

Hidden in Plain Sight: A Mixed-methods Study of Young Carers in New Delhi and Mumbai

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Abstract

Young carers are children who assume caregiving responsibilities for a family member who is ill, disabled, or otherwise in need of care. While such children exist worldwide, awareness of their presence varies significantly between contexts. In India, recognition of young carers remains minimal, with their experiences largely absent from public discourse and policy considerations.

This research study aimed to understand the experience of being a young carer in the Indian context by drawing on the knowledge of children with caregiving responsibilities from two cities in India, New Delhi and Mumbai, using an exploratory sequential mixed methods approach. Qualitative interviews were conducted with 21 young carers and six adult key informants. This was followed by a quantitative survey of 528 school going children.

Using the Children's Engagement in Household Tasks (CEHT) Measure and Impact of Children's Engagement in Household Tasks ICEHT measure (ICEHT), this research has illustrated that children are not merely passive recipients of care and reproductive labour within Indian households. They undertake a range of domestic tasks. At the same time, there are a group of children in India who undertake intense domestic and care tasks for their family members. These 'adult-like' tasks are substantially greater than those in which children and young people in India typically engage in. Therefore, calling for inclusion of children, especially young carers, as active participants in reproductive labour debates, from which they are currently absent. These young carers experience severe implications due to their role. However, epistemic injustices towards children and young carers in India contribute to their hidden nature. This study also accounts for the limited support they receive and highlights that poverty and lack of welfare provisions in the country are the key indicators influencing their role in the Indian context.

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Introduction

The Ramayana, an ancient Hindu text, narrates the story of *Shravan Kumar*, who devoted his life caring for his hermit and blind parents. In the story, when his old and weak parents wanted to go on a pilgrimage, he fashioned a palanquin of sorts, using a stick and two baskets, put each parent in a basket and carried them on his shoulders to the pilgrim sites, barefooted. During this journey, when he paused in a jungle to get some water for his thirsty parents, he was mistaken for a deer and fatally shot by an arrow. *Shravan Kumar*, quite literally, shouldered the responsibilities of his parents' care and his household his whole life. Story or real, mythology or history, most Indian children grow up listening to this story of the ideal and dutiful son. This typically serves as either an encouragement to emulate him or a critique of the extent to which we fall short of his example. This thesis reports of modern-day *Shravan Kumars* (boys) and *Kumaris* (girls) about whom little or nothing is known.

It reports on the answers to the following research questions:

1. What are the specific experiences of children who undertake caring roles in New Delhi and Mumbai? What are the challenges they face and how supportive are the social systems around them?
2. What are the daily tasks performed by children in New Delhi and Mumbai, to support their family functioning?

To answer the above mentioned research questions an exploratory sequential mixed methods approach was used (Creswell, 2022). The qualitative study explored the lives of children with caring responsibilities in two cities in India - New Delhi and Mumbai. These children were living with one or more family members who were ill, disabled or had other caring needs, and it was these children who were primarily responsible for catering to this family members' physical, emotional and/or other types of needs. Semi-structured interviews were conducted with 21 young carers aged 12-18 years and six adult key informants to understand the experience of being a young carer in India.

To establish the baseline against which young carers' responsibilities could be assessed, it was essential to understand the typical domestic tasks undertaken by children in India. Subsequently, enabling the identification of characteristics which made children in India fall into the category of a 'young carer'. A quantitative approach

was adopted to aid this understanding. The rich qualitative interview data aided in the construction of a quantitative questionnaire to answer the second research question. This survey questionnaire was implemented with 528 children and young people in the age group of 13-19 years from New Delhi and Mumbai, irrespective of their caring roles, to understand engagement of children in various household chores. This was done to contextualise the frequency of their engagement in these chores with that of young carers from the qualitative study.

Furthermore, such children do not have a popularly acknowledged and dedicated term defining them in the Indian context. Hence, in this thesis a study specific definition was used, influenced from global literature on young carers. Therefore, for the purpose of this study, which was undertaken in India, children aged eighteen or below, who undertake caring responsibilities for family member(s) who are ill, disabled or have any other needs for which they require external support will be referred to as 'young carers.' The family members with care needs could be adults or other children in the family.

Thesis Overview

This thesis is divided into five major sections. Section one consists of the Literature Review. It sets the context for the reader and elaborates on the existing knowledge which influenced this research study.

Section one consists of three chapters. Chapter one of this thesis will introduce the reader to the existing body of global research on young carers and the impacts of caregiving responsibilities on children and young people. It will also provide a comprehensive overview of literature on children with caring responsibilities in the Indian context. This review will lay the groundwork for this study, emphasising on the importance of bridging the existing gaps in understanding and support for young carers in India. Chapter two will furnish the essential background information about the study population to ensure that the findings are relatable to the reader. The social, demographic and economic characteristics of the study location will be elaborated in this chapter. Chapter three will introduce the reader to the varied childhoods in India and the Indian education system. It will also introduce the reader to the welfare policies available to children in India and the role of social workers.

Section Two provides a detailed examination of the theories and methodologies underpinning this thesis and consists of chapter four and five. Chapter four will elaborate on the theoretical frameworks used to study the research problem and the positionality of the researcher. Chapter five will introduce the reader to the research problem being studied. It also discusses the key methodological decisions and ethical considerations relevant to this research project. It outlines the sequential exploratory mixed methods approach used in the study. It also serves as the foundation for understanding the subsequent analysis and findings of this study.

Section Three discusses the qualitative study methods and findings of this research project and consists of chapters six to nine. Chapter six elaborates on the qualitative study design and the methods used to conduct the qualitative interviews. It also elaborates on the methodological decisions taken to answer the first research question of this study. Chapter seven to nine present the findings from the qualitative data. Chapter seven delves into the range of tasks children undertake and the experience of being a young carer in the Indian context. Chapter eight examines the profound impacts of caregiving on the young carers and discusses the support systems or lack thereof, both within and outside their families. Chapter nine on the other hand focusses on key informant data and the various policy responses suggested by them to support young carers.

Section Four, containing chapter ten and eleven, discusses the quantitative study methods and findings of this research. Chapter ten details the quantitative study design and methods employed to address the second research question. It discusses the methodological choices made in the development of the survey questionnaire, informed by findings from the qualitative study, and describes the strategies used to pilot and administer the survey. Chapter eleven focuses on the analytical methods used to develop scales measuring children's engagement in household tasks and the associated impacts. It also presents findings from the survey data, and the results of hypothesis testing conducted on the quantitative data.

Section Five consists of chapter twelve which brings the qualitative and quantitative data together meaningfully. It also synthesises the findings of this study in relation to existing literature on young carers, drawing meaningful conclusions while suggesting

policy implications. It also discusses the limitations of the study and areas for future research.

Section 1

Literature Review

Chapter 1: Young Carers

Introduction

In most cultures, informal or unpaid caregiving is often associated within the institution of the family (Smyth, Blaxland and Cass, 2010; ILO, 2016). This is especially true when policies of community care and reduced social expenditure force families to care for their ill members (D'Cruz, 2004). Caregiving draws individuals from various age groups within the families. When children and young people grow up in such households, they may also take on caregiving roles for the family member in need. Research suggests such children are present in every country, with prevalence rates estimated to range between 2-8 % (Joseph et al., 2020).

The terminologies used to describe children with caregiving responsibilities may differ according to their age and location. For example, in the United Kingdom, the term 'young carers' is used for children with caring responsibilities who are under 18 years of age, while young adults between the age of 18 to 24 are called 'young adult carers.' In Australia, the term 'young carer' is used to describe people up to the age of 25 who undertake informal caring responsibilities for family members (Smyth, Blaxland and Cass, 2010; Walker, Mason and Moulding, 2024). Along similar lines, Canada also uses the term 'young carer' to describe those under the age of 25 years who provide substantial, consistent or significant unpaid support to family members due to factors including but not limited to, chronic illness, familial or parental absence, disability, mental health issues, frailty due to aging or substance abuse issues (Stamatopoulos, 2015; Saragosa et al., 2022). Studies from the United States of America have used the term 'caregiving youth' or 'youth caregivers' to describe caregivers who are under the age of 18 and provide care for family members who are aging or have a chronic illness, disability or other health conditions that require assistance (Kavanaugh et al., 2016; Chadi and Stamatopoulos, 2017; Edmonds and Olson, 2024). In Norway, having a parent with mental illness, substance dependence or severe illness/injury puts children and young people in the role of 'next of kin.' They could be between the age group of 0-26 years (Ytterhus et al., 2024). Countries like Italy, Netherlands, Sweden, Germany and Slovenia translate the term 'young carer' directly to their respective languages (Frech et al., 2019; Lewis et al., 2023). Definition of young carers in Kenya,

allude to children below the age of 18 who provide care to sick, disabled or elderly members regularly but also highlight conditions of poverty, lack of state support services and the resultant income generating role played by the young carers in sustaining their households (Andreouli, Skovdal and Campbell, 2013). Irrespective of definition, cultural and legal understandings, caregiving practices by children and young people are a global phenomenon, although their prevalence rates may differ from country to country (Pot, Kadi and Staflinger, 2024).

Care-recipients, i.e. individuals who receive care and support from the young carers, could be adults, children, family or non-family members. Lewis *et al.*'s, (2023) research with adolescent young carers in six European countries reported that majority of the children were carers for their mothers (42%). Other studies have also supported this finding (Dearden and Becker, 2004; Metzing *et al.*, 2020). This was followed by father (25%), brother (19%), grandmother (17%), sister (16%) and grandfather (11%), while others were carers for relatives like uncles or aunts (less than 10%). Some adolescent young carers also provided care to close friends, partners, colleagues, neighbour and ex-partner. Adolescents (28.4%) were also caring for more than one person (Lewis *et al.*, 2023).

The explicit reasons for children taking on caregiving roles for care-recipients, could range from long term health conditions, age-related decline (Armstrong-Carter *et al.*, 2023), physical disabilities, mental illness, cognitive impairments, to substance addictions (Lewis *et al.*, 2023). Studies have indicated a higher prevalence of young carers within single-parent households (Dearden and Becker, 2004; Boumans and Dorant, 2018). Broader socio-political factors like, inadequate formal long term eldercare systems, family-oriented welfare system, rising prevalence of chronic diseases, have been reported as reasons for children to take on caregiving responsibilities (Dearden and Becker, 2004). Lack of support services and household poverty are also considered key determinants of young caregiving especially in low income countries (Robson, 2000). Other socio-cultural factors like filial obligations, religious values, cultural reliance on intergenerational familial care and refusal of the care-recipients to accept external support have also been cited as reasons for children taking on caregiver roles (Robson, 2000; Evans and Becker, 2009b; Sahoo and Suar, 2009; Olang'O, Nyamongo and Nyambedha, 2012; Saragosa *et al.*, 2022). In many

cultures, caring is integrated within the normative framework of the family system and therefore, for many children care work is not an additional duty but an extension of their role within the family (Saragosa *et al.*, 2022). More discussion on cultural norms around caregiving will be presented in later chapters.

The kind of assistance young carers provide are mostly tailored to the needs of their care-recipients. These could range from support with supervising younger siblings, monitoring parents' emotional needs to assistance with activities of daily living like bathing (Armstrong-Carter *et al.*, 2023). These have been discussed in detail later in the chapter, but it is safe to say that young carers do not conform to the typical idea of a helpless 'child' who is dependent on adults and is 'cared for' by the adults. This underscores the need for more inclusive conceptualisations that acknowledge the diversity of children's experiences.

As with adult carers (Goldblatt, Granot and Zarbiv, 2019), research with young carers also indicates that they frequently face 'conflicting responsibilities' or 'split loyalties' between their own well-being and the care required for their care-recipient. Although studies detailing direct comparisons between young carers and adult carers (those above 25 years of age) are rare, it is only reasonable to assume that young carers face greater pressures of being a carer, given their relatively vulnerable position in society as children, limited access to resources and their physical and emotional underdevelopment, in comparison to adults.

Consequently, the role of a young carer has major implications on children's health (both physical and mental), education, professional and social opportunities and additionally their overall well-being (Joseph *et al.*, 2023; Samman, Pandolfelli and Cappa, 2025).

These implications tend to be multifaceted, particularly in the majority world, which largely include low- and middle-income countries, where welfare systems and other protective factors are limited. In these contexts, research and understanding on young carers also remains low in comparison to the minority world countries (which include the high-income nations) (Samman, Pandolfelli and Cappa, 2025). Consequently, awareness and relevant support systems for children with caring responsibilities are also minimal.

India is one of those countries from the majority world, where care giving practices by children have not received much attention, leading to a serious deficit of literature. Caring is romanticised in society as being part of the country's culture or the child's duty towards the family system and is not compartmentalised as additional labour. However, it has been proven even in the limited literature from India (Sahoo and Suar, 2010; Pande, 2022) that caring has demonstrated effects on children and their social and psychological development. Therefore, highlighting the need to understand the experiences of children who undertake caring roles for family members to further understand their needs and challenges, in order to provide them with the necessary support.

Additionally, as there is a popular notion that children from the majority nations help with the quotidian household tasks more than children from the minority nations, differentiating young carers from children without caring responsibilities in the majority world can be a difficult task. Thus, calling for understanding Indian children's contributions within the domestic spheres, the complete disregard of which can be a major cause for children with caring responsibilities being hidden from popular gaze for such a long time.

This chapter is dedicated to the understanding of what is known about children, adolescents, and young people who assist and support a parent, sibling, grandparent, or a relative who may have an illness, disability, mental health issues or any other care need (Joseph *et al.*, 2020, 2023). It will elaborate on the known impacts of the role and the reasons for undertaking them. It will also discuss some of the differences between young carers from the majority and minority worlds. Finally, this chapter will elaborate on what is known about children with such caring responsibilities in the Indian context and introduce the reader to the research problem being studied.

This chapter draws on empirical research studies undertaken with young carers, globally, to set the scene for what is known about young carers. The studies discussed employ a range of methodological approaches and are examined in terms of both their findings and methods, with critical analysis where appropriate. It also draws on systematic/ scoping reviews and charity reports on young carers.

What do Young Carers do and how are they different?

Young carers differ from their non-caring counterparts by virtue of the nature and extent of the tasks that they undertake (Sahoo and Suar, 2009). They provide regular, unpaid and significant amounts of care to their families. Their tasks may range from domestic chores, intimate personal tasks, sibling support, medicalised care, emotional support to other types of support tasks which are usually considered to be adult roles (Clabburn and O'Brien, 2015; Leu et al., 2022; Saragosa et al., 2022; Lewis et al., 2023).

Five indicators, to distinguish children undertaking inappropriate and excessive levels of caring responsibilities as compared to their non-caring counterparts, which have also been identified in the UK's Care Act 2014, include- personal care for a care-recipient, which may include bathing, dressing, toileting and are common when the care recipient has physical health problems (Dearden and Becker, 2004); strenuous physical activities which may include lifting heavy shopping bags or assisting the care-recipient with physical movements; responsibility for medication, including administering medications or giving injections, even when the care-recipient is uncooperative and may also include tasks like cleaning infected wounds (Saragosa et al., 2022); emotional support for adults, which are hidden and harder to quantify, can look like, managing moods of the care-recipient or trying to cheer them up (Dearden and Becker, 2004), being the primary social relationship, alleviating the healthy parent's burden (Clabburn and O'Brien, 2015) and is common when the care recipient has mental health problems (Dearden and Becker, 2004) but may not be limited to such cases only; and household financial responsibilities which may include maintaining the family budget, paying bills, worrying about money to pay them or using their own money to make payments (Gowen et al., 2022).

Qualitative study conducted by Gowen et al. (2022), using focus group discussions with 21 self-selecting young carers, was instrumental in identifying two more areas of inappropriate care. These are - parenting responsibilities which may include, the child acting in a parenting role towards they care-recipient, siblings or other family members, and may include tasks like looking after siblings' wellbeing, advising them and taking them away from home for some respite (Clabburn and O'Brien, 2015); and self-care responsibilities wherein the child is responsible for one's own well-being,

keeping their emotions in check, staying calm, tolerating parents' anger or aggression and/or excessive mental stress (Gowen *et al.*, 2022).

Additionally, undertaking domestic chores like cleaning, grocery shopping, cooking, ironing, etc are also young carers' responsibilities (Dearden and Becker, 2004). Responsibility for domestic chores also indicates to a change in familial roles (Clabburn and O'Brien, 2015).

Other forms of adult-like support tasks undertaken by the young carers, especially those from Black African, Afro-Caribbean, South Asian and Chinese heritage (collectively known as BAME young carers) may take the form of translating for non-English speaking parents, especially while navigating the health care systems (Dearden and Becker, 2004). A Barnardo's report on BAME young carers highlights that these individuals were frequently required to interpret complex and personal medical information for their parents. This increases the risk of medical miscommunication, potentially leading to misdiagnosis and elevated anxiety within the family (James, 2019).

Research from the UK suggests that BAME young carers have been found to be a particularly vulnerable group of young carers (Aldridge, 2018). "Young carers are 1.5 times more likely to be from black Asian or minority ethnic communities and are twice as likely to not speak English as their first language" (Hounsell, 2013:5). They often have added challenges originating from cultural expectation around family-based caregiving for older or ill family members. Stigma related to mental health and disability issues prevents such families from seeking support, further exacerbating the young carer's challenges (James, 2019). In addition to the challenges as young carers they also face systemic inequalities due to their minority identities, further complicating their role (Alexander, 2021) and are less likely to receive support (Barnardo's, 2019). BAME young carers are a group of vulnerable children who need significant attention within the UK and European contexts as they remain among the most marginalised and overlooked groups (Aldridge, 2018).

Gowen *et al.* (2022) also indicate that dimensions of care such as – frequency (hourly, daily, weekly, non-stop), duration (over week, month, year), range of activities (combination of tasks), and severity (intensity, time, effort, risk) are also important factors to consider while distinguishing young carers from non-carers. Additionally,

factors like the frequency with which the young person provides overnight care (regular, intermittent, unpredictable), whether they perceive themselves as sole carer or not (never, always, sometimes), and whether they have a choice (never, always, sometimes) provide a clearer guide for defining and assessing the inappropriate care undertaken by the young carer (Gowen *et al.*, 2022).

These indicators help distinguish young carers' tasks from that of any other child. It is important to note that caring tasks undertaken by young carers exceeds what is expected of most children in families (Smyth, Blaxland and Cass, 2010; Lewis *et al.*, 2023). Warren, (2007) has argued that helping others with personal and intimate care most certainly distinguishes young carers from other children who may be just helping at home.

The kinds of tasks young carers undertake may depend on a variety of external factors like socio-economic circumstances of the family, national/local population demographics characteristics, welfare provisions available locally (Joseph *et al.*, 2023; Lewis *et al.*, 2023). At the same time, the kind of tasks that are considered inappropriate or excessive for children also depend on legal frameworks available in a country and the prevalent social norms and practices (Gowen *et al.*, 2022). Owing to the different understandings of childhoods across the globe and the consequent subjective constructions and experiences of being a 'young carer,' there isn't a universal definition of the term (Tremmel *et al.*, 2023). Even within a regional population there would be young carers who perform some caring roles for family members and some others who perform intense levels of caring responsibilities. Therefore, young carers are not a homogenous population. The tasks they perform and the challenges they face is better understood on a continuum (Joseph *et al.*, 2023).

Instead of treating young carers as a single population, Joseph and colleagues, (2023), in their paper critically analysing existing research on young carers, propose to view children with caring responsibilities within three concentric circles. These concentric circles are as follows:

- The outermost circle includes children who 'care about' - these are children who are helping a relative in some small ways with household tasks. Their roles do not differ to a large extent from their non-caring peers.

- The second circle is for children who 'care for' - these children have taken on the responsibilities of household tasks but also have specialist and medical roles. However, these do not interfere excessively with their social and educational activities.
- The inner circle is for 'children who themselves need care' - these children have taken on caring activities well beyond children who are not carers. Their roles may involve specialised medical activities and emotional work. Their role prevents them from engaging in their social and educational activities (Joseph *et al.*, 2023).

These conceptualisations of young carers and the tasks they undertake clearly state how young carers are different from children without caring responsibilities. It also allows one to see that young carers are not a homogenous group and have inherent differences amongst themselves as a group of vulnerable children, who require distinctive and tailored policy responses and support systems. This support should also be individualised based on the tasks that they undertake, their age, gender, developmental and socioeconomic status and family structures, to help with the burden of care and to reduce its impacts (Warhurst, Bayless and Maynard, 2022; Joseph *et al.*, 2023; Ytterhus *et al.*, 2024).

How does the Role Impact them?

Understanding how the role of a young carer impact children is important to create and implement nuanced systemic interventions to support them and their families. The impacts can be broadly split into negative and positive impacts. It is important to note that cultural beliefs and values can influence these perceptions of caregiving, such as intergenerational family relationships and values, cultural interpretations and representations of illness and long-term health conditions, the availability and perception of social support, the caregiver's self-awareness of their role, and trust in social and healthcare service (Santini *et al.*, 2020).

Negative Impacts

Research indicates that children who engage in caregiving for more than two years are at a higher risk of experiencing a wide range of adverse outcomes, especially in terms

of physical health, emotional and mental wellbeing, education, time and socio-economic opportunities (Aldridge, 2018; Joseph *et al.*, 2023).

Physical Health

Qualitative studies with young carers and professionals working closely with young carers across Europe have found that prolonged caring can increase health inequalities for young carers (Nap *et al.*, 2020; Gowen *et al.*, 2022). Physical health impacts on young carers can range from back or other injuries from lifting care recipients, ill health due to poor nutrition as a result of limited cooking skills and low family income. The time devoted to caring activities can also cut into their time for physical exercise and leisure activities (Gowen *et al.*, 2022). Young carers may also experience problems like exhaustion, lack of sleep and disrupted sleep (Lewis *et al.*, 2023).

Survey conducted with 6002 children aged 10-17 years in South Africa observed that children caring for parents with HIV/AIDS are susceptible to infections like pulmonary tuberculosis (Cluver *et al.*, 2013).

