to participate due to being indirectly affected by the virus.[250]

In comparison to the PEDI-CAT data collection in the previous chapter, EASIER, in which the data collection was completed by parents online in their own time, in the primary data collection for the present chapter the parents were read out the questions over the phone. This is an older version of the PEDI-CAT that was the only version available to the researchers at the start of the primary study. Whilst the content of questions was the same as for the EASIER study the significant difference in the administration of the PEDI-CAT could have possibly impacted on the data collected.

In contrast to the EASIER study discussed in the previous chapter, the method of researchers reading the parents the questions over the phone allowed for parents to clarify the meaning of a question they were not sure about. However, it is possible that parents who find telephone conversations difficult and would have preferred to see the questions in writing, might have preferred to receive a PEDI-CAT questionnaire to complete in their own time the same as participants in the EASIER study.

Whilst parents in the primary study were presented with the opportunity to ask the researchers to clarify questions over the phone, parents would not have seen the written questions in front of them. That could have presented parents with auditory processing difficulties with some challenges, and parents with English as a second language who might not have found it easy to ask the researchers to clarify terms that they were unsure of. Further, parents who answered the questions directly to the research team could have felt under pressure to answer questions in a particular way which could have skewed the results. Further differences on how the method of data collection for the EASIER study and ActiveCHILD varied with the same test battery are reflected on in section 9.4.3.

Finally, a further limitation of the study was that whilst the quantitative results provided a snapshot of factors influencing self-care in the dataset analysed, further details around the context and children and parent’s in-depth experiences with self-care are lacking.

6.11 Conclusion

The quantitative results of the secondary data analysed in this chapter showed strong evidence that children with developmental (particularly mobility and cognitive) difficulties are more likely to present with an increase of self-care difficulties over time as activity and environmental demands increase. It is therefore important to keep monitoring this area of performance in children with developmental difficulties over time in order to ensure that they do not fall behind at a later stage, and to ensure that they get the support they need. Further, as in Chapter 4 mobility and social/cognitive skills emerged as key predictors for self-care in young children included in this secondary data analysis. In the next chapter, chapter 7, I discuss the findings from qualitative data collected from online parent forums on how the COVID-19 lockdown measures impacted on their children's self-care. The next chapter provides a real-life insight in how the numerical data discussed in this chapter can impact on children and their families.

Chapter 7: A qualitative investigation of the impact of the COVID-19 pandemic lockdown restrictions on children's self-care as reported by their parents

In Chapters 1 to 3, I set out the real-world problem on which this research programme was based: children and young people with motor impairments are more restricted in participation in self-care than their peers without motor impairments. Whilst allied health professionals are well positioned to support self-care, they have limited evidence of factors influencing self-care in children and young people, and evidence-based intervention options from which to choose. Chapter 4 consists of a systematic evidence synthesis of on this topic and in Chapters 5 and 6 I presented quantitative data on children's self-care. In this chapter, I will present qualitative data from online parent forums on how the COVID-19 lockdown measures impacted on their children's self-care, and how this subsequently impacted on parents, and their relationships with their children.

7.1 Background

As this doctoral programme of research was carried out during the COVID-19 pandemic, it was important to consider the impact of this global event on children and young people's self-care. Early years of life are a period particularly sensitive to stress, with known negative impacts both on the health and wellbeing of children.[262] The global COVID-19 pandemic, and the associated lockdown measures have been a new, extreme stressor affecting most of the world population[263, 264], and little is known about how it impacted on children's participation in daily activities and their self-care independence. Therefore, I sought out the views of parents on this topic in two online parent forums, Mumsnet and Netmums.[103, 265]

In recent years, there has been an increase in participation in online forums with the aim to seek health information and support by communication with others who have similar health issues.[266] With the use of online health forums steadily increasing, greater efforts are being made to understand this mode of data collection for qualitative research. Online patient communities represent an important source of information, offering access to hard-to-reach groups who are often excluded (or exclude themselves) from traditional research studies. This can include for example, participants with mobility problems, individuals based in rural areas and parents of young children who can respond to online forum posts at a time and place of their own convenience.[267]

Online forums allow users to engage in discussions and interact in a supportive way with other individuals facing similar challenges, through the medium of asynchronous written communication.[268] Whilst forum postings and discussions for many forums can be viewed by every Internet user, members must register and log in to be able to post messages and participate in forum discussions. The ability to view such forums in the public domain provides researchers with a rich and valuable source of primary data about users' perspectives and experiences of a particular health issue related to themselves and/or their children. It also provides researchers with the opportunity of analysing discourses taking place within the online setting in relation to these topics.[269] In addition to the above, awareness of what families discuss in online forums can provide health care professionals with valuable insight into the perspectives, expectations, and experiences of families who have concerns regarding their children's development and self-care.[267]

The setting for the use of online discussion forums in this study is the COVID-19 pandemic and the associated lockdown measures. The COVID-19 pandemic had a significant impact on the daily routines of parents across the world.[270] In the UK where this study took place, schools and pre-schools closed for all children, except vulnerable children and the children of keyworkers from the 20th of March 2020 and school attendance only resumed in many parts of the UK in September 2020. Following this, schools were locked down again between January and late February 2021 in Scotland and Wales, and between January and March 2021 in England and Northern Ireland. For most UK parents this meant that they were responsible for caring and educating their children at home whilst also fulfilling other family and personal obligations, which included work and household tasks.[270] It was suggested that caring and educating responsibilities were disproportionately carried out by woman during the pandemic as they were more likely to lose their jobs or cut back their working hours. Further, they were also more likely to have their work interrupted by their children.[270, 271]

7.2 Method

7.2.1 Data source and retrieval

I systematically explored online discussions by parent and carried out a qualitative analysis about the impact of the COVID-19 pandemic lockdown measures on children's self-care on two UK-based online discussion forums for mothers. The source of data was discussions on the Chat and Talk threads of two UK based online forums, Mumsnet and Netmums, between March 2020 and January 2021. These are moderated forums, with the scope of facilitating online communication between parents and caregivers, sharing information on any aspect of parenthood and children, and offering emotional support. Mumsnet states that their aim is to: " Make parents' lives easier by pooling knowledge, advice and support" whilst Netmums state that their aims are: " We're here to make parents feel heard, supported and entertained on every step of their parenting journey."

Within the selected forum, the search function was used to identify user-generated content relating to COVID-19 and children's self-care. Date restrictions were applied in the search and posts between 26 March 2020 and 31 January 2021 were collected. The start date coincided with the start of the first UK COVID-19 lockdown measures.

I searched for forum content using key search terms including “COVID,” “corona,” or “pandemic.” The search identified articles, comments, and posts, which was then narrowed to posts. All posts were extracted in a deidentified format into a Word (Microsoft Corporation) document, which included the post title, date, and content. The inclusion criteria were posts related to children's self-care and the COVID-19 lockdown measures up until 30 January 2021 (inclusive). The exclusion criteria were posts that did not relate to self-care and the COVID-19 lockdown, and post that were duplicates (the original post was collected once).

The final data set includes responses by 69 participants. Whilst the dominant demographic for Mumsnet Talk and Netmums Chat are typically mothers, the membership has broadened[272] and in this study one of the respondents identified himself as male on the thread. As posts on forums are anonymous, it is possible that other respondents could possibly be male, too, but there is no means of verifying these details without contacting individuals directly. Further, for the sake of the data analysis it was not required to know the sex of the parents. A couple of posters also indicated that they were grandparents. In this chapter, parents are referred to as parent 1,2,3 etc, to cover both mothers and fathers; however, for the purpose of data analysis, the assumption is that the majority of respondents were mothers posting about their own children.

7.2.2 Critical discourse analysis of parents' views of the impact of the COVID-19 lockdown restrictions on their children's self-care

Critical Discourse Analysis (CDA) is a particular method of qualitative analysis that focuses on the role of language in society and in political processes. The aim of this method is to reveal discourses buried in language used to maintain power and sustain existing social relations.[273] CDA was deemed a relevant approach to analyse the qualitative data collected for this chapter as this method provides the opportunity to examine how social structures, such as identity and inequality manifest through language.[274]

The Discourse-Historical Approach (DHA)[275], a method of CDA, was utilised to analyse the data collected on the topic of children's self-care on Mumsnet Talk and Netmums Chat threads. According to Reisigl[275], this approach considers discourse analysis to be a multidimensional project incorporating theory and methodology rather than just a method of language analysis. Analysis using DHA follows a three-dimensional approach: 1) identifying the specific contents or topics for a specific discourse; 2) investigating discursive strategies, which includes referential and predicational strategies and 3) examining linguistic means (as tokens) and specific linguistic realisations related to a specific context (as tokens).[275, 276] In the DHA, discourse is considered at micro, meso and macro levels.[275] In this study micro level analysis considers the forum posts made by parents in the study, and macro-level analysis considers to the broader social context of parenting, and in particular, mothering during the lockdown. Meso analysis interprets the discourse of the parents in the study in relation to the context identified in the macro-level analysis.

When using the DHA, there are five questions[275] to consider when analysing a specific discourse, in this case, parent discussions on a public forum around the impact of the COVID-19 lockdown restrictions on their children's self-care.

1. Which linguistical terms are used to name and refer to persons, objects, phenomes/events, processes, and actions? This question assists in recognising the referential and predicational strategies utilised by study participants. In the text discussed in this chapter, this relates to nicknames given for individuals, for example, dd (darling daughter) or ds (darling son), and the way parents describe their children's self-care and experiences. When a parent describes their child as their 'darling daughter', 'daughter' is the referential and 'darling' is the predication that is attributed by the parent to the social actor, which in this case is the child.
2. What characteristics are assigned to the text's social actors, events, and processes? In this text, we can see different characteristics assigned to events relating to the lockdown experience and individual's experience of it. For example, one parent states that their child is "feeling lonely and insecure". Another parent states: "It really is a weird time for us all".
3. What is the argument in the discourse of question? In the body of text analysed, we were particularly interested to see how the lockdown impacted on children's self-care.
4. From which perspective are individuals who are expressing their arguments coming from? In the body of the text analysed, the pandemic and the lockdown restrictions would have played a role in the perspective of Mumsnet and Netmum forum users.
5. How are the utterances articulated, are they intensified or mitigated? Throughout the body of the text, a variation of tone was noted between different participants in the forums.

Ideally, DHA follows eight steps which are implemented recursively.[275] The steps are discussed below.

1) **Consulting preceding theoretical knowledge**: Throughout the analysis process, research on the topic of using discourse analysis for social media and internet forums was consulted. There has been a particular increase in research interest around online media communication and interaction between mothers or on the topic of motherhood, now known as the unique of field of interdisciplinary study, 'motherhood online'.[277] Whilst motherhood and practices of mothers have been the subject of scholarly interest in several disciplines over a long time, the role of digital media and social media in shaping identity and social practices in mothers is a more recent area of study.[277] It has been stated that the evolution of new environments created through new digital technologies, has created the space for mothers to contest and redefine practices of motherhood; especially the stereotype of the 'natural mother.[277] The ideology of intensive mothering[278] which consists of the idea that mothers need to invest a great deal of personal resources in mothering has particularly been challenged in online forums for mothers.[279, 280] In this doctoral research programme , the DHA was utilised to examine the practices of parents, including mothers, in the dataset, and their willingness to challenge this ideology by admitting their true experiences in relation to their children's self-care during the lockdown.

2) **Collecting data and context information systematically:** First, I entered the search terms referred to in section 7.2.1 within the dates specified. Links for threads that came up with the search terms were pasted manually into a word document along with the date accessed. Each thread was manually searched, and the content of relevant threads were then copied into a transcript into an offline, word format. This was important step in retaining the data for analysis, as it is possible for online forum users to go back and edit their posts.

   Following this, the text was entered into NVivo 17 where analysis took place. Throughout the analysis process I considered the rationale, range and relevance of data collected. Along with information on children's self-care, the data set also referred to parent's experiences of children's self-care and their associated feelings. Alongside the analysis of texts, I searched the literature to explore the use and contexts of parent discussion forums. Further, I explored the social and cultural fabrics in relation to the use of MumsNet and NetMums with specific focus on parent experiences and expectations.[279-281]

3) **The selection and preparation of data for specific analyses**. This included selecting threads only relevant to children's self-care during as captured from the commencement of the COVID-19 lockdown restrictions up till the date referred to in section 7.2.1. To prepare the data for analyses, quotes were grouped in self-care categories toileting, dressing skills, and getting ready, and eating.

4) **The specification of the research questions and the formulation of assumptions in the data based on reviewing the literature in this area, and skimming data available on this topic:** This step was carried out concurrently with step number 2, the systematic collection of data and context information. The context information collected (macro level analysis) supported the assumptions made from posts made by parents in the study.

5) **A qualitative pilot analysis of the data to test categories and first assumptions:** Data analysis for this study consisted of a pilot analysis to investigate categories of self-care difficulties mentioned. From this pilot analysis, clear themes from contributors emerged which supported the use of DHA as a method of data analysis for this study.[277]

6) **Detailing the range of qualitative and quantitative data:** During this step, responses in relation to children's self-care were grouped together and the frequency of comments in relation to a theme or topic was also considered to inform the data analysis.

7) **Formulating the critique of the data which includes the interpretation of the results and the context:** As part of this step, I followed the three-layer model of

data thickening[282] used for thickening data (enhancing the depth of the data)[283] in social media research:

a. *Contextualisation:*

   This is a key step in setting the scene for any critical discourse discussion. The context of the discussion taking place on a public online forum and during a pandemic is crucial to understand the discussion that follows in the rest of this chapter. Participation in the forum suggests that parents were reaching out to other parents and perhaps felt that posting in forums was easier than reaching out to family members or friends for help or that participation in the forum was more convenient. A number of studies[104, 284, 285] agree that women value parent forums for support and information and that the anonymity of the forums means that participants are not constrained by the norms expected from them in face-to-face contact. Another study suggested that parents of children with special needs also perceive less judgment online than in person when discussing their children's difficulties.[286]

   It is also important to consider that many child health appointments and other standard appointments were cancelled during the pandemic and labelled as non- essential, therefore it is likely that many participants in the study would not have had the opportunity to present these questions or comments to a health care professional. According to these forums, social contact was also limited during the lockdown in the UK and parents would not have had the opportunity to participate in in-person support groups or take their children to play groups where they could have had these types of discussions with other parents.

   Finally, one needs to consider the context of the two sites themselves. It is reported that the culture of Mumsnet is skewed towards middle-to upper-middle-class, with users often well-educated and older mothers.[287] In contrast, Netmums skews more towards the lower-middle or working-class.[288]

b. Description of events:

This refers to the types of experience posters were reporting. A few parents reported that their children used to be independent with dressing and toileting pre pandemic, but by the time they were posting on forums during the pandemic, their children were no longer able to carry out these activities. Some posts appeared anxious in nature with parents expressing concerns over their children's development. Some parents posted:

> "*I'm just worried about his physical development*" – Parent 50 (21st June 2020)

> *"I am starting to worry about him doing things independently when he starts school in Sept"* – Parent 67 (27th May 2020)

c. Signification

In this step I looked at what the forum tells us about how parents were finding their children's self-care during the pandemic, and how this made them feel. It was clear from forum posts that the associated experience was impacted on parents' overall mental wellbeing.

> "*I'm really losing patience with this one*" – Parent 11 (13th October 2020)

> "*I'm at the end of my rope with this particular daily battle. What do I do?!*" – Parent 21 (20th May 2020)

> "*But now he will do nothing on his own and its driving me crazy*" – Parent 67 (27th May 2020)

8) **Application of the detailed analytical results:** The final step of the DHA is sharing and applying the findings. A poster abstract based on the results of this study

was accepted for the European Academy of Childhood Disability Conference in Ljubljana in 2023. Beyond scientific conferences the aim is to make the results of this accessible to the general public post PhD to raise awareness of the impact of children's developmental difficulties on parents' mental health.

7.3 Ethical Considerations:

The data for this study consisted of posts openly available to the general public without registration or log in. Users on both Netmums Chat and Mumsnet Talk are informed in the terms of conditions of joining the sites that all posts they make, are in the public domain.

Prior to data collection, the administrators for both sites were contacted regarding the study and permission to use posts as the terms and conditions for both sites state that content posted on these sites are the intellectual property of Netmums and Mumsnet. Approval was obtained and it was agreed that the study would take the format of observational rather than a participatory approach. This means that the participants were not aware of the study as the author did not contact participants to ask them for permission to use their content. This study was agreed on the terms that the author should not interact with participants on the forum by asking them questions, and that the identity of participants should remain anonymous. For this reason, the online pseudonyms were removed from all quotes.

As with research carried out offline, it was important to consider the autonomy of forum participants. In this context autonomy refers to the concept that all individuals have the right to privacy and dignity, and where participants were unable to provide consents for their posts to be used, it is the duty of researchers to protect the personal information of internet users or disclose information of which their personal information can be inferred from.[289] Whilst this method[290] of secondary online content analysis, without researcher interaction and influence, is similar to the approach that researchers might take with other written texts it is important to avoid online searchability for participants.[291]

Despite the steps and measures taken above, social media data analysis presents with unique ethical challenges that are discussed in more detail in the following section.