Mental Wellbeing and Behavioural Impacts

Growing up with a family member who is ill is a recognised risk for mental health and emotional well-being (Nap *et al.*, 2020; Saragosa *et al.*, 2022). In a survey conducted with 402 children who were identified as adolescent young carers in the UK, 50% reported to have experienced stress related to caring activities, and 40% experienced mental health problems (Lewis *et al.*, 2023). Taking on carer roles can cause distress, tiredness, worry, stress, anxiety, depression, isolation and other emotional problems; like thoughts of self-harm and harm to others due to their caring roles (Carers Trust, 2016; Lewis *et al.*, 2023). Saragosa *et al.*'s, (2022) systematic review of 28 studies conducted with young carers across 12 countries revealed that some young carers even required antidepressant medications. Insomnia, somatic symptoms and lower life satisfaction have also been reported among others (Saragosa *et al.*, 2022). Sustained caregiving has also been linked to lower self-esteem and diminished optimism about their future (Gowen *et al.*, 2022).

Some young carers are also sheltered from the care-recipient circumstances especially in situations when they provide end of life care for family members. This is

usually done to reduce fear but leaves them feeling confused and ill equipped (Clabburn and O'Brien, 2015; Saragosa *et al.*, 2022).

Blake-Holmes and colleagues (2023), developed the Model of Acquiescence to explore the psychological impacts of being a young carer for parents with mental illness. Their work illustrates that in complex and challenging family environments children may suppress their own needs and prioritise their parent's well-being. This often resulted in a diminished sense of self and impacted their future relationships.

This tendency to suppress one's own needs in favour of prioritising others' can be associated with young carers 'growing up fast,' their 'maturity' and forfeiting being a 'child' (Bibby and Becker, 2000; Saragosa *et al.*, 2022). While some accept their adult-like roles willingly others have reported feelings of resentment and wanting a 'normal' life (Saragosa *et al.*, 2022).

Joseph *et al.*, (2023) suggest that children providing intimate personal care to parents, transgress the accepted social norms of the relationship between a child and parent which may also have detrimental effects on them, especially their development, social integration and interaction with peers.

Some studies (Cree, 2003; ME-WE, 2021; Lewis *et al.*, 2023) with young carers across Europe have also reported self-harming tendencies and suicidal ideation amongst such children. However, this remains a significantly under-researched area.

Young caregivers also face a 1.5 times higher likelihood of having a special educational need or disability compared to their peers, as reported by Hounsell, (2013: 5) using data from the Longitudinal Survey of Young people in England (LSYPE). While certain children may develop coping mechanisms, those engaged in caregiving for extended periods (exceeding 2 years) may also experience difficulties in coping (Gowen *et al.*, 2022).

Education

Young carers experience severe impacts to their educational experience. It is often the most adversely affected aspect of their lives (Gowen *et al.*, 2022). Qualitative and quantitative studies with young carers across Europe have reported that they often display less school engagement, their education is disrupted due to absenteeism, lateness, falling behind with schoolwork, tiredness, and fatigue leading to low

educational attainment, and limited opportunities for participating in social activities (Becker and Becker, 2009; Nap *et al.*, 2020; Gowen *et al.*, 2022; Saragosa *et al.*, 2022; Lewis *et al.*, 2023). They demonstrate lower educational aspirations and attainment when compared to non-carers (Saragosa *et al.*, 2022). For some young carers, caring for a family member can also lead to dropping out of the educational system to become full time carers (Nap *et al.*, 2020; Laver-Bradbury *et al.*, 2021). For example, a comparative study on young carers in Tanzania and UK, which interviewed young carers, young adult carers, parents/relatives and NGO workers found that and their children in Tanzania who were carers for parents with HIV/AIDS, especially young girls aged 9-17 years, had to discontinue school education because of caring responsibilities and extreme poverty (Evans and Becker, 2009a). This reduces their likelihood of participating in further education, especially for girls (Becker and Becker, 2009), thus affecting their employment prospects and future earning capacities (Smyth, Blaxland and Cass, 2010).

In contrast, Clabburn and O'Brien (2015) conducted semi-structured interviews with seven carers (all the participants were adults at the time of the interview but were 18 or younger when their parents was diagnosed) for parents with motor neuron disease in England, and have found that parental illness instilled motivation in children who were their carers to achieve academic success. Some also used education as an escape/respite from their household duties and responsibilities. However, it is to be noted that this study had a small sample, and most interviews had a retrospective element to it, which may introduce recall bias.

Schools have been slow to recognise, understand, address and support the needs of such children, further contributing to their worsening condition (Hamilton and Adamson, 2013; Clabburn and O'Brien, 2015). The study by Warhurst, Bayless and Maynard (2022) in the UK, which interviewed 18 teaching staff, highlights that teachers find it difficult to recognise young carers however they do acknowledge the emotional and physical challenges faced by young carers, which significantly impacts their academic performance.

Interviews conducted with 23 young carers and 13 young adult carers in Australia observed that young people found university education to be more flexible and accommodating of their needs (Hamilton and Adamson, 2013). At the same time,

young people with caring responsibilities are also known to adjust their career and educational aspirations, not only based on their current responsibilities but also according to their anticipated caring responsibilities in the future (Hamilton and Adamson, 2013). They tend to choose educational courses or jobs which were relatively near to home, allowing them to return to their caring responsibilities whenever required (Becker and Becker, 2009; Blake-Holmes, 2019).

Time and Socio-Economic Repercussions

Young carers undertake caregiving responsibilities in addition to the normative childhood tasks of play/socialisation and physical and mental development, and often at the expense of these normative childhood tasks. As caring for the parent or family member takes precedence (Hamilton and Adamson, 2013), they get limited time and opportunities for other tasks like balancing a social life with peers (Clabburn and O'Brien, 2015; Saragosa *et al.*, 2022). To put it simply, it's a trade-off, the more time they spend on caregiving, the less time they have for themselves, putting them at a loss when compared to their peers without caring responsibilities.

Limited access to school, food and financial strain also forced some to depend on external relatives or friends for support (Nap *et al.*, 2020).

Limitation on time can also have cascading economic consequences like less time to study which can lead to lower employability rates and lower earnings from paid work (Nap *et al.*, 2020; Saragosa *et al.*, 2022). Additionally, arriving to work late or leaving early, and taking time off from work because of caregiving responsibilities can pose further difficulties for them (Saragosa *et al.*, 2022).

Social repercussions of being a young carer may present as bullying due to the stigma associated with diseases like mental illness, or HIV/AIDS, which may further lead to social isolation and exclusion (Sahoo and Suar, 2009; Nap *et al.*, 2020). Saragosa *et al.*'s, (2022) systematic review of 28 qualitative papers also noted that children felt embarrassed by their circumstances and attempted to prevent others from discovering their situation, thus consciously preserving the appearance of a typical parent-child relationship.

Blake-Holmes'(2019) study with young adult carers who grew up with parental mental illness, also suggests that the young carers struggled with transitions into adulthood.

They found it challenging to exercise agency and define their own identity, create and maintain boundaries, manage healthy relationships with partners and to become a parent. BAME young carers, are more likely to experience poverty, discrimination and unemployment (Pelle, 2021).

Positive Impacts

Being a young carer also had some positive effects on the children. In addition to having positive effects on the parent-child bond (Aldridge, 2006), the adult like role that the children undertake may give rise to feelings of pride, self-worth and a sense of accomplishment in the young person. Research suggests that ability to make a loved one feel better or cope with daily activities makes some young carers feel better about themselves (Becker and Becker, 2009; Smyth, Blaxland and Cass, 2010).

In addition to beneficial skills like time management, organisational skills, budgeting, effective communication and the ability to multi-task, the role may also foster greater resilience, empathy, and also a positive, mature, responsible and rational outlook towards everyday concerns (Becker and Becker, 2009; Smyth, Blaxland and Cass, 2010; Clabburn and O'Brien, 2015; Santini *et al.*, 2020). Confidence and inner strength are also some of the attributes that young carers may show along with caring attitude towards others and a greater understanding of subjects like illness, disability, and social responsibility (Clabburn and O'Brien, 2015).

Clabburn and O'Brien (2015) suggest that young carers had closer family relations and a greater appreciation and admiration towards their parents, both ill and healthy. Other studies have also found similar positive aspects to caring roles (Santini *et al.*, 2020; Saragosa *et al.*, 2022; Lewis *et al.*, 2023).

Although not always positive, some even choose to further transfer these caring skills into career and job choices in fields like medicine or palliative care (Saragosa *et al.*, 2022).

This suggests that caregiving may not be entirely negative or harmful for young carers as it involves some degree of learning and personal growth (Lewis *et al.*, 2023). It is crucial that these positive aspects are acknowledged. Becker & Becker, (2009) are of the opinion that caring can bring 'positives' to the young carer, however, it is important

that the support services attempt to accentuate the positives while trying to reduce the negatives.

Gender in Caregiving

Just like caregiving in general (Patterson and Margolis, 2019), young caring is also typically gendered in nature. In many cultures, including India, girls are often socialised into caring and domestic roles early on (Suar, 1994). Consequently, there is greater involvement of girls in caring tasks, especially as they get older (Dearden and Becker, 2004; Santini *et al.*, 2020; Ytterhus *et al.*, 2024).

Contrastingly, a scoping review of 18 studies of varied design, on young carers in the African context by Ndungu, Bergen and Mineo (2025), found that some studies (Skovdal and Ogutu, 2009; Olang'o, Nyamongo and Nyambedha, 2012; Kavanaugh and Mochan, 2020) suggest that gender may not be a key determinant in children assuming caregiving roles. Some studies included in the review noted instances of gender matching between caregiver and care recipient, with male children typically providing care to fathers and female children to mothers. The authors also highlighted that in some households, especially those with children of only one gender, following local gender norms was not always feasible. In such cases, boys and girls undertook caregiving responsibilities that were culturally associated with the opposite gender (Ndungu, Bergen and Mineo, 2025).

Nonetheless, the review (Ndungu, Bergen and Mineo, 2025) also agrees that there are notable difference in the impacts faced by young carers based on their gender. Consequences like education disruption, early marriages, transactional sexual relations, risk of HIV and sexually transmitted diseases are observed more amongst girls than boys. While both boys and girls have similar positive experience of caring, girls have greater negative effects than boys (Santini *et al.*, 2020; Lewis *et al.*, 2023). Girls also reported having a lower state of well-being than boys as they performed more caring than boys (Lewis *et al.*, 2023).

Data on non-heterosexual young carers are minimal, but we know that transgender/ non-binary young carers are at more risk of emotional distress as compared to cisgendered/heterosexual young carers (Santini *et al.*, 2020).

Are the Young Carers in the Minority Worlds different from young carers in the Majority Worlds?

Research, recognition and regulations on young carers as a group of vulnerable children started in the United Kingdom and has since spread to other countries across Europe, North America, Asia, Oceania and parts of Africa (Robson *et al.*, 2006; Evans and Becker, 2009a; Skovdal and Ogutu, 2009; Chan and Heidi, 2010; Leu *et al.*, 2022; Ndungu, Bergen and Mineo, 2025). A more detailed analysis of countries has been offered by Leu *et al.*'s, (2022) cross-national classification of countries where they use a 7-point classification system to grade countries based on the different legislations, policies and service frameworks to support young carers. Most of the countries who have some sort of recognition on young carers are countries from the minority world. Young carers have been studied widely in the minority world countries as compared to the majority world (Sahoo and Suar, 2009; Joseph *et al.*, 2023; Ndungu, Bergen and Mineo, 2025). Evidently, young carers from majority world countries remain largely unrecognised and unsupported within the health and social service sectors (Thrush and Hyder, 2014).

This gap could also be attributed to the conceptualisations of children and childhoods in different cultures. For example, in Britain and other western countries, young carers are often perceived as experiencing a disrupted or non-normative childhood, particularly where their right to formal education and social development is disrupted (Evans and Becker, 2009b; Andreouli, Skovdal and Campbell, 2013). However, many African cultures view children and communities as having reciprocal rights and responsibilities, wherein children are morally obligated to support family members in need (Evans and Becker, 2009b). Childhood is considered to be a time of duty and service (Ndungu, Bergen and Mineo, 2025) and children are expected to contribute to the productive and reproductive domains of a household (Evans and Becker, 2009b). In Kenya, for example, young carers are recognised and respected for their contributions and the skills they develop through their caring roles (Andreouli, Skovdal and Campbell, 2013). Although this may facilitate in the construction of social identities and resilience as suggested by Andreouli, Skovdal and Campbell, (2013), it may not always translate into support for them.

Another distinction lies in the cultural norms that govern children's obligations toward their family elders. Yu *et al.*'s, (2013) quantitative study with 1449 children aged 6-18 years, living in families affected by HIV/AIDS in rural China explain that socio-cultural norms of filial piety and obligations towards family members especially parents in China, might be the reason why such children are overlooked in society. Chan and Heidi's, (2010) ethnographic study with five adolescent girl children living with a parent suffering from schizophrenia suggests that mental illness in China is highly stigmatised, leading to discrimination and social segregation of affected families. They have also reported that such social alienation puts additional pressures on the children and hinders them from seeking support from peers or teachers. They experience mixed emotions, such as love, anger, guilt, and self-condemnation, influenced by filial expectations. Additionally, they struggle with feelings of worry, hopelessness, and sorrow, often suppressing these emotions to protect their parents, which negatively impacts their self-esteem (Chan and Heidi, 2010). However, this study is limited by its small sample size and the unaccounted experiences of male children.

Poverty and lack of welfare provisions in poorer countries exacerbate young carers' situations (Robson, 2004). "Young carers in Africa enjoy much less institutional support and live under more deprived circumstances" (Andreouli *et al.*, 2013:20). Additionally, the backdrop of the HIV/AIDS epidemic in African countries has only resulted in increase in the number of young carers and the intensity of their responsibilities (Ndungu, Bergen and Mineo, 2025). Therefore, most of the research studies in the majority world are set in the aftermath of the HIV/AIDS epidemic and related illnesses, especially in African countries. This means they not only lack access to external support but also manage their caregiving responsibilities alongside adversities.

Research with 22 young carers in Tanzania observed that almost half of them were involved in some form of income generation for the family. This was in addition to their household and caring duties (Evans and Becker, 2009a). This has also been observed in studies with young carers in Kenya (Andreouli, Skovdal and Campbell, 2013). Joseph *et al.* (2023) explain that in poorer countries, in the absence of a state provided welfare

system and income protection schemes, parents' inability to earn money due to illness or disability exacerbates the family's financial difficulties, forcing children into income generating roles (Becker, 2007; Evans and Becker, 2009a).

Another key difference between young carers from the majority and minority worlds lies in the intensity, risk and consequently the impacts of the tasks they perform. Even though comparative studies across both contexts reveal that young carers carry out the same range of tasks (Joseph *et al.*, 2023), young carers from the majority world countries have been reported to have more demanding caregiving duties, and live with parents suffering from more risky, detrimental and stigmatised diseases like HIV/AIDS (Andreouli, Skovdal and Campbell, 2013). Children living in families affected by HIV/AIDS performed higher levels and longer hours of domestic chores which were directly proportional to their depressive symptoms (Yu *et al.*, 2012).

In addition to the physical, psychological and educational distress experienced by young carers in the minority worlds, children from the majority worlds also have to face the risk of early marriages and sometimes even transactional sexual relations pushed by financial needs predisposing them to sexually transmitted diseases and unwanted pregnancies (Olang'o, Nyamongo and Nyambedha, 2012). These differences may be connected to the previously mentioned factors like poverty and limited welfare provisions.

Therefore, it can be concluded that varied conceptualisations of childhoods and family relations, poverty and lack of welfare provisions combined with demanding caregiving responsibilities and limited research and awareness of their role sets young carers in the majority worlds apart from their peers in the minority worlds.

Young Carers: A Nascent Field of Study

Since their identification as a vulnerable group requiring support, research on young carers has progressed considerably. Research and policy frameworks on young carers is extensive especially in the United Kingdom, where the topic originated as a field of study. However, when compared to other areas of study, it remains a relatively recent field. Consequently, the field demands greater scholarly and policy attention, and significant gaps remain.

One striking example of the continued need for awareness, even in countries with a relatively advanced policy landscape, is the June 2024 school census in the United Kingdom. In this census, approximately 72% of schools reported having no young carers, a finding that has been widely challenged as inaccurate and reflective of ongoing underreporting of the presence of young carers (Carers Trust, no date). These persistent gaps have been thoroughly documented by Joseph *et al.* (2023), who advocate for the adoption of a broad, universal definition of young caring to enhance generalisability and facilitate international policy alignment. They also recommend the use of validated tools to strengthen methodological rigour and enable cross-contextual comparisons. However, the applicability of tools developed in the UK in contexts such as India is questionable. Joseph *et al.* (2023) also call for the application of more sophisticated theoretical frameworks to better understand the complexities of caregiving and its outcomes. They emphasise the importance of participatory research involving young carers themselves, undertaken with a multi-agency and interdisciplinary approach.

As noted by Ndungu, Bergen, and Mineo (2025), future research on young carers must consider the diversity of socio-economic contexts and avoid treating children as a monolithic group and more research is needed to understand the experiences of young carers as they transition into adulthood (Aldridge, 2018). Ultimately, there is an urgent need to ensure that young carers receive adequate support, delivered in ways that are sensitive and free from stigmatisation.

What do we know about Young Carers in India?

Before understanding caregiving practices by children in India, it is important to note that kinship caregiving is highly prevalent in the Indian cultural context (Ballal, Navaneetham and Chandra, 2019). Caregiving is believed to be a virtue (Sahoo and Suar, 2009) and family caregiving is a cultural expectation and part of the mandatory social responsibilities. Reciprocity, which can be described as giving back to parents or other family members, is an obligation taught to children both explicitly and implicitly (Singh and Dubey, 2016). As evident from the story of Shravan Kumar in the introductory chapter, such filial reciprocity is engrained in the social fabric of India, with socio-cultural norms dictating obligations towards family members especially parents.

Use of external support services to care for a member of the family are limited, expensive and are also looked down upon. Sahoo and Suar (2009) are of the opinion that informal caregiving within families is also a preferred, reliable and economic source of care as it reduces monetary pressures. This is the background in which children become carers for family members. More details about the ecosystem in India under which children become carers will be comprehensively discussed in chapters two and three.

Similar to studies with young carers in the African context (Robson *et al.*, 2006; Andreouli, Skovdal and Campbell, 2013), much of the knowledge about children caring for adults and other family members in India also comes from research with HIV/AIDS affected families and its aftermaths (D'Cruz, 2004; Mehta and Gupta, 2005; Visvanathan and Rani, 2015a, 2015b). However, with the exception of Visvanathan and Rani, (2015a, 2015b), these studies were conducted with adult caregivers and did not include children as participants..

A qualitative research study on families affected with HIV/AIDS conducted by D'Cruz, (2004), in Mumbai with 19 adult caregivers and care-recipients affected with HIV/AIDS pointed to the existence of this group of children who were single-handedly responsible for caregiving duties, unsuited for their age. The children providing care in this study were 8, 12 and 16 years old. D'Cruz, (2004) suggests that these children had to undertake caregiving duties due to the absence of another adult and the lack of informal support sources. In some cases, the children themselves were symptomatic of HIV infection and they alternated between periods of providing and receiving care (D'Cruz, 2004).

Mehta and Gupta's (2005) multi-method and multi-site study on the impact of HIV/AIDS on women carers, also reported that children often take on household responsibilities and care work for their HIV positive parents across Delhi, Mumbai, Pune, Vijayawada and Chennai. Due to the financial pressures, children especially girls, drop out of school to care for the sick and maintain the family. Some of these children were also forced into sex work. The authors also suggest that these children may be at risk of early marriage due to fears that, once their family's HIV status becomes public, stigma may reduce their chances of getting married. Although the authors do not explicitly claim that these early marriages are child marriages, given the

prevalence of the same in many parts of India (Sen, Banerjee and Chakma, 2025), it could be a possibility.

Visvanathan and Rani, (2015a, 2015b) interviewed 205 children affected by HIV/AIDS in the age group of 12-17 years using a tool consisting of the Pediatric Quality of Life Inventory (PedsQL) measure. Although Visvanathan and Rani's, (2015a, 2015b), study primarily focused on children living with parents or siblings affected by HIV/AIDS and not explicitly on children with caregiving roles, they nevertheless found that most children (60.5%) take on caregiving duties like ensuring timely administration of medication, accompanying them to the hospital, feeding the ill family member, and supporting them with bathing. They also performed intimate tasks such as cleaning bedsores, which put them at risk of infection. They were also involved in household chores and part time/ full time employment. The study also revealed that care work affected the children's physical health and school performance (Visvanathan and Rani, 2015a). Their research demonstrated that nearly 40% of children cared for more than one family member (Visvanathan & Rani, 2015a). More boys were involved in caregiving tasks, while girls took on more household responsibilities. Additionally, caregiving activities were linked to lower quality of life, especially among girls, demonstrating the negative impact of these roles on children. Many also struggled to meet their educational requirements (Visvanathan & Rani, 2015b).

Other quantitative research (Malhotra and Kaur, 1997; Manigandan *et al.*, 2000; Dhanaraj, 2016; Borga, D'Ambrosio and Lepinteur, 2022; Chakraborty and Waraich, 2023; Vikram, Ganguly and Goli, 2024) in India has also been suggestive of the consequences of children living with ill family members in India, such as effects on schooling, time use, leisure, life satisfaction, and overall well-being. However, with the exception of Manigandan *et al.*, (2000) and Vikram, Ganguly and Goli, (2024) these studies often did not often clarify whether the children were directly involved in caregiving. These studies also do not describe the extent of the children's caregiving responsibilities.

Malhotra and Kaur's, (1997) study conducted in Chandigarh, India, examining temperament of children (aged 5-14 years) living with mentally ill parents, found that when compared to children living with healthy parents, such children displayed temperament issues like lower sociability, persistent negative mood, low energy etc,

among other temperament issues. However, the paper does not clearly state if they were carers for their parents. Manigandan *et al.*'s, (2000) study in Vellore, India, with carers of people with spinal cord injuries makes a reference to carers who were below the age of 18 but they were not included in the study.

Dhanaraj (2016), examined the effects of parental health shocks on the schooling of their children in Andhra Pradesh, a state in south India, using the longitudinal datasets from three rounds of survey from the *Young Lives* project. They found that parental health shocks significantly reduced children's school participation. Borga, D'Ambrosio and Lepinteur (2022) also examined the data from the *Young Lives* Project across four countries Kenya, India, Peru and Vietnam and found that parental and sibling ill health in the family reduced life satisfaction amongst children and young people. They also suggest that health of a parent matters more for children growing up in poor and rural households, although the reasons for the same are not explicitly stated.

A study by Vikram, Ganguly and Goli (2024) on time use patterns among adolescents aged eight to fifteen, using data from 2000 children from the *Young Lives* study, in Andhra Pradesh and Telangana, states in India, found that girls spent significantly more time on household chores and caregiving compared to boys, especially during times of adversity, such as the death of a father, parental ill health, or climatic/ agricultural/ economic adversities. Care work in this context included looking after younger siblings or caring for ill household members and had detrimental effects on their time spent on school or leisure.

Sahoo and Suar's (2009) work, which is presented as a review of literature but aligns more closely with a position paper, highlights the lack of awareness amongst government and welfare agencies about young carers in Indian society and their consequent hidden nature. They attribute this hidden nature to risk of parents being perceived as inadequate, fear of bullying, and negative interventions by the state. They also state when caregiving responsibilities are undertaken by children, their invisible nature is amplified because informal caregiving provided by family members, which is based on love and reciprocity, is already largely invisible. The methodology used in this paper is not clearly articulated but the authors claim that the lack of social security provisions for sick and elderly is a major reason for children becoming young carers in majority world countries like India. Other reasons like decreasing family sizes, growing

number of old people, low socio-economic status and increasing illness were also mentioned. The paper goes on to propose that children from lower-socioeconomic groups, lower castes, nuclear or single parent families and female gender offer more care compared to children from high socio-economic groups, higher castes, joint/extended or double parent families and male gender.

At the time of writing, there were only two studies (Sahoo and Suar, 2010; Pande, 2022) in India which specifically focused on children who were carers for immediate family members. Sahoo and Suar (2010) conducted the foremost in-depth examination of young carers outside the context of HIV/AIDS in India. This was a comparative qualitative study with 50 carers and 50 non-carers in Cuttack, India. The children in the sample were aged 18 years or below. The mean age of carers was 13.3 years and 12.3 years for non-carers. The study used the Thematic Apperception Test (TAT) (Morgan and Murray, 1935) and open-ended questions to explore the influence of family environment on the young carers' minds, the nature of assistance that young carers provided, and the consequences of young caregiving. Participants created stories using black-and-white cards, and the content of these stories was analysed to explore the needs and pressures affecting the children.

The study revealed that family environment was found to cultivate a range of emotional and psychological responses in young carers, including nurturance, endurance, sympathy, affiliation, anxiety, sadness, aggression, heightened awareness, harm-avoidance, and internal conflict. Individuals with caregiving responsibilities reported experiencing greater pressure and more complex needs compared to their non-caregiving peers. It further demonstrated that growing up in a family affected by illness heightened children's sensitivity to caregiving and provided them with deeper insights into the nature of care through their direct involvement in it (Sahoo and Suar, 2010).

These young carers often assumed both emotional and domestic caregiving roles in support of ill family members. Participants also reported experiencing diminished concentration, feelings of sadness and worthlessness, insecurity, distrust, anxiety, depression, and concern for their future well-being. Participants also felt reluctant to disclose their family conditions (Sahoo and Suar, 2010).

Consistent with global research on young carers, Sahoo and Suar (2010) identified positive effects of caring responsibilities on the children. Children become

understanding and responsible through involvement in caregiving roles. However, authors also agreed that caregiving had more negative than positive consequences. (Sahoo and Suar, 2010).

The study called for the need to provide young carers with age-appropriate health education and information, enabling them to better understand the illnesses affecting their family members and manage their caregiving roles more effectively. Additionally, the study advocates for respite care services and the provision of broader social and institutional support for young carers (Sahoo and Suar, 2010).

Pande's (2022) paper which drew on findings from their ethnographic, multi-method doctoral research published in 2014, represents another comprehensive examination of young carers in the Indian context. This study defined young carers as "children who are involved in caring activities for their families which includes paid and unpaid work, especially providing care, assistance and support to the family and as a result drop out of school" (Pande, 2014:2). The twelve young carers in this study were aged between 11-16 years. They had dropped out of school due to their caregiving role and were residents of an urban slum in Uttar Pradesh. This study approaches young carers' experiences through the lens of child labour, exploring its intersections with poverty and schooling of children.

Pande's (2022) study illustrated that ill health or income shocks (due to death of breadwinner, floods, drought, or shortage of money due to sister's wedding) in low-income families resulted in children dropping out of school and sacrificing their education. This was not because the families did not value education but because the opportunity cost of children going to school instead of engaging in waged labour were very high. The children supplemented their family incomes either through paid labour, or by freeing-up another family member for waged labour, usually the mother, by taking on household and child-care responsibilities from them. Consequently, a redistribution of roles and labour took place in these families and young carers had to choose between education and caring. Poor quality of education was also an added factor in children leaving school. The study also provided evidence of the gendered division of labour, highlighting the disproportionate burden and impact on girl children. In some cases, girls undertook both waged labour outside the house and unpaid domestic labour inside the home to support their families (Pande, 2022).

Pande (2022) argues that an outright ban on child labour fails to account for the complex realities of families in which children undertake caregiving responsibilities. The study recommends reducing the opportunity costs associated with school participation for such children and their families. Rather than focusing solely on mainstream education, the paper advocates for flexible and non-formal educational options that offer diverse learning opportunities. Additionally, it emphasises the need to raise awareness among teachers regarding the specific needs of young carers. Conditional transfers, which involves provision of benefits like monetary support by the government upon school attendance, are also recommended as a form of support for these families (Pande, 2022).

As both, Sahoo and Suar (2010) and Pande (2022), focused on the impacts of the caregiving roles undertaken by children, there remained a gap in the understanding of what it means to be a young carer in the Indian context, particularly in terms of defining the characteristics and experiences that constitute this role. Therefore, the gap that this project aimed to address was exploring what it is like to be a young carer within Indian cultural context.

Chapter Summary

This chapter discussed the nature and range of tasks that young carers undertake which distinguishes them from their non-caring peers and presented the impacts these roles had on them. The chapter also discussed the gendered nature of care work and the differences between children performing caring roles in the majority and minority worlds. Lastly, it illustrated that literature on young carers in Indian context is limited and explained the rationale and research questions of this research.

Chapter 2: Society and Culture in India

Introduction

Before delving into my framing of the research problem, how this study was conducted and its results, it is imperative for the reader to understand the norms and conventions followed in the social realm where the participants of this study were situated. Interaction with social life is what makes us human and without an understanding of these norms, the understanding of the people in them would be incomplete (Burr, Dick and Gough, 2017).

This chapter will examine the contextual background of the study population, providing insights into their social, demographic, and economic characteristics to furnish essential background information about the population to ensure that the study's findings remain relatable within their specific context.

About India

India is a constitutional democracy, divided into 28 states and eight union territories. These are further divided into districts for administrative purposes. Each region in India has a language and/or a dialect local to it.

India is the most populous country in the world. It is home to more than 1.38 billion people and falls in the low-middle income category (WHO, no date). The country struggles with both population explosion and scarcity of resources (Fatima *et al.*, 2022). Even though the birth rates have declined over the years, a more rapid decline in death rates (indicating strengthening of health services) has added to the population growth. Population explosion is an economic problem which influences social problems like unemployment, low standard of living, poverty, food scarcity, pressure on environment, etc. Due to the paucity of resources, the people living in the lower rungs of the society are forced to survive with inadequate resources.

Majority of the Indian population lives in rural areas and agriculture is the largest livelihood provider in the country but often lowly paid. 70% of the population is engaged in agriculture, of which 75% are women, partly in response to men's migration to the cities (Notermans and Swelsen, 2022). Additionally, gender, religious, and caste stratifications are deep rooted in the Indian society and equality of opportunities is

highly dependent on the social location of the individual (Kumar, Balasubramanian and Loungani, 2022). Any study in India is inadequate without recognising social variables like caste, religion and gender. These social markers are also said to influence the experiences of childhood significantly (Madan, Srinivasan and Pandya, 2017). More details on these social variables will be discussed later in this chapter and next.

Poverty

India has only 2.4% of the world's landmass while being home to almost 18% of the world's population. Consequently, the country grapples with poverty and wealth inequalities, with nearly 23.6% of its population living on less than \$1.25 a day (World Bank prescribed levels of poverty). Additionally, India has very high income and spatial inequalities among various social groups and geographies. Although the country has made significant progress over the years and fared well on the multidimensional poverty index, which encompasses various dimensions of deprivation such as access to healthcare, education, and overall life satisfaction, research indicates considerable heterogeneity across different regions of the country. Basic services like health, education, housing and clean water are still inaccessible to large sections of the population (Das, Ghosh and Paria, 2022).

India is also home to 31% of the global population of children living in poverty. Child poverty damages the mental, physical, emotional and spiritual development of children, which hinders their ability to participate as equal members of society (M.D. and S.K., 2019).

Cutting down the poverty rate to 10.95% by 2030 is one of the major goals of India. To ensure this, India has various poverty alleviating schemes including- the Public Distribution System (PDS) programme, which ensures households below the poverty line (BPL) are entitled to regular provision of food grains and other social welfare benefits; the Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA), 2005 which assures 100 days of guaranteed annual employment for rural households across India; National Bank for Agriculture and Rural Development (NABARD)'s microfinance initiatives; construction of free houses for rural poor under the Pradhan Mantri Grameen Awaas Yojna; pension schemes and maternity benefit schemes, among others (Rodriguez, 2022). These schemes are beneficial to many but

at the same time are fraught with corruption and local connections with politicians significantly affect access to these benefits (Panda, 2015).

As discussed in the previous chapter, poverty is a key determinant contributing to children assuming caregiving responsibilities. Therefore, children in India, especially those living in poverty, are at an increased risk of becoming young carers and supporting their families. Thus, they require greater support and attention.

Caste and Religion

Caste and religion are intertwined entities in India. It is difficult to understand one without the other.

Caste is a system of social stratification in India, characterised by hierarchy, heredity and inequality (Jha, 1997), with historical roots. Caste is not unique to one religion. Muslims, Christians, Jains and Buddhists also follow caste hierarchies in India.

Legal categorisations routinely used for population monitoring in post-independence India are: scheduled castes (SC) who prefer to call themselves *Dalits* (Stephen, 2012), scheduled tribes (ST) who are also called *Adivasi*, and other backward class (OBC). Those who do not belong to these categories are grouped under what is called the 'General' category (Vyas, Hathi and Gupta, 2022). SCs or Dalits belong to the lowest rungs of the caste hierarchy. They were formerly untouchables and, even now, are often socially and economically depressed. They make up almost 16% of the Indian population.

Similarly, STs or *Adivasi*, who were historically treated as outcastes and were excluded from the caste hierarchy entirely, has members from the economically and socially depressed tribes who were also treated as untouchables. There are 705 such recognised tribes in India who amount to approximately 8% of the Indian population. ST and SC are the most socially disadvantaged groups in India (Balarajan, Selvaraj and Subramanian, 2011; Goel and Husain, 2018). SC and ST groups amount to around 24% of the Indian population.

Caste groups other than SC and ST which are also economically and educationally disadvantaged are designated as OBCs. There are no accurate figures on the population of OBCs in the country, however, some estimates based on school enrolment data consider them to be close to 40% which indicates that they are larger

in population than any of the other groups (Nagrajan, 2021). The population of marginalised groups in India are larger than the total population of many other countries around the world. These are features of social stratification that are common across India, however marginalisation manifests differently from region to region (Vyas, Hathi and Gupta, 2022).

In 1948, negative discrimination based on caste was banned by law. In response to the historical discrimination faced by disadvantaged communities and to break the caste hierarchy, the Indian government enacted a policy of positive discrimination. Under this policy, there are reservation of seats for SC, ST and OBC communities in educational institutions and public sector jobs, residential schools are established for backward caste students, scholarships fee waivers, and concessions, free coaching facilities, etc (Goel and Husain, 2018). There is data to suggest that these policies have been instrumental in raising the proportion of people from SC and ST communities in salaried employment (Tiwari *et al.*, 2022).

However, despite decades of affirmative policies being mandated by the Constitution, underprivileged groups, especially SC and ST communities still have living standards much lower than that of others. They are oppressed in all spheres- economic, social, political, and religious (Shah *et al.*, 2006; Shah and Debnath, 2021). The majority of SC and ST still face severe discrimination and continue to live on the fringes of the villages in their own ghettos. They still engage in the most ill-paid, menial, dirty and ‘ritually polluting’ tasks, including sanitation work, manual scavenging of human and animal waste and dead animals, skinning the hide and tanning, digging graves, and bringing news of death. The impact of such unpleasant burdens and cultures of exclusion and discrimination have entrenched at all levels for these communities. The demographic figures of SC communities in India are among the worst in the world, especially for children. Children from the SC communities are subjected to discrimination and forced to drop out of school. SC women and girl children are subjected to further disadvantage due to their gender (Stephen, 2012b). More discussion on caste and its effects on children and women will be presented in the following sections of this thesis.

India is the world’s largest religiously pluralist and multi-ethnic democracy. The population of the country includes the majority of the world’s Hindus (80%), the

second largest group of Muslims (14.2%) in a single country, 2.3% Christians, 1.7% Sikhs, and Buddhist, Jains and Zoroastrians (2%) of the population (Ghosh, 2022).

Despite being the second largest in population, Muslims are the poorest religious sub-group in India (Shah and Debnath, 2021). They are socially marginalised and lag behind other religious groups in health, employment, education and literacy (Goel and Husain, 2018; Chakraborty and Bohara, 2021; Sk *et al.*, 2021). In addition, caste hierarchies are also prevalent among Muslims in India, which are not legally recognised. This creates a situation of ‘double disadvantage’ for Muslims belonging to lower castes in India (Tiwari *et al.*, 2022).

Rituals and religious practices continue to have a strong hold on the psyche of the majority of people in India (Madan, Srinivasan and Pandya, 2017). Simultaneously, communal tensions triggered by Islamophobia, Hindu majoritarianism, caste supremacism and intolerance towards minorities continues to be a prevalent feature in Indian socio-cultural environment (Wilson, Loh and Purewal, 2018; Ahuja, 2019).

Shah *et al.*, (2006) note that SCs, STs, OBCs, and Muslims collectively make up 90% of the rural population and over 80% of the urban population living below the poverty line in India. The economic situation of people from the SC communities living in urban areas is much worse than those living in rural areas (Shah *et al.*, 2006). Despite Article 15 of the Indian Constitution prohibiting discrimination based on religion, race, caste, gender or place of birth, social identity-based disparity remains a persistent feature of Indian societies (Goel and Husain, 2018; Pal, 2018).

Poverty and social discrimination go hand in hand in India with households belonging to lower socio-economic groups being susceptible to higher incidences of poverty (Shah and Debnath, 2021). Therefore, indicating that there is a higher risk for children from these disadvantaged communities to assume caregiving responsibilities for their family members due to their social and economic marginalisation.

Gender

India has a highly masculine sex ratio at birth with 940 girls for 1000 boys. Families prefer to have sons over daughters (Lin and Adserà, 2013). Preferential treatment for boys permeates all social classes and communities rendering girl’s inferior/secondary to boys from birth. In many parts of India, gender norms dictate that girls should be

docile and obedient (Kumar *et al.*, 2022). The female child receives less nurturing, care, and parental attention than males, making them far more susceptible to diseases and infection than boys (Batra and Reio, 2016).

Traditional gender roles expect girls to perform household chores, like looking after younger siblings, cooking, washing clothes, and cleaning the house, particularly if the mother is a paid labourer (Goel and Husain, 2018). Girls are often referred to as *paraya dhan* (someone else's property) signifying that they would marry and go away (Jha, 2017). They are expected to be hardworking and responsible members of the household and well prepared for marriage where they simply transfer these skills to their conjugal home (Pande, 2014).

Most of the unpaid household and care work is also performed by women and girls (ILO, 2016). At the same time, participation by women in labour force has been dropping steeply over the years and gender inequality in the workforce highly prevalent. Women earn close to 40% less than their male counterparts (Batra and Reio, 2016).

India is a collectivist society where the welfare of the group is endorsed over individual needs, and most of the time this sacrifice is made by the women in the society. Patriarchal norms dictate that women's lives should be controlled and monitored by male members of the family, initially by the father, then by the husband and eventually by the son. In keeping with this trend, work performed by the women, especially in the home, such as taking care of the young and old family members and household chores, fails to gain favourable recognition both within the family and the nation (Batra and Reio, 2016).

As a result of the above mentioned socio-cultural disparities, women's well-being, both physical and mental is compromised in India (Saha and Saha, 2010; Malhotra and Shah, 2015). This puts them at a higher risk of illnesses and therefore higher likelihood of requiring care.

Like most parts of the world, gender equity and empowerment of sexual minorities are charged discourses in India. In response to these persistent gender inequalities, the government has attempted to take prudent steps to ensure gender equity in all aspects, at least on paper. The parliament enacted the 73rd and 74th Constitutional Amendments in 1994, ensuring reservation of 1/3rd of the seats for women in the local

government bodies. It has been proved to be an important tool to increase participation of women in governance, which they have been consistently deprived of (Stephen, 2012b). Some examples of attempts at encouraging gender justice and equity in the country are laws and policies like- the Right to (free and compulsory) Education Act, 2009, the Domestic Violence Act, 2005, Section 498 (A) of the Indian Penal Code pertaining to making receiving and giving dowry illegal, the Sexual Harassment of Women at Workplace (Prevention, prohibition, and redressal) Act, 2013, the Immoral Traffic (Prevention) Act, 1956, the ruling of Section 377 (a colonial penal law which criminalised sexual acts “against the order of nature”) as unconstitutional in 2018, and hence decriminalising consensual sexual behaviour between adults of the same sex, among others.

However, despite these provisions, gender inequality in India exists in the form of socially constructed, defined gender roles firmly anchored in India’s socio-cultural fabric that has deep cultural and historical roots. This deeply patriarchal nature of society embeds in it an automatic disadvantage for anyone who is not an upper class, upper caste, heteronormative male in India.

As highlighted in the previous chapter, international literature on young carers (Lewis et al., 2023) indicates that mothers are most frequently the recipients of care. Considering the prevailing socio-cultural norms in India, a similar pattern is likely. Literature also suggests that girls are the primary providers of care for adult family members (Dearden and Becker, 2004; Santini *et al.*, 2020; Ytterhus *et al.*, 2024). When viewed together, these dynamics of firstly, women being the primary recipients of care, secondly, girls being the primary providers of care and third, care in general being a ‘feminine’ or ‘domestic’ affair, reflects the potential causes for the invisibility of the phenomenon of young caring from the mainstream conversations in India. This is in contrast to highly recognised policy and public discourses on child labour in the country or work done outside the home, which is majorly undertaken by male children (Putnick and Bornstein, 2016), reiterating the gendered/patriarchal nature of dialogues that receive mass attention.

Caregiving Norms

The socio-cultural order in India, or the dominant Hindu culture is governed by *kartavya/dharma* or duty based traditions which influences every aspect of an

individual's life like friendship, parenting, conjugal ties, etc (Ghai, 1998; Sharma, 1998; Bhatia, 2000; Bhangaokar and Kapadia, 2019). Duties are “rooted in morality and not legal obligations” (Ghai, 1998:29). These duties also include care for the vulnerable.

Like many South and Southeast Asian countries, socio-cultural norms in India also dictate that family should be the primary site for informal caregiving of vulnerable members of the family such as children, elderly, sick and disabled (Kashyap, 1989; D'Cruz and Bharat, 2001; Gupta, Pillai and Levy, 2012; Kumar and Saini, 2012; Goyal-Honavar *et al.*, 2025). This is traditionally done through co-residence, but limited formal and institutional support systems reinforce these norms (Ajay *et al.*, 2017; Chakraborty, Jana and Vibhute, 2023).

Additionally, like many Asian societies, notions of filial piety and filial obligations are cherished ideals in Indian families as well (Ugargol and Bailey, 2021). Care and maintenance of elderly parents, who are unable to maintain themselves, is not only a moral obligation for adult children but is also mandated by law (Section 125, The Code of Criminal Procedures, 1973). Ugargol and Bailey (2021) also highlight older parents' reciprocal expectations of care and support from their adult children, in return for the love and nurturing they provided during the children's early years. Older parents traditionally live with married sons and thus extending these filial roles to the daughters-in-law. There is also an expectation from non-adult children to observe the care-giving process in the family and emulate it later in their lives (Ugargol and Bailey, 2021).

As elaborated by Ghai, (1998), the hierarchical nature of most duty-based societies ensures that duties are unequally distributed and, in such societies, the position of women is generally inferior. Contextually, *kartavyas* or duties within a family unit also differ greatly based on gender (Bhangaokar and Kapadia, 2019). Furthermore, patriarchal norms perpetuate gendered stereotypes around caregiving that position the women in the family at a disadvantage, especially the daughters-in-law, who are significant load-bearing pillars of this structure of informal caregiving (Gupta, Rashmi, Rowe and Pillai, 2009; Brinda *et al.*, 2014; Chakraborty, Jana and Vibhute, 2023). Caregiving for vulnerable family members along with household tasks are considered to be women's duties (Kashyap, 1989; D'Cruz and Bharat, 2001). This kind of family-based care remains unpaid and for most family carers especially women,

underappreciated. Studies on adult informal caregiver burdens in India (Gupta, Pillai and Levy, 2012; Ajay *et al.*, 2017; Chakraborty, Jana and Vibhute, 2023; Parsekar *et al.*, 2023) have identified poor physical and mental health for caregivers, especially women (Brinda *et al.*, 2014; Goyal-Honavar *et al.*, 2025; Sonobe *et al.*, 2025). Thereby, re-emphasising the gendered nature and impacts of care-work.

Despite the significant caregiving burden borne by families, formal recognition of and state support for unpaid family carers is limited in India.

Family Forms

There are more than ten types of households or family forms in India, including, joint families, nuclear families, single-parent families, dual-earner families and adoptive families. Families of choice or LGBTQI families do not have legal approval yet and therefore little information is available on the same. For ease of discussion, families in India are predominantly categorised as joint families and nuclear families.

There is no single definition of joint family in modern India. While some define it in terms of household composition, where multiple generations of individuals (grandparents, parents, uncles, aunts and children) live together, others define it in terms of property ownership and economic partnership, where either land or an enterprise, is co-owned amongst brothers in a family (Ramu, 2006).