7.3.1 Ethical dilemmas of online research

The availability of vast amounts of data in the public domain have created new opportunities for social science researchers along with methodological and technical challenges.[292] Along with this, research generated from social media and online forums also present unique ethical challenges.[292-294] Risk of harm, the use of private vs public data, informed consent and anonymity are four key areas to consider when conducting research online.[294]

When collecting data online, there is a risk that researchers may come across data on social media which could reveal activities that suggests that participants are at risk in real time.[294] These activities could have ethical implications for researchers and their duty of care.[295] In the data collected for this chapter, I did not come across any data which raised concerns or appeared to be harmful to others. Both Mumsnet and Netmums, where the data was collected from, indicate in their terms, conditions and guidelines that their forums are moderated and that they remove posts considered to be harmful or hateful to others.[288, 296] Mumsnet also state that whilst they do not pass on any personal information of users as stated in their privacy policy, it might be necessary on rare occasions to contact relevant local authorities to safeguard the welfare of forum users or their families about a clearly identifiable member and their post.[297]

The second and third ethical dilemmas identified by researchers relates to the use of private vs public data and the need for informed consent from the social media users or forum users whose data is being analysed.[294] This refers to social media and forum posts that are restricted by the user as opposed to posts that are in the public domain and can be found through an internet browser search without being a member of the social media application or forum. In the case of research carried out in closed social media groups where posts are restricted, direct consent from participants to analyse and use their data is advised.[298] The data collected for this chapter from Mumsnet and Netmums is in the public domain and can be read by both members and non-members of the forums. Members are also informed in the terms and conditions that any internet user can view their comments and that threads can be searched for by non-members.[288, 299] It is usual in this case not to contact individual forum participants for informed consent; only the data controllers which were Mumsnet and Netmums in this study.[296, 299] I followed this procedure and the instructions of Mumsnet and Netmums, which included only observing in forums and not contacting forum users in any way or eliciting data by commenting on posts.

The fourth ethical area of concern when conducting research in cyberspace is maintaining anonymity of participants.[294] The concept of anonymity of research participants ideally refers to the non-traceability of participants based on the data presented about them.[293] However, researchers[293, 300] argue that anonymisation is a complex process. Changing names, including usernames on online forums, or disguising other details such as religion, profession or placenames are just the first steps in the more nuanced process of addressing identifying details from research participants.[293] Some[300] argue that anonymity should be viewed as a continuum along where researchers have to juggle the competing demands of maximising the protection of participants' identity against maintaining the integrity of the data obtained.

In the analysis and transcription of the data collected this data, I removed pseudonyms used by participants on Mumsnet and Netmums, and allocated participant numbers instead when including direct quotes. In studies where consent is obtained from participants, participants are usually informed about the risk of traceability from their direct quotes.[301] However, as I was not permitted to interact with participants in any form and I only obtained consent from the data controllers there was no opportunity to make participants aware of the fact that their quotes were being used for research purposes. In relation to the ethical aspects of using quotes from Mumsnet and Netmums in relation to anonymity, both sites advise users in their guidelines and policies[302, 303] that their posts are visible to all internet users. Users are encouraged to use pseudonyms and are reminded to be mindful of creating posts that could compromise their anonymity, especially in relation to sensitive topics.[303]

Nevertheless, it is recommended that the use of direct quotes should be carefully considered and should only be used in full if the benefits outweigh the risks.[293, 301] For the quotes extracted in this chapter, only text that was relevant to the discourse analysis steps in section 7.2.2 were selected. In some instances that was a complete quote if relevant, and in other instances only part of the quote was selected. The date was included to give context with regards to the time within the lockdown period, i.e. how far into the lockdown the comments were made. Whilst the quotes can be traced back to the forums when entered in an internet search engine, posters generally used pseudonyms as encouraged by Mumsnet and Netmums.[297, 302] Further posts were scrutinised to ensure that no placenames or other potentially identifying information was included in the direct quotations in this chapter.

All the quotes selected were integral to my analysis and for the reasons listed above I deemed the risk of exposing participants offline identities as minimal. Therefore, I made the decision to include the quotes in the analysis as seen in other papers[270, 304] applying discourse analysis to data collected from forums in the public domain. If the quotes had been obtained from sources such as blogs or social media sites like LinkedIn or X (formerly Twitter) where participants’ offline identity could easily be exposed further measures such as changing details such as sex or age would have been applied.[293]

7.4 Discourse Analysis Themes

Three key themes emerged from analysis of these posts on children’s self-care: feelings, the role of online forums and need for social support, and self-care practices that work. (Figure 7.1). Discussion of each theme will identify key concerns of these forum users. This section will then explore the relationship between these concerns and the narrative of raising a child with disabilities or developmental delays.

7.4.1 Feelings

A significant recurring theme in the discussion threads from parents was the feeling of referring to being in a 'battle' with their child. The Oxford Dictionary[305] defines 'battle' as "struggle tenaciously to achieve or resist something".

> "*No tips but my son is 3 in March abs he's started to do this lately, resist me taking his clothes off etc is is a battle*" – Parent 9 (3rd January 2021)
>
> "*Has always dressed himself but it has been an ongoing battle over the last few months*" – Parent 21 (20th May 2020)
>
> "*..but without fail, every morning it is a battle to get him dressed*" – Parent 11 (13th October 2020)
>
> "*God we went through this. What a battle!*" – Parent 20 (14th October 2020)
>
> "*..I'm at the end of the rope with this particular daily battle. What do I do?!*" – Parent 21 (20th May 2020)
>
> "*Has always dressed himself but it has been an ongoing battle over the last few months*" – Parent 21 (20th May 2020)
>
> "*Just refuse to engage. I wouldn't get into a battle*" – Parent 23 (20th May 2020)
>
> "*To be honest, I just assist him to dress. I know he can do it, I'm sure when he's a little older he will want to do it himself, but I pick my battles*" – Parent 24 (20th May 2020)

By using adverbs such as 'ongoing', 'every morning' etc, these parents persisted with these battles, possibly in the hope that they could facilitate a change in their child's ability to participate in daily self-care activities.

By expressions such as 'God we went through this', 'I'm at the end of my rope' or without fail' other parents indicated that they were exhausted by the experience and appeared to have reached a limit to be in a 'battle' with their child. The repetition of the word 'battle' provided me with the impression and sense that parents were in a power struggle with their children over aspects of parenting that they appeared to find challenging during the pandemic. In the case of the participants, this often related to children being unable or unwilling to participate in daily activities such as dressing or using the bathroom in the same way that they did before the COVID-19 pandemic. This power struggle appeared to exacerbate the stress that parents were already experiencing as a result of the pandemic.

During the period that data collection for this study took place (January 2021), Mumsnet released the findings of its own survey to find out how 1500 of its users experienced the pandemic. Of the 1500 respondents, 76% indicated that they felt that the pandemic had a negative impact on their mental health, and 79% indicated that they largely had the responsibility for home-schooling in their household.[281] To demonstrate the burdens placed on mothers (and parents in general) Mumsnet shared a graph indicating a significant increase in swearing at time points when the UK government announced a school closure.[281] This use of language was also observed in the data for this study.

> *"The only way to get my 2 year old into clothes is to put Blippi on YouTube…So I put Blippi on every.fucking.morning"* – Parent 14 (13th October 2020)

> "*My son is 5 next month, he has been able to dress himself for well over a year. Still takes fucking ages and still 'forgets' certain items…when he's spending half an hour putting a sock on I go back to the living area and mentally scream my head off*" – Parent 26 (20th May 2020)

These findings indicate that Mumsnet is a space where parents feel free to express their anger and frustrations, perhaps in ways (e.g. swearing) that are not acceptable to them in other contexts.[281]

7.4.2 Role of online forums and need for social support

Following the theme of parents being in a 'battle' with their children and feeling fed up, another theme that emerged was the supporting role that the online forum played for parents during the COVID-19 lockdown restrictions. Solidarity, defined by the Oxford Dictionary[305] as "unity or agreement of feeling or action, especially among individuals with a common interest; mutual support within a group", came through strongly on the forum posts.

> "*I don't know what to suggest for your son, sorry, as my son is younger. But I can relate that I think even young children pick up on stress and change and sometimes this comes out in behaviours we aren't expecting. Hope things improve soon x*" – Parent 2 (23rd April 2020)
>
> "*Lockdown has been pretty tough on the little ones, i think maybe cut them some slack, the odd day of pyjamas isn't going to do any harm*" – Parent 22 (20th May 2020)
>
> "*It's so hard but it won't be forever. You're not alone in this x*" – Parent 4 (30th April 2020).

Many parents also shared their experiences to provide reassurance to others.

> "Y*es regression is normal when stressful or things change for children. My dd [darling daughter] who is 3.5 we have had her wetting herself on / off during this & same for some of her nursery friends*" – Parent 6 (30th April 2020).
>
> "*We have this issue…"* – Parent 17 (13th October 2020)

Besides parents providing reassurance for others, some were also actively looking for reassurance and expressing gratefulness for help from others.

> "*Sorry if this is not in the correct place but just looking for some advice if I can… Anyone else finding their children seem stressed with the lockdown in place I know children will all react differently*." - Parent 1 (23rd April 2020)
>
> *"Keen to hear from anyone's experiences and learnings. Thanks so much"* – Parent 8 (3rd January 2021)
>
> "*Thanks soooo much for these ideas! I'm really grateful for the help."* – Parent 11 (13th October 2020)
>
> *"This has been very helpful for me"* – Parent 19 (13th October 2020)
>
> *"Some very helpful advice, thanks everyone."* – Parent 21 (20th May 2020)
>
> "*Thank you everyone, Thanks*" – Parent 50 (21st June 2020)

Other researchers have reported many benefits of online support for mothers.[306] Online networks provide mothers, and parents in general, with the opportunity to look for others who share the same life experiences and a community who are willing to listen to complaints and frustrations, offer sympathy, and practical parenting advice. For some parents, the anonymity of online interactions without the fear of being judged might be preferable. Further, anonymous online interactions provide individuals with more freedom to post or not to respond without feeling guilty. Overall, support in online forums offers the opportunity to increase mothers' sense of empowerment in their parenting roles.[307]

7.4.3 Self-care practices that work

Another theme that emerged from the data was parents sharing advice and tips for what worked well for them and their children.

> "*Timers are good I had egg timers for one of mine she was such a faffer and needed the motivation to concentrate on*" – Parent 68 (27th May 2020)
>
> "*On getting dressed by himself, I have been using a combination of reverse psychology (so putting his clothes out and acting all surprised when he appears dressing/asking if he had some help etc*." – Parent 69 (27th May 2020)
>
> "*You could try letting your DC [Darling Child] pick out their outfit. Or give a choice of two if they're likely to pick something completely unsuitable. Then try a reward chart. But start small and manageable eg they put their own socks on and build it up.*" – Parent 13 (13 October 2020)
>
> "*The only way to get my 2 year old into clothes is to put Blippi on YouTube. No amount of encouragement, cajoling, bribery will work for him. I've held him down and put his leggings on before- he just takes them right back off. So I put Blippi on every. fucking. morning. I know all his "songs".*" – Parent 14 (13 October 2020).

Sharing resources and techniques are not unique to this study, and in another similar study, over 50% of the threads had a theme of providing advice and information to others.[104] Other research[265] has indicated that sharing advice is an important motivating factor and source of satisfaction for parents participating in online forums. In a 2009 survey of Mumsnet users, 76% of respondents indicated that they derived satisfaction by providing advice to others.[265] For other parents, this provides them with the opportunity to have their experience and expertise validated by other parents, and for some, this fulfils a need to act out their role as caregivers even when not providing care to their own children.[265] For parents of children with special needs, it is also common practice to share advice with each other online.[286] This is attributed to the information and support needed for this population to be complex and presenting with unique challenges not commonly experienced by parents of typically developing children.[286]

It was noticeable that whilst parents were giving practical tips and advice to others, the topic of getting support from a healthcare professional was rarely mentioned. Only one parent mentioned an occupational therapy assessment and asked whether a child had been assessed for dyspraxia.

7.5 Self-care difficulties

Two key areas of self-care difficulties emerged from the posts in the online forums: toileting and dressing/getting ready. In addition, one parent posted that they had concerns with their child's ability to feed themselves. Toileting and dressing skills are discussed in more detail below.

7.5.1 Toileting

Several posters reported that there was a regression in their child's ability to use the toilet and an increase in children wetting and soiling themselves both during the day and at night.

> "*So my 4 year old has been dry through the night for over a year now and the past 2 weeks he has been wetting the bed pretty much every night!..is it normal for children to go back to a stage of wetting the bed?*" – Parent 1 (23rd April 2020)
>
> *"My 4 year old DD [darling daughter] has had a few changes since lockdown. She has had a few nightmares, wed during the day on several occasions…"* – Parent 4 (30th April 2020)
>
> "*My sons 3 4 in june hes been potty trained over a year. Since all this started hes been wetting and pooping him self daily*." – Parent 5 (30th April 2020)
>
> "*…my DD [darling daughter] who is 3.5 we have had her wetting herself on/off during this & the same for some of her nursery friends*" – Parent 6 (2nd May 2020)

It is reported that involuntary urination, also known as enuresis, usually occurs in children as a symptom of psychological stress.[308] However, regardless of the cause this regression in children's toileting has impacted on some families' ability to participate in daily activities.

> *"I think it is having a negative effect on children, my 2.5yo dd was completely potty trained for 4 months, has now gone back to being worse than she was before she started potty training, weeing everywhere, even in the trolley at asda the other day! Its driving me mad I feel like putting her back in nappies until this is all over and starting from scratch."* – Parent 7 (2nd May 2020)
>
> *"My 4 yo DS [Darling Son] (only child) is very able and can be pretty independent when he wants. During lockdown he has had either my or my husband's attention as we are both wfh [working from home] but in shifts to deal with childcare, but now he will do nothing on his own and its driving me crazy! He used to take himself to the toilet and now he asks for help before he goes every time."* – Parent 67 (27th May 2020)

Some of the stressors during the pandemic that could have impacted on children's psychological wellbeing include fear of infection and lack of information, frustration and boredom, lack of contact with family and friends, as well as family difficulties.[309]

7.5.2 Dressing

Challenges with dressing was another one of the key concerns raised by parents and the most frequently mentioned. From the data provide two themes emerged: 1) children who had difficulties with dressing themselves, and 2) children who refused to get dressed or changed during the pandemic.

> *"My son is 5 next month, he has been able to dress himself for well over a year. Still takes fucking ages and still sometimes 'forgets' certain items' or " Daddy I can't reach my feet."*" – Parent 26 (20th May 2020)
>
> *"Hi all, my son has begun to massively resist clothes changes. I've been wondering about what's wrong in our routine but it's dawned on me tonight that perhaps the issue lies in his lack of independence with this activity"* – Parent 8 (3rd January 2021)

The posts above suggest that self-care was already an area of difficulty, pre-pandemic, for the children discussed. However, as many children's health services came to a standstill in March 2020[310], with staff being redeployed in Covid wards, it is likely that there was reduced support for children and parents. This could have potentially impacted on some children's ability to get the help they need to improve self-care at the start of the pandemic. Further, whilst many child health services moved on to provide telehealth services during the pandemic, challenges in using telehealth in diagnosing and providing care for children have been identified. These include missing out on nuances of children's responses, not getting a complete sense of parental emotional states, as well as interruptions due to technical difficulties.[311]

Other parents noted a deterioration in their children's ability to dress themselves during the lockdown period.

> "*Every day is the same pantomime- repeated requests to get dressed followed by tantrum, sometimes shouting (both them and I). They are physically capable but act like they aren't. Dressed self from around 2 and suddenly struggles with socks in particular."*- Parent 21 (20th May 2020)
>
> "*My DS [Darling Son] is 5 next month. Perfectly physically capable of getting himself fully dressed and we had a routine pre lockdown. Nowadays it takes him forever to get dressed as we have nowhere to be and I just roll with it, although it does drive me ma*d" – Parent 47 (20th May 2020)
>
> "*Just before this could dress herself quite easily and even put her own coat on but now almost a year later I usually end up dressing her myself coz otherwise we'd never get anywhere lol and she still insists that she can't get her tops off although I'm sure she must have the skill*." – Parent 10 (3rd January 2021)

Currently, there are no other studies that specifically focused on children's self-care deteriorating during the pandemic. However, a systematic review[312] investigating the impact of the COVID-19 pandemic on child growth and development more broadly found that, for both parents and children, the balance of daily activities was altered during the lockdown period and that there was an increase in mental health difficulties. Several parents posted that their children were refusing to get dressed since the start of the pandemic, which is referred to in one study as a common symptom of psychological distress in younger children.[313]

> "*I feel ridiculous saying this - I'm 36, he's 2. Every morning I have to almost physically restrain him to get his clothes on. Is this normal?"* – Parent 11 (13th October 2020)
>
> "*My 4yo can dress herself but also often refuses when it's to order, ie morning and bedtime."* – Parent 37 (20th May 2020)

The same parent goes on to say that they think the lockdown has contributed to this.

> '*It is just a comfort thing made worse by the lockdown I think*" – Parent 37 (20th May 2020)

The main findings from sections 7.4 and 7.5 are summarised in Figure 7.1 below.

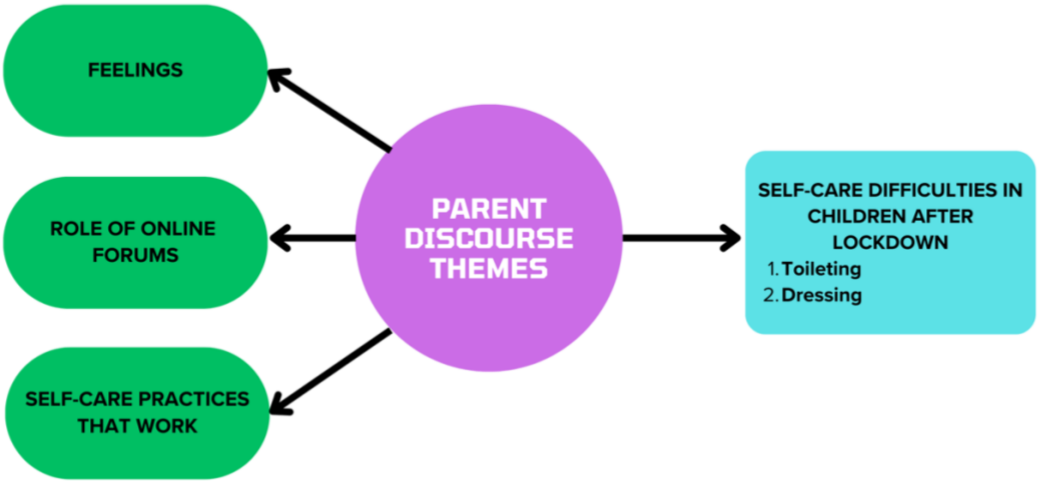


Figure 7.1 Themes identified from parent discourses on how the pandemic and lockdown affected children's self-care.

7.6 Discussion

In this chapter, I explored the question of how the COVID-19 pandemic impacted on children’s self-care drawing on online posts by parents about the self-care difficulties that children presented with during the lockdown. In this doctoral programme of research, along with new evidence about the self-care difficulties that children presented with during the lockdown, three themes emerged from parents’ posts: 1) feelings of parents; 2) the use of online forums as support; and 3) self-care practices that work, including the practice of giving advice or tips to others.

Posts from parents suggest that they welcomed having an online space to share concerns and provide each other with reassurance regarding their children’s development and ability to participate in daily activities. Considering the impact of the pandemic and lockdown on parental mental health and changes to support systems, it appears that online parent forums have a valuable contribution to make in terms of providing parents with a place of support. This study also demonstrated the level of support needed by parents of children with developmental difficulties.

The COVID-19 pandemic was a global emergency, which led to unprecedented public health policy changes and behavioural adherence to limit viral spread. This vital public health response also came at a significant health, societal, and economic cost. It has been shown to have a profound effect on well-being and mental health for both adults and children.[309, 314] In a UK study, five themes were identified that affected parental mental health and well-being during the pandemic: 1) navigation of multiple responsibilities and change inside the home; 2) disruption to home life; 3) changes to usuals support networks; 4) changes in personal relationships; and 5) use of coping strategies.[314] From the data I collected, I observed that children's self-care difficulties also impacted on the stress levels and wellbeing of parents.

During childhood, children have specific developmental needs and are vulnerable to factors influencing their development, and health and well-being.[62, 63] In this study, the impact of the lockdown on children's self-care in relation to toileting and dressing was observed. This adds to the body of knowledge of the impact of the pandemic and lockdown measures on children's health and development.

In summary, understanding the unique needs of children and parents, and the developmental impact, because of the COVID-19 lockdown measures is critical in informing healthcare interventions for the well-being of children and their families. This is also a useful point for healthcare professionals to consider for similar situations in the future, such as future pandemics. Alongside considering the health and development of children, it is vital that parental stress and mental health are taken into account.

7.7 Strengths and limitations

A limitation of online forums is the natural selection of specific participants who have access to and can use the Internet.[267] Internet forum users in particular, tend to be highly educated, predominantly white, and younger participants.[267] In particular, it has been shown that Mumsnet users tend to be well educated, and in a 2009 Mumsnet Survey, 74% of respondents indicated a household income above the UK average.[265] Therefore, the sample in this study is not representative of the average UK family. Furthermore, compared with simple Internet survey questionnaires, online forums require more advanced IT skills because online forums usually require the users to register and log in using usernames and passwords.[315]

A further limitation was that anonymised data were analysed and, therefore, no information about demographical information about the user could be obtained that may have influenced the user's engagement with the forum; and their perception and reaction to the impact of the COVID-19 lockdown measures on their child's development. In addition, with this method of data collection, it is not possible to confirm that all posts were true and accurate. Although forum users are required to enter details of their child's date of birth to become a forum member, there is no guarantee that the information entered is accurate.[316]

Additionally, the real-world implications of users' online posts are unclear, and detrimental effects may have been exaggerated in the absence of sufficient data pertaining to real-world behaviour. For example, parents may use forums when they feel frustrated with their child's behaviour or in need of advice to address these behaviours. In turn, they may stop posting when they have no concerns or their child presents with positive behaviours, which may lead to bias where negative behaviours and parenting challenges are overrepresented.[316] A further limitation is the lack of non-verbal cues that would have enhanced data provided in face-to-face interviews.[317]

In contrast, a strength of the study was that this online study had the ability to include research participants who are commonly excluded from research activity, for example parents of young children, disabled parents and parents living in rural settings. Further, in online forums participants are more likely to respond at a time of their own convenience than wait for a turn which could give parents who are more reserved in face-to-face interactions an opportunity to have their voice heard online.[267] Others report that forum discussion can be considered more naturalistic as the researcher, as an observer, has no influence on the topic being discussed or the interaction between forum users.[316]

Another strength of this study was that the anonymity of the forums provided participants with the opportunity to be more open about the experiences of themselves and their children during the lockdown.[269] Contribution in forums also typically provoke more content and more detailed responses as participants have more time to think and to respond in an online forum than in a face-to-face group.[269]

General benefits of the methodology utilised in this study was that the study was relatively quick to carry out as there was no need to recruit participants, conduct interviews or surveys, and transcribe the data. Public forums also archive messages under headings for the benefit of forum users to easily find topics that they are searching for. This in turn makes it easy for researchers to find forum and messages related to a specific research topic.[316]

7.8 Implications for research and practice

This study shows that the COVID-19 Pandemic lockdown measures have impacted on children's health and wellbeing in many ways, including their development. Whilst restriction measures were implemented to safeguard the public to exposure of the virus the lockdown measures in themselves increased the risk of developmental difficulties for some children.[309, 312] Further research is needed to see the extent of how the pandemic affected children's participation in daily activities across other spheres.

It is anticipated from the study results that there might be an increased number of parents and carers might pick up on concerns related to their child's participation in self-care now that public health restrictions are lifted, and children's participation in activities outside their homes has increased. Healthcare professionals need to be aware of this, and the possibility that a number of children with developmental difficulties "have fallen through the net" during this period. Difficulties with self-care that have not been addressed during this time can impact on children's overall participation in activities and school readiness.

The study results also demonstrate that a number of parents found an internet discussion group a useful place to reach out for support and to support others in a similar position. The value of an anonymous space for parents to share experiences and support without fear of being judged should be further investigated in health research.

7.9 Conclusion

The results from this chapter demonstrate that for some children, early self-care development has been uniquely impacted by the lockdown measures as a result of the COVID-19 pandemic. The lack of social support appears to have exacerbated the risk of difficulties in self-care. These findings suggest the need for targeted and accessible support to meet the unique needs of this cohort of children affected by the COVID-19 pandemic lockdown restrictions. Further, it was observed that a number of parents had strong feelings about their children's self-care during the lockdown and sought support on parent forums to address their concerns. In the next chapter, chapter 8, I discuss teachers' perceptions of children's self-care difficulties in school following the pandemic.

Chapter 8: Self-care at UK schools following the COVID-19 pandemic

In Chapters 4,5,6 and 7, a systematic evidence synthesis, two quantitative studies, and one qualitative study looking at children's self-care, factors influencing their self-care, and the impact on their parents were discussed. In this chapter, I will discuss findings related to self-care at school and the educational implications following YouGov reports[41, 106] on school readiness published in November 2021 and 2022. I investigated the impact of children's self-care difficulties on their participation in school, including the impact on teachers and other pupils. My aim was to demonstrate the impact on children, teachers, and the wider society when self-care is a challenge for young children and to outline why addressing participation in self-care in young children should be a priority for professionals involved in early intervention.

8.1 Background

Following the parental discourse analysis discussed in the previous chapter, Chapter 7, on how the pandemic and lockdown restrictions impacted children's self-care, I also deemed it important to investigate teachers' perspectives on this topic. Particularly as some parents who participated in the qualitative study discussed in Chapter 7 expressed concern about how their children will manage independently in school after the lockdown. In Chapter 1, I also referred to the importance of being independent in self-care to participate in age-appropriate activities in the school environment.

Parents expressed how the pandemic impacted on children's ability in key school-readiness tasks (e.g. getting dressed and using the toilet). Therefore, I decided that it would be useful to gain the perspectives of reception teachers in England on how children in reception presented in relation to their ability to participate in self-care tasks after the pandemic. Particularly in comparison to cohorts of children who entered reception prior to the pandemic, as this perspective was missing from the findings so far.

I initially intended to carry out a focus group with reception teachers on the topic of children's self-care but failed to recruit participants for this stream of research. I have reflected on the reasons for this in Chapter 9 in Section 9.4.4.

Based on the findings from Chapter 7, I drafted questions for teachers (Appendix D) and requested ethics permission from Newcastle University to carry out a focus group with reception teachers. Questions related to observations of children’s self-care in the school environment and comparisons of children in their first year of formal schooling’s self-care before and after the pandemic. Following the ethics approval, I designed a flyer (Appendix E) to circulate to teachers and circulated this amongst teachers in the North-East of England. After initially expressing an interest in participating in the study, there were no responses from the teachers who were approached by email regarding the focus group. Following this, I discussed the possibility of providing a financial incentive in the form of vouchers for classroom supplies to study participants with the supervisory team. I then approached the SENCO of a primary school based in South London with the details of the financial incentive, who again thought this was a worthwhile study after explaining the study aims to her. Unfortunately, there was no uptake from the reception teachers in her school following the details being shared with them and therefore, a decision was made not to continue with the focus group.

Recruiting participants for qualitative research can be challenging.[318] One of the systemic barriers is potential participants being reluctant to enrol and participate in research they consider as time-consuming and burdensome.[318] Even more so if they perceive the research to be exploring sensitive topics.[318] Barriers specific to recruiting teachers for research include their availability and the willingness of the school's headteacher to allow them to participate. In the case of my study, a practical obstacle was classroom cover when the teachers were participating in the focus group. On the other hand, participating in the research when children were not around would have impacted on their own free time. Other barriers include school demands such as reports and school events when participation in research may not be a priority for teachers. This can result in emails sent to teachers being overlooked and teachers failing to get in contact with researchers.[319]

I therefore decided not to approach any other schools as the data collection period would have coincided with teacher strikes[320] in the UK, and other end-of-year activities. Instead, I carried out a document analysis (quantitative and qualitative) of recent UK government reports and other relevant reports and studies on children's self-care and school readiness. I discuss the method for this in the section below.

8.2 Method

In this descriptive document analysis[321], I defined the problem as the impact of self-care difficulties on children’s participation in school. My objectives were to find out how children’s self-care difficulties impacted on them and others in the school environment, and to see if there were any differences in children’s self-care in school before and after the COVID-19 pandemic. The analysis drew on UK government school readiness reports published just after (2021 and 2022) the COVID-19 pandemic, and it focused on teachers' perspectives on children's self-care after the COVID-19 pandemic and lockdown restrictions.

For this document analysis, I followed the READ[322] approach. This approach consists of four steps. The first step is ‘ready the materials’[322] which refers to the process of setting parameters around the number of documents to analyse and the type of information one plans to extract from them. I searched online for relevant teacher or education reports using the search term ‘UK government school readiness survey’. This search term was used as school readiness in the UK refers to being ready from a developmental perspective, not just academic attainment. [322] I chose the search term survey as I was specifically looking for survey results whilst UK government restricted the search to schools in the UK.

Through using the Google search tool, I came across the Kindred Square School Readiness surveys[41, 106] and upon further online inspection, I observed that these survey results were also referred to by other publishers and news agencies. I used this to conclude that the Kindred Square surveys are reliable surveys on this topic. As the Kindred Squared School Readiness surveys were carried out in 2021 and 2022 after being introduced in 2021, I analysed the reports from these two years. To learn more about self-care and school readiness pre-pandemic, my search brought up a Department of Education report[323] which was the closest match to the surveys that I analysed from 2021 and 2022.

The second step in this approach is to extract the relevant data. I focused on quantitative and qualitative data related to children's self-care. The reports[41, 106] that I extracted the data form included questions on toilet training, eating independently and drinking from a cup without a lid as part of the school readiness survey. I extracted the numerical data from responses to these questions, along with qualitative feedback from study participants related to these questions. From Department of Education reports[323, 324] I extracted numerical data on level of development, which included health and self-care. Numerical data for all reports comprised of percentages of children with difficulties in the areas discussed above, and these percentages were extracted to Excel.

The third step is to analyse the data. In my analysis I asked questions related to the individual documents and the overall body of documents suggested by the authors of the READ[322] method. The method uses analysis at a level of key concepts which include the following: the purpose and audience of the documents; the contributors or authors of the reports; the credibility of the reports; the agenda of the reports; sources of evidence cited; the voices represented in the documents; and the issues identified. Where questions were identical, I compared quantitative data (raw data consisting of percentages included in the reports) for different periods of time for the survey questions identified in the data extraction whereas in my qualitative analysis I considered the impact of children's self-care on respondents in the reports. I used a mixed method content analysis approach[325] to analyse the data from the documents.

The fourth and final step of the READ method is to distil the data, which refers to the refining of the data obtained.[322] In line with my research objective, to identify the impact of the COVID-19 pandemic restrictions on children's self-care and parents I focused on children's self-care at school post the COVID-19 pandemic. Following the mixed method content analysis[325] in the previous step, I identified three key themes from the findings. To support my findings, I used a triangulation approach[326] to refer to other research findings in this Thesis and other recent literature on the topic. The findings from the analysis following the refining process are discussed in the section below.

8.3 Analysis findings

I identified three themes based on the qualitative and quantitative findings from my content analysis. These were as follows: 1) The overall impact of children not being independent with self-care at school; 2) Self-care and school readiness following the COVID-19 pandemic; 3) What needs to be done to support self-care in young children?

8.3.1 The impact of children not being independent with self-care at school

The first theme that I identified from the reports was the significant impact that children's self-care difficulties had on themselves, other learners, and school staff. Teachers reported that the behaviours and needs of children who are not independent in self-care and ready for school significantly impacted on other pupils in the classroom as they lost out on teacher time and attention. As a result, children's learning was also affected as, in some cases, helping children with self-care detracted from teachers' time to teach and support academic learning.[41, 106] Teachers who participated in the focus groups of the study carried out by Kindred Squared[41] reported that the quality of whole class teaching and learning has been impacted on recently because of so many children being behind in their development, and not being able to carry out personal care tasks. Direct quotes from teachers who participated in the 2022 survey[41] demonstrate the impact of this on all children and staff.

> "*Teachers often can't get down to the 'meat and potatoes' of teaching the curriculum because they're doing things like changing wet children, dealing with emotional outbreaks etc. Many of our Reception staff, especially this autumn term, have missed out on their lunches and thus their prep time due to supporting children who can't feed themselves.*" - Teacher, West Midlands.
>
> "*You try to not let it impact [the children] too much, but they are having learning time taken away whilst adults deal with behaviour/toileting etc.*" - Teacher, East Midlands

Teachers who participated in the 2021 Kindred Squared report[106] observed similar challenges with self-care along with the impact that it had on all individuals in the classroom, and school. Their quotes[106] demonstrate toileting as a particular area of concern.

> *"Some children who aren't fully toilet trained are having to change their clothes 2 or 3 times a day - that's a lot of time out of class, and other children start to notice as well"* - Teacher, East of England

> *"Children that aren't ready toilet-wise, that takes up a lot of time, if they can't do their buttons themselves, or their trousers up"*- Teacher, Scotland

Further, participants of the recent YouGov study[41] reported that limited school readiness and challenges have a significant impact on schools and staffing. As a result of these difficulties, participants reported that schools need higher levels of staffing to be able to support children to focus on basic self-care tasks, such as toileting and dressing. In some cases, other members of staff, including admin support staff, were asked to help with children who needed support with self-care, which in turn left another department of the school unattended.[41]

However, many of the respondents of the survey[41] who were headteachers and senior leaders in education reported that increasing staffing levels is not a realistic or doable option for most primary schools, particularly government-funded state schools. There are already significant financial constraints in the teaching sector which limits schools' ability to employ extra staff to support children with self-care. This has caused a significant amount of stress in schools, as can be seen in the following quotes.

> "*Staff in our school are being pushed to their limit at the moment. Lots of children not toilet trained means two members of staff are having to be released from classes to change a child each time they have an accident*." - Teacher, West Midlands.

> "*You are just forever playing catch up, so you are starting behind … we're in a huge deficit budget and we have got nowhere near enough staff to be able to catch the children up.*" - Assistant Headteacher, East Midlands

A respondent from the 2021 survey[106] reported the same which shows the impact of children not being independent in self-care on school staffing in the whole school.

> *"A couple are not toilet trained – does draw on teachers' time. I have to help! I go in and help clean up a child. Secretary may help. It is not ideal. It's expensive time – me cleaning up etc."*- Teacher, East of England

Besides staffing levels, teachers who participated in the survey[41] also indicated that they estimated that the average financial cost to their school for the additional time spent supporting children, who were not school ready, was £21,652. This was an increase from the estimated £17,784 in 2021.[106] Furthermore, senior school leaders costed this at £23,403, which was higher than estimated and an amount that is equivalent to a full-time staff member's salary. Based on the survey results, it is estimated that the cost of children not being school ready equates to approximately £450 million per year in the UK.

Headteachers have expressed concern that the financial resources to support children with difficulties with self-care and school readiness are lacking and are worried that they are not able to provide children with the support they need in order to progress.[41, 106] One headteacher stated:

> *"Adults are the most valuable but most expensive resource in schools and this is essential to support these children as effectively as we can. We simply do not have the finances to meet these needs and I feel we are failing a number of children because of these limitations."* - Headteacher, South of England

It is clear from the statements above that there are significant cost implications, along with other detrimental impacts on staffing and children's learning, if children are not supported with self-care at an earlier stage of their development. Children who are independent with self-care at reception age will be able to participate in the activities expected for their age group and better able to focus on their learning. If children are supported with self-care before they start formal schooling from their reception year and require less support from staff and financial resources from school, there will also be more resources available to support all children in other areas of their development.

As mentioned in Chapter 1, self-care has been identified as a priority area of improvement by children, families and commissioners, and difficulty with self-care is also one of the biggest reasons for children in primary schools to be referred to children's occupational therapy services in the UK. There is a significant waiting list for children with developmental difficulties to be seen for therapy appointments, and in some cases, children are waiting up to two years to be seen for a therapy appointment.[327] This highlights the further need to support children's participation in self-care before it gets to the stage where they are waiting for therapy assessments and intervention, and their challenges with self-care disrupt their education and social development.