It is widely believed that modernisation, urbanisation, migration, education, industrialisation, land division, education and employment of women, etc are contributing to the decline of the joint family system, leading to a loss of traditional Indian values and norms, while promoting the rise of the 'western' nuclear family structure (Sharma, 1998; D'Cruz and Bharat, 2001; Sebastian and Sekher, 2012).

While there might be some accuracy to this belief, it has been illustrated that these changes have not brought about a complete breakdown of the joint family system. Even though structural changes have occurred, “functional jointness” still continues amongst Indian families (D'Cruz and Bharat, 2001:172). The networks of extended family relationships among kin are sustained across distances and changing aspirations, occupations, lifestyles, etc.

Additionally, scholars also argue that the joint family has been a feature of property-owning Hindu households, while nuclear and smaller households have been the norm

among lower class, caste and non-property-owning groups. They also argue that the joint family has never been universal across India (Sriram, 1993; D'Cruz and Bharat, 2001; Ramu, 2006).

Nevertheless, the norms associated with traditional joint family system, which is a patriarchal institution influenced by gender-based hierarchy, are highly idolised. Even though some regions and communities practice matrilineality; patrilineal and patrilocal kinship rules are the dominant norm, whereby sons remain living with the parents after marriage. In this system, the patriarch of the family holds the most influence, followed by any male bread winners and then inheritors of property who are also generally male members (D'Cruz and Bharat, 2001). Female inheritors or daughters receive a dowry or movable property like gold, jewellery, furniture, household items and vehicles upon marrying. Although there are gender sensitive legislations and policies, customs still dominate practice (Notermans and Swelsen, 2022). For example, women are entitled to an equal share in the property of the parents, however, women usually choose to let go of this right to avoid animosity. Another example is even though giving or taking dowry is illegal in India, it is still widely practised, and families do not deter from taking loans to pay wedding and dowry expenses.

Women in the family, more specifically daughters-in-laws, who are unrelated strangers, are considered to be subordinate to the men (D'Cruz and Bharat, 2001) and also undertake most of the unpaid household labour making them time-poor and affects their well-being (Srivastava, 2020).

As mentioned previously, family remains the primary site for caregiving for ill, elderly and disabled. In joint families, with multiple adults, caregiving duties of the vulnerable have a greater tendency to be distributed amongst these adults. Therefore, reducing the likelihood of the burden falling on the children. Additionally, as this arrangement is typically observed amongst the privileged groups who already possess greater access to resources, they may also have the means to compensate for additional care burdens by employing external paid support. However, in smaller nuclear families, which is the norm amongst less privileged families with fewer adults and fewer resources, the burden of care for the vulnerable is inadvertently shared by the children in the family.

Thus, putting children from nuclear families from less privileged background at a higher risk of becoming young carers in India.

Health Systems

India's health care-sector can be broadly divided into – formal and informal. The formal health care sector comprises of trained medical professionals. These include Allopathy, Ayurveda, Yoga, Unani, Naturopathy, Siddhi, Homeopathy and trained community health workers. The formal sector is further divided into state funded public health sector and private health care providers.

The informal sector on the other hand comprises of untrained personnel typically dispensing allopathic treatments (Thapa *et al.*, 2024). These informal practitioners are prevalent in rural India, where formal public health centres are sparsely located and understaffed (Khare *et al.*, 2019; Das *et al.*, 2022). Therefore, making these informal practitioners significant health-care providers (Thapa *et al.*, 2024).

The public health system is heavily underfunded in India (Shah, 2006). This increases dependency on the private sector and the informal sector. Resultantly, like many low- and middle-income countries, health care financing in India is heavily reliant upon out-of-pocket (OOP) payments (Balla *et al.*, 2022). OOP payments are costs that individuals pay directly for their own care (World Health Organisation, 2019). These payments could be both in cash or kind and made to private doctors, pharmacies (Jalali, Bikineh and Delavari, 2021) and in India's case, to informal health care practitioners.

High levels of OOP expenditures are said to be suggestive of a “regressive health care system” (Balla *et al.*, 2022:12). In India, the OOP expenditure is close to 62.2% placing a significant financial burden on the population and impeding households to maintain a basic standard of living (Sangar, Dutt and Thakur, 2019; Singh and Jayaram, 2020). Consequently, in the event of a health care crisis, households cut down on necessities such as food and clothing and compromise with education of their children. In the absence of a universal health coverage and inadequate publicly financed schemes for health, incidences of households falling below the poverty line due to OOP expenditures is around 8% in the country (Sangar, Dutt and Thakur, 2019).

Although the life expectancy has improved significantly over the years, averaging 63 years for men and 66 years for women, India also accounts for a substantial proportion of the global burden of deaths due to disease, with 18% of deaths and 20% of disability adjusted life years. A fifth of the maternal deaths and a quarter of the child deaths in the world, occur in India (Balarajan, Selvaraj and Subramanian, 2011).

Health outcomes in India are also strongly determined by factors such as gender, caste, wealth, education, and geography. For example, immunisation coverage among ST and SC communities was 31.3% and 39.7% respectively in 2005-06 as compared to 53% among other castes (Balarajan, Selvaraj and Subramanian, 2011). Vyas, Hathi and Gupta, (2022) have also demonstrated that social disadvantage and health are closely linked. They have demonstrated that the difference in life expectancy between upper caste Hindus and ST and SC communities is “comparable to Black-White gap in the United States in absolute magnitude” (Vyas, Hathi and Gupta, 2022:1). A study by Shah *et al.* (2006) in rural India found that individuals from SC communities or Dalits were denied access to public healthcare facilities in 18.1% of the villages surveyed. Furthermore, in 32.7% villages, public health workers refused to visit villages predominantly inhabited by Dalits, further worsening their exclusion from essential health services (Shah *et al.*, 2006). Muslims are more likely to incur disastrous expenditures and to fall below the poverty line than Hindus and other religions as they are more prone to discriminatory factors previously discussed (Sangar, Dutt and Thakur, 2019; Singh and Jayaram, 2020). Disadvantaged communities and people earning their living through casual/ agricultural labour and who are self-employed are also more likely to fall below the poverty line due to health issues and subsequent OOP expenditures (Sangar, Dutt and Thakur, 2019).

Whilst health policies in India, especially the National Health Policy, 2017 aim to provide universal health coverage through the public health care sector (Sagayam, Sengupta and Mazundar, 2025) access to affordable and quality healthcare still remains a problem for a large section of Indian population (Radheshyam, Ramani and Naik, 2025). Consequently, in a country with widespread poverty, inadequate welfare benefits and inaccessible public health care systems, the responsibility of caregiving inevitably falls on the family members (Goyal-Honavar *et al.*, 2025). As discussed previously, this burden is disproportionately borne by the women and children in families.

Disability

Despite India's recognition of the rights of persons with disabilities, numerous socio-economic challenges, societal stigma, inadequate infrastructure, and limited awareness continue to impede their accessibility and inclusion. As a result, individuals with disabilities face persistent disadvantages (Pal, 2018; Babu and Iyer, 2024).

Employment rates among people with disabilities remain significantly lower, a situation exacerbated by the poor educational conditions faced by this group (Pal, 2018; Babu and Iyer, 2024). Only 11% of individuals with disabilities benefit from government schemes offering free aid and appliances, with access being even more limited in rural areas (Pal, 2018). Furthermore, people with disabilities continue to be denied their fundamental rights to education, employment, healthcare, and participation in public life, primarily due to the gap between legal provisions and their implementation on the ground (Babu and Iyer, 2024).

The intersectionality of social identity factors such as religion, caste, and gender exacerbates the marginalisation of disabled individuals (Thompson, Rohwerder and Arockiasamy, 2021). Data reveals that the proportion of individuals with disabilities is higher among SC communities compared to other social groups. For many individuals with disabilities, particularly in rural areas, access to medical care and rehabilitation services remains out of reach (Pal, 2018).

The legal framework governing disability rights in India is established by the Rights of Persons with Disabilities Act, 2016. This legislation addresses both physical and mental disabilities, with the primary goal of enhancing the social, economic, and educational rights of individuals with disabilities. It is also one of the few legislations to recognise 'caregivers' and make provision for a caregiver allowance for caregivers of persons with high support needs. However, provisions available individuals with disabilities may differ based on state schemes. An online cross-sectional survey conducted with 316 parents of children with disabilities revealed that awareness about various national schemes and consequently their utilisation was very low (around 18%) (Chauhan *et al.*, 2021).

People with disabilities constitute a group that has been significantly overlooked by policymakers, with the government relying heavily on charitable organisations to

deliver essential services. In the absence of state services and benefits, support for this population remains largely confined to family care and initiatives by civil society organisations (Pal, 2018).

Intra-country Migration

With an average of 14 million every year, the rates of intra-country migration in India is estimated to be increasing every year (Krishna and Raj, 2022). New Delhi and Mumbai are popular destination cities for intra-country migrants with most migrants moving from rural areas to the cities (Srivastava, 2011). This is motivated by economic opportunities in the cities (Tiwari *et al.*, 2022) and the lack of suitable employment opportunities and low wages in the rural areas (Gawde, Sivakami and Babu, 2016). Presence of social networks like family relations and caste-networks including co-villagers, neighbours, etc at the destination city play a significant role in the initial stages of migration (Pandey, Mishra and Singh, 2022). Although there are educated and privileged migrants, the majority belong to disadvantaged communities who have not received formal education. They work in the informal sector as undocumented daily wage workers (Krishna and Raj, 2022).

Migrant labourers make enormous contributions to the country's economy through major sectors like construction, textiles, brickmaking, mines, quarries, fisheries and hospitality services (Akter, 2009). These are high risk sectors prone to occupational hazards or work-related illness like skin diseases, respiratory conditions and musculoskeletal disorders. Additionally, their susceptibility to illness can also be attributed to low-wages and resultant living conditions without basic amenities like potable drinking water, toilets etc. Additionally, engagement in the informal sector also means that in most cases they lack access to essential health care and labour welfare schemes (Pandey, Mishra and Singh, 2022).

Migration is also a highly gendered phenomenon. Women make up 70.7% of the internal migrants in the country. While men migrate for economic opportunities, women migrate for family, marriage and related reasons (UNICEF, 2020). Studies with women migrants have indicated that they face greater health risks especially during pregnancy (Krishna and Raj, 2022).

“When migration takes place as a family unit, each member of the family, excluding infants, contributes to family subsistence in one way or another, in work or as part of the household ‘care’ economy” (Srivastava, 2011:23). 70% of migrant children in India were found to be accompanying their parents or other earning members in the country (Srivastava, 2011).

Although migration opens various social and economic spheres for these children, it also comes with various risks. Migrant children may have better health and nutritional outcomes but they are also more likely to be engaged in paid work (UNICEF, 2020). They may also have additional responsibilities of caring for their siblings (Verma, 2023). This section highlights how belonging to a migrant family from an economically disadvantaged background can increase the likelihood of children assuming caregiving responsibilities at a young age. Over the years, the Indian government has adopted various policies and programs to protect the rights of migrant workers (both formal and informal sectors) and their families like the Interstate Migrant Workmen (Regulation of Employment and Conditions of Service) Act, 1979, Contract Labour (Regulation and Abolition) Act, 1970, Minimum Wages Act, 1948, and more recently through four new labour codes including the Occupational Safety, Health and Working Conditions Code, 2020 (Mandal, 2016; Sanjaya, 2022). However, as noted by Mandal (2016), the previous provisions lacked proper implementation, and the efficacy of the new legislations remains to be determined.

Chapter Summary

This chapter highlights the various horizontal and vertical socio-economic inequalities prevalent in India and the broader context in which children grow up. As evident from the chapter, India is a young nation grappling with persistent structural inequalities. The country faces a multitude of pressing issues that often take precedence in public discourse and policy. Within this context, concerns related to children, particularly those situated within the domestic sphere, are frequently marginalised or overlooked.

Factors such as poverty, family’s migration, gender, religion, caste, family and caregiving norms, disability rights and health of family members have a significant influence on the ‘domestic sphere.’ These factors are interconnected and influence the functioning of the family unit and the distribution of roles and responsibilities among its members. These social and economic factors, have a key role to play in the

likelihood of children assuming caregiving roles and becoming carers for siblings, parents, grandparents, or other relatives. These factors also determine the intensity and range of tasks that children undertake. Hence, an understanding of these factors is vital to understanding young carers in India.

At present, children with caregiving responsibilities in India play a crucial role in upholding the 'family ideal', while compensating for the significant lack of formal social support systems for the ill, elderly, and disabled. However, this reliance on children's unpaid care work places their own health and well-being at considerable risk, thereby perpetuating their structurally disadvantaged positions. Next chapter will take a closer look at the various childhoods and child-centred welfare provisions existing in the country.

Chapter 3: Children and Child Safeguarding in India

Introduction

This chapter will provide the reader with a brief review of children and the various childhoods in India. It will also elaborate on the education system in India and end with an understanding of the child protection policies and social work with children in India.

This chapter draws on literature from qualitative and quantitative research exploring childhoods, education and child welfare in India. It also engages with civil society publications, key policy documents along with laws and regulations concerned with safeguarding and protection of children in the country.

Children and Childhoods in India

The 2011 census reported that 440 million people in India are below the age of 18 years which constitutes 37% of the total population of the country. India is reported to have the largest adolescent population in the world, 253 million (Roy, 2015). It is also said to have a large proportion of its children living in “extreme situations of deprivation” (Duerr Berrick, Gilbert and Skivenes, 2023:5). It ranks fourth (after Bangladesh, Nepal and Afghanistan) among the eight South Asian countries in terms of child marriage prevalence. Neglect and disfavoured of girl children leads to clear health inequalities recorded between genders, for e.g. almost 54% of adolescent girls are anaemic compared to 30% of boys (UNICEF, no date a). The issue of low Body Mass Index in adolescent girls coupled with challenges of child marriage and adolescent pregnancies are said to have intergenerational impacts- such as high maternal and infant mortality rates, low educational attainment of mother leading to low education attainment and division of resources among more children, among others (UNICEF, no date b).

India is also said to have more than 400,000 children living on the streets who are unable to access educational opportunities and are forced into child labour (Aarambh India Initiative, 2020; Berrick, Gilbert and Skivenes, 2023). They are thus, denied the rights recommended by the United Nations Convention on the Rights of Child (UNCRC) to which India is a signatory (Chakramakkil, 2017). 25% of children living in India belong to the poorest population. Unequal distribution of income, goods and services pushes

children born into disadvantaged communities like SC and ST into the category of the most deprived. They are also less likely to access basic services due to poor social policies, programmes, unfair occupational opportunities and low and erratic incomes (Rajivan *et al.*, 2020).

Childhood in India is a contested grouping. It varies by domains, and this is highly visible in the contradicting age ceiling prescribed in various Indian laws (Saraswathi, Menon and Madan, 2017). Different laws in India have varying definitions of the terms 'child' and 'minor'.

The Child Labour (Prohibition and Regulation) Act of 1986 defines a 'child' as anyone who has not attained the age of 14 years. The Motor Transport Workers Act 1961 and the Beedi and Cigar Workers (Conditions of Employment) Act 1966 too defines a 'child' as anyone who has not completed 14 years of age. The Plantation Labour Act, 1951 has separate definitions for 'child' (a person who has not completed his 14th year), 'adolescent' (a person who has completed his 14th year but has not completed his 18th year) and 'adult' (a person who is 18 years old and above).

The Juvenile Justice (Care and Protection of Children) Act 2015 and Protection of Children from Sexual Offences Act 2012 consider a 'child' to be anyone below the age of 18 years. The age of criminal responsibility in India is seven and can be raised to twelve if they are not mature enough to understand the consequence of their actions. Also, children within the age group of 16-18 years can be tried as adults for heinous offences, which are punishable with imprisonment of seven years or more (Bhatt and Sanyal, 2023).

The Immoral Trafficking (Prevention) Act 1965 defines a 'child' (a person who has not completed the age of 16 years) and 'minor' (a person who has completed the age of 16 years but has not completed the age of 18 years) separately. In contrast, The Prohibition of Child Marriage Act, 2006 defines a 'child' as a person who, if a male, has not completed 21 years of age and if a female, has not completed 18 years of age. Muslim Personal Laws in India allow individuals who have attained puberty to be married. The right to vote is granted when an individual turns 18 years old. These varying interpretations of children demonstrate that childhood is not a uniform concept. It can evolve depending on circumstances and the individual maturity and understanding of the child.

In addition to age-based definitions mentioned above, constructions of childhood also differ based on, local customs and beliefs, gender and caste which vary across different communities in India and play a significant role in shaping understandings of childhood. Boyhood and girlhood are different experiences in India. For instance, in certain communities, the onset of menstruation marks the transition from childhood to adulthood for girls (Bhatt and Sanyal, 2023).

Simultaneously, caste and community differences play a significant role in the experience of childhoods (Sreenivas, 2010). As mentioned in the previous chapter, children from underprivileged communities are at a disadvantage when compared to privileged communities. A stark example of disparities between the communities is that children from the privileged castes, given their historically better access to resources, are taller than children from underprivileged castes among whom prevalence of child malnutrition and resultant stunting is higher. Additionally, children from underprivileged castes also face widespread discrimination in public health care services which affects diagnosis and dispensation of medications (Deshpande and Ramachandran, 2020). Therefore, the social location of the child, the context of the family and other social diversities of caste and community are key constructs in determining child welfare and development in non-western societies like India (Saraswathi, Menon and Madan, 2017).

Education

In the past, education was a prerogative of only men from the upper castes while the people belonging to lower castes and women were not given the right to education (Chakramakkil, 2017). Today the Indian Constitution and various educational policies of the government grant education as a right to every citizen. The Indian state endeavours to provide free and compulsory education to all children up to the age of 14 years regardless of gender, caste, religion, and social status. School education policies and programs are framed by the central government and state governments have autonomy in implementing those policies (Goel and Husain, 2018).

School education in India consists of 12 years of education (sometimes also referred to as the 10+2 system). Wherein, starting at the age of 5 years a child is enrolled in 1st class. These 12 years are divided into -primary (1st-5th class), middle (6th-8th class), secondary (9th and 10th class) and higher secondary levels (11th and 12th class).

The higher secondary levels offer stream-based education namely- science, commerce, and humanities (Goel and Husain, 2018). 10th class (equivalent to GCSE's in the UK) and 12th class (equivalent to A Levels in the UK) are crucial stages of school education in India (Srivastava and Agnihotri, 2022).

Schools in India are broadly classified into public (funded by the central, state or local government) and private (though some may receive regular grants from the government, local body or public authority). Public schools in India are plagued by poor infrastructure low teacher-pupil ratios, teacher absenteeism, inadequate teaching materials and facilities, burden of non-academic tasks on teachers, lack of adequate training to deal with children from varied backgrounds, and unfilled vacancies (Gouda *et al.*, 2013; Goel and Husain, 2018). This has given rise to a rapidly growing private sector, especially in the urban areas (Kingdon, 2007). However, the state is still said to have the biggest outlay in the education sector in India as schooling costs in public schools is less compared to private school. The schooling costs in privately run schools can be hundred times higher than public schools (Gouda *et al.*, 2013).

There is also a wide disparity in the quality of education delivered to Indian citizens in public and private schools (Gouda *et al.*, 2013; Goel and Husain, 2018). Public schools, which are dominated by children from the disadvantaged sections of society, do not deliver quality education to children (Gouda *et al.*, 2013; Subramanian, 2020). Public schools run by municipal bodies (local government administrations) are reported to be at the lowest rungs of state schooling system hierarchy (Subramanian, 2020). However, it is not to be concluded that all students attending private schools belong to affluent backgrounds. Due to poor quality education in public schools, parents from poor households opt for private school education for their children, especially boys, which puts immense pressures on their finances. Inequalities have also been observed in the performance and learning outcomes of students, wherein private school students outperform public school students (Kingdon, 2007; Gouda *et al.*, 2013; Malvankar, 2018).

Even though elementary education (class 1-8th, approximately 6-14 years of age) is recognised as a human right, research has consistently highlighted the existence of a learning gap (Kumar *et al.*, 2022). Despite a high proportion of student enrolment and completion rates at the primary level, there is a sharp drop-out rate among children

after the primary levels and school completion rates have been found to be low (Goel and Husain, 2018). Targeted policies have led to improvements in girl child education in India and gender disparity in completing school has decreased over the years in both rural and urban areas. In urban areas girls have been found to do as well as boys or even better (Goel and Husain, 2018). At the same time school dropout rates remain higher amongst girls than boys (Kumar *et al.*, 2023). This is even more pertinent for children born in socially disadvantaged families such as SC, ST and Muslims (Kumar *et al.*, 2022). Out of 100 children joining class 1 from the SC community, only four reach class 12 (Shah *et al.*, 2006).

The reasons for dropping out of school can be attributed to inability to relate education with daily realities, lack of empathy between teachers and students, need to support family and attractions of labour markets. For girls, issues like, parental attitudes (preferential attitudes towards male children), social norms (educated girls may find it difficult to find a suitably educated groom further increasing the cost of marriage), physical safety, menstruation and access to toilets, and limited number of female teachers can also act as additional obstacles to school completion. It has been reported that if household expenditure on education rises above the set limit, it is generally girls who are first withdrawn from schools (Goel and Husain, 2018).

There is considerable evidence that underprivileged castes (SC, ST and OBC) lag behind others in access to education and educational attainment. Muslims, who are outside the purview of reservation, have been found to be behind SC, ST and OBCs (Goel and Husain, 2018). Social disadvantage can perpetuate illiteracy and poverty among children (M.D. and S.K., 2019).

Enactment of state policies and programs like Right to (Free and Compulsory) Education Act, 2009, the *Sarva Shiksha Abhiyan* (Education for All Campaign), and the Mid-Day Meals Schemes (to provide nutritious and cooked food to children), *Beti Bachao Beti Padhao* Campaign (save the daughter, educate the daughter) have demonstrated encouraging progress in school enrolments in recent times (Goel and Husain, 2018). The Right to Education Act, 2009 guarantees free and compulsory education in India up to age 14, originally prohibiting detention or expulsion until completion of elementary education (classes 1-8). A 2019 amendment allows state governments to hold examinations in classes 5 and 8, and if a student fails twice, they

may be held back, but emphasises on re-examination and not expulsion from school until elementary education is complete (Rai and Majumder, 2019; Sarin, 2020). However, the country has a long path to tread before it can ensure comprehensive education for all its citizens, as reflected in India's literacy rate of 74.04%, with men (82.14%) faring significantly better than women (65.46%) (Kumar *et al.*, 2022).