8.3.2 Self-care and school readiness following the COVID-19 pandemic

The second theme that emerged from my analysis was the impact of the pandemic on children’s self-care as observed by teachers. In the recent YouGov school readiness survey[41], reception teachers indicated that they expected children to be "sufficiently independent, able to use the toilet, dress and feed themselves and to be separate from parents". In this 2022 school readiness report[41], teachers reported that they had observed an increase in the number of children who are not independent in self-care activities. Of the teachers who participated in the survey, 91% of participants reported that they had at least one child in their class who was not toilet trained, and 89% of participants indicated that they had at least one child in their class who was not able to eat independently. This was a one percent increase in both areas of self-care from the 2021 report[106], where 90% of teachers indicated that at least one child in their child was not toilet trained, and 88% of teachers indicated that at least one child in their class was unable to eat independently.

The Kindred Squared school readiness reports[41, 106] were only launched in 2021, and therefore, there is no exact match to compare these results with before the pandemic. However, a 2019 Department of Education report[323] found that in England, based on the Early Years foundation stage profile, that 71.8% of children nationally achieved what is described as a 'good level of development'. In the most recent report[324] completed in

2022, the number of children with a 'good level of development' decreased to 65.2%. Unfortunately, these reports did not refer to specific self-care tasks like the Kindred Squared reports, but instead referred to general health and self-care needed for school readiness. Based on comparing statistics from these reports for before and after the pandemic I was able to draw conclusions on how children's general levels of self-care and school readiness decreased from before the pandemic.

In line with these findings, two studies included in the systematic evidence synthesis in Chapter 4, found that the pandemic had a detrimental impact on children's self-care. In Chapter 7, I also saw that parents expressed their concern that their children were not going to manage with carrying out self-care activities independently in the school environment once they started in reception after the lockdown. Further, In the YouGov survey[41] carried out in 2022, both parents and teachers indicated that they thought that the COVID-19 pandemic played a significant role in the deterioration of children's school readiness for starting reception in a mainstream school.

Another UK study[328] explored the implications of the COVID-19 restrictions on the transition from Early Years Education to Key Stage 1 for children with special educational needs and disability. The study[328] also found that professionals observed significant disruptions and delays in children's self-care and independence skills and in adhering to behavioural expectations, in comparison to children in previous academic years. Usually, the potentially complex needs of children with special educational needs and disabilities (SEND) are considered by schools within their planning and provision, and it was speculated by the authors of the study that the COVID-19 pandemic interrupted this process. As teachers did not have the opportunity to support SEND children with this transition process due to the pandemic, it is likely that many of the behavioural difficulties, typically a sign of anxiety in SEND children, can be attributed to this change in transition preparation necessitated by the lockdown restrictions.[328]

Further, in a "Children's access to occupational therapy" survey carried out by the Royal College of Occupational Therapists (RCOT) in the UK in 2022[329], 85% of respondents reported that there has been an 85% increase in the demand for OT since July 2021. Of these respondents, 52% indicated an increase in the number of younger children referred for OT assessments due missed early developmental opportunities during the COVID-19 pandemic. This survey[329] included valid responses from 339 children's occupational therapists working in the NHS, charity settings, and independent practices across the UK. The survey and report do not specifically imply that children were referred to OT due to challenges with self-care, however it does show that there is a significant increase in the demand for OT assessments and interventions following the COVID-19 pandemic. This correlates with parents' and teachers' views that the pandemic and circumstances related to it impacted on children's overall development.

8.3.3 What needs to be done to support self-care in young children?

The third theme that emerged from the data analysis was the identification of actions and guidance required to support children to participate in self-care. This includes education and awareness. A significant finding in the 2022 YouGov report[41] was the discrepancy between parent's and teacher's perception on what self-care activities were essential for participation in school. Teachers believed that they have observed a decrease in parents' understanding of what activities form part of school readiness and attributed this to a reduction of government funding in early years education and support.

A key concern was that many parents[41] (44% of respondents from the YouGov survey) stated that they were unaware of the developmental milestones their children needed to reach before starting reception. This is much too late for parents to be able to seek appropriate guidance and support to their child for their entry into reception. In fact, several interviewees stated that it would be most helpful for parents to learn about the expected milestones in self-care their children needed to achieve when their children were infants. As there was a significant reduction in health visitor support, and many children were not able to attend a nursery during the COVID-19 pandemic, it can be inferred that there will be a further decrease in parents' understanding of school readiness in the future.

Staff in education also feel the need for guidance on self-care independence and school readiness to be distributed at a national level with one head teacher stating[41]:

> *"At the national level, there just could be better information for new parents about what will really help children in those first few years. Just a few key things that become very common knowledge."* - Headteacher, South of England

Other teachers stated[41]:

> *"I think there should definitely be more support and guidance out there for what is expected of parents. Some parents choose not to do things for an easy life and leave certain areas for teachers to tackle, whereas other parents genuinely don't know what is expected." – Teacher, West Midlands*

> *"I really don't think parents have any idea [of the developmental milestones expected by Reception]. There is so little given to them before they start school, the most in-depth information is around the two-year developmental check but then there's a huge gap between that and starting school." – Senior teacher, West Midlands*

These perspectives align with my views that it will be useful to have self-care milestones detailed in a central place (i.e., the NHS red book) where parents can tick off self-care milestones alongside other developmental milestones. This might also contribute to health visitor, including questions related to nursery and pre-school, check-ups.

Some teachers also felt, that along with some parents being unclear about children's expectations, there was a mismatch between whom teachers and parents considered being responsible for teaching children self-care. One teacher stated[41]:

> *"Parents need to know what the priorities are for children at school and realise that parenting is not a teacher's job. There needs to be a distinction between what parents should teach their children and what teachers are there to teach.'" – Teacher, East Midlands*

Another teacher illustrated how some parents do not consider that it is their role to support their children with self-care and highlighted the need for clearer guidance for parents.[41]

> "I*t is parents' responsibility, but I think there are a lot of parents in our school who don't realise they are doing far too much for their children. If they had clear advice, I think a lot of parents would take this on board*." - Teacher, South of England

A qualitative study[330] which explored the understanding of parents' and teachers' perspectives on motor skills related to self-care skills, also found that many parents demonstrated a limited understanding of their children's needs and developments in relation to self-care. There was also evidence to show that nursery or pre-school teachers had limited knowledge of motor skills in young children and how this related to their self-care ability in nursery or preschool settings.

From that qualitative study[330], five main themes emerged in relation to children's self-care: 1) a lack of knowledge; 2) time constraints; 3) child factors; 4) the need for guidance; and 5) non-standardised guidance.[330] A lack of knowledge referred to parents' understanding of their child's development and needs and teacher's knowledge of developmental motor milestones and how this relates to participation in self-care in young children. Time constraints referred to working parents and the barrier that working life presented with in relation to monitoring their children's self-care. Child factors related to children's varying needs and attitudes and how some children responded better to certain adults when learning self-care tasks.

In relation to the need for guidance, teachers who participated in the study[330] expressed that they had no formal guidance on children's self-care and would value guidance on this topic. Parents expressed the same need. Preschool teachers particularly expressed that they were lacking in ideas to help children with a range of self-care needs and would value a teaching module to better support children who were developing at a different level or pace. The fifth theme, non-standardised guidance, related to limited continuity between home and school, with a number of parents expressing concern that there was a lack of consistency at how self-care was supported in nursery in comparison to home.[330]

8.4 Discussion

The findings from this chapter highlight the importance of professionals being aware of self-care development and challenges in young children, to best support them to participate in daily life. As seen in section 8.3.1, the impact of children not being independent in daily activities has a significant impact on children and others involved in their care. Besides impacting on individual children's participation at home, school and in the public domain, there is a significant societal cost to pay for school aged children who are not able to participate in self-care activities independently.

On a local level, their inability to complete personal care tasks independently impacts directly on their peers. On a larger scale there are significant financial implications for the schools and local authorities to meet the extra costs of providing children with self-care challenges with the support they need to function independently in the mainstream school setting. Teachers reported that difficulties with self-care in reception have been exacerbated by the COVID-19 pandemic and associated lockdown restrictions. This was the case for both children in mainstream and special education school settings. These difficulties impact on all children's learning, not just the child who presents with delays and difficulties with self-care. Further, there are also financial and human resource implications for schools and local authorities due to the increasing number of children requiring support with self-care in the school setting. Alongside this, children's occupational therapists in the UK also reported a significant increase in referrals for children to be assessed by OT since July 2021, indicating implications for therapists and children waiting for appointments as well.

The findings from this chapter also highlight the need to support children at a younger age to facilitate their participation in self-care and to provide appropriate intervention and guidance to children and their families in this area of development. This includes increasing parental awareness of self-care demands at different developmental stages, including self-care expectations for school starters. Throughout this Thesis, there has been a focus on investigating factors influencing self-care in young children, and to contribute to the evidence base on this topic for professionals to draw on when supporting this population with self-care challenges. For parents to be aware of self-care challenges it is also important for them to understand what factors can influence self-care in young children and why participation in self-care is an important part of a child's daily life.

8.5 Strengths and limitations

There are several strengths and limitations for conducting a document analysis, and more specifically the document analysis carried out in this chapter. The first strength of this method is the opportunity to collect data that would have been difficult or event impossible to do.[331] Due to a lack of participants, I did not have the opportunity to discuss self-care and school readiness in reception pupils with research participants directly. However, recent YouGov surveys[41, 106] and other reports from the Department of Education[323, 324, 332] reported on the type of data that I was planning to obtain from teachers, and I reported on this instead.

Whilst speaking with teachers directly would have been ideal, there were distinct strengths and advantages in reporting on secondary data from these reports. Firstly, there was a higher number of participants from across the UK who shared their views. For example, the 2022 Kindred Squared School Readiness Report[41] included quantitative data from 1043 participants working in primary education. Qualitative data for this report[41] was sourced through two focus groups for teachers and 15 interviews with headteachers. Sourcing this quantity of data through document analysis was more cost effective and less time consuming then obtaining the same amount of info through research fieldwork. This is a strength of this particular research method.[331] Similarly data obtained from the Early Years Foundation Stage Profile results[323, 324] draw on data collected from all local authorities in England which is a significant sample size.

Another strength of the analysis is the voices represented in the documents, and particularly the inclusion of the view of headteachers. In my initial research plan, I intended to carry out a focus group with reception teachers which would have provided insight of how children's self-care difficulties impacted children and staff in the classroom. However, the YouGov reports also included the views of senior leaders in education who were able to provide insight on the financial impact in schools from children who required extra support with self-care tasks in the school environment. This has added to the findings and provides more in-depth feedback of the real-world impact of children's self-care difficulties.

Finally, another strength of the analysis and this research methods was the robustness of the data and the credibility of the sources. Data for the Early Year Foundation Stage results were collected by local authorities through a bespoke data collection system which identifies invalid data.[323] Kindred School Readiness surveys also clearly documented the research methods and analysis used for the data in their reports. The main purpose of these reports is to provide advice for policy monitoring and setting future policies regarding early years education.

A limitation of the data is that whilst it included useful information on children's self-care and the impact of self-care challenges at school, research with teachers directly would have been able to explore the exact self-care challenges in more detail. In relation to the methodology itself, it is important to realise that information in documents is not without bias and that documents and sources should be viewed critically.[333]

8.6 Conclusion

In summary, this chapter found that a significant number of children in the UK are not ready for school and present with challenges with self-care that impacts on their ability to participate in daily activities at school. The findings from the reports discussed in this chapter, along with the findings from the overall doctoral research programme, highlight the urgency of ensuring that both children in mainstream school settings and children in special schools get the support they need at an early stage to participate in self-care activities. In the next chapter, Chapter 9, I bring the findings from all the research streams discussed in Chapters 4-8 together.

Chapter 9: Discussion of key overarching themes

In Chapters 4 to 7, a systematic evidence synthesis, two quantitative studies, and one qualitative study looking at children's self-care and factors influencing children's self-care found that that children's mobility and cognitive ability are consistent and significant predictors of self-care development, and that the COVID-19 pandemic impacted on children's self-care and parental stress levels. Chapter 8, an analysis of UK Government documents, found that there was an increase in the number of children who presented with difficulties with self-care at school following the COVID-19 pandemic in comparison to school starters before the pandemic. In this chapter, I synthesise the findings from these previous five chapters and present them in the format of the conceptual framework discussed in Chapter 2. I also share reflections on my experience of the research in this doctoral programme.

Early childhood is the time when individuals form skills and behaviours that may influence the rest of their life.[334] Recent observational studies and feedback from other stakeholders, for example, teachers and headteachers, have provided evidence that outcomes in self-care affect other areas of participation, such as education and participation in social events, across the life course.[41, 42, 106] These outcomes in self-care are facilitated and created by a complex range of interconnecting factors, including individual determinants such as body factors, household characteristics, including socioeconomic status, the socio-political and social context, and neighbourhood-level factors including access to healthcare as seen from figure 2.1 in Chapter 2. To help children achieve their full potential in the domain of self-care, it is essential to understand the factors which may influence children's self-care independence. Rather than focusing on individual dimensions, child health and well-being needs are better tackled by combining policies and resources at these wider social determinants of health and well-being.[335-338]

Analysis and synthesis of the four studies and policy documents discussed in the previous chapters informed the development of interrelated concepts that are described in this chapter. In this chapter, I report the synthesised data in relation to the concepts identified from the previous studies discussed. I followed a sequential synthesis design[339] throughout this doctoral research programme, where data extraction and analysis of one type of evidence informed the collection and synthesis of other types of data collected. The theory generated from the systematic evidence synthesis in Chapter 4, informed the research questions for the quantitative data analyses in Chapters 5 and 6. In turn, findings from these chapters informed the need for the qualitative data that was collected in Chapters 7 and 8. Therefore the integration of evidence of each phase occurred before the next phase, and is brought together in the discussion, key themes, below.

9.1 Key themes drawn from the analysis in this research programme

From across the studies included in this doctoral programme of research, four key themes emerged. The first relates to the evidence base for self-care interventions and method of intervention for self-care. In the UK, children's interventions are mostly offered by OTs and interventions are offered by the NHS, in clinics or schools. In this doctoral research programme, I investigated the factors influencing children's self-care and interventions for self-care. What emerged was an opportunity for a population-based approach to address self-care to supplement the existing NHS-based interventions. There may be unexploited opportunities, for example, engagement in community activities impacted by self-care difficulties. This was particularly evident from the analysis of qualitative data in Chapter 7 where parents used online forums to seek support and support others in relation to children's self-care. From that analysis it was also found that only one parent in the threads analysed mentioned OT as a source of support for self-care difficulties. Whilst the synthesis in Chapter 4 discussed interventions known to be effective to support self-care, I suggest that interventions need to be more accessible and be pitched a population-based level, shifting the focus from reactive care to proactive, preventative care. This way more children will benefit from self-care support and children will not be excluded from care through long waiting lists, or inability to access care as a direct result of poverty. This includes children with mobility and social/cognitive difficulties as seen in Chapter 6.

Secondly, the findings from Chapters 4 and 6 found similarly to other research in this field that mobility and cognitive skills are consistent predictors of children's self-care. However, while this evidence comes across as conclusive, there are some caveats. For example, this evidence is mostly informed by quantitative approaches that use definitions and outcomes of self-care set by adults. The existing models do not explore or capture children's views about how they experience self-care and difficulties in this area. Further in Chapter 6, 10.71% of the dataset presented with mobility difficulties for the first wave of data collection, and for the second wave of the data collection this percentage was 11.42% of the dataset. As mentioned in Chapter 6, a previous study[260] investigating mother-child interactions in children with disabilities found that in some circumstances, the parents of children with reduced mobility assisted their child with self-care activities regardless of whether the child required assistance with self-care. As the PEDI-CAT is a caregiver questionnaire capturing parents' views on their child's ability, it would be useful to also investigate the correlation between mobility and self-care in other ways. This should include qualitative data from children on what aspects of self-care they find challenging themselves, and why.

Thirdly, there is a sociocultural nature of self-care practice that needs to be taken into account for all children and families. For example, the social nature of eating together and celebrations. Another context to consider is cultural practices in relation to self-care for example different the use of different eating utensils, a knife and fork vs chopsticks. In Chapter 4, a number of studies also made reference to cultural expectations in terms of children's self-care. This sociocultural aspect falls within the macrosystem in Bronfenbrenner's ecological systems theory model.[63] As discussed in Chapter 2, this system encompasses the broader cultural, societal, and ideological forces that play a role in an individual's development and accounts for the impact of cultural beliefs, values, customs, and social norms on a child's development.

Finally, the fourth point is the importance of observing children's self-care alongside their family dynamics. In Chapter 5, parents presented with high levels of parental stress and in Chapter 7, the impact of children's self-care difficulties on parents' wellbeing was also visible. In Chapter 4, it was observed that parental stress levels can negatively impact on children’s self-care. Therefore, it is important for researchers and health care professionals to consider the whole family when investigating and addressing children’s health needs and difficulties with self-care.

9.2 Self-care in children seen through the perspective of an ecological systems theory

Personal and Contextual factors influencing self-care in this doctoral research programme are discussed below in the context of Bronfenbrenner’s[63] ecological systems theory model. The logic model discussed in chapter two has also been revised following the analysis of the findings discussed in Chapters 3 to seven 8. This model[63] is seen as a suitable framework for representing factors influencing children's self-care due to the range of ecological factors found in this programme of research. One of the first researchers to adopt this framework to investigate childhood development and disabilities was Joanne Sontag.[340] She argued that this framework allowed for the influence of children's environments and families to be included to have a better understanding of their development. Another study[341], outlining trends and implications in current child research, also suggested that the interrelated biological, psychological, and social aspects should be considered when recommending interventions for children.

The five levels of Bronfenbrenner’s ecological systems theory[63], the microsystem, mesosystem, exosystem, macrosystem, and chronosystem were discussed in detail in Chapter 2. In this section, I will discuss the findings from Chapters 3 to 8 in the context of these levels to demonstrate how the five systems contribute to children's development and participation in self-care in England where this programme of research took place. Bi-directional and reciprocal relationships are addressed by focussing on the effect of personal and contextual factors influencing self-care. One of the key points about the ecological systems theory framework, is Bronfenbrenner’s idea that it is not one or a few factors that influence children's development, but rather the interaction of a range of factors, which can take place across time.[342] In this programme of research, I identified the four themes described above in section 9.1 but also recognised factors influencing self-care in the context of the ecological systems theory. These are discussed in more detail below.

9.2.1 The microsystem

As discussed in Chapter 2, the microsystem refers to the immediate environment surrounding an individual, and family dynamics play a key role in this system, including daily interactions with others who play a significant role in children's lives. In Chapter 7, where the impact of the COVID-19 pandemic lockdown restrictions on children's self-care and their families was discussed, family dynamics came up as one of the key themes. Parents who had children who presented with challenges with self-care described how they were in a 'battle with their child', and others described how they were unwilling to engage with their children when they deemed their child as being uncooperative with self-care.

Parents' responses from the Mumsnet and Netmums forums indicated that parents were under a significant amount of stress due to the lockdown. Many parents in the Mumsnet and Netmums forums also noted that their children's self-care deteriorated and that this exacerbated the stress that they were under, as seen in the quote below.

> *"My 4 yo DS [darling son] (only child) is very able and can be pretty independent when he wants. During lockdown he has had either my or my husband's attention as we are both wfh [work from home] but in shifts to deal with childcare, but now he will do nothing on his own and its driving me crazy!" - Parent 67, 27 May 2020*

It is possible that these high levels of stress, directly or indirectly, impacted on the relationships between parents and their children and also the overall family dynamics. This, in turn, could have resulted in a spiral affecting children's participation in self-care. This result was echoed by one study included in the systematic evidence synthesis in Chapter 4, which found an association between children's self-care and parental stress levels. Although the impact of parental stress on children’s self-care was not seen in all the studies in Chapter 4, one can see a distinct bidirectional relationship between children's self-care and their interaction with their parents, particularly during the COVID-19 lockdown, from the qualitative findings discussed in Chapter 7.

Further, children from single-parent households are subjected to different tensions in their household than a child from a two-parent household. In single-parent families, there is an increased risk of parental stress, particularly when children are developmentally delayed or present with a disability.[343] Whilst data on household demographics in relation to family status, were not collected for the two longitudinal studies, the increased stress levels in single parents were observed in parent responses analysed in a government report.[344] During the lockdown, single parents were under increased stress due to financial constraints and lack of support with home-schooling as illustrated in the quote below.

> *"'I'm on my own and I found the lockdown with both children at home stressful... It's been horrendous. I think it's really affected my three-year-old because ... she's barely been at nursery... and the school putting a lot of pressure on me to homeschool and it's like, I don't think they take into appreciation it's quite difficult when you've got children at home... ... I went on to the Universal Credit at the beginning of lockdown ... I've had to use food banks and stuff a couple of times, because we just really, really struggle. I don't think they've taken into a consideration the extra cost of having the children at home all the time. So I'm like having to find different ways to entertain them"* - parent quote from Implications of COVID for Early Childhood Education and Care in England Report.[344]

Another study[345] found that the lockdown restrictions from the pandemic affected children's mental health between single-parent and two-parent households disproportionately, with children from single-parent homes presenting with higher levels of poor mental health.

At the microsystem level, personal factors including motor and cognitive abilities can significantly influence an individual's development and ability to participate in self-care. Chapters 4 and 6 discussed personal factors influencing self-care development and participation in self-care. Some of the most significant child factors that influenced self-care were children's mobility, gross and fine motor abilities, along with cognitive skills. Sensory processing differences also impacted on children's ability to participate in self-care.[136, 176, 177, 346]

Additionally, environmental factors such as socioeconomic status, family resources, and community resources can have a significant impact on an individual's experiences within this level. From the studies analysed in Chapter 4, I found that children with Cerebral Palsy who came from a higher socio-economic background were more independent in self-care than children from a lower socioeconomic background.[185] Another study[123] also reported that a higher level of self-care independence was significantly associated with a better physical environment at home. However, as IMD-Deciles were identified as a confounder in Chapter 6, further research needs to be done in this area to confirm a definitive link between socioeconomic status and self-care for all children.

Health services and access to care also fall within the microsystem, and the results from the systematic evidence synthesis in Chapter 4 demonstrated that therapy or medical interventions made a difference in facilitating participation in self-care. The interventions discussed included CIMT, which showed some positive outcomes in self-care for children with CP. Other therapy interventions that were described as facilitating self-care in children and young people included: conductive education for children with CP; sit-to-stand training for children with CP; a visual perceptual intervention; goalsetting training; hand-arm bimanual intensive therapy; occupational therapy; hippotherapy; video prompt models and backward chaining for autistic children; and intensive goal-directed physiotherapy. However, in Table 4.6 one can see that the strongest intervention evidence was for CIMT for children with CP.

Medical and pharmaceutical interventions that facilitated self-care included dorsal rhizotomy, a surgical procedure that aims to reduce spasticity in the lower limbs for children with CP, and the drug Etanercept, which is used to treat autoimmune conditions such as juvenile idiopathic arthritis. On this system level, one can see how children who had access to healthcare and interventions that contributed to improved function in gross and fine motor skills, or other body functions presented with different self-care outcomes than those who did not.

9.2.2 The mesosystem

As discussed in Chapter 2, the mesosystem relates to the connections and interactions between the microsystems in an individual's life, and in this doctoral research programme, the mesosystem referred to the relationships between family members, and teachers, peers, and other social groups that play a role in a child's life. Understanding this system in a child's life is crucial to understanding and appreciating how the different microsystems work together to influence their development. As the data collection for the EASIER study and the qualitative study took place during the COVID-19 lockdown, many of the study participants would not have been in school at the time and would have been home-schooled during this period. As a result, children in these studies would not have had the same opportunities to interact with teachers and peers, during the lockdown.

As this research programme did not focus on children's social interactions (and the impact of this on self-care) there is no other empirical evidence from this programme to add to this section. However, in Chapter 8 teachers reported a deterioration in children's self-care in schools in comparison to cohorts before the pandemic. The cause for this needs to be investigated further.

9.2.3 The exosystem

In this system, one finds the broader social and environmental contexts that indirectly influence children's development and self-care. This includes factors such as community resources, government policies, and the availability of social services. One of the key findings from this doctoral research programme in relation to this system is that there is a need for more population-based approaches to support children's self-care. This was particularly evident in Chapter 7, where parents sought support from other parents in online forums in relation to their children's self-care. In relation to community resources, waiting lists for therapy and access to home adaptations fall under this system.

9.2.4 The macrosystem

As discussed in Chapter 2, this system encompasses the broader cultural, societal, and ideological forces that play a role in an individual's development and accounts for the impact of cultural beliefs, values, customs, and social norms on a child’s development. Three studies included in the systematic evidence synthesis in Chapter 4 compared differences in self-care between different cultures, and one compared different self-care expectations between boys and girls in these cultures. The study[18] found that parents had lower self-care expectations from boys than from girls. I also found differences in physical activity and motor competence in different societies that could have impacted on self-care performance for children in these societies.

9.2.5 The chronosystem

As discussed in Chapter 2, this system is concerned with the role of time in shaping a child’s development, and in this section, I consider the influence of relevant historical events, personal experiences, and major life transitions on children's self-care.

From the results discussed in Chapters 4,7, and 8, the COVID-19 pandemic had a significant impact on children with and without motor impairment's participation in self-care. For children with CP the lockdown contributed to spasticity in their limbs which affected their ability to participate in self-care.[172] This correlates with the finding from another study[347] on the impact of the pandemic on children with CP, where the researchers found that 56.4% of children had experienced deterioration in ambulatory status, 33.7% of children showed worsening in the function of the upper limb, 41.6% of parents reported that children had increased joint contracture, and 63.4% of children had an increase in muscle stiffness or tightness. This deterioration in children with cerebral palsy's physical health and mobility is attributed to a decrease in the access to rehabilitation during the lockdown and parents lack in confidence or inability to carry out a therapy home programme with their child with CP.[347]

Some children with additional needs were also negatively affected by delays in assessments or by remote assessments that did not adequately identify their needs for additional support.[347] These findings correlate with findings from the ‘Implications of

COVID for Early Childhood Education and Care in England' report that was published in June 2022 by the Centre for Evidence and Implementation.[344] The aim of the report was to explore the implications of the COVID-19 pandemic for access to and provision of early childhood education and care (ECEC) for 0–4-year-olds in England, along with ways in which the ECEC system could be strengthened. One of the key findings of the report was how significantly different the pandemic and lockdown experience was for children from ethnic and minority groups and poor SES, in comparison to their peers.

Parents of children with ASD reported a significant regression in their children's self-care post-lockdown in one of the studies included in the systematic review in Chapter 4.[137] Parents reported that their children showed a deterioration in all self-care activities, with changes in toileting and brushing their teeth being the most significant areas affected.[137] These changes were attributed to a change in routine, limited opportunities for children to socialise, and the absence of children's usual therapy sessions.[137]

In Chapter 7, the findings also suggest that the COVID-19 pandemic and lockdown restrictions had a definite impact on children's self-care, and in particular, toileting and dressing. The qualitative findings from parent discourses on how the pandemic influenced their children's self-care indicated that parents observed that their children's self-care had deteriorated during the lockdown period. It was observed that these changes in self-care impacted on parents' mental well-being, with some parents indicating that they felt they were in a 'battle' with their child. One parent reported that they thought these changes were due to the lockdown being "pretty tough on the little ones".

However, not all children demonstrated a deterioration in self-care during the pandemic. One study[149] found that participants with ADHD showed an increased engagement in personal care during the pandemic, as they benefitted from spending more time with their families and being at home. Some children with special educational needs also benefited from attending less busy school settings during the pandemic.

In Figure 9.1 I have updated the figure first presented in Chapter 2, Figure 2.1. In Chapter 2, I hypothesised how different factors in the context of the systems from Bronfenbrenner’s ecological systems theory model could have influenced children in this programme of research’s self-care. Figure 9.1 represents the findings, following the data analysis for Chapters 4 to 8, of factors influencing self-care in the schema of Bronfenbrenner’s model. Updates to the figure are shown in white text whilst factors which remain unchanged from the previous figure are still labelled in black.

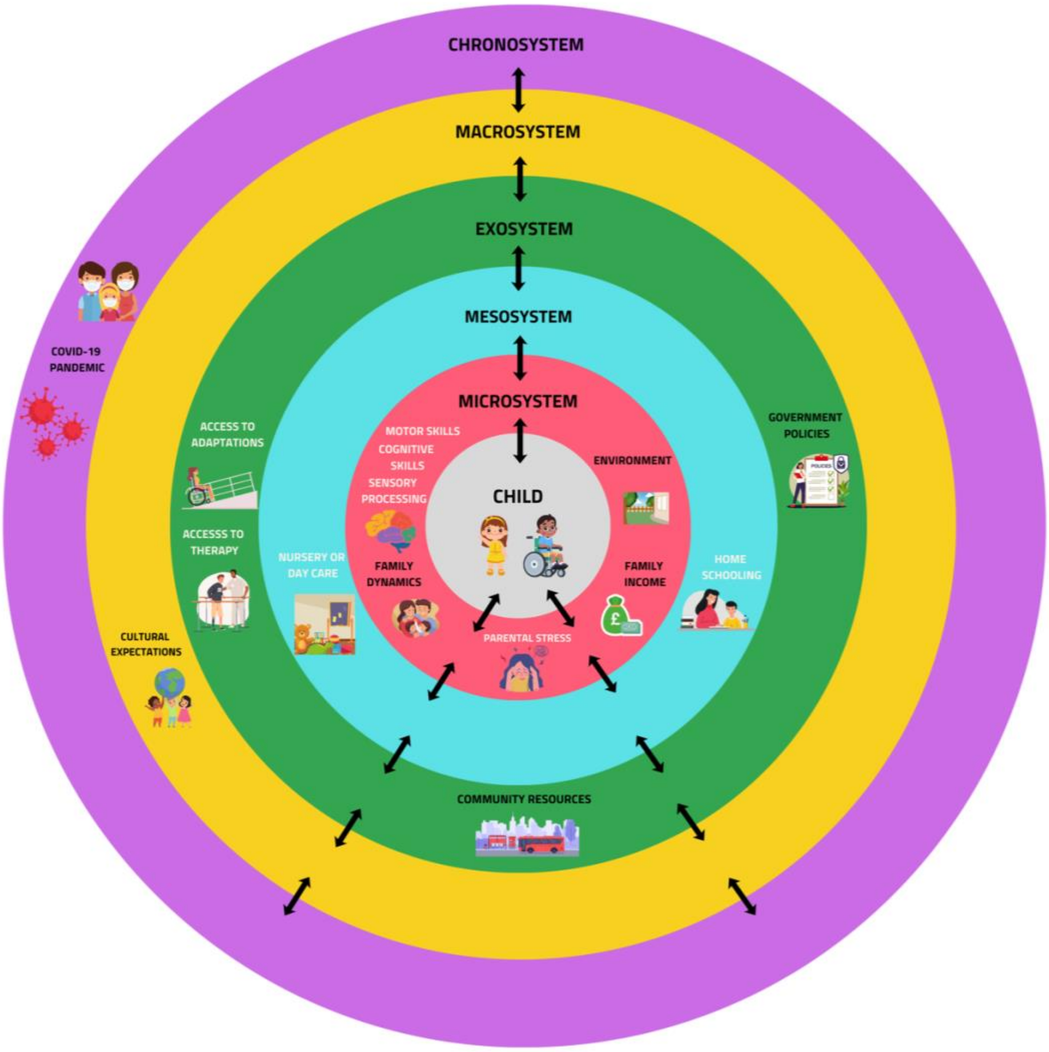


Figure 9.1 Research findings on factors influencing self-care presented in the schema of Bronfenbrenner's ecological systems theory model.

9.3 Logic model of factors influencing self-care

Following the data analysis in Chapters 4 to 8, the logic model proposed in Chapter 2 was revisited and updated based on the study findings. To indicate changes in the logic model, boxes where content has changed following the analysis and synthesis are shown in a different colour, yellow. New unidirectional and bidirectional relationships following the analysis and synthesis are illustrated through red arrows. In the logic model shown in Chapter 2, it was proposed that child factors, including mobility and fine motor skills, are some of the key intervention elements, along with the provision of appropriate equipment and adaptations to address to provide children with the opportunity to participate in self-care. It was also proposed that potential difficulties in the areas outlined in the box, child factors could impact on parent self-efficacy, willingness to take risks, and parental stress levels. On a macrolevel outcome, it was anticipated that the level of participation in self-care would affect children's long-term health, development, social integration, and school readiness. It was also anticipated that self-care would be moderated by children's intellectual ability, their level of disability, birth order in their family, ethnicity, complex medical needs and possibly birthweight. Further, socio-economic status, parental education levels, the physical environment, along with the time spent in and out of home environments were included as contextual factors to consider for the distal and macrolevel outcomes proposed in the logic model in Chapter 2.

In the reconstructed logic model shown in Figure 9.2, the impact of personal factors on self-care still played a significant role as seen from the findings in Chapters and 6 which found that motor and cognitive ability plays an important role in self-care. In addition, I found promising evidence from the findings of the systematic review in Chapter 4, the parent forums in Chapter 7 and the document analysis in Chapter 8 that the role of contextual and environmental factors, along with children's relationships with others and social experiences, also played an important role in self-care. For example, a child with a motor impairment or difficulties with mobility who lived in a well-supported environment and with good family support and social networks would have similar opportunities to participate in self-care and daily activities compared to a child with no mobility or motor impairments.[123, 348] The logic model was therefore updated to illustrate the impact of context on self-care macrolevel outcomes, through influencing equipment and adaptations, the child's opportunities to explore and interact, parental factors and therapy interventions for self-care.

In Chapter 4, the results of the systematic review indicated that health conditions, including arthrogryposis, MMC, FOP, and neurological disorders, impacted on children with these conditions' ability to participate in self-care. For these children, it is important to consider their participation in self-care and to refer them to the relevant therapy services so that they can be supported with appropriate interventions and equipment. Along with providing support to help children participate in self-care, it is also important to support the parents of this group of children.[349] In Chapter 7, which discussed parent discourses on the impact of the COVID-19 pandemic on their children's self-care, the findings suggested that children's difficulties with self-care impacted on parental stress levels and possibly mental health. Parents indicated that dealing with their children's self-care challenges felt like a struggle, and many parents used the word 'battle' to indicate this. In the logic model in Figure 9.2, the relationship between parental stress and children's self-care is depicted as having a bi-directional relationship as some of the findings in Chapter 4 indicated that parental stress can also impact on children's self-care negatively.

Despite initially questioning whether children's birth order or whether they were an only child could affect their participation in self-care, no evidence of this was observed in this doctoral research programme. This observation could have been attributed to the low uptake of research participants in the EASIER study, and therefore, it is difficult to come to a definite conclusion on this factor. The same applies to parental education, the number of hours worked by the main carer, and the children's place of care.

Finally, another predictor of children's self-care, which emerged through this doctoral programme and was not included in the original logic model, was the COVID-19 pandemic and the lockdown restrictions associated with it which is shown in the box labelled context. This was observed in Chapters 4,7 and 8. Although there is no longer a worldwide lockdown, and COVID-19 is no longer classed as requiring quarantine or lockdown[350], these findings are still important to consider. The pandemic directly impacted on children's lives for almost two years in the form of missing out on school, not seeing friends and families, and missing out on opportunities and celebrations that are typically part of a child's life.

The full impact of the pandemic on children's development and health outcomes are unknown yet, and experts[351] predict that it will take years of research to fully understand the impact of the pandemic on children's health and development. Findings from this doctoral research programme in relation to the pandemic and children's self-care will also be useful to consider for future pandemics. Based on these findings, parents and healthcare professionals will have an increased understanding of how pandemics and periods of lockdown can impact on children's self-care and participation in daily activities and know what to look out for.