Social Welfare and Social Work with Children in India

The Constitution of India ensures fundamental rights for all children, directing the state to safeguard them, protect them from abuse, and provide opportunities for their physical, social, and mental development (Khurania, Singal and Singh, 2023). Child welfare and the responsibility for implementation of various programs lies with the state governments in India (Khurania, Singal and Singh, 2023).

Children in India who come in contact with the state machinery are broadly divided into three – (1) children in conflict with law, (2) children in contact with law as victims or witnesses or any other circumstances and (3) children in need of care and protection (Rotabi *et al.*, 2019). In this thesis, we will concentrate on children in need of care and protection.

A "child in need of care and protection", as defined by the Juvenile Justice Act (JJ Act), 2015, means an individual under the age of eighteen in any of following circumstances:

- 'Found without any home or settled place of abode and without any ostensible means of subsistence or are found working in contravention of the labour laws in force, begging, or living on the street.
- Residing with a person who may or may not be their guardian, and who has injured, exploited, abused or neglected the child; violated any law meant for protection of children; threatened to kill, injure, exploit, or abuse the child; or killed, abused, or neglected another child, and where there is a likelihood that the child in question could face a similar fate.
- Is mentally ill or mentally or physically challenged or suffering from terminal or incurable diseases, having no one to support or look after or having parents or guardians unfit to take care.
- Have a parent or guardian who is found to be unfit or incapacitated to care for and protect the safety and well-being of the child.

- Do not have parents and no one is willing to take care of or whose parents have abandoned or surrendered them.
- Is missing or run-away child, or whose parents cannot be found.
- Has been or are being or are likely to be abused, tortured or exploited for the purpose of sexual abuse or illegal acts.
- Found vulnerable and are likely to be inducted into drug abuse or trafficking.
- Is being or are likely to be abused for unconscionable gains.
- Is a victim of or affected by any armed conflict, civil unrest or natural calamity.
- Is at imminent risk of marriage before attaining the age of marriage and whose parents, family members, guardian and any other persons are likely to be responsible for solemnisation of such marriage.'

The statutory body dealing with cases of 'children in need of care and protection' is the Child Welfare Committee (CWC), a regional level body which functions as a Bench of Magistrates and enforces regulations under the JJ Act, (2015).

A key programme implemented for children in India is the Mission Vatsalya, formally known as Integrated Child Protection Scheme (ICPS) by the Indian government's Ministry of Women and Child Development (MWCD). It is a centrally sponsored scheme which is implemented through state and union territory governments. Its motto is "Leave no child behind" and vision is to guarantee a happy and healthy childhood for every child in India, provide opportunities for them to realize their full potential, and support their growth in all aspects of life, in a sustained manner. It promotes non-institutional family-based care and aims to use institutionalisation as a measure of last resort (MWCD, 2022 a).

Amongst its various provisions, the Mission Vatsalya has a provision for sponsorship. It can be defined as the 'provision of supplementary support, financial or otherwise, to the families to meet the medical, educational and developmental needs of the child.' It is conditional and can be extended to both biological or extended families of vulnerable children in need of care and protection to ensure that the children get the opportunity to stay and grow within their social and cultural milieu in the community, without displacement. This could be government or private sponsorship (MWCD, 2022 a).

Another key programme supporting children below the age of 6 years is the Integrated Child Development Scheme (ICDS) or now called the '*Saksham Anganwadi and Poshan 2.0*' Programme. It is aimed at promoting early childhood care and development and reducing maternal and infant mortality rates. It also provides free supplementary nutrition, immunisation, health check-ups and education in *Anganwadis* (pre-schools) (MWCD, 2022 b). There is a vast network of *Anganwadis* and *Anganwadi* workers (who are mostly women) in India (Bhatt and Sanyal, 2023).

Another alternative care and support program implemented by the department of Women and Child Development (WCD), Government of Maharashtra (one of the 28 states in India), is the *Bal Sangopan Yojana* (WCD, 2013), which also warrants attention in this context. This scheme was designed to promote family-based care and prevent the institutionalisation of children. It provides support to low-income families experiencing crises that hinder their ability to care for their children. Such crises may include the death or desertion of one or both parents, accidents, severe disabilities, chronic or stigmatised illnesses, the incarceration of a parent, etc (WCD, 2013). Under the scheme, financial assistance is provided to these families. If, despite this support, the family remains unable to care for the child, alternative care options such as foster care are arranged. The program also offers counselling services for affected children. However, it is important to note that this scheme is currently limited to the state of Maharashtra only (Ghate, 2022).

According to Berrick, Gilbert and Skivenes, (2023), child welfare systems in India are in nascent stages of development. This means that the systemic structures have the policies and legislations to support the objectives of the UNCRC but do not have the financial or organisational resources to implement these programs effectively or are in the early stages of implementations. It is here that the non-governmental organisations (NGOs) or civil society organisations step in to support the government structures. The ICPS also highlights the role of civil society organisations (Bhatt and Sanyal, 2023).

NGOs in India play a crucial role in both advocacy and in program delivery (Majumdar and Sarkar, 2025). Based on their mandate, NGOs take on projects to address various issues ranging from child rights to poverty alleviation to health and nutrition (Sharma, 2023) and collaborate with the government in effective application of state/central programs (SAKSHI, 2025). A key example of public-private collaboration in supporting

vulnerable children is Childline 1098, a national 24/7 toll free helpline for children in distress. Childline, managed by Childline India Foundation in collaboration with local NGOs, responds to emergency calls from children (or calls from adults about vulnerable children) and connects them relevant services like - shelter homes, counselling services, legal aid, etc (Majumdar and Sarkar, 2025). In both New Delhi and Mumbai there are numerous NGOs which support the government with identifying and supporting vulnerable children.

Unlike countries like the United Kingdom, social work profession in India, is not formalised and regulated. Although there are numerous universities training cadres of professional social workers, “like social work in general, anyone in India can work in the field of interventions with children and many of them do a very good job” (Desai, 2022:14). This is essential, given the significant gap between the number of trained social workers and the vast population of children requiring care (Nigudkar, 2022). There is also a “lack of indigenously produced academic material” (Mehendale, 2022:255).

Being a signatory to the UNCRC, child centred social work is a specialised stream of social work in India, based on the child-rights framework, keeping children’s best interests at the centre of intervention (Desai *et al.*, 2022). Social workers working with vulnerable children work within the framework of the JJ Act and under the guidance of the CWC. Under this framework, social workers undertake a wide range of functions including identifying children in need of care and protection, preparing social investigation reports and individual care plans, conducting counselling, performing outreach work at community level, linking children and families to available services or any other function assigned by the CWC (Rotabi *et al.*, 2019). However, this is an essential yet less visible area of work, as issues concerning children are often overlooked within the broader development sector (Nigudkar, 2022). Child rights are often considered a western concept in the mainstream discourses (Mehendale, 2022).

At the time of the study, no formal social work interventions were being implemented for children with caregiving responsibilities in India. Any support they received was episodic in nature, as there were no policies or programs specifically designed to address their needs.

Chapter Summary

This chapter provided an overview of the diverse forms of childhood experienced in India, highlighting how definitions of childhood and children's lived experiences are deeply shaped by their socio-economic backgrounds. It also demonstrated that, while there have been investments and welfare initiatives targeting children by the state, NGOs, and academic institutions, there has been a notable absence of attention toward young carers specifically, due to which they fall through the gaps of the child safeguarding systems in India.

Based on the definition of 'children in need of care and protection,' children whose parent or guardian is deemed unfit or unable to ensure their safety and well-being, may assume the role of young carers for their guardians. This makes them eligible for inclusion in the Mission Vatsalya scheme of the Indian government. Additionally, the extension of the *Bal Sangopan Yojna* to other parts of India can also be beneficial to young carers. This means that as a first step, existing policies and provisions can be leveraged to support young carers in India and we do not have to start from scratch. The need is for an increased awareness among the government and civil society regarding their existence.

Section 2

Theory and Methodology

Chapter 4: Theoretical Framework

Introduction

In the previous section, this thesis looked at the social location within which the study is situated and the level of awareness about children with caring responsibilities globally and within India. The work so far has set the context for the reader to understand the extent of research in the area and the gaps which this research intends to fill.

Before addressing the methodologies used to conduct this research, this chapter introduces the theoretical concepts that have guided both the research approach and the understanding of this study. This establishes a framework within which the social phenomenon being studied was understood and the research findings interpreted (Bryman, 2016).

This chapter explores how children experience epistemic injustices and are often denied recognition as competent social actors, primarily due to adultism and the unequal power dynamics between adults and children in society. It also highlights children's competencies in the form of labour they provide towards the maintenance of their family system, particularly within the domestic sphere.

Epistemic Injustice, Adultism and Children as Competent Social Actors

When I was in the initial stages of idea generation for this project and presented the research idea to an esteemed academic in India, they were unsure about the merit of research with “hormonal teenagers.” This comment is indicative of the conventional and internalised ideas around children's capacities as ‘knowers,’ making them epistemically untrustworthy and subjecting them to epistemic injustice.

Epistemic injustice is a kind of injustice in which someone is wronged “specifically in their capacity as a knower” (Fricker, 2007:1). Fricker in their 2007 book, talk about two forms of epistemic injustice- testimonial and hermeneutical. Testimonial Injustice is defined as “prejudice which causes the hearer to give a deflated level of credibility to

the speaker's words" (Fricker, 2007:1). Fricker gives the example of a black person not being believed by the police due to their racial identity.

Hermeneutical injustice on the other hand can be defined as injustice of having some significant area of one's social experience obscured from collective understanding owing to a structural identity prejudice in collective hermeneutical resource, i.e. collective understanding of a situation/experience (Fricker, 2007: 155). In this form of injustice, individuals cannot fully comprehend or communicate their experiences to others. Fricker illustrates that this can occur when a person suffers from sexual harassment within a culture which lacks the conceptual or linguistic frameworks necessary to articulate or comprehend that experience (Fricker, 2007). This section will elaborate on how children are subjected to epistemic injustices and not considered competent social actors due to adultism or unequal power relations between adults and children in society (Liebel and Philip, 2024).

Hanna (2022) identifies prejudicial stereotyping of children as 'lacking discipline,' 'immature' or 'having nothing to say' by adults which portrays children as lacking in capacity and therefore justifying absence of spaces for children to express their views and opinions. The author highlights that this constitutes hermeneutical injustice towards children which excludes them from participation in decision making and thus enables a systemic silencing of children's epistemologies. Children's powerlessness, owing to their social position, means that they are unfavoured and sidelined by social institutions and practices which influence and generate collective forms of social understandings or collective hermeneutical resources (Hanna, 2022).

Along similar lines, the anecdote at the beginning of this section is an example of testimonial injustice against children due to assumptions about their 'hormonal' nature, which tends to view children as unreliable social agents. It is worth mentioning here that until relatively recently, women's words and knowledge were, and in some parts of the world still are, treated as unreliable when compared to men. This parallel raises the critical question of whether all adults are credible sources of knowledge and if not, what are the reasons for the prevalent biases against children, even when they speak about their own lives and experiences.

Burr & Dick (2017) are of the opinion that what we value as 'knowledge', its creation and reproduction is intimately tied to power relations. That is, general acceptance of

realities and perspectives is dependent on the power wielded by the social actors to whom those perspectives belong (Burr, Dick and Gough, 2017). Therefore, the above mentioned delegitimisation of children as sources of knowledge can be attributed to unequal power relations between adults and children, which allows adults to have greater authority and knowledge credibility than children. This phenomenon is called *adultism* (Herring, 2023; Liebel and Philip, 2024).

Adultism dictates that the ‘rational’ and ‘mature’ adults occupy influential positions in society and can set the tone, standards and norms which ‘irrational’ and ‘immature’ children are expected to conform to, consequently promoting an adult-centric view of the world. Adultism ensures that children are disregarded as reliable social agents from mainstream discourses therefore, occupying a position of disadvantage when compared to adults (Herring, 2023). Children, in such an adultified world, are defined as adult aspirants or deficient adults (Herring, 2023; Liebel and Philip, 2024). Because of this secondary status ascribed to children, most of their lives are controlled and dominated by adults (Punch, 2002).

Rosen and Newberry (2018) believe that reliance of human infants on others for basic survival is over-extended to all children resulting in them being viewed as in constant need of support, care and practical assistance from adults (Rosen and Newberry, 2018; Herring, 2023). As rightly noted by Boszormenyi-Nagy and Spark (1973:105), “It is part of our myths that parenthood is a one-way street for giving, and childhood for unilateral dependence.” As established in Chapter 1, this statement is indeed a myth and not only do children provide high amounts of care for adults, adults also can be dependent on children. Herring (2023) adds that humans are social and interdependent beings and there are very few adults that lead truly independent and self-sufficient lives, and most adults need support from others. Thereby, challenging the adult superiority over children.

However, adultism dictates that current shared knowledge in society, has a gap when it comes to children’s distinctive social experiences as they are excluded from the processes that generate social meanings. Children’s experiences are not intelligible to adults and therefore, not included in the social realm. Such a lacuna in extant collective hermeneutical resources subjects’ children to epistemic injustices (Fricker, 2007) and ‘competence bias’ (Hinton, 2008). This deflation of their capacities and

competencies not only leads to non-comprehension of their situation by adults but also prevents them from having the required vocabulary to understand their own social experiences. Thus, depriving them of self-understanding and the ability to communicate their experiences to others. As a result, they are wronged in their capacity as a subject of social understanding (Fricker, 2007).

For example, when there is no collective understanding of the concept of a young carer, no common vocabulary to describe one's experiences or public awareness about the meaning and impacts, it becomes difficult for young carers to make sense of their own experiences and consequently communicate it to another. As a result, significant areas of their experience are obscured from mainstream, and they are overlooked as social subjects.

Yates and colleagues (2024) found that children and young people who have parents experiencing mental health challenges often face invalidation and dismissal of their lived experiences. Their marginalisation stems from both being children and from having parents with mental health issues. Additionally, the intersection of multiple stigmatised identities, including their own mental health status, sexual marginalisation, disability, and social class also diminish their capacity as reliable epistemic agents. The extreme consequences of children's epistemic exclusion in the adult-governed health care sector have been highlighted by Carel and Györfy (2014), who demonstrate that health care professionals overlook cases of child abuse because of their tendency to deflate children's credibility and favour the more articulate adult who may also be the abuser.

As illustrated, the ramifications of epistemic injustice can be far-reaching for children. It may include loss of epistemic confidence (Fricker, 2007; Hanna, 2022) which may trigger self-doubt and internalisation of negative self-beliefs (Yates et al., 2024) especially when their credibility is questioned by seemingly 'knowledgeable' and 'mature' adults, which can leave them deeply troubled, confused, isolated and unsupported.

In their book 'Child-Centred Social Work in India: Journeys and the Way Forward' Desai *et al.*, (2022) observe the impact of adultism on child-centred social work in India. They argue that dominant perceptions of children as innocent, incapable, and lacking knowledge have contributed to their subordinate status in society and have legitimised

adult authority and control. This social construction of childhood, particularly the intense binary distinction between ‘normal’ and ‘deviant’ childhoods, results in the systematic exclusion of children from decisions that affect them, with adults often acting on their behalf. Such practices foster domestication, dependency, and isolation among children. When adultism intersects with other forms of structural oppression such as sexism, ableism, racism, and casteism it exacerbates children’s vulnerability and social marginalisation. The authors advocate for recognising children’s rights to self-determination and meaningful participation, particularly in matters that directly impact their lives. They emphasise that policy-making processes, including framing of questions, the language used, and the explanations and justifications provided, should be made accessible and understandable to children (Desai *et al.*, 2022).

Along similar lines, Hanna (2022) proposes a new theory of participation of children, grounded in the UNCRC and focuses on achieving epistemic justice. She argues that the focus should shift away from questioning children’s capacities and instead address the prejudices and stereotypes adults hold against them. Hanna emphasises that participation is a fundamental entitlement of children and that they must be genuinely heard. Her theory calls for strengthening children’s participation rights by recognising young people as active participants in debates and facilitating the development of their capability and inclination to engage in decision-making processes affecting them.

This section challenges the assumption of adult epistemic superiority over children and emphasises that, children possess distinct competencies which, although different from adults, warrant credibility. It also highlights how adultism contributes to epistemic injustice experienced by children. Child carers who participated in this study were subjected to both forms of epistemic injustice as children who were subjected to testimonial injustice owing to their social identity as children in an adult-centric society. They were not used to being asked for opinions or their feelings on issues. They were also subjected to hermeneutical injustice as children with caring responsibilities in a society where their existence was unknown. As is elucidated in the following chapters, these children suffered from the lack of collective hermeneutical resources to describe their situation. The unintelligibility of their situation to people around them made them operate in a space of social invisibility. This social invisibility resulted in

requiring 12 months to recruit 21 children to this research project in two highly populated cities.

Children's Labour and Social Reproduction Theory

Childhood is often portrayed and defined by spontaneity, play, vulnerability, and a clear separation from adult worries and responsibilities (Sreenivas, 2010). Working children are considered to be an anomaly, with representations frequently emphasising that they have been deprived of the typical joys and experiences of childhood (Vasanta, 2004). However, it is to be noted that 'childhood' is not a monolith. It is a category that varies socially, culturally (from place to place) and historically (over time) and expresses changing expectations and activities (Markowska-Manista, 2018). McCarthy (2023:4) suggests that conversations on childhoods around the world have only been able to "partially capture the complexities of childhoods as lived by children."

Liebel & Philip (2024) are of the opinion that the typical definitions of childhood and adulthood as we know them are constructions of western bourgeoisie capitalist structures. Capitalistic adult centric societies ensure the exclusion, marginalisation, domination and disempowerment of children (Punch, 2002; Liebel and Philip, 2024). It aims at keeping children and young people out of the workforce until they become 'economically exploitable human capital' (Liebel and Philip, 2024). Thereby, making schools, little more than glorified day-care centres where children are kept safe while their adult parents engage in production of capital. Such specialised spaces for children leave them with limited access and exposure of the world around them (Norozi and Moen, 2016). Capitalistic structures, therefore, warrant that children's worth is measured only in terms of future prosperity, rather than their present contributions (Liebel and Philip, 2024).

Capitalist understandings of 'labour' which are often aligned with money or wealth generation ensure that only paid work garners recognition as 'work' or 'labour.' Unpaid work or domestic work undertaken within the confines of a household, is not considered valuable labour. This understanding of 'labour' has been extensively criticised in literature, through theories like social reproduction theory. Social reproduction theory, emphasises that capitalism heavily relies on domestic labour within the household for the creation and maintenance of the 'labourer' (Graham, 1991, 1993; Rosen, 2023a). The theory underlines that the activities which facilitate

money making are also work, even if they are unpaid, because it is this labour that ensures that the 'worker' is fed, clothed and cared for, thus producing a functional workforce (Federici, 2019; Backer and Cairns, 2021).

Adultism or prejudice against children's sensibilities and capacities is also reflected in their exclusion from theories critiquing capitalistic structures. Social reproduction theory mostly highlights the contributions of adult women, therefore rendering the contributions of children under recognised and undervalued (Rosen and Newberry, 2018; Rosen, 2023a). Rosen in their 2023 work titled 'Childhood in and through Social Reproduction Theory' elaborates on the relationships between social reproduction theory and childhood studies and questions the erasure of the child figure from reproductive labour debates. Rosen's work foregrounds children as active human agents in activities necessary for the repair and maintenance of self and others rather than mere consumers of labour and resources until they become 'future agents of production' (Rosen, 2023a:423).

Although UNICEF (2007) considers household chores to be child labour if they exceed four or more hours per day and 28 hours per week, significant empirical attention is still concentrated on children's contributions outside the home when they undertake market oriented or paid tasks (Liebel, Overwien and Recknagel, 2001; Putnick and Bornstein, 2016). However, studies (Edmonds, 2007; Lin and Adserà, 2013) have highlighted that majority of children's labour engagement often takes the form of domestic chores that are not intended for market exchange and that children's activities extend beyond learning, recreation, and socialising with peers especially in majority world countries. Reproductive labour tasks undertaken by children including childcare, cleaning, cooking, laundry, shopping, fetching water, collecting and preparing heating and cooking fuel, tending to the kitchen gardens, managing household animals and home maintenance, are often underrecognised because of their unpaid nature (Putnick and Bornstein, 2016; Rosen, 2023a).

In many communities around the world, children begin to take on responsibility for tending to other children as early as the age of 5-7 years and in some other places when they are even younger (Rogoff, 2003). Among Appalachian communities in the United States, it is common for Appalachian youth to leave junior high or high school when hard times arise for family members or neighbours (Timm and Borman, 1997, cited in

Rogoff, 2023). In rural Malawi, children replace adults who are busy in credit-stimulated household enterprises, in shouldering of domestic chores (Hazarika and Sarangi, 2008). In many African countries participation in family maintenance tasks is considered appropriate for children aged ten and above as long as their schooling and psychosocial wellbeing is not compromised (Ndungu, Bergen and Mineo, 2025). Alternatively, in many majority world countries, a significant number of children are neither attending school nor participating in paid employment, as they are involved in unpaid work within the household, on family farms and livestock, or in family-run businesses (Webbink, Smits and de Jong, 2012; Chauhan and Pramanik, 2021). Among the Gond tribal groups of India, children's contribution to the household economy is a significant aspect of their lives. They contribute towards agriculture, collection of forest produce, and household activities (Chauhan and Pramanik, 2021).

In many parts of the world women's paid employment entails such long hours that little time is left for domestic work. Therefore, children stay at home to look after the younger siblings and the elderly in families while the mother is out working (Nieuwenhuys, 2020). In large poor families, women are not the only caretakers, they share this role with the older children of the family and particularly, but not only, their teenage daughters. The latter often becomes the main worker when mothers are either ill, deceased, or working far away from home (Nieuwenhuys, 2020; Pande, 2022).

Research with unaccompanied minors suggests that they care for others during migration journeys. They cooked and ensured that those newly arrived have a welcoming meal, while also providing advice to newly arrived children navigating restrictive migration regimes. Sometimes, they translate for other young people to enable them to engage with social workers, teachers, and medical staff (Rosen, 2023b). In families who are denied mainstream welfare benefits in the UK due to their immigration status, mothers have to take on under-the table work or flexible shift work. In such families, children often engage in significant reproductive labour for their families (Rosen, 2023a).