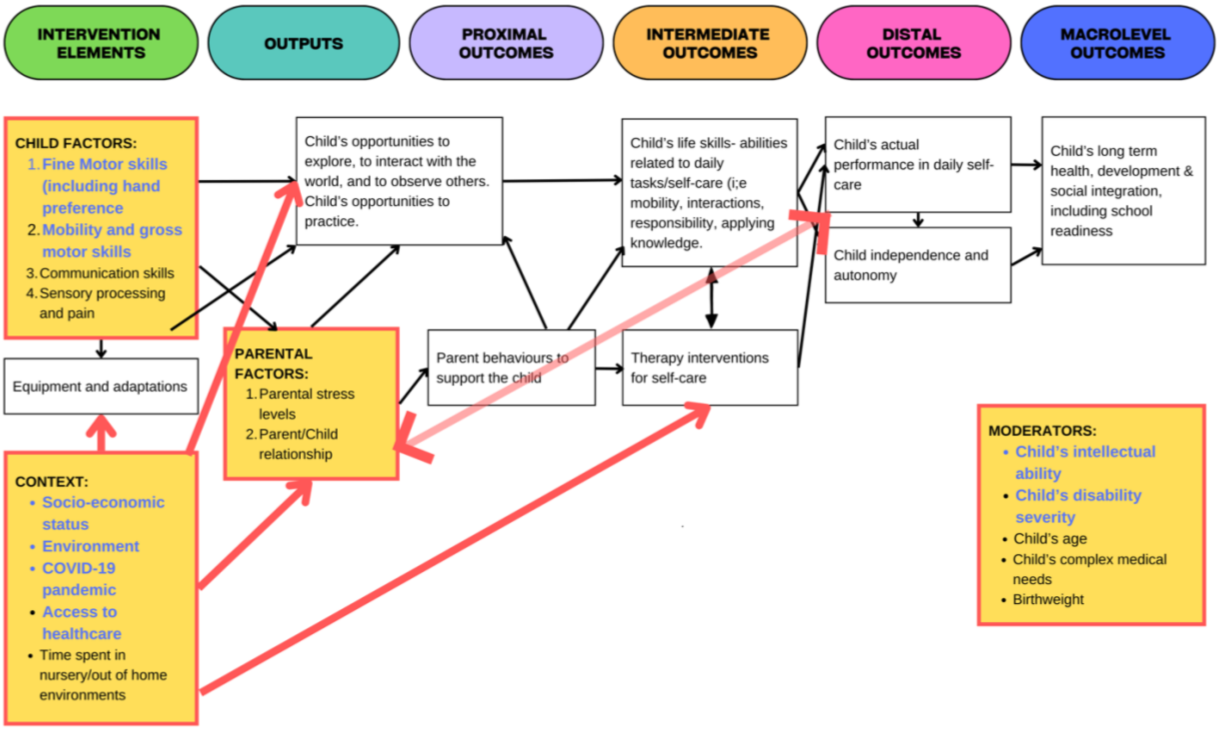


Figure 9.2 A revised logic model of factors influencing children's self-care

9.4. Reflective Account

Below I share some of my reflections and thoughts collected while carrying out the research and some retrospective thoughts since completing the data collection and data analysis. These reflections provide context for the research methods and data shared throughout this thesis.

9.4.1 My personal experience entering this research

Firstly, as a researcher, it is important to acknowledge my position and experience with children and parenting during the COVID-19 pandemic. I am a parent of an 11-year-old girl and was directly impacted by the closure of schools associated with the COVID-19 pandemic lockdown restrictions. My daughter was seven years old at the start of the pandemic and required home-schooling from the 23rd of March 2020, along with several millions of other children in the UK.

When carrying out the qualitative research discussed in Chapter 7, I was thinking about my own experiences during the lockdown the entire time I collected the data from parents on Mumsnet and Netmums. The data extracted focused on children's self-care during the pandemic and lockdown restrictions; however, I recognised the experiences of the parents on the forum and could empathise with what they were experiencing during the lockdown. Many parents were referring to working whilst home educating their children at the same time and referred to their children's extra need for attention during this period.

My child did not have any additional needs that required extra care and support during this time, as many of the Mumsnet or Netmums respondents reported, so I can only imagine how high the levels of parental stress in those households were. It was challenging enough in my own household, with only one child who needed home education and had no additional needs. We were also in the fortunate position that we had access to a relatively spacious home with outdoor space for a large part of the lockdown restrictions that eased the burden of the lockdown restrictions. I also recognise what a privilege it was to have been able to have worked from home and have a consistent income at a time when many others had to go to work and risk contracting the virus or losing their jobs. This has made me very interested and focused on the challenges and experiences of families who did not have access to the same privileges during the pandemic and how this would have impacted on children's overall health and development, including their self-care.

In addition to my experience as a parent of a school-aged child during the pandemic, I also feel that it is important to highlight my experience as a paediatric occupational therapist prior to entering academia. I have worked with many children with self-care difficulties over the years but carrying out this research has made me reconsider much of my clinical decision-making. Whilst I have always considered the evidence base of the approach I was using and the therapeutic needs of the child along with their own therapy goals, I now see that I did not pay enough attention to environmental and contextual factors influencing their difficulties with self-care. I have used many of the motor assessments mentioned in Chapter 4, but without considering all the relevant information about children and their circumstances, it is not possible to plan and carry out an intervention that meets the need of a specific child in the context of their own family needs.

9.4.2 Lessons learnt from the research process

There were many challenges along the way however, one of the biggest lessons I learned was how challenging it was to recruit participants for a longitudinal cohort study. I significantly underestimated the amount of time and effort it would require first to engage stakeholders, i.e., NHS trusts or nursery schools to promote the recruitment of study participants and second for participants to sign up once the study materials were shared with them. Once participants signed up for the study, attrition of participants was another challenge as the dropout rate was higher than I anticipated it to be. I assumed that once people gave consent to participate in the study, they would engage with my correspondence and complete the information they consented to provide. I thought that the time commitment for completing a short questionnaire via an email link sent on a six-monthly basis would be minimal for participants, however on reflection this was probably not the case.

A significant amount of my study time was also spent following up with NHS Trust to secure a site to facilitate NHS REC and HRA approval which I believe is something that more students in the UK participating and contributing to health-related research should be aware of. After spending several months on the required paperwork to secure a research site and receiving the necessary HRA and REC approvals, the COVID-19 pandemic arrived in the UK in February 2020. Significantly more paperwork was then required to adapt the study at a later stage.

As seen in Chapter 5 the EASIER study did not result in the research study I planned or wished it to be. The limited number of participants meant that the results were not significant enough for statistically relevant results for the selected population. However, by continuing to contribute to other research studies, I succeeded in gathering the data and completing the body of work required for completing this doctoral programme of research and gathered meaningful data on children’s self-care and the impact of self-care difficulties on family dynamics and participation at school. Whilst I was keen to complete the doctoral study programme, I also learned that that is possible to still make a meaningful contribution to your field of research by being flexible and approaching your research topic from a different angle. Besides furthering my research skills and learning a brand-new methodology, critical discourse analysis, the research covered in Chapter 7 makes a novel contribution to how the COVID-19 pandemic and the associated lockdown restrictions impacted on children’s self-care and their parents.

9.4.3 Reflections on doing the research

For the quantitative research, I noticed significant differences whilst administering the PEDI-CAT for two of the research studies discussed in this thesis. The PEDI-CAT was used for both the data collection for the EASIER study discussed in Chapter 5 and the ActiveCHILD study discussed in Chapter 6. However, there was an important difference in the administration of the PEDI-CAT test for the data collection of these two studies.

Whilst collecting data for these two studies in a similar time period, I made some observations on how differences in the test administration could impact on study results in research. For the ActiveCHILD study, the PEDI-CAT was administered by a member of the research team calling the parents by phone, or in some cases, a member of the research team carried out the PEDI-CAT test in person with the family member. For the EASIER study, parents were sent a link to the PEDI-CAT questionnaire by email. One of the biggest implications for this way of administering the PEDI-CAT for the ActiveCHILD study was that the questions were read out by the researcher instead of being read by the parent, who was expected to pick an answer. This provided parents completing the test the opportunity to ask the researcher to clarify any questions they were unsure of. In the case of participants where English was their second language, this would have also provided participants with the opportunity to check if they understood the questions correctly. However, for parents with auditory processing or hearing difficulties, this could have been a challenge if they did not get the opportunity to hear all the questions correctly and if they did not feel confident enough to ask the researcher to repeat the question.

PEDI-CAT questions for participants of both studies were computer generated based on participants' answers to previous questions. Whilst parents of children in both studies would have been presented with the same questions, I believe the difference in administering the assessment could have played a role in parents' choice of answers and the subsequent questions presented to them. The PEDI-CAT selects the level of difficulty of questions based on the previous response. If parents had misunderstood a question and provided the wrong answer, this would have triggered a different set of questions than what they would have been asked otherwise.

A convenient aspect of the PEDI-CAT Q-global test was the ability to send assessment links by email to parents to complete the test at a time convenient to them. I observed during the administration of the PEDI-CAT for the ActiveCHILD study that it took several phone calls to a parent to get one assessment completed. As usually, the first time when you called the parent, they asked you to call back at a different time as they were busy with another activity, and it was not a convenient time for them to complete the assessment. I also found that parents often forgot about the time they had agreed on to complete the assessment, so therefore in my experience, it took on average three phone calls per participant to complete the PEDI-CAT with participants where the Q-global version was not used.

In the EASIER study, my experience was that the completion time for the PEDI-CAT Q-global varied. Some parents opened the link immediately and completed the assessment; others took a few weeks; in other cases, parents did not complete the assessment on time and needed reminders. The link expired after 30 days, in which a new assessment had to be set up for parents who failed to complete the assessment on time the first time. This happened for 4/24 (16%) of respondents and is not dissimilar from the experience of having to call some parents in the ActiveCHILD study up to three times to complete the assessment. I observed that some parents completed the PEDI-CAT Q-global assessment in as little as 12 minutes. In contrast, the average phone call I made to complete the PEDI-CAT with an ActiveCHILD study participant took between 30 and 40 minutes, depending on how much clarification the parent sought. Despite receiving less support from the researcher, completing the PEDI-CAT for the EASIER study required less of a time commitment from parents participating in the study, which might make participation in research more appealing to some parents.

As a researcher, the administration of the PEDI-CAT Q-global was significantly less time-consuming. Instead of making numerous phone calls and taking up to half an hour to complete an assessment over the phone, sending one email with an assessment link was a less time-consuming process. The only time commitment from me for sending a PEDI-CAT Q-global link was the time required to set up a test profile for participants and send the assessment link by email. This was minimal compared to the time it took to phone parents to administer the test. Scoring for the PEDI-CAT Q-global was also automatic which significantly reduced the time spent collecting data per child on the EASIER study. For the ActiveCHILD study, the use of the regular PEDI-CAT assessment required the assessment to be scored manually and for scaled and normative scores to be calculated using the test manual.

Interestingly, I observed no difference in the attrition rates for the two different methods of completing the PEDI-CAT. I expected fewer parents to drop out from the

EASIER study than the Active CHILD study, as I thought that parents would have found it more convenient to complete an assessment in their own time. Further, some of the contact details for participants in the ActiveCHILD study had changed, which made it impossible to contact them for further data collection, which naturally impacted on attrition rates. I anticipated that it might be less likely for participants to change their personal email addresses, and therefore assumed at the start of the EASIER data collection that it would be a better method to contact parents for ongoing data collection for a longitudinal cohort study. However, a similar number of parents did not read or ignored the emails as those who did not answer the phone for the ActiveCHILD study.

Whilst I initially assumed that an online questionnaire that parents could complete in their own time would be more convenient than a phone call, I now recognise that I underestimated the mental load placed on parents by expecting them to complete a questionnaire by themselves. Not all parents were one hundred per cent certain of their children's abilities and development expectations. One participant from the EASIER study contacted me via email to express her concern about the PEDI-CAT items being too difficult for her child and to ask whether the test items were developmentally appropriate. I explained to the parent that the age range of the PEDI-CAT assessment was from 0-20 years, and therefore it didn't mean that younger parents scoring lower on the test was necessarily indicative of a problem in any of the domains tested. The parent expressed appreciation for the explanation but failed to respond to emails regarding the second wave of data collection and dropped out of the study. It is possible that her concern about her child finding certain test items challenging contributed to her decision to not further participate in the study.

9.4.4 Reflection on trying to recruit participants and involve schools in the research

As stated in section 9.4.2, the recruitment of study participants was one of the most significant challenges for the EASIER longitudinal cohort study. After the study was put on hold indefinitely by the NHS trust where it was supposed to be hosted, I spent time reflecting on ways to continue the study. During this period, there appeared to be a shift towards more research studies taking place online due to the pandemic and lockdown restrictions. As a result, I rewrote the research protocol to move the EASIER study online. I engaged with research updates related to carrying out research with families and children online and also sought advice from my supervisors on this topic. This period also coincided with the release of the online PEDI-CAT Q-global test discussed in section 9.4.3 above.

Moving the study online required a major REC amendment from the HRA, which was only obtained in December 2020. As recruitment and data collection were originally due to start in March 2020, the pandemic resulted in a delay of nine months to the data collection for the EASIER study. One of the amendments, along with moving the data collection online, was the ability to recruit typically developing children without motor impairments online instead of through health visitor checks as initially intended. Further, the amendments also made it possible to recruit participants with motor difficulties online and list Newcastle University as the study sponsor for the purposes of the NHS research portfolio. This change meant that I was able to share details of my study on social media to recruit participants and designed a flyer (Appendix B) for this purpose.

Following the study's approval, I shared the flyer on various social media platforms. I asked parents to get in touch and also asked other researchers or healthcare professionals to share the study details. The first few social media posts generated some initial interest, as this was during the December 2020 lockdown, when many individuals were at home and likely to follow social media to stay up to date with the news related to the pandemic and to keep in touch with individuals on social media. However, the initial interest waned quickly, and after a promising start of participants signing up, this method of sharing the study online no longer generated new study participants.

Details of the study were then shared by a parent’s group and nursery from Newcastle University, which generated a small number of participants (four in total). In a further attempt to boost recruitment to the study, I searched for the details of headteachers of nurseries from different geographical areas, varying in levels of deprivation, across the

UK. I emailed the study details to fifty headteachers and only received acknowledgement from one headteacher in the Southeast of England who shared the study details with parents in their school. In total, I only gained two study participants from this effort after the headteacher had emailed the study details to the entire school.

The challenges with recruiting participants made me reflect on and reconsider the method of posting information online to recruit study participants. All parents, but parents of children with disabilities even more so, are bombarded with digital information and requests for help or information on a regular basis. This can range from information about events at school, fundraisers, requests for information and hospital appointments. During the pandemic, parents also would have received extra information about precautions at school or for medical appointments. It is likely that many of the parents and headteachers were cognitively overloaded from the digital information that they were already receiving and therefore did not have the capacity to read and consider my study information.

In addition to the attempts to recruit participants online, I also applied to have the study adopted by the NIHR Clinical Research Network (CRN) portfolio. This generated interest with a few NHS trusts, and I participated in meetings with five NHS trusts in total between February and April 2021 to discuss the possibility of them hosting the study. Following these discussions only one of the trusts agreed to hosts the study. One hundred information packs were put together and sent to therapy staff for eligible participants. From eligible participants three new participants signed up in total. After all the efforts above, recruitment and data collection were discontinued when I was still not able to recruit a sample size large enough to produce statistically significant data on comparisons between self-care in children with and without motor impairments.

Following the data collection for Chapter 7, which analysed parent responses from Mumsnet and Netmums in relation to how the pandemic affected their children's self-care, I thought it would be helpful to conduct interviews with reception teachers to see if they made similar observations to parents in relations to children's self-care. The aim was to have a focus group with a group of four to five teachers to find out how they perceived the pandemic and lockdown restrictions had impacted on children's self-care. I was particularly interested to see whether they saw a difference in the levels of self-care in cohorts of children who entered reception after the Covid-19 pandemic in comparison to those children starting reception pre-2020.

As this stream of research with teachers was not part of the original research plans which ethical approval was obtained for, I applied for ethical approval for interviewing teachers. I adapted the parent flyer seen in Appendix B to recruit teachers for the study. For this recruitment, I had similar challenges finding teachers willing to participate in the study. Teachers who initially verbally agreed to participate did not respond to the flyer or emails sent. Speaking directly to a special needs coordinator (SENCO) about the research with a voucher incentive generated some interest but no further follow-up from the teacher group that I needed to participate in the study. I found it interesting that not even a financial award towards classroom supplies incentivised teachers to participate in the research and reflected on why that was the case.

During the period of the scheduled data collection, social media and the press were reporting regularly that schoolteachers in the UK were under a significant amount of stress. This period also coincided with teacher strikes in state schools across the UK. Therefore, I believe that the study's timing was unsuitable for teachers to participate in a focus group that required 'extra work' when they were already overloaded. It was also suggested that teaching cover could have an been an issue whilst teachers attend the focus group, and therefore that was prioritised above attending a focus group.

In summary, I still believe that families and teachers are the right demographic for researchers to target to learn more about children's self-care; however, the pandemic and other economic stressors have meant that participating in a research study was most likely not something that would have been a priority for prospective participants. In order to obtain richer data on children's self-care, it is recommended that other ways of engaging families and teachers in research are explored.

9.5 Conclusion

The overarching theme of this chapter is that there is more to consider when addressing children's self-care, than just body factors even though mobility and social/cognitive factors showed a strong correlation with self-care in two of the chapters in this thesis. Many clinicians, including paediatricians, health visitors, and occupational or physiotherapists typically carry out developmental check-ups or assessments on children. These assessments often include standardised assessments of motor, cognitive or perceptual skills and sometimes sensory processing differences. In many cases clinicians will ask for some demographic information and a parent perspective on concern's regarding the child's functioning but this is not always the case, particularly in school-based therapy services.

However, this doctoral research programme demonstrates that performance-based assessments of children's functioning are only one indicator of their overall functioning and participation in daily activities and provides a one-dimensional view of factors causing difficulties in these areas. Further, to have a thorough understanding of children's self-care and why they are having difficulties in this area it is of utmost importance to consider all five of the systems in Bronfenbrenner’s ecological systems theory as shown in Figure 9.1 and elements shown in Figure 9.2.

This level of understanding of factors that influence children's development and participation is also crucial for planning and carrying out effective interventions to address children's self-care. Providing therapy and/or medical interventions with the aim to improve participation in self-care will be ineffective unless the full profile of the child, that of the family and their social circumstances, and the wider social contexts are considered. In the next chapter, Chapter 10, I make recommendations for future research based on the discussions in this chapter.

Chapter 10: Summary and implications

This doctoral research programme aimed to investigate self-care in children with and without motor impairments and the factors influencing it. Through a comprehensive literature search and systematic evidence synthesis, carrying out a longitudinal cohort study, a secondary analysis of longitudinal data, and a qualitative analysis of parents' and teachers' perceptions of the impact of the COVID-19 restrictions on their children's self-care, my objectives were to:

1) To identify personal and environmental factors influencing self-care in children and young people.
2) To investigate intervention techniques for supporting self-care.
3) To identify the impact of the COVID-19 pandemic restrictions on children's self-care and parents.

In this final chapter, I summarise the key results of this doctoral research programme, reflect on its overall strengths and weaknesses, and set out implications for the stakeholder groups for whom this applies too: healthcare professionals, parents, and children, researchers, and teachers or others working in childhood education. I also make recommendations for future research.

10.1 Summary of results

In Chapter 4, I described the factors that influence self-care in children and young people. This systematic review included 97 studies and is the most extensive systematic review on this topic that I am aware of. The systematic review was updated in November 2022 after the first selection of articles was carried out in March 2019. The ICF-framework[68] was used for this review, and I found that body functions showed strong associations with self-care, along with preliminary evidence to suggest that environmental factors are also crucial in self-care for children. Several interventions to address participation in self-care in children were discussed. However, research about effective interventions to address self-care is limited and skewed towards one diagnostic condition, CP. Further research is recommended to investigate interventions applicable to a wider range of children and young people. From the synthesis of this review, I also found that the COVID-19 pandemic had an adverse impact on some children's self-care.

In Chapter 5, I described the EASIER study, which was designed to be a longitudinal cohort study to investigate self-care in 3-6-year-old children with and without motor impairments. The study itself was impacted upon by the COVID-19 pandemic, and due to a poor uptake of participants there was a lack of sufficient quantitative data for meaningful statistical analysis of the data obtained. However, I made an important observation that parents whose children had more difficulty with the PEDI-CAT test items were more likely to drop out of the next wave of the study. In addition, I found that there were lower rates of parental stress in participants who participated in both waves of data collection in comparison to those who dropped out after the first wave. Participants who dropped out after the first wave had significantly higher scores on the Parental Stress Scale (PSS). Children and parents of young children are described by the NIHR as under-served groups where inclusion in research is lower than one would expect from the population estimates for this group.[352] Reasons for this can include barriers related to the health of participants and inadequate incentives to participate in research.[352] Findings from Chapter 5 further demonstrate the need for supporting parents whilst engaging them in research about their children in order for this population to be better represented in research. As the data in this chapter did not lend itself to ascertaining which child factors influenced self-care, I took this question forward to the next chapter, where the dataset consisted of a larger sample size.

In Chapter 6, I described the analysis of existing data from a longitudinal cohort where I investigated factors correlated with self-care. I found that PEDI-CAT Mobility and PEDI-CAT Social/Cognitive T-scores explained 74% of the variation in PEDI-CAT Daily Activities T-Scores for the first wave of data collection and 80% for the second wave of data collection. When I compared these results with the findings from the systematic review in Chapter 4, I was able to summatively conclude that children's mobility and cognitive ability are consistent and significant predictors of self-care development, with children who have the greatest limitations in mobility and/or cognition also at the greatest risk of self-care limitations. These data did not easily lend itself to ascertaining how the pandemic influenced children's self-care, and I took this question forward to the subsequent chapter.

In Chapter 7, I focused on the impact of the COVID-19 pandemic on children's participation in self-care and self-care behaviours, along with the effects of this on their parents or caregivers. This was achieved by analysing comments by parents on the online forums, Netmums and Mumsnet during the COVID-19 pandemic. By using CDA and the DHA framework, parents' responses were analysed to capture their use of language and key themes related to their children's self-care during the pandemic and associated lockdown restrictions. Participants reported a regression in their children's toileting and dressing during this period. Three other notable discourse themes emerged from the study results: 1) feelings: the discourse of parents describing being in a 'battle with their children' and parents appearing to be emotionally exhausted by their children's difficulties with self-care; 2) the role of online forums and need for social support, particularly for providing opportunities for solidarity and reassurance, especially for those seeking advice anonymously; 3) self-care practices that work, especially the value of online forums to share advice and resources and for parents to share practical tips with each other. These data provided insight into how the pandemic influenced children's self-care at home but did not lend itself to ascertaining how the pandemic affected children's self-care at school. I took this question forward to the subsequent chapter.

In Chapter 8, I discussed the impact of the COVID-19 pandemic restrictions on children's self-care in school. In YouGov reports[41, 106] from November 2021 and 2022, teachers reported that a significant number of children presented with difficulties with self-care and school readiness compared to previous intakes before the pandemic. Teachers also discussed the impact of children who had difficulties with dressing themselves independently, difficulty with eating, and who were not toilet trained on the rest of the class and on teachers. As a result of delays in self-care, many children presented with delayed school readiness, which impacted their learning and the learning of others. These findings correlate with statements made by parents in the qualitative study discussed in Chapter 7. Parents expressed concern about their children's ability to manage independently with self-care after the pandemic and stated that they were worried about how their children were going to manage in reception. Whilst these findings explicitly related to mainstream schools, teachers from SEND schools also reported a decline in children's self-care following the pandemic.

In Chapter 9, I identified four key themes drawn from the analysis and utilised Bronfenbrenner's ecological systems theory[63, 71] to provide a framework for combining the findings from Chapters 4 to 8. From this framework, it becomes clear how personal factors, along with environmental and contextual factors, impact on children's self-care and that personal and body factors (as viewed from the ICF framework) cannot be assessed and treated in isolation when addressing children's self-care. Based on the findings from the research programme, I also updated a logic model of children's self-care, which I first presented in Chapter 2 of this thesis.

10.2 Strengths and Weaknesses of the Doctoral Research Programme

I have reflected on the overall strengths and weaknesses of the doctoral research programme, especially in light of the COVID-19 pandemic and how it influenced the overall course of study. As a result of the changes made to this programme following the pandemic, the design of this research programme took a multiphase mixed-method approach, pragmatically reflecting the complexity of the three research questions discussed in Chapter 3.

A particular strength of this research programme was the size, scope, and rigorous methodology of the systematic review focussing on self-care in children and young people. To my knowledge, this is the biggest systematic review, and also the most recent, on this particular topic. This piece of work has significantly enriched my research and was critical in developing the protocol and questionnaire for the EASIER study discussed in Chapter 5. Further, the qualitative findings discussed in Chapter 7 bring a strong voice from parents on how the COVID-19 pandemic affected their children's self-care and the resulting impact on the whole family.

Another strength of this research programme is the learning from reflections, which are discussed in Chapter 9, on the research methodology. I have made some important observations, particularly regarding the difference in the administration of the PEDI-CAT in the EASIER and ACTIVE Child studies. I found that the difference in the administration between the online test completed by parents or caregivers in comparison to tests conducted by researchers or therapists could potentially influence test responses. This is an important consideration for researchers who plan to carry out similar studies in the future.

Further, the mixed method methodology used in the study programme was also a strength of this doctoral programme. The methodology applied brings a diverse selection of methods and perspectives to the programme which adds depth and breadth to the research carried out to learn more about children's self-care.[96]

A limitation of the study programme was the limited number of participants for the EASIER study which meant that it was not possible to obtain meaningful results in relation to children's self-care from this study. This meant that the original research objectives could not be met. As a result there is still a gap in knowledge related to the self-care development trajectories for children with and without motor impairments. However, had the EASIER study been carried out as planned, I would not have had the opportunity to carry out the qualitative research discussed in Chapter 7 and the opportunity to contribute to the data collection for the ActiveCHILD study. As a result of completing these extra streams of research, I had the opportunity to significantly develop my research skills in both qualitative and quantitative research. These experiences will be valuable in my future academic career.

10.3 Implications for Health Care Professionals

The most significant implication for health care professionals is the specification of factors influencing self-care in children and young people and the impact of challenges in self-care participation on children and their parents and caregivers.

The results of this study will raise awareness amongst clinicians about the importance of considering the whole family when addressing challenges in participation, in this case, self-care, in a child. It is crucial to consider the emotional impact of children's participation challenges on parents and caregivers, the extent and impact of parental stress, and how this contributes to the relationship between the child and their parent/parents.

More broadly, this study enhances healthcare professionals' understanding of children's participation in self-care and self-care behaviours and how participation in self-care contributes to other domains, such as education and socialising. Health visitors and school nurses, in particular, will benefit from understanding the link between participation in self-care and school readiness.

The findings from this programme of research also provide guidance for all healthcare workers on how best to support families in future pandemics and lockdown situations. During the COVID-19 pandemic, parents observed a change in their children's ability to do things for themselves. In this doctoral research programme, it was observed that these changes contributed to significant stress for parents, which would have exacerbated the stress already experienced during the pandemic and lockdown.

The way that parents sought out support from other parents and valued the opportunity to express their experiences and feelings anonymously also highlights the importance of providing a support structure for parents of children with additional needs. A study[99], which investigated the effectiveness and cost-effectiveness of a universal digital parenting intervention which was designed and implemented during the COVID-19 pandemic found promising outcomes in relation to children’s development and support for parents. The intervention, which is called ‘Parent Positive’ consisted of three components: (i) Parenting Boosters: where advice, delivered in the form of narrated animations, videos, graphics and text, was provided to assist parents with parenting challenges; (ii) Parenting Exchange: a facilitated parent-to-parent communication and peer support platform not too dissimilar from the parent forums discussed in Chapter 7; and (iii) Parent Resources: giving parents access to carefully selected high-quality, evidence-based online parenting resources.[353] Given the long waiting lists[329] for children's therapy appointments, digital interventions can be a helpful addition to traditionally provided face-to-face therapy input.

For allied health professionals, particularly occupational therapists, working with children with participation challenges, this programme of research also provides insight into interventions that are evidence-based and effective in addressing challenges with participation in self-care. As discussed in Chapter 9, a further significant implication for healthcare professionals from this programme of research is the fact that self-care and child factors, such as their motor or cognitive skills, cannot be assessed and/or treated in isolation without knowledge and understanding of other factors that play a role in children's lives.

10.4 Implications for parents

This doctoral research programme offers a contextualised account of how children's participation in self-care impacts on parents. Findings from this programme of research provide parents with insight into the reasons children might present with challenges in participating in self-care and what that means for the child and the family. It also provides parents with reassurance about the need for peer support and the value of interacting with other parents in a similar situation in order to share advice and ideas.

This programme of research has also highlighted the need for parents to have an earlier understanding of self-care independence and at the stage at which children should be able to participate and be independent in personal care activities. Along with developing parents' understanding of self-care in children, it will also help parents to identify when their children have challenges in this area, and when it would be appropriate to seek help to address this.

This information should be provided in a manner accessible to all parents, and routes for distributing this information should be widespread and should include parent groups, early years settings and child health services. Third-sector organisations or other parent support groups also have a crucial role to play in supporting parents in accessing this information. Increasing collaborations between occupational therapy services and national and local organisations to support the development of accessible information would be helpful, and parents should also be involved in the design of any information leaflets.

10.5 Implications for children and young people

For children, this study highlights the importance of participation in self-care and the need to support all children and young people to participate in self-care activities. The novel contribution of this programme of research for children is that their ability to participate in self-care is influenced by a wide range of environmental and contextual factors alongside personal factors and that it is important to consider all these factors alongside the personal factors of the child when addressing children's participation challenges in self-care.

These findings also highlight the importance of supporting children to get the right equipment to help facilitate their participation in self-care, along with supporting them and advocating for them to get the necessary environmental adaptations and equipment where needed to assist with and facilitate their participation in self-care. The imperative now is to implement these findings in health and social care to ensure that children of all abilities have the resources they need to participate in self-care.

10.6 Implications for teaching professionals and head teachers

For teaching professionals, this study highlights the impact of children's self-care difficulties and the inability to do everyday things for themselves independently on children's school readiness and ability to participate in activities in the school environment.

These findings also indicate the need to refer children for appropriate support at an early stage so that teachers' time and children's learning are not impacted on by children who are not able to complete self-care tasks to the level required to participate in school activities.

Further, the study highlights the need for Early Years educators to be supported with sufficient resources in order to support children with school readiness. In 2022, the UK government changed the mandatory staff-to-child ratio for two-year-olds from a ratio of 1:4 to 1:5.[41] Based on the feedback from teachers and the YouGov report[41] , this increased ratio will have a detrimental impact on children's self-care and development and is likely contribute to an increase in children who are not ready to start school. I recommend that this Early Years education ratio is reconsidered and advocated for by teachers and education leaders.

10.7 Implications for researchers

The research programme generated several points for researchers in the field of child health to consider for future studies. First, researchers need to consider how best to engage children and families in research in a way that is sensitive to their needs and does not contribute to additional stress. This will help with the retention of participants in future longitudinal cohort studies. This will be essential to capture meaningful data on children's self-care in future longitudinal cohort studies.

Feedback from parents and teachers suggests that a longitudinal cohort study to help establish milestones for self-care in children, with and without motor impairments, is still needed. In Chapter 8, it was found that many parents and teachers reported that parents were not aware of the level of self-care independence children needed to achieve before starting school and would have valued more specific information at an earlier stage to make them aware of self-care milestones that their children need to achieve.

This doctoral research programme also highlights the need for more voices of children and their families to be heard on research topics relevant to children. The qualitative study discussed in Chapter 7 gave an insight into how the lockdown restrictions associated with the COVID-19 pandemic impacted on families from a parent’s perspective; however, it would have been beneficial to have had the opportunity to hear from children themselves.

Where possible, more children should be included in research about themselves, as a significant amount of research on child health and development is still presented through the eyes of researchers and/or medical professionals. It is recommended to work with groups like YPAG to discuss the best ways to include children in research about themselves.

However, it is important to note that the following areas continue to be challenges in child health research and should be carefully considered by researchers: the potential vulnerability of study participants, issues of capacity (particularly with under 5's), legal protections (especially with participants where there are safeguarding concerns), and the need to adapt study designs and outcome measures for children specific to their age and developmental stage.[354] Further recommendations for future research are discussed below in section 10.9.

10.8 Implications for policymakers

A clear outcome from this programme is the need for children's self-care needs to be addressed earlier, rather than later in life. By creating policies highlighting the importance of self-care, and policies that address the ecological system levels discussed in Chapters 2 and 9, children in the UK are more likely to get the support they need to participate in self-care earlier in life. This could result in an increase in four-year-old children who are independent in self-care and ready for school, which in turn will improve their opportunities for academic learning.

In 1998, the Labour government outlined a plan to support child development for all children in the UK, with the flagship policy being the Sure Start programme.[355] This was aimed at developing and enhancing the services provided for households in deprived areas to improve the health and well-being of young children. In February 2020, a review[356] found that over 1000 Sure Start centres have been closed during the previous ten years by the Conservative government. This is more than one in three centres and happens to coincide with the increased number of children who are not ready for school, according to the Kindred Squared report[41]. However, it is difficult to attribute this to be more than a coincidence, as this programme of research did not specifically investigate the impact of Sure Start centres on children's self-care.

Further, this doctoral research programme also highlights the need for children with developmental and physical disabilities, including difficulties with mobility, to receive appropriate equipment and adaptations to participate in self-care. This does not only reduce the burden on carers but allows for children to be autonomous in their own personal care.[357] Limiting budgets for children to receive adaptive and specialist equipment or adaptations is short-sighted as it will increase the funding requirements for carers to assist children with disabilities further down the line.[358] It is, therefore, of the utmost importance that policymakers consider funding to support children to participate in self-care. Finally, the qualitative research carried out in Chapter 7 demonstrates that policymakers should also take note of parent views in online forums in order to better understand the needs of this population.[257]

10.9 Recommendations for future research

There are a number of different directions for future research that would develop the findings presented in this thesis. Further qualitative and quantitative research is needed across the UK to ascertain the transferability of the findings from this research to practice, and to further enhance our understanding of the development of self-care in children with and without motor impairments.

While I was able to make observations on self-care during the EASIER study and analyse data in relation to factors influencing self-care in young children, data on the self-care trajectories for children with and without motor impairments is still lacking. A large-scale, longitudinal cohort study in the UK would still be useful and is recommended to address this knowledge gap. However, to make it a viable and successful study, consideration needs to be paid to the recruitment and retention of study participants. Many research centres spend a considerable amount of time cultivating relationships and building trust with potential study participants, which in turn increases their motivation to participate in research.[359] Increasing engagement with families will also allow family perspectives, priorities, and insights to be incorporated into the design, conduct and dissemination of the research.

The qualitative data analysis from the online parent forums, Mumsnet and Netmums, provided valuable insight into how the COVID-19 pandemic and lockdown restrictions impacted on children's self-care, along with the wider impact of these difficulties on the family. However, as this method of research relied on the natural conversations of parents online with no prompt questions, it would be helpful to supplement these findings with parent interviews. Seeking the views of more parents representing different ages, family structures, and types of impairment or disability in their children will provide us with more insight on the longer-term impact of the COVID-19 pandemic and lockdown restrictions on children's participation and self-care.