Literature from the Indian context also suggests similar observations. Lin and Adserà's (2013) analysis of data from India's National Family Health Survey-3 (NFHS-3, 2005–06) reveals that majority of children (59.5%) in the age group of 6-14 years were involved in household chores, which was more than their participation in market work. The

NFHS-3 data, also observed that that around 3% of children performed household chores for 28 or more hours per week, as reported by their mothers. Unsurprisingly, girls were more likely than boys to engage in these household tasks (IIPS, 2007). This trend is consistent with previous research and reflects a global pattern (Edmonds, 2007; Webbink, Smits and de Jong, 2012).

Gibby (2022) found that adolescent girls in southern states in India spent an average of four times more time in housework in a day (114 minutes) as compared to their male counterparts (30 minutes). They also found that fathers spent an even lower amount of time (24 minutes) on housework, while the mothers spend more than double the time spent by their daughters (275 minutes). This underscores the significant role that children, particularly adolescent girls, play in sustaining household labour and the social reproduction of labour, often exceeding the contributions of many adults. Gibby (2022) also found that adolescent girls who were in paid employment spent more time on housework than their unemployed counterparts. Therefore, this research study calls for the need to look beyond adulthood when studying labour and gender divides in labour.

These examples, clearly suggest that reproductive roles of children and their informal labour are above and beyond capital generation. Chapter one also illustrated how children who are young carers undertake more than seemingly banal everyday tasks. These young carers undertake intense care tasks and domestic responsibilities for family members, thus, questioning the bourgeois definitions of childhoods, in which children are dependents of adults. Therefore, this section illustrates that children are not just helpless victims of their circumstances. Their contributions to their families and society are valuable and therefore deserve more recognition.

In academic literature, children who take on such roles which do not conform to the mainstream definitions of 'childhoods' are often described as 'parentified children' (Masiran *et al.*, 2023) or as experiencing 'childhood adultification' (Burton, 2007). While both concepts highlight the important point that children, albeit in crisis situations like poverty, domestic violence, homelessness, etc, are not merely passive recipients of care but also active contributors within their social and familial contexts, such labels also reflect a tendency to view children through an adult lens. These frameworks also reinforce the rigid boundaries drawn between childhood and

adulthood. Such dichotomies, as inferred from this section, risk pathologising certain experiences of childhood and adulthood that do not conform to normative definitions. The roles and responsibilities a person assumes, are often shaped by their social and economic context. Attempting to fit all experiences into predetermined categories of what a "child" or an "adult" should be, can be reductive and may cause more harm than good.

This is not to deny the very real vulnerabilities some children may face and the support they need, but to caution against frameworks that interpret their contributions solely through an adult lens. Instead of being 'parentified children' or children who experience 'childhood adultification,' this research views them as children who contribute meaningfully to the social reproduction of their families.

It is from a similar critique that the 'new' sociology of childhood emerged, which views children as integral contributors to society (Tisdall and Punch, 2012). Tisdall & Punch (2012) provide a detailed and critical overview of the developments in this field over the past few decades. Some of the basic tenants of 'new' childhood studies to which this research study adheres are - Children's social relationships and cultures are worthy of study in their own right; and children are and must be seen as active in the construction and determination of their own social lives, the lives of those around them, and of the societies in which they live (Tisdall and Punch, 2012).

Thus, this section emphasises the importance of recognising and respecting the diversity of childhood experiences without forcing them into rigid moulds. Rather, it is essential to have a just and context-sensitive understandings of childhood. Pathologising children who do not conform to capitalist definitions of childhood, risks reinforcing narrow mainstream narratives and neglects the agency and realities of children's lived experiences. This section also highlights the invisibility of the child figure from reproductive labour debates and calls for the recognition of children's contributions towards the reproductive labour of their families because children's self-worth is critically constituted through the roles they play in the survival and well-being of their families (Vasanta, 2004).

Chapter Summary

This chapter introduces the reader to critical theoretical standpoints used to approach the research problem like, epistemic injustice and its two forms- testimonial and hermeneutical, adultism and social reproduction theory. An engagement with these theoretical perspectives informed the analytical approach to this research study.

Firstly, it explores children's experiences of exclusion and inequality within an adult-centric society. It argues that children are different but not inferior to adults. It challenges capitalist definitions of childhood which marginalise children's experiences and overlook their competencies. It illustrates how children are subjected to testimonial and hermeneutical injustices in adult-centric societies and emphasises the importance of their active and meaningful participation in matters concerning their own well-being.

Secondly, the chapter illustrates children's significant contributions, particularly towards their family systems which are often greater than some adults. These could be in the form of paid or unpaid labour. While there is enough discussion on children's labour contributions outside the house, when it is paid, their unpaid contribution within the household often go unnoticed. Adultism operates by rendering children's contributions either invisible or pathologised as deviant, thereby disregarding the legitimacy of diverse childhoods. This same adult centric logic also underpins their systematic exclusion from discourses on the social reproduction of labour, further marginalising their roles within both the household and broader societal structures. Therefore, calling for their inclusion in reproductive labour discourses.

The chapter also argues that the hierarchical nature of the child-adult relationship is largely rooted in prejudice, contributing to the systematic marginalisation of children and the invisibility of their contributions within mainstream social, cultural, and academic discourses. It also highlights the importance of the recognition of children as competent social actors capable of epistemic credibility, especially in matters related to their own wellbeing. In the absence of such recognition, the lived experiences of many children, like young carers in India, risk being systematically devalued and excluded from mainstream discourses. This also explains young carers persistent invisibility from conventional narratives in India. It is with this understanding

that this research will view young carers as competent social actors and interpret their accounts through the lens of social reproduction theory.

Chapter 5: Methodology

Introduction

This chapter introduces the reader to the methodology undertaken to conduct this research. This chapter starts by elaborating on the strategy I used to conduct the literature review, before introducing the reader to the philosophical lens and my positionality as a researcher shaped by varied identities. I then present the rationale and the research questions guiding the study. Following this, I discuss the sequential exploratory mixed methods approach utilised in this research, combining qualitative data collection through semi-structured interviews with quantitative data collection via surveys to study the presence of children with caring responsibilities in the Indian context. In this chapter, I also discuss the methodological decisions and ethical considerations of this mixed methods research project with children and young people in India.

Literature Review Strategy

To identify studies relevant to this thesis, a broad range of academic databases were consulted, including Google Scholar, PubMed, Ethos, Shodhganga, and Scopus. Additionally search engines like Google and Duck Duck Go were also utilised. The search terms included: "young carer," "young carer" AND "India" OR "New Delhi" OR "Mumbai," "low-income countries", "global south", "caregiving children," "children caring for parents," "parental caregivers," "sibling caregivers," "love labour" AND "children," "children's housework," "household labour" AND "children," "parentification", "minority young carers", "BAME young carers" among others. These keywords were used in various combinations to retrieve the most comprehensive information possible on the topic.

Young carer studies included in this thesis were from a broad geographical location, including, Europe, North America, Africa, Oceania and Asia. The review of literature in this thesis has included varying types of studies including - qualitative, quantitative, mixed methods, systematic/scoping reviews, charity reports, and PhD theses from early 1990s to 2025. The main participant groups in these studies were the young carers themselves.

Given the limited availability of literature on young carers in the Indian context, reviewing the reference lists for relevant articles, and using Google Scholar's citation tracking feature to identify subsequent works that had cited those articles were employed to reach more sources and enrich the literature base for this study.

Ontological and Epistemological Stance

As elaborated by Onwuegbuzie and Leech (2005), there are three main perspectives on the use of quantitative and qualitative research paradigms in a research study - purist, situationalist and pragmatist. Purists believe that quantitative and qualitative paradigms stem from different ontological, epistemological and axiological assumptions and therefore are incompatible and should not be mixed. Situationalist retain a stance that quantitative and qualitative methods represent different theoretical orientations. However, they accept that they are complementary and therefore can be utilised separately. Pragmatists on the other hand advocate for the promotion of methodological pluralism in social science research by integrating the qualitative and quantitative methods in a single study which enables a better understanding of a social phenomenon by utilising the strengths of both the methods. Pragmatist do not believe in epistemological purity (Onwuegbuzie and Leech, 2005).

The main research problem being studied in this research is - what is it like to be a young carer in the Indian cultural context. During the course of designing the study, it quickly became apparent that studying the research problem using a single method would produce an incomplete understanding of the issue. It was important to understand the experiences of children with caring responsibilities within the wider socio-cultural context of childhoods in India and the engagement of children in domestic tasks in general to contextualise the gravity of the burden placed on young carers. This required both the inquiry of deep personal accounts and collection of statistical data. Therefore, the philosophical framework used for this study is pragmatism, which enabled the research problem to be studied by combining qualitative and quantitative data i.e. using a mixed methods approach. A mixed methods design for this study ensured a better understanding of the research problem through integration of both data sets and drawing inferences and conclusions from both. More details about the mixed methods design of this study will be discussed later in the chapter.

A pragmatist theoretical orientation also enables the use of multiple philosophical approaches in social science inquiry to investigate a particular research problem (Kaushik and Walsh, 2019). Pragmatism holds that individuals are socially, historically and culturally constituted while accepting that realities can be single or multiple (Kaushik and Walsh, 2019). For example, care work may exist independently of our interpretation of that experience, however, the interpretation of it changes from the point of view of each social actor who is involved in it. Additionally, the ethnicity, gender, age, culture, social and economic backgrounds of the social actors may also influence the way they contextualise care-work. I subscribe to the notion of multiple realities, but this study is concerned with the young carers' interpretation of the reality of care work performed by them, which is situated within the context of a society in which they are marginalised.

Young carers as children in need of support were first studied in the United Kingdom (Joseph *et al.*, 2020) and at the time of this study are a group of vulnerable children who are elaborately researched and receive support provisions in the minority world countries like United Kingdom, the United States of America, Australia, New Zealand etc. However, they are under researched and unrecognised in India. Therefore, a study of such a vulnerable group of children needs to be contextually relevant. This is because imposition of ideas from one cultural context to another without proper adaptations may raise issues of bias and misinterpretations (Richthofen and Gümüşay, 2023). Therefore, I used a social constructionist lens to study young carers in the Indian context. Social constructionism enables researchers to take a pluralistic or relativist view of the phenomena being studied, and to understand behaviours and meanings grounded in the social context (Burr, Dick and Gough, 2017). Thereby minimising chances of imposition of ideas and enabling a better understanding of Indian children's constructions of being a child with caring responsibilities within their socio-political realities, while they described important events in their lives and the various roles they played.

Studying young carers in India, through a pragmatist lens enables me to view the research problem from the point of view of the young carers and the realities that they construct for themselves. Viewing children as social agents actively involved in the construction of their realities aids the visualisation of the research problem from children's perspective. Thereby preventing a solely adult-centric and paternalistic

approach. Accounts from children are important to sense-making and understanding the negotiations necessary to be young carers in India. Therefore, this research endeavours to glance into the world of young carers in India from their particular social location, and stems from the assumptions embedded in their perspectives of the work they do.

Positionality

Researchers are intrinsically affected by their own perspectives when collecting data and analysing it (Bryman, 2016). Therefore, before moving forward it is important for the reader to understand ‘the gaze’ with which I viewed the research problem and consequently presented it in this thesis.

I carried many of my identities into the field which influenced my experiences. This research study is an outcome of these complex identity interactions as they influenced and aided this research study in multiple ways.

I was a social work practitioner in India before I started my doctoral studies. The problem statement of the study was inspired by my professional social work experiences of working with vulnerable children and families in New Delhi and Mumbai, which led me to approach this thesis through the lens of my social worker identity. It stems from a desire to better understand the lives of children who contribute significantly to the household reproductive labour, more than many of their peers. Additionally, I also found my social worker and researcher identities to be constantly interacting synergistically especially during distressing times in the interviews with children, wherein I drew upon my social work training to support them. Details elaborating on these incidents have been discussed in chapter six. Furthermore, my social-work network was instrumental in facilitating access to the field, which may have been difficult for someone without such a network.

I consider myself a feminist with Marxist leanings. A feminist research framework provides a critical lens for examining and challenging mainstream structural dominations. As both childhoods and care have been historically situated in the domestic or feminine spheres, patriarchal structures governing society have rendered them trivial or subordinate. Using this orientation also aided in a deeper analysis of the

intersections of care and children, care work by children and the invisibility of children who perform care work, from the mainstream.

Feminist perspective also enabled the use of tools and approaches to empower marginalised and silenced groups, by positioning them as experts of their own lives and experiences and therefore not questioning or undermining their interpretation of their experiences. It also influenced the interview process by emphasising on the participants' right to ask questions or any kind of information from me during the interview. This was aimed at redressing some of the power issues which are a common occurrence in interviewee-interviewer relationships, due to its hierarchical nature. This was in contrast to standard survey interviews which are one-way and extractionist in nature (Bryman, 2016).

In line with social reproduction theory, I also acknowledge all forms of unpaid labour within the household as integral to the sustenance of the family as a key social unit. However, this theory considers women to be the primary contributors of this labour and neglects children's contributions. Therefore, this research also looked at the young carers' responsibilities or the tasks they undertook as unpaid 'labour' encouraging the reader to recognise their contributions to the social reproduction of the 'labourer' and in turn the functioning of the family unit.

I was a 28-year-old, Indian cisgender adult female researcher belonging to privileged caste and upper-middle class background conducting research with children aged 18 years and below in New Delhi and Mumbai. New Delhi was the city I was raised in and lived for 20 years of my life. Mumbai on the other hand was where I undertook my two year post graduate course and subsequent social work practice. My familiarity with the research sites, prior contacts and fluency in speaking, reading and writing the major languages spoken in these regions aided with data collection.

As mentioned above, children, housework and care work are 'feminine' areas. In such a scenario, my female identity may have had privileges in an otherwise patriarchal set-up. Furthermore, a male wanting to talk to children about such 'feminine' issues may have raised eyebrows in the Indian cultural context. My gender identity may also have put children at ease to talk about the intimate tasks they performed with me as opposed to an older male. Although there is a possibility that male young carers would have been more comfortable and forthcoming with a male researcher.

Social dissonance caused by my upper-middle class background, which might have been evident in my body language, appearance and use of language, was minimised using the strategy of dressing down as suggested by Myers and Newman (2007). I wore Indian attires and avoided western wear. I also used minimal jewellery and used no make-up while conducting fieldwork.

My positionality as a researcher from a foreign university introduced additional power dynamics that required careful consideration. This became particularly evident during a group session with young girls where the organisation requested, I share ‘how I reached a university in the UK’. My affiliation with a foreign institution granted me elevated status compared to researchers from Indian universities. This also illustrates how institutional affiliations can inadvertently reinforce power hierarchies in research settings.

Rationale and Research Questions

As seen from the previous section of this thesis, current knowledge on Indian children’s unpaid care work within families, beyond the context of HIV/AIDS, is limited. Implying that young carers in the Indian context are a group of vulnerable children hidden from the mainstream educators, health and social care professionals and policymakers. This creates a pressing need for in-depth investigation of the subject in India. Additionally, studies with young carers in India, focus on the impacts associated with the role and do not elaborate on the extent of their caregiving duties. There was a crucial gap in the understanding of what it means to be young carers in India. Therefore, this gap informed the first research question of this study which was:

What are the specific experiences of children who undertake caring roles in New Delhi and Mumbai? What are the challenges they face and how supportive are the social systems around them?

As discussed previously, the expectation of normality of involvement in caring and household tasks varies from region to region and so does the appropriateness of tasks undertaken by children. Therefore, to contextualise the responsibilities of young carers, it was essential to identify the daily tasks typically performed by children in India and considered normative within their context.

Evidence from studies on children's time use patterns suggests that there is a negative association between children's time spent in household-related work and national wealth of countries (Rees, 2017). Nieuwenhuys (2020) also suggest that children from majority world countries are extensively involved in reproductive labour or work within the household, as compared to their peers from the minority worlds. Putnick and Bornstein's (2016) study with 38 low- and middle-income countries (not including India) also found that girls were more likely than boys to engage in excessive unpaid housework like childcare, cleaning, cooking, laundry, shopping, fetching water and wood, and home maintenance. A detailed discussion on children's reproductive labour can be found in chapter four. India's status as low-to-middle income country means that children in India predictably spend more time in household chores than their minority world counterparts.

Studies from India have alluded to the gendered nature of participation in housework amongst children in India (Gibby, 2022; Vikram, Ganguly and Goli, 2024). However, they do not offer detailed information on the specific tasks involved within these categories. Therefore, the second research question of this research study is:

What are the daily household tasks performed by children in New Delhi and Mumbai, to support their family functioning?

Exploratory Sequential Mixed Methods Research Design

A research design is a plan that outlines the decisions regarding the identification/development of procedures to undertake the study (Kumar, 2019). "The main function of a research design is to explain how you will find answers to your research questions" (Kumar, 1999:16).

Data which provides answers to the research problem could either be from a single paradigm or both qualitative and quantitative paradigms. From the pragmatist perspective adopted in this research, a mixed methods research design was considered the most suitable approach to enhance the accuracy, depth and validity of the findings of a research study (Kumar, 2019). Accordingly, both qualitative and quantitative approaches were integrated to describe and explore the issue of young carers in India, and to provide a more comprehensive and contextually relevant response to the research problem.

Mixed-methods research have three core designs namely- Convergent Design, Explanatory Sequential Design and Exploratory Sequential Design. In a convergent design, the researcher collects qualitative and quantitative data and then compares the results to test if they confirm with each other or present contrasting findings. In an explanatory sequential design the researcher, collects quantitative data first and builds on this database with qualitative data to explain or expand the results. An exploratory sequential design on the other hand involves building an understanding of a phenomenon using a qualitative data and then developing quantitative measures or assessments that capture broader understandings (Creswell, 2022).

This study used an exploratory sequential mixed methods research design to understand the experiences of young carers in New Delhi and Mumbai. It used qualitative semi-structured interviews to answer the first research question and quantitative survey to answer the second research question.

As the aim of the first research question was to understand and explore the feelings and experiences (Kumar, 2019) of young carers, a qualitative research approach was deemed most appropriate to address it. Qualitative research also allows the participants to tell their story in their own words from their own cognitive positioning (Ritchie *et al.*, 2013). Thus, this research project started with a qualitative research design to build an understanding of young carers and their roles in the Indian context.

Qualitative research approaches come with a wide array of research methods- including interviews, group discussions, observations, analysis of textual and narrative sources (Carter and Henderson, 2005). As, the qualitative research design focused on describing the phenomenon of caring by children, interviews were considered to be the best method to understand this, especially as literature on the same is deficient and because interview is a powerful method of producing knowledge of the human situation (Brinkmann and Kvale, 2018).

Other methods like participatory research methods which are creative, flexible and are a powerful equalising tool (Bradbury-Jones, Isham and Taylor, 2018) were considered. However, I was mindful that this approach required children to be involved in multiple stages which would have been time intensive (Bradbury-Jones, Isham and Taylor, 2018), which young carers are generally short on as elaborated in chapter one. Therefore, for this study participatory approaches were deemed inappropriate.

Nonetheless, this could be a methodology utilised for future research with young carers in the country, with appropriate safeguards in place to support the care-recipient in their absence.

Narrative interview design, which invites participants to share their experiences via storytelling (Clandinin *et al.*, 2016) and narrate their lived experiences at their own pace with little interference as possible (Thunberg, 2022), was also considered. However, as mentioned previously, there was little awareness about the role of young carers in public and also amongst young carers themselves, which could have made reflecting on their role as ‘carers’ with minimal prompts very difficult. In such a scenario, narrative interviews ran the risk of diverging too far from the intended topic, taking a lot more time, and much data being excluded from the study due to it not meeting the objectives (Anderson and Kirkpatrick, 2016; Thunberg, 2022). Moreover, the objective of the qualitative study was to understand the tasks that a young carer undertook and the impacts these tasks had on them. Thus, the interviews were designed to be semi-structured in nature which provided flexibility to adapt the interview process according to each participant's comfort and interests, while still maintaining a degree of structure through the use of an interview schedule. This approach ensured that specific issues relevant to the research objectives were addressed (Bryman, 2016).

Further details on designing the interview schedule, conducting the interviews, the translation and transcription process, and the analysis are provided in chapter six.

To address the second research question, which aimed at determining the daily tasks performed by children within their households in general (irrespective of their carer roles), a quantitative research approach was selected. A quantitative research approach enabled to identify patterns and relationships across a broad population (Bryman, 2016).

The study wanted to collect comparable information from many participants which demonstrated the ‘naturally occurring’ variations in the sample, therefore a survey was selected as an appropriate tool to collect this data (de Vaus, 2013).

As there were no pre-existing tools to measure the attributes necessary to answer the research question in the Indian context, it was determined that a new context-specific

measure would be developed to measure children's engagement in daily tasks within their household and the impacts of these tasks. Aligning with the principles of exploratory sequential mixed methods research, this measure, was developed using data from the qualitative research study. Using the data from the qualitative study to build the survey questionnaire enabled the inclusion of variables attuned to the Indian population. This quantitative feature was instrumental in adding context to the qualitative data collected from children who were carers.

Other methodological aspects, such as the construction of survey questionnaire, piloting, implementation procedure and analysis strategies are discussed in detail in chapter ten.

Locations of the Study

The participants in this study were recruited from one union territory, which is also the national capital of the country, i.e., New Delhi. The second site involved in this study, Mumbai, is the economic capital city of India, which is situated in Maharashtra, one of the 28 states. Both cities serve as major economic hubs and, as a result, have high population densities with residents originating from across the country. Hindi is the popular language used by people living in New Delhi and both Marathi and Hindi are used in Mumbai. Figure 1 illustrates the geographic map of India with the red arrows depicting the locations of this study. Both the locations chosen for this study were urban settings.

These cities were chosen for the study as they are the most populated cities in India with a diverse range of demographics. These cities attract immigrants from all over the peninsula who come in search of better livelihoods, educational opportunities for their children and economic prosperity.

Both cities shared similar characteristics and were urban regions. The selection of the cities was also guided by pragmatic considerations of my access to the field, facilitated by pre-existing connections in these locations as mentioned in the previous section.