Similarly, a large-scale mixed methods study carried out in different parts of the UK, from areas with varying IMD deciles, of the impact of self-care difficulties in schools will be a valuable addition to the annual Kindred Squared school readiness reports. This can provide further and more varied insight on how self-care difficulties impact on the whole school, and more specific questions on aspects of self-care that children are delayed in or find challenging will improve the ability of healthcare professionals to provide targeted support for this group of children. Studies in schools will need to take into account teacher's workload and ways to involve teachers and schools so that they are invested in participating in the study.

The child voice is currently lacking in this area of research; therefore, the inclusion of the child voice would be extremely beneficial in enhancing our understanding of how difficulties with self-care impact on children's lives. It would also be useful for researchers to get children's perspectives on intervention studies, for example, qualitative feedback on how interventions for self-care improve their quality of life alongside quantitative data on the effectiveness of interventions. Consideration will need to be paid to how to include children with disabilities and language impairments so that all children are represented fairly.

Children who are neurodivergent or with a physical or learning disability will not always be able to answer direct questions verbally[360], and therefore, alternative methods to interviewing should be considered. Helpful strategies that could be implemented to obtain the perspectives of children with disabilities include using alternative communication methods or visual cues. Methods can include artistic methods (e.g., drawing, painting or photography), arranging alternative locations for interviews (e.g., in schools or clubs), or allowing the child to choose someone to aid their participation in the research.[361] [362, 363] Making the availability of other communication methods known to potential participants in advance may also help alleviate parents' concerns or assumptions that their child will not be able to take part in research or contribute to the research topic.[364, 365] Including methods that allow children to express their views, with and without the use of spoken language, will also help ensure children's own experiences and opinions can be captured without potential influence from others.

This doctoral programme of research included children with a range of disabilities, including ASD, CP, and Dyspraxia. These are similar to disabilities that have been included in previous research focussing on children's self-care. However, the majority of the evidence for interventions in self-care discussed in Chapter 4 was skewed towards one population, children with CP. It is recommended that researchers who plan to investigate the effectiveness of interventions to address self-care should focus on other clinical groups of children, too.

Further, as discussed in Chapter 4, future studies are needed to formally evaluate, at a large scale, the range of self-care interventions in practice and in later stages of development to produce summative conclusions and inform guidelines about which self-care interventions to use when and with whom. While some intervention studies were identified, overall, the evidence base about the effectiveness of interventions on children's self-care is very limited. This is especially concerning when considering the high prevalence of self-care problems observed in practice. The findings from the systematic review discussed in Chapter 4 provide proof that, in principle, self-care interventions for children can be formally evaluated.

Next, the precise relationship between the various social determinants of inequalities in child health outcomes is still an open debate for both academics and public policymakers. Further research considering the cost-of-living crisis and the impact of cuts in the NHS and social services that disproportionately affect children with a disability[366] will add to the evidence base of the impact of low socio-economic status on children's self-care and ensure that no child is left behind.

Finally, the full extent of the long-term impact of the COVID-19 pandemic and lockdown restrictions on children's developmental outcomes is still unknown. Further research in this area is recommended to investigate the impact of the pandemic and lockdown restrictions on children's function and participation in all areas of daily life. Understanding the impact of the pandemic on children's overall development and participation is crucial in order to be able to support them in their development and health going forward.

10.10 Conclusions

This doctoral research programme generated theory in relation to children's self-care and the impact of difficulties in this area on children and their families. The research programme also expanded on existing theories of the wider factors influencing children's self-care, including the impact of the COVID-19 pandemic lockdown restrictions, and added to the evidence base of this topic. Four key themes drawn from this research programme included: 1) the need to include self-care support for children at a population-based level; 2) to consider children’s views of self-care alongside quantitative findings showing mobility and cognitive skills as predictors of self-care; 3) the importance of considering the sociocultural nature of self-care; and 4) the importance of viewing and addressing children’s self-care in their family context. This theory will support the assessment and intervention of children with challenges in self-care and contribute to better care for children and families affected by these difficulties. Finally, the theory will also be helpful for healthcare professionals to support parents and children with children’s self-care in the event of a future pandemic.

Appendix A - MEDLINE Search Strategy

Two key databases for therapy and rehabilitation were used for this systematic review search: MEDLINE (1946 – March 2019, via Ovid) and CINAHL (1981- January 2019, via EBSCO). The search strategy was developed to locate papers reporting on factors influencing self-care in young children, and covered two facets, ‘children and young people’ and ‘self-care’, using free text terms and thesaurus-controlled standard terms (MeSH) where available. Terms within each facet were combined using the Boolean operator ‘OR’, and resulting sets of papers were combined using ‘AND’. For more details see the MEDLINE strategy below. The included figure details the inclusion and exclusion criteria.

The first search was conducted in March 2019.

Database: OVID MEDLINE(R) < 1946 to February Week 5 2019>

Search Strategy (conducted 10 March 2019)

1. child/ (1601124)
2. Limit 1 to (English language and yr = “2007 – Current”. (486541)
3. child*.mp [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (2162409)
4. Limit 3 to (English language and yr = “2007 – Current” (700143)
5. youth.mp (52884)
6. Limit 5 to (English language and yr = “2007 – Current” (31718)
7. adolescent/ (1915030)
8. Limit 7 to (English language and yr = “2007 – Current” (691697)
9. exp *Infant/ (58951)
10. Limit 9 to (English language and yr = “2007 – Current” (15943)
11. young people.mp (20720)
12. Limit 11 to (English language and yr = “2007 – Current” (11085)
13. self care.mp (38077)
14. Limit 13 to (English language and yr = “2007 – Current” (19981)
15. self care/ (31256)

16. Limit 15 to (English language and yr = “2007 – Current” (16411)
17. activities of daily living.mp (68728)
18. Limit 17 to (English language and yr = “2007 – Current” (31610)
19. “activities of daily living’/ (60705)
20. Limit 19 to (English language and yr = “2007 – Current” (27049)
21. Personal care.mp (3691)
22. Limit 21 to (English language and yr = “2007 – Current” (2733)
23. 2 or 4 or 6 or 8 or 10 or 12 (1086395)
24. 14 or 16 or 18 or 20 or 22 (52697)

23 and 24 (8825)

The search was subsequently updated in November 2022.

Database: OVID MEDLINE(R) < 2019 to November Week 3>

Search Strategy (conducted 15 November 2022)

1. child/ (1) (1193540)
2. Limit 1 to (English language and yr = “2019 – Current”. (273011)
3. child*.mp [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (1651120)
4. Limit 3 to (English language and yr = “2019 – Current” (357053)
5. youth.mp (71572)
6. Limit 5 to (English language and yr = “2019 – Current” (24579)
7. adolescent/ (1472533)
8. Limit 7 to (English language and yr = “2019 – Current” (256537)
9. exp *Infant/ (36386)
10. Limit 9 to (English language and yr = “2019 – Current” (6329)
11. young people.mp (27227)
12. Limit 11 to (English language and yr = “2019 – Current” (8747)
13. self care.mp (40630)
14. Limit 13 to (English language and yr = “2019 – Current” (8123)

15. self care/ (30463)

16. Limit 15 to (English language and yr = “2019 – Current” (4004)

17. activities of daily living.mp (69479)

18. Limit 17 to (English language and yr = “2019 – Current” (12433)

19. “activities of daily living’/ (60068)

20. Limit 19 to (English language and yr = “2019 – Current” (10689)

21. Personal care.mp (5735)

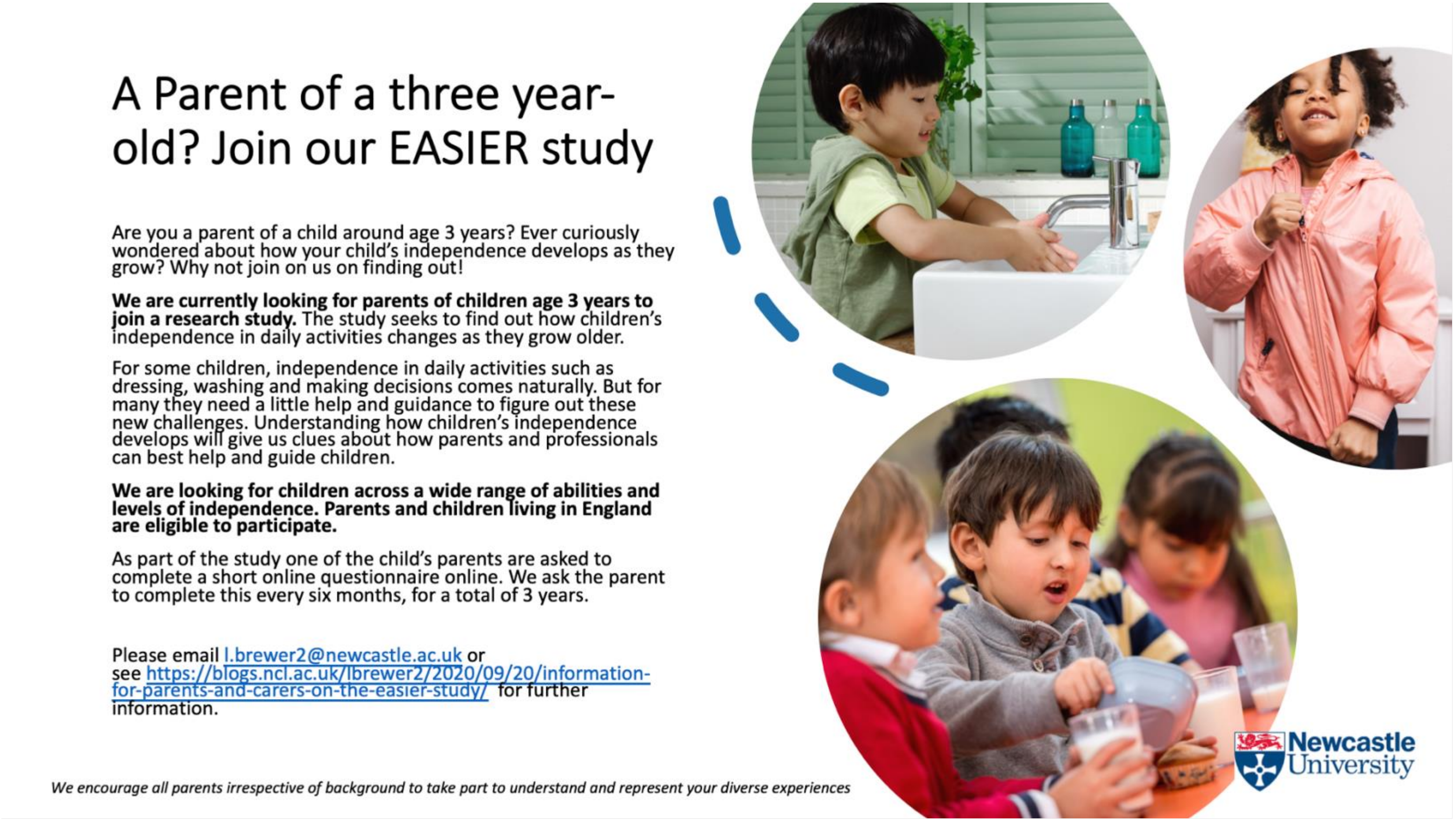
22. Limit 21 to (English language and yr = “2019 – Current” (2216)

23. 2 or 4 or 6 or 8 or 10 or 12 (495882)

24. 14 or 16 or 18 or 20 or 22 (22252)

23 and 24 (2859)

Appendix B: Flyer for recruiting participants online for EASIER study



A Parent of a three year-old? Join our EASIER study

Are you a parent of a child around age 3 years? Ever curiously wondered about how your child's independence develops as they grow? Why not join on us on finding out!

We are currently looking for parents of children age 3 years to join a research study. The study seeks to find out how children's independence in daily activities changes as they grow older.

For some children, independence in daily activities such as dressing, washing and making decisions comes naturally. But for many they need a little help and guidance to figure out these new challenges. Understanding how children's independence develops will give us clues about how parents and professionals can best help and guide children.

We are looking for children across a wide range of abilities and levels of independence. Parents and children living in England are eligible to participate.

As part of the study one of the child's parents are asked to complete a short online questionnaire online. We ask the parent to complete this every six months, for a total of 3 years.

Please email l.brewer2@newcastle.ac.uk or see https://blogs.ncl.ac.uk/lbrewer2/2020/09/20/information-for-parents-and-carers-on-the-easier-study/ for further information.

We encourage all parents irrespective of background to take part to understand and represent your diverse experiences

Newcastle University

Appendix C: Information sheet for children participating in the EASIER study

For the parent:

This information sheet can be used to tell your child more about the research study. It is important that even young children have an opportunity to express their views and participate in research on their terms.

We believe that you know your child best and are best placed to tell your child about the research. However, we have experience of telling children about research and can help you with this. If you would like more information or help with this, please contact me at l.brewer2@newcastle.ac.uk to discuss this.

Lelanie

Thank you again for your interest.

Newcastle
University

Children doing Self-Care

I’m Lelanie

I want to know more about you do self-care like eating, getting dressed and cleaning yourself?

Appendix D: Proposed focus group questions for teachers

1. Do you have concerns about the children in your class's ability to carry out self-care tasks (i.e., getting dressed, using the toilet, using cutlery etc) independently?

2. How long have you been a reception teacher?

3. Have you seen changes in children's ability to carry out self-care tasks independently in recent years?

4. What type of self-care difficulties do you see most often?

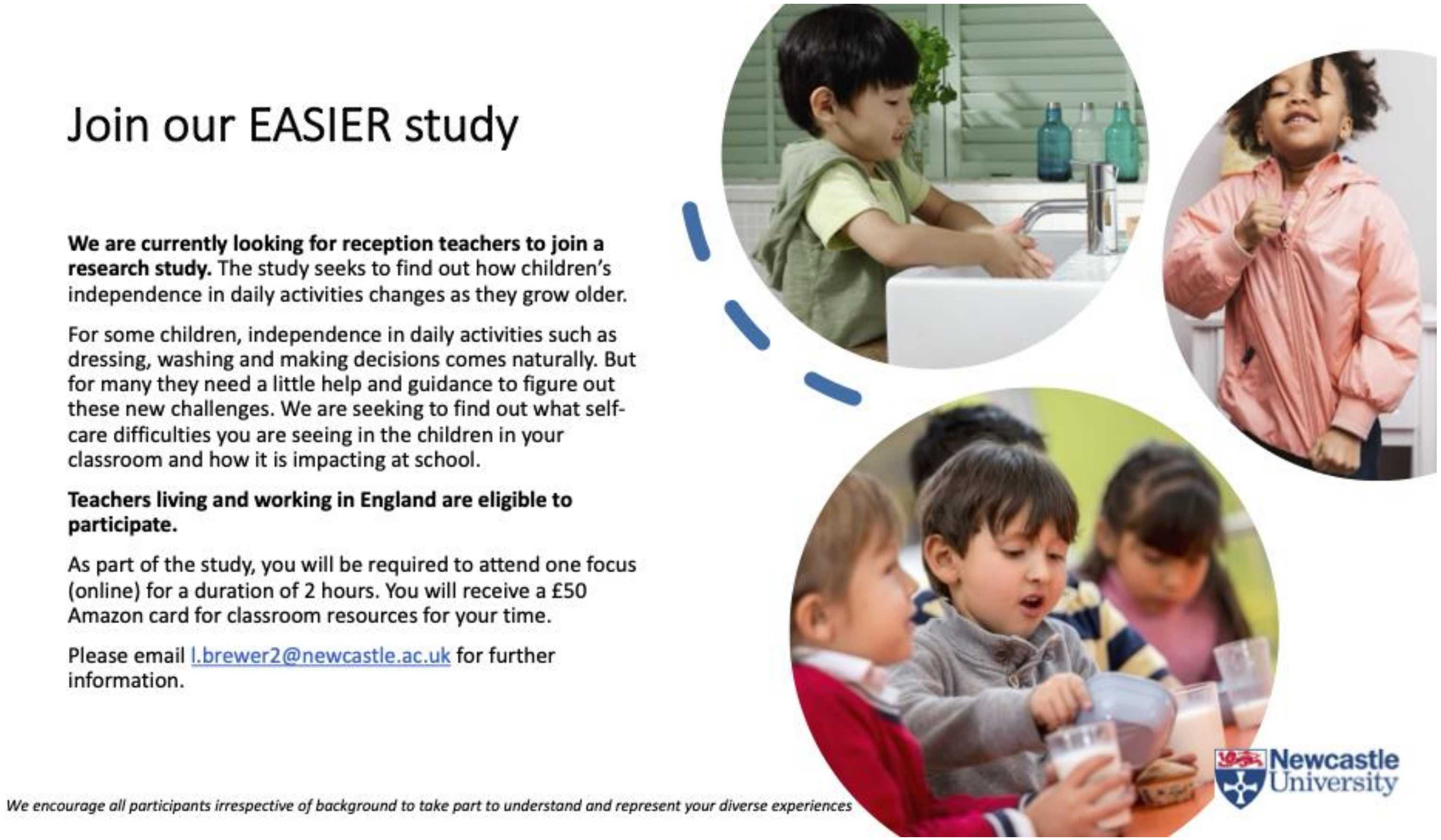
5. What do you think might be contributing to these self-care difficulties?

6. How does self-care difficulties impact on the child's participation in classroom activities?

7. How does the self-care difficulties of your pupils' impact on the running of your classroom?

8. How do you think children can be supported to be more independent in self-care tasks?

Appendix E: Flyer to recruit teachers for research



Join our EASIER study

We are currently looking for reception teachers to join a research study. The study seeks to find out how children's independence in daily activities changes as they grow older.

For some children, independence in daily activities such as dressing, washing and making decisions comes naturally. But for many they need a little help and guidance to figure out these new challenges. We are seeking to find out what self-care difficulties you are seeing in the children in your classroom and how it is impacting at school.

Teachers living and working in England are eligible to participate.

As part of the study, you will be required to attend one focus (online) for a duration of 2 hours. You will receive a £50 Amazon card for classroom resources for your time.

Please email l.brewer2@newcastle.ac.uk for further information.

We encourage all participants irrespective of background to take part to understand and represent your diverse experiences

Newcastle University

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