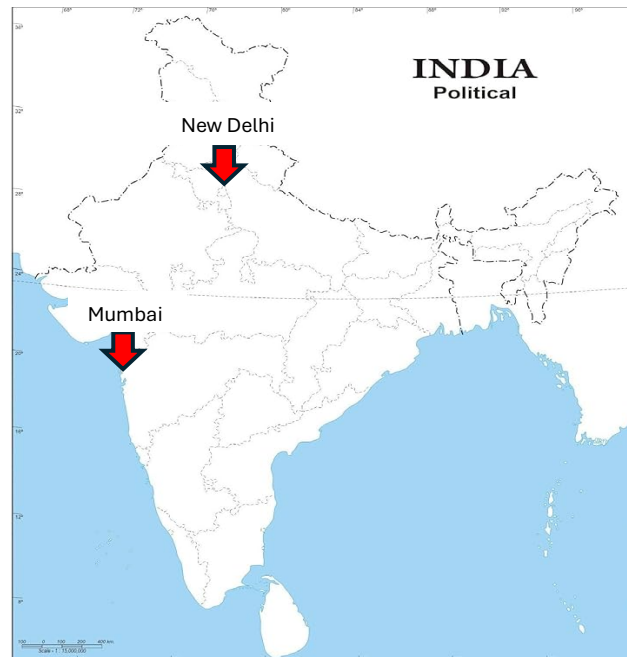


Figure 1: Geographic Map of India and the Locations of the Study

Research Participants

While the research questions outlined above could be explored through various methodological approaches, this research project as discussed in chapter four, was guided by the belief that children undertaking caregiving responsibilities would be best positioned to speak authentically about their own experiences and therefore determined that children would serve as the primary participants in the study. Such an approach also respected children's competencies and prioritised their voices.

This research had two categories of child participants. The qualitative interviews employed children who were young carers. Children who participated in the quantitative survey were not exclusively young carers but included school-going children more broadly.

In addition, to the child participants, some adult key informants who worked closely with children like social workers, teachers, etc were also recruited. It is to be noted that in this study, adults were not recruited to validate the perspectives of children, instead they provided an additional viewpoint to secure an in-depth understanding. Perspectives from adults allowed for data triangulation (Denzin, 2015) and to view the issue within the larger socio-cultural context of India.

Age Range of Child Participants

The age range of children and young people who participated in this research project was 12-19 years and they were residents of New Delhi and Mumbai. Careful considerations were given to the age of the children participating in the research.

Initially, the age range of 15-18 years was chosen for this study to be able to holistically understand the experiences of a particular age group of carers and therefore contribute effectively to the knowledge base around young carers in India.

This, makes the age group of 15-18 years particularly relevant for examining the negotiations that children with dual student-carer roles made and the impact their role as a caregiver had on their education, mental and physical health, future prospects, etc. However, it was not necessary for the young carers in this study to be school goers. In cases where they were not, their reasons for leaving school and its association with their caregiving role were assessed.

Moreover, at this developmental age, children were believed to possess the epistemic capacity to reflect on and articulate both their past experiences and the prospective implications of their caregiving roles and also, to make decisions regarding their participation in the research project.

Additionally, as young carers in the qualitative study were already undertaking ‘adult-like’ roles, drawing on the concept of Gillick Competency¹ (Griffith, 2015), they were deemed capable of reflecting on their caregiving role and providing informed consent to participate in the research. Moreover, the quantitative study survey questionnaire focused on behaviours (what participants did or did not do, and the frequency of those actions), while minimising questions that could elicit strong emotional responses, and therefore was considered appropriate for this age group of children. However, the potential for participant distress remained a consideration. These concerns were carefully anticipated and are discussed in detail in the following sections of this chapter. This also does not imply that parents/guardians were unaware of their children's participation in the research. The process of gathering parental/guardian consent and informed consent from children have been discussed in greater detail later in this chapter.

The previous study (Pande, 2014) conducted with young carers in India focused on the 11–16 age group, specifically those who had dropped out of school. Selecting the age group of 15–18 years for this research thus seemed like a logical progression for further inquiry of the topic.

Nevertheless, one 12-year-old participant was included in the qualitative study and some 13, 14, and 19-year-olds were included in the quantitative study. These children met the criteria of competence that was set for the 15–18 years olds. In consultation with the university ethics committee, it was decided that their contribution was appropriate and powerful and thus, deserved to be included. This has been discussed in greater detail further in the chapter. Therefore, the child participants in this research were in the age range of 12–19 years. In the qualitative component of this thesis, young carers were aged between 12 and 18 years, while in the quantitative component, the age range was 13 to 19 years (two participants aged 19). In this study, the 12–18 age

¹ Gillick Competency and Fraser Guidelines provide a framework for assessing whether a child under the age of 16 possesses the capacity to provide informed consent depending on their maturity and understanding (MDU, 2025). This assessment is based on several factors, including the child's maturity, prior experiences, cognitive abilities, capacity to resist external influences, understanding of risks and benefits, and awareness of the potential long-term implications for family life and education. It is a functional measure of decision-making capacity, independent of parental consent (Griffith, 2015). Although the Fraser Guidelines are generally used in clinical treatments (Boddy, 2014). Gillick Competency has broader applicability in assessing whether a child possesses sufficient maturity to make independent decisions and to comprehend the consequences of those decisions (*Gillick competence and Fraser guidelines*, 2022).

group will be referred to as children, whereas the latter group will be referred to as children and young people.

Sampling and Recruitment for Qualitative Study

This qualitative study was conducted with 21 young carers (ten from New Delhi and eleven from Mumbai) and six key informants (three from New Delhi and three from Mumbai).

Children

Purposive sampling technique was utilised for recruitment of participants to the qualitative study. Purposive sampling was chosen to be the most suitable method for this study as it enabled deliberate choice of participants based on their life experiences (Tongco, 2007; Campbell *et al.*, 2020). This was important for this study as there was no mainstream definition or awareness about the presence of young carers in the Indian context.

The qualitative study used a specific criterion of involvement and characteristics to find children who were carers for immediate family members. This was- children who live with and take care of family members who are critically ill, have a mental illness, disability or are in a situation where they require regular care from another family member. These young carers were caring for at least one family member and, in some cases, more than one.

Purposive sampling provided a pool of participants who had lived experience of the phenomena being studied and who were most likely to yield appropriate and useful information (Campbell *et al.*, 2020). It also aided in selection of a varied sample representing both genders. This enhanced the depth of understanding and aided the trustworthiness and dependability of the data (Campbell *et al.*, 2020).

For the qualitative study, young carers were recruited through community-based organisations. At the time of data collection, due to general lack of awareness about young carers, there were no organisations, governmental or non-governmental who were working with young carers in New Delhi or Mumbai. Therefore, community-based organisations who were not supporting the children with their caring responsibilities but were associated with vulnerable children, young people and families in New Delhi and Mumbai in other capacities such as educational support for underprivileged

children, livelihood support for migrant families, support for patients with HIV/AIDS and prevention, child health and nutrition, skill development, etc were approached for this study. These organisations, because of their presence and prior associations with the communities, had an idea of children who were undertaking caregiving roles for family members with long term illness, disability, or any other care requirement. In Mumbai, five organisations were approached out of which three participated in the study. The remaining two organisations said that they did not work with any children who were ‘carers.’ In New Delhi, only one organisation was approached, and I was able to recruit ten young carers who were beneficiaries of the organisation. These organisations were approached through my social work network, based on their work with children and young people. It is to be noted that, the community-based organisations were already working with the all the young carers who participated in this study or their families, in some capacity, although they were not being supported for their ‘caring role.’

The brief provided to the community-based-organisations was that I would like to talk to children within the age group of 15-18 years, who were living with a family member who is ill, disabled or has any other care need and the child was involved in the family member’s assistance in any capacity. However, the first child that the organisation in Mumbai introduced to me was 12-year-old Pihu. This was due to some miscommunications with the community contact. Although she did not meet the age criteria that was initially set, I recognised that she had made a significant effort to meet despite her busy schedule. Rejecting the first participant could have been perceived as disrespectful, so I decided to engage with her. Throughout the interview, I continuously monitored her understanding and emotional well-being in relation to participation and consent. My training as a social worker came in handy here. Moreover, for the first half of Pihu’s interview, the community contact, known to her was present with us till she became comfortable with me. Her story was so powerful and profound it deserved to be reported in the spirit that she had given it. I consulted the ethics committee and was granted an amendment to the original approval, allowing her data to be included in the study. The miscommunication was later cleared and only children within the age group of 15-18 were recruited after this. Ultimately, a total of 21 young carers in the age group of 12-18 years were recruited through four community based-organisations- ten from New Delhi and eleven from Mumbai.

Adult Key Informants

Six key informants were recruited to the qualitative study, three from New Delhi and three from Mumbai. These adult key informants had substantial expertise and experience of working with children. The selection criteria set for key informants was- professionals who held key positions in sectors like education, child rights or other sectors related to children. Four social workers, one project lead, and one schoolteacher participated in the study. Their professional position, exposure to socio-political situation in the cities, and range of experiences with vulnerable children and families were key in reflection on the issue. These key informants were also recruited through the above-mentioned community-based organisations. The key-informants who participated in this study were volunteered by the organisation based on the above-mentioned criteria provided to them.

In this study only professionals working with children were included, however, in future studies, professionals working within the disability and health sectors could offer greater nuance into the issue of young carers.

Sampling and Recruitment for Quantitative Study

The quantitative study aimed at recruiting 150 school going children from New Delhi and 150 school going children from Mumbai, aged 15-18 years. Children attending school were chosen as the target population for this study as school and schoolwork are significant aspects of children's lives. Therefore, evaluating children's involvement in household chores while navigating their school-based commitments was key to understanding the extent of their participation in household tasks and its impacts. The eligibility criteria for participating in the quantitative study did not include the need to be a young carer as the aim was to understand the typical levels of participation of children in various chores within a household.

As mentioned earlier careful considerations were given to the age of the children participating in this study. Children in the age group of 15-18 years are in the crucial stages of their formal education as they prepare for nationalised exams in 10th class (15 years) and 12th class (17 years). After 10th class children in India, are divided into three streams of study for their 11th class namely- Science, Humanities, and Commerce. It was decided that this study will primarily recruit children in 11th class as they were not preparing for these exams. However, it is important to note that these age

ranges are not fixed, and variations can occur as some children may be held back in certain classes and others may have been enrolled in school earlier than the typical age (6 years) which is a common practice in India.

Additionally, with three streams (Science, Humanities, and Commerce) and an average class size of approximately 50 students in each, a total of around 150 participants from a single school was considered an appropriate target, but class sizes can vary from school to school. Therefore, in cases where a school did not have the required number of students in class 11, additional schools were to be recruited, or the existing school was to be requested to include students from classes 10 or 12 as they fell within the required age group. As the quantitative survey concentrated on participants' behaviours and their frequency, the questions were designed to minimise the potential for emotional distress among children. Furthermore, several strategies were implemented to reduce the risk of distress which have been discussed in detail later in the chapter.

Using purposive sampling only public or state-aided schools and junior colleges² were involved in this study. Private schools were not involved as private institutions charged higher tuition fees. Therefore, children from low socio-economic backgrounds, similar to those of the young carers in the qualitative sample, were more likely to enrol in public or state-aided institutions. The community-based organisations who participated in the study and my social work network facilitated with recruitment of the schools. To minimise confusion, all the participant schools and junior colleges will be referred to as 'schools' in the following sections. Only co-educational schools with both boys and girls were approached to allow for diverse gender representation in the sample.

² Classes 11th and 12th are called junior colleges in Mumbai and are a separate from classes 1-10.

In this study, 577 survey responses were collected from four public and state-aided schools. Individual school data can be found in table 1. As shown in table 1, a greater number of schools were recruited in Mumbai compared to New Delhi. This was because of a short period of political instability in New Delhi, due to the incarceration of the then education minister, during which schools approached were hesitant to grant research access. However, after a few months the situation began to stabilise, and permissions were obtained. In School 4, class 11 had fewer than 150 students. Therefore, as agreed previously, some class 10 students were also involved in this sample. This was done with the permission of the school principal. Amongst the 577 participants, 42 were outside the designated age range of 15-18 years. Four participants were 13 years old, 36 participants were 14 years old, and two participants were 19 years old. However, as they were studying in the same classes as 15–18-year-olds, it was decided that they would be retained in the sample for this study. Thus, a total of 577 children and young people in the age group of 13-19 years were recruited for the quantitative study.

Table 1: School Data

School, Region	Participants
School 1, Mumbai	200
School 2, Mumbai	50
School 3, Mumbai	157
School 4, New Delhi	170
Total	577

Data Analysis Strategies

Given the distinct nature of the qualitative and quantitative datasets, each was analysed independently using analysis strategies appropriate to each data type. The qualitative interview data were subjected to thematic analysis as propounded by Braun and Clarke (2006, 2012) to identify and interpret recurring patterns and themes. MAXQDA, a qualitative data analysis software, was employed to facilitate systematic coding and data management. The exploratory and experiential nature of the research questions and data collected also suited thematic analysis (Braun and Clarke, 2012). The survey questionnaire data, on the other hand, was analysed using SPSS, which

enabled efficient statistical analysis and exploration of quantitative trends. More details about the use of these strategies will be detailed in chapters six and ten of this thesis.

Research Objectives

Guided by the research questions and the research design, this research project fulfilled the following objectives:

1. To explore the specific caregiving experiences of children in New Delhi and Mumbai who undertake caregiving tasks for immediate family members using semi structured interviews with young carers in the age range of 12-18 years and key informants.
2. To identify the key impacts associated with caregiving on these children's lives and the support systems available to them using semi structured interviews with young carers and key informants.
3. To use a survey to examine the typical types and frequency of daily household tasks undertaken by children in the age range of 13-19 years, regardless of caregiving status in New Delhi and Mumbai, and to assess the impacts of these tasks by developing and validating culturally sensitive measures.
4. To use the results from the measures to contextualise the type and frequency of tasks undertaken by children who are young carers.
5. To use the measures to test selected hypotheses guided by literature and the findings from the qualitative interviews.

Ethical Considerations

Ethics Approval for this study was granted by the University of East Anglia's School of Social Work Research Ethics Subcommittee that was hosting the research and was conferred with the organisations in India who supported with recruitment of participants.

India does not have a formal code of conduct for researchers (Chaturvedi, 2023) or specific guidelines or protocols for social science research. In the absence of such direction, the United Nations Convention on the Rights of the Child (UNCRC), which has been ratified by India, was used as a frame of reference for ethical research with children and young people. The UNCRC's articles 12, 13 and 17 (Appendix 23) which

deal with children's participation rights and their "right to be consulted on matters which affect them" (Hanna, 2022:49) have been used as guiding principles for this study. Additionally, the National Ethical Guidelines for Bio-Medical Research Involving Children by the Indian Council for Medical Research (ICMR, 2017) have also been used as a guide.

Ethics of Research with Children and Risk Assessment

Research with children, generates new knowledge and understanding about children's experiences and offers a better understanding of their experiences than those generated by using adults as proxies (Lomax, 2012; Huang *et al.*, 2016; Norozi and Moen, 2016). Also, as emphasised in the chapter four, children are active social agents having complex capacities who have been subjected to unfair credibility judgements by adults (Smith, Cowie and Blades, 2015). Children are active co-creators and credible and essential sources of knowledge. Thus, advocating for children's participation in research which empowers them, amplifies their voices, and respects their self-identity by highlighting their unique ways of perceiving and understanding the world (Markowska-Manista, 2018). Article 12 of the UNCRC also states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. However, research involving children may involve certain risks, and it is essential for researchers to be adequately prepared to address these risks through thorough risk assessment procedures.

Huang *et al.* (2016) suggest some ethical and methodological considerations for adult researchers while working with children. Firstly, they emphasise that researchers must evaluate potential physical and emotional risks to child participants. This consideration is especially important given that for many children, research participation may represent their first opportunity to discuss their feelings and experiences. Secondly, access to child participants must be negotiated through gatekeepers/ guardians, though this can create potential conflicts when a child's willingness to participate conflicts with a gatekeeper's protective concerns. Current research practices however, limit participation to children who have received gatekeeper approval. Researchers must also obtain informed consent from children after explaining the research in a manner they comprehend, emphasising their autonomy in decision-making and their right to withdraw without consequences.

Researchers must protect children's confidentiality and privacy and build rapport with them. Lastly, researchers must focus on collecting rich data without extrapolating or overlaying adult assumptions. Language interpretation requires particular attention when working with children. This should be done through clarifications rather than making adult-centric assumptions about meaning. These methodological considerations must be balanced with awareness of cultural differences throughout the research process (Huang *et al.*, 2016).

The decision to involve children as the primary participants was made only after it was determined that the study would yield substantial advantages, given that young carers remain a largely overlooked group in India. This neglect is reflected in the limited available literature, the scarcity of organisations addressing their welfare, and the absence of targeted policies or programmes. Therefore, bringing their experiences and needs into public awareness was anticipated to produce predominantly positive outcomes for this group. Although the direct benefits to individual participants were minimal, the broader benefits to young carers in general were considered significant.

Drawing from Huang *et al.*'s (2016) recommendations, careful attention was given to the potential benefits for child participants, for young carers as a group, and for other children in similar circumstances, as well as to the potential risks of participation. Every study entails some risk to the participants (Boddy, 2014). National Ethical Guidelines for Bio-Medical Research Involving Children (ICMR, 2017), classifies risks as:

- Less than minimal: where the probability of harm or discomfort anticipated is nil or not expected.
- Minimal: where the anticipated harm or discomfort would not be greater than those ordinarily encountered in daily life. It is expected that harm caused by the minimum risk level research would be very slight and temporary.
- Low risk: where there is a slight increase in the potential for harm or discomfort beyond or more than minimal risk. This may include small bruises, temporary distress etc.
- High risk: all procedures which have a risk over and above low risk are classified as high risk.

As per these guidelines, the qualitative study was classified as a minimal to low-risk study while the quantitative study was considered less than minimal to minimal risk study.

Furthermore, potential risks for the young carers participating in the qualitative study, children participating in the quantitative study, adult participants of the qualitative study and myself as the researcher was carefully assessed and documented in detail prior to commencing the study. These involved risks of eliciting distress by bringing up traumatic memories, over-disclosure, incidences of illegal behaviour, feelings of attachment to the researcher, expectations that the researcher might improve their current circumstances, among others. Each of these risks and the actions measures to minimise harm to the participants have been outlined in detail in Appendix 9. High priority was placed on minimising the risks to the participant's both during and after their involvement in the study (Shaw *et al.*, 2020).

Access to Child Participants

Another key ethical concern was gaining access to children. As suggested by Huang *et al.*, (2016) access to child participants was negotiated through gatekeepers like community-based organisations and schools. None of the child participants in this research were directly approached by me. Due to safeguarding concerns, they were introduced to me by an adult previously known to them.

As mentioned earlier, young carers engaged in the qualitative study were approached through community-based organisations working with vulnerable children in New Delhi and Mumbai. These organisations were employed because of their prior associations with the children. Involvement of these organisations as gatekeepers also minimised any child safeguarding issues before or after the interviews.

The organisations were initially contacted through emails (Appendix 18) and thereafter, an in-person meeting was arranged with organisation leads or personnel in-charge to explain the research objectives and the project requirements. A short research brief, information sheets (Appendix 13 and 14) and copies of the interview schedules (Appendix 1 and 2) were also shared in the initial email. Once the leads were happy to participate in the study, they put me in touch with community contacts who in-turn approached the children and their families for me. These community contacts

graciously assisted me with recruitment in addition to fulfilling their regular duties. Gatekeepers were involved so that the children and their families were approached by a trusted person, instead of a stranger like me, and had the opportunity to refuse to participate. Four community-based organisations participated in the study- one from New Delhi and three from Mumbai.

The use of gatekeepers already known to the children, to recruit them for the study gave the children an opportunity to discuss their participation with a trusted adult. This also meant that there were existing systems of support available to them should they require it following their participation in the study (Stapf *et al.*, 2023). However, this also meant that the study included only those children who were 'known' to contribute to their families more significantly than their peers and were already on the radar of the gatekeepers. In the absence of established support systems for young carers in the country, such an approach was considered appropriate as this ensured that they had access to some form of assistance if needed following their participation.

For the quantitative study, children were recruited through schools. As stated in the National Ethical Guidelines for Bio-Medical Research Involving Children by the Indian Council for Medical Research (ICMR, 2017), 'For any research that is to be conducted within school settings, the researcher should submit the protocol to school authorities and obtain written approval to conduct research. Researchers should comply with the school's policies and procedures for the proposed research.' Following these guidelines, the school principal was approached to obtain permission to access the students. The questionnaire (Appendix 3), consent form (Appendix 21 and 22) and information sheet (Appendix 15) were shared in advance with the principal or person-in-charge either through email or in-person. This was done so that the schools would have enough time to discuss about their participation with relevant authorities, like board members or parent bodies. School principals in India can give permission for participation in surveys without parental consent (McManus and Dhar, 2008; Benzaken, Palep and Gill, 2011). After the school agreed to participate, I was introduced to the class by a schoolteacher, and the survey was administered in the presence of the schoolteacher.

Access to Key Informants

As mentioned earlier the key informants in the study were also recruited through the community-based organisations. As all the key informants were adults, I approached them individually to request their participation in the study.

Informed Consent

Since the children in this study were accessed through gatekeepers, such as community-based organisations and schools, initial permissions were obtained from these gatekeepers. For the qualitative study, the permission from the community-based organisations was recorded through confirmation emails. The confirmation from the schools were recorded on signed/stamped consent forms (Appendix 22) from the principal or person-in-charge.

Parental consent for this research was facilitated through gatekeepers. For this study, while parental consent for children's participation was essential, it was not obligatory for parents to provide a written signature. This was because some parents might be illiterate or uncomfortable signing the form, as 'signing' on papers is often associated with legal obligations, property matters, or other formal contracts, which could raise concerns or suspicion in the Indian cultural context.

In the qualitative study, parental consent was negotiated by the community contacts. As mentioned earlier, this was done so that the families were approached by a known face and had the opportunity to opt out of the study. Additionally, it was felt that if a formal meeting is required to be set up with the parents it may seem like a very serious issue and parents might be fearful that something is being hidden from them, especially since I would be a new face in the community. Potential fears of the children being removed from the families by child protective services could have arisen. Such a formal meeting could have also drawn attention from neighbours and other community members. Therefore, it was considered best that the initial permissions for the interview are gathered by a person that the family recognises. As a researcher, I had to trust that the organisations had fulfilled their responsibility of communicating with the parents, and I had no reason to believe otherwise.

The consent forms and the information sheet were shared in advance with the community-based organisations that facilitated the recruitment of young carers. These

forms included a section for the parent/guardian's signature, but signing was left entirely optional. Notably, none of the parents signed the consent forms. Instead, the forms were signed by the adult community workers who acted as intermediaries and were familiar with the children and their families. This approach helped honour and navigate cultural sensitivities while ensuring ethical integrity in the consent process.

For the quantitative study, signed/stamped permission from the school was treated as parental/guardian consent based on the expectation that the school would grant approval only after adhering to its established policies and procedures.

Regardless of consent from gatekeepers the consent of the child was considered final. I was committed to ensuring that children's consent was obtained in addition to adult consent, thereby giving due importance to the voices and agency of the children involved. Informed consent was gathered from each child participant after providing them with adequate information about the study.

In the qualitative study hard copies of the information sheet and the consent form were shared with each participant. The information sheets had my contact information (my local number, email and my supervisor's email). I also read out the information sheet to them and they were also given some time to read and to ask questions. It was clearly explained to the participants that their participation was not compulsory. Each participant was informed that they could leave the interview anytime during the process and did not have to give any reason to withdraw. They were also informed that using my contact details provided on the information sheet they could withdraw from the study or request to change the information, they gave me within a period of fourteen days (Corbin and Morse, 2003) without needing to provide a reason. The qualitative interview participants could just quote their name and ask me to delete their data. The survey participants were encouraged to note down the unique number on each survey form and request withdrawal using the same.

Following the briefing, the participants signed the consent form. In the qualitative interviews, the participants consent was also recorded verbally in the voice recorder. These consent forms were later counter signed by adult community contacts who were representative of the gatekeeping organisations.

A similar approach was followed in the quantitative study, wherein the information sheet was read out to the class and time was provided to the participants to ask questions. Each participant was also given a hard copy of the information sheet with my contact information. They were clearly informed that their participation was not compulsory and that they could either refuse to take the forms, which some participants did or choose to return the survey form untouched or not return it at all. To maintain complete anonymity, no signatures were collected on the survey forms. Instead, participants' consent was implied through the act of ticking all the boxes on the consent form.

As I was approaching the children through gatekeepers, there was an issue of children feeling obliged to participate in the study due to their dependency on the gatekeepers or due to the inherent authoritative order between adults and children. To address this issue consent was treated as an ongoing process throughout this study (Shaw *et al.*, 2020). In both the qualitative and the quantitative studies, the children were given full autonomy to withdraw their consent anytime. They were informed that their refusal to participate would not affect their relations with the organisation or with their school.

For the key informant interviews, a hard copy of the information sheet and consent form was provided to participants, who were then given time to read and ask any questions. I was aware that the professionals might feel obliged to take part in the research because of my association with the organisation. I was alert for indicators suggesting involuntary participation. They were informed that their participation was completely voluntary and if they decide to withdraw from the interview, it was okay and will not affect their job, or relationship with their employer. Additionally, they were also provided with fourteen days to change or withdraw from the study by contacting me using the information provided on the information sheet.

Confidentiality and Anonymity

The participants were also assured of complete confidentiality of their responses. All identifying materials were removed from the interviews and pseudonyms have been used to protect the children's identities (Markowska-Manista, 2018). In the qualitative study, some participants chose their own pseudonym. The name and other identifying details of the participants were stored separately from the transcripts and audio recordings. None of the transcripts or audio recording were shared with the

gatekeepers. Additionally, any report or publication sent back to the gatekeepers will use pseudonyms to protect the child's identity and will avoid using direct quotes that could be identifiable. Some data that is too sensitive even with anonymisation might still be removed from final report. As mentioned previously, no identifying details were collected in the quantitative study.

Confidentiality of participants was to be breached only if a child disclosed information of safeguarding concern or if key informants revealed dangerous professional practices. This condition was clearly stated in the information sheets provided to both child and adult participants. Action measures to address such situations were also anticipated and have been outlined in the Risk Assessment procedure undertaken prior to the study (Appendix 9). However, no such incidents occurred during the study.

Safe Space

The locations chosen for interactions with children were spaces familiar to them. At the same time, the presence of the care-recipient was consistently avoided throughout the research process. For this reason, as far as possible the interviews were not conducted in the children's homes. I was aware that conducting interviews in the houses of the children may also place additional monetary demands on the children and their families like tea or snacks for me as a guest. Additionally, discussing sensitive topics in a neutral setting also helped ensure that the child retained a physical and emotional 'safe space' to return to after the interview.

Excluding two cases (17-year-old Ayana and 15-year-old Kavita), all the other interviews were conducted at the organisations' community centres. These centres were frequented by these children and in some cases were spaces created for children which added to their comfort.

The interview with 17-year-old Ayana, was conducted at her house, because she lived far from the community organisation's office, so I travelled to her. The interview was conducted while her parents, for whom she was a carer, were visiting their village. Her sister was at home and did interrupt the interviews a couple of times after which I requested Ayana to ask her sister to stay in the other room. While this might have caused some discomfort for Ayana or her sister, no such discomfort was visibly evident.

An exception was also made in 15-year-old Kavita's case. This was done because this organisation did not have an office/centre near the child's residence. The social workers usually met the participant at her home. This interview, however, could not be conducted at the child's house because her father, for whom she was the carer, was always at home as he was incapacitated due to a major leg wound. Therefore, the interview was conducted at a community contact's house, who lived in the child's neighbourhood. The community contact's mother was in the other room doing her chores and did not disturb the interview in any way. This ensured that Kavita did not have to travel for the interview while providing her a familiar space away from her home and care-recipient to talk openly about her experiences.

Support post-participation

As mentioned above, all the participants were informed that they could contact me using the information provided on the information sheet within fourteen days of their participation. The child participants were informed that if they needed further support, they could also contact the community contact or their teacher. They were also provided with help sheets (Appendix 16 and 17), which were a customised list of NGOs and support organisations in their cities with whom they could connect in case of any distress.

Thank You Gift

In consultation with the gatekeepers each participant was offered a small thank you gift for their time and participation in the study. These were also mentioned in the information sheet shared. I was aware that offering participants remunerations for their involvement in research is a form of inducement and financial inducement may unduly influence participants. Therefore, the rewards were kept to a minimum, intended as gratitude for the participant's time and not as incentive to participate in the study.

In the qualitative study, the child participants of the interviews were offered a small backpack. The adult participants were offered a voucher of ₹1000 (approx. £10) at the end of each interview for their time. One participant did not accept this voucher as they felt it was inappropriate for them to accept the voucher from me.

In the quantitative study, each participant was also given an inexpensive basic pen along with the survey form to fill in the questionnaire. This pen was not collected back and was given to them as a thank you for their time and participation. Each school was also offered a minor sum of ₹3000 (approx. £30) as a thank you for their time, which was declined by all the schools except one.

Undertaking India-Based Research within a UK Institutional Framework

Following Economic and Social Research Council's (ESRC) framework for research ethics, safeguarding approaches were contextualised to the setting of the study (ESRC, 2015). A poignant example of ethical dilemmas stemming from researchers and participants sharing the same cultural background but operating under the protocols of a foreign university was the case of a two-year-old child left at home while 16-year-old Naira, her older sister and her primary carer, attended school. It is to be noted here that this was not a daily occurrence as the older sister went to school only when absolutely necessary. In the context of UK child protection and safeguarding frameworks such a situation would typically be flagged as a serious safeguarding concern. However, within the Indian cultural context, this arrangement operated within an informal yet trusted communal support system. The child was never entirely alone. Community members such as neighbours or extended relatives provided informal supervision. While not formally structured, this arrangement was trusted by the family and reflected local norms. Moreover, the community-based organisation with whom the older sister was affiliated were aware of her situation and were monitoring the risk as per their protocols.

Importing UK safeguarding standards to this context could have caused more harm than good, particularly in the absence of understanding or systemic support for families with young carers. In such a situation, raising safeguarding concerns according to UK norms might have led to unintended consequences, including the possibility of the child being institutionalised. Therefore, adaptation to the situation and environments of the research subjects was important (Markowska-Manista, 2018). The intention throughout the research was to ensure that participation in the interviews did not disrupt the children's lives in any way, particularly not in a negative manner. However, as mentioned previously, if there were clear instances of harm/abuse to the

participant, I would have intervened and requested support from the community-based organisations or from state agencies. Throughout the process of data collection, my professional knowledge and social work training in India was utilised to be able to recognise and assess potential risk/ safeguarding issues.

Regular debriefing sessions and check-ins were arranged with the supervisors to respond to changing needs of the project. Additionally, as a doctoral researcher with UK-based supervisors and India-based fieldwork, any challenges experienced due to time zone differences or contextual gaps were mitigated either by consulting with former colleagues like experienced social workers or professors from my social work training in India, who were briefed about the project. Furthermore, as the research was conducted in collaboration with gatekeepers, it was decided that in case of any challenges, I would follow their guidance given their deeper knowledge of the children and the community they lived in.

It is to be noted that although participants in this study were recognised as autonomous subjects (Shaw *et al.*, 2020) ultimately, this is an adult-led research with all aspects of the research formulated and controlled by the adult researcher. Therefore, stating that this study has put forward the unadulterated children's perception would be an overstatement (Punch, 2002). It is a biased adult interpretation of the situation of young carers in India. Nonetheless, children in this study were considered competent and reliable social agents, who were actively aware of their social situation.

Ethical Sensitivity in-Situ

Ethical questions or dilemmas are not completely resolved at the planning stage of a study, rather they may emerge throughout the research process and are relational in nature (Rutanen *et al.*, 2023). Even after getting ethical approval for a study, a researcher needs to continually weigh the risks and benefits during the course of the study. As Guillemin and Gillam (2004) note, there is a day-to-day ethics in practice that arises in the course of doing research. Thus, requiring sensitivity when the research takes another direction that what was planned (Schürer and Jensen, 2022).

One such key example is of 12-year-old Pihu. As mentioned earlier in this chapter. The age requirement for this study was 15-18 years. However, 12-year-old Pihu was the first

participant introduced to me by the community-based organisation. As per protocol, the organisation had gathered informed consent from Pihu's parents but due to some miscommunication, the age of the participant was not as per the requirements of the project. Spiel and colleagues, (2020) have elaborated on such unforeseeable circumstances during the course of a study where anticipatory ethical frameworks can fall short and where researchers must work out ethical choices of action in the moment through careful judgement, shaped by the contexts at hand.

My decision to continue to interact with Pihu was situated in several considerations. Firstly, Pihu had invested time and effort to come and meet me. To not interview Pihu could have been perceived as a waste of her time at the least, or worse, that she had done something wrong or that her experiences were invalid. Pihu demonstrated clear understanding and willingness to participate. She was asking questions about the research during the introduction and demonstrated her willingness to engage with me. Furthermore, Pihu was a young carer already undertaking adult-like roles which required maturity, responsibility, and a level of expertise more commonly associated with adults (Becker et al., 2001). As discussed previously in this chapter, this lived experience informed her capacity to consent and participate meaningfully. To have excluded her voice solely on the basis of age would have overlooked the exact kind of knowledge this study aimed to bring to the forefront.

Additional safeguards were also put in place to ensure Pihu's safety and comfort. Pihu, like all other participants in the study, was given the choice of having a known community contact present throughout, which she initially chose. I did not ask pressing questions, took regular emotional check-ins, and repeatedly reminded her that she could stop or leave at any time, and that any benefits received from the community organisation would not be withheld as a result of her refusal. This was stated explicitly in the presence of the community contact. Moreover, I remained vigilant to any signs of distress and was ready to pause or stop the interview immediately. Notably, half-way through the interview, during a natural break, the community contact checked if she was okay for them to leave. Pihu affirmed and said that she was comfortable to continue the interview without the community contact present.

Following the interview, the deviation was reported to my supervisory team and the ethics committee. An amendment to the ethics protocol was subsequently approved to retain and use the data. This approach ensured the study remained ethically robust, balancing adherence to ethical protocol with responsiveness to participant welfare and emerging ethical considerations in situ, thus reflecting the need for an ongoing process of reflection throughout the course of a study (Loveridge et al., 2024).

As rightly pointed out by Spiel et al., (2020), researchers may not be able to know or assess whether the decisions made in-situ are correct or even the best available. However, as suggested by Schürer and Jensen, (2022) researchers need “ethical sensitivity” when dealing with such dilemmas.

Chapter Summary

This chapter introduced the reader to the ontological and epistemological stance of the research and my varied positionalities. It also discussed the research design that was employed in this study in detail. The chapter also described the objectives that this research project fulfilled along with the ethical considerations that this study addressed, and the measures taken to ensure well-being of all participants. I will discuss the methods used for each study in chapter 6 (qualitative) and chapter 10 (quantitative) of this thesis .

Section 3

Qualitative Methods and Findings

Chapter 6: Qualitative Study Methods

Introduction

This chapter discusses the qualitative methods used to answer the following research question:

What are the specific experiences of children who undertake caring roles in New Delhi and Mumbai? What are the challenges they face and how supportive are the social systems around them?

This chapter elaborates on the qualitative study design, the sampling and recruitment techniques used, the strategies used and challenges faced during the interviews, the translation and transcription procedures and the analysis undertaken to obtain an in-depth understanding of the concept, experience and dynamics of being a child with caring responsibilities in the Indian context.

Designing Interview Schedule

The qualitative study used two semi-structured interview schedules (one for young carers and one for key informants) with open-ended questions to answer the research question. The schedules were prepared with specific themes to be covered based on the research questions. It also had prompt questions for instances of silence or incomprehension. The schedule also ensured that the interviews did not digress from the main topic too much and that it continued in the intended direction and that all themes were covered (Myers and Newman, 2007).

The semi-structured nature allowed for flexibility and improvisation of the questionnaire based on each participant's attitudes (Myers and Newman, 2007; Hemming, 2008). The open-ended nature of the questionnaire allowed the participants space to delve deeply into their social situation as perceived by them.

A detailed semi-structured interview schedule (Appendix 1) was constructed for qualitative interviews with the children who were carers. The schedule had open-ended questions so that the participants could fully describe their experiences, along the following subjects- 1. Background Demographic Information, 2. Information About

the Care Recipient, 3. Types of Caring, 4. Impacts, 5. Feelings About the Carer Role 6. Support Systems and COVID-19.

The language of the schedule was kept simple, using a casual and spoken style. I translated the schedule into Hindi, and with the help of a native Hindi-speaking friend, it was back-translated into English to identify discrepancies and ensure that the meanings and essence of the original schedule were accurately conveyed (Epstein, Santo and Guillemin, 2015). Additionally, the Hindi interview schedule was also shared with a 17-year-old Hindi speaking acquaintance, to ensure comprehension of the questions by young participants.

The interview schedule (Appendix 2) for the key informants was also designed in a semi-structured manner. The schedule had open ended questions along the following subjects- 1. Background Information about the participant, 2. Information/ Knowledge about Young Carers, 3. Impacts of being a Young Carer 4. Support Systems for children with caring responsibilities and Impact of COVID-19. This schedule was also translated to Hindi and then back translated to check for inconsistencies.

Interviews

In the qualitative study a total of 27 semi-structured interviews were conducted across New Delhi and Mumbai. 10 children from New Delhi, 11 children from Mumbai, 3 key informants from New Delhi and 3 key informants from Mumbai were recruited for the study. All these interviews were audio recorded with the permission of the participants and were stored in a password protected device which could be accessed only by me. They were later uploaded on to the University's cloud storage system and were accessed only through a password protected device.

Children

As mentioned above children who were identified by the gatekeepers as meeting the definition of a young carer were recruited by a community worker familiar to them. The community contact decided on the location and the time of the interview as per the child's convenience and informed me. Contact details of the children were not shared with me which enabled complete anonymity. It was made sure that the interviews with the children, were conducted in a neutral location, comfortable to the children. The chosen locations were also near the child's house which ensured that they did not have

to bear any travel costs. The presence of the care-recipient was deliberately avoided to ensure the child felt comfortable speaking freely.

After finalising the location, the community contact either travelled with me to the set location or met me there to introduce the child to me. Before beginning the interview, the first few minutes of the meeting were spent in rapport building. I introduced myself to the participants and spoke to them about their day, where they lived, or other topics unrelated to the study. For example, one participant mentioned that they had just received their grades the day before and that they had done very well. So, a few minutes were spent acknowledging the child's achievement and congratulating them. These preliminary questions were intended to put the child at ease. Once they were comfortable, I introduced the topic to them. They were given the options of speaking to me alone or in the presence of the community contact. All the participants said that they were comfortable to talk to me alone.

The children were also given the option of participating in one or multiple sittings. All the participants preferred one sitting interviews. They were given breaks as required, this was done when they seemed tired or feeling overwhelmed after talking about a sensitive topic. On an average, the interviews with the child participants were 1.5 hours long which did not appear to be overly tiring for them.

As described previously, before beginning the interviews I carefully explained the purpose of the interviews and gave time for any questions. The interviews were presented as an opportunity for the children to talk about their lives, caring responsibilities and challenges and emphasised how important I believed their voices were.

After the introduction they were given some time to read the consent form and sign. Some participants requested me to read it out for them after which they signed it. Verbal consents were also recorded from all the participants with the recording device used to record the interviews. For participants who were below 18 years old, the consent forms were counter signed by the adult community contact. For participants who were 18 years old, their consent was considered final. Additionally, the child participants in this study were carers and were used to carrying out tasks beyond what is expected of their age. As a result, they demonstrated a level of maturity that enabled them to understand the nature and purpose of their participation. As consent is often

a dynamic process, especially with children, they were given the opportunity to contact me within fourteen days after the interview and withdraw their consent using the contact details on the information sheet. No withdrawal requests were received.

The interviews were conducted in a language convenient to the participant. They could choose to be interviewed in Hindi, Marathi or English. All the child participants chose to speak in Hindi. Even though, I have native proficiency in Hindi, some of the words that these children used were new, highlighting the class difference between me and participants. For example, one participant from New Delhi used a term *haudiya* in conversation with me. As I had never heard of the term the participant was asked for clarification, who then explained that it was space inside the house for wet jobs, like washing utensils, washing clothes, bathing etc. As mentioned earlier, I spent the first 20 years of my life in New Delhi. However, my socio-economic background ensured that the use of such a common space was unnecessary and had separate spaces and even machinery for them. Hence, I did not know its name. At the same time, I was aware of the existence of such a space in houses from low socio-economic backgrounds through my social work practice in Mumbai. However, due to regional differences, it was called '*mori*' there, which allowed me to quickly recognise it. Another example was when one participant from Mumbai, spoke in the *Tapori*³ style of the Hindi language, which is a street dialect unique to Mumbai which is a mixture of Hindi, Marathi and other languages. This dialect is also usually associated with people from low-socio-economic backgrounds. Therefore, there were times when both the participant and I needed clarifications.

In many of these interviews, participants were reflecting on issues that they had not considered so explicitly before. Therefore, throughout the engagement, I kept alert to any signs of distress or discomfort. For some participants, these interviews unearthed painful memories and emotions and they over-shared about certain aspects of their lives. One participant opened to me about a distressing event potentially under the reassurance of confidentiality and the presence of an impartial stranger willing to listen. I did not interrupt them and tried to be an active sounding board for them. This information was not used for this study. This was not a safeguarding issue and therefore did not need follow up.

³ The word *Tapori* is also used to describe rowdy or street behaviour.

There were instances where the participants' eyes welled up or voice trembled while talking about their care-recipient. We immediately paused the interview at these times. I offered them water and/or tissues. Some participants preferred to continue the conversation after this, while others took a water break and came back after a few minutes. After the break the participants were asked if they preferred to continue another day but all of them chose to carry on with the conversation. There were some other participants, who started sharing and then suddenly stopped themselves. They were not pressured to disclose more than what they were comfortable with. In such instances my training as a social worker aided my decision making.

Like many non-western cultures, communication in the Indian cultures entails the use of many non-verbal cues (Singh, McKay and Singh, 1998). These could be both intentional and unintentional (Dash, 2013). During the interviews in this study many non-verbal responses were used by the children as a substitute for verbal messages. These involved- body movements or gestures, eye contact or lack of it, pauses and silences, etc. For example, a shrug, taking the form of hunching the shoulder slightly under the ears could indicate 'I don't know' (Singh, McKay and Singh, 1998) Another example would be breaking eye contact and blushing or looking at one's feet while lowering the tone of one's voice, which indicated 'shame.' I tried to observe these non-verbal cues and either made written notes of them or made verbal notes in the voice recorder. For example, if a participant responded non-verbally to a question asking them if they worked for an income by shaking their head to indicate disagreement, I would verbally confirm the response by stating, "Okay, no you don't." This was done to ensure that the participant's answer was recorded in the voice recorder.

Due to the authoritative order between adults and children in society, the power difference between adults and children are unavoidable (Hemming, 2008). This is true for these interviews too. Therefore, to reduce some power disparities, some strategies were used in these interviews like- at the end of the interviews, I asked the children if they had any comments or suggestions for me and if I could have done anything differently. This was aimed at giving them some power to give me feedback. Most participants had no additional comments and expressed that they appreciated the opportunity to share these experiences. However, one participant asked where they could read what I would write. They were informed that I would be sharing a report of the study with the organisation and that they could approach them for it.

Additionally, the participants were also requested to choose their own pseudonyms for their interviews. One participant chose the name, 'Khushi' which translated to happiness in English. It appeared as though the child was indicating to the lack of the same in her life. Another participant chose the name 'Rani' inspired from Rani Laxmibai (Queen Laxmibai) a historical figure known for her courage and grit. One participant chose the name of her deceased mother. Others chose names of their favourite TV characters or other names they liked.

They were informed that if there was anything else that they felt like sharing, they could contact me on the number provided on the Information Sheet.

Additionally, to end the interview on a lighter note, I spoke to the children about, their plans for the rest of their day, their favourite games or TV shows. I ensured that the children were not distressed and left the interview in a similar physical and emotional state as they arrived.

For a detailed list of the participants, their biological sex, age at the time of the interview and their care-recipients please refer to table 2. The care-recipients have been mentioned in the decreasing order of their care requirements, with the primary care-recipient mentioned first. All the names used in this research are pseudonyms.

Table 2: List of Child Participants and the Family Members they Cared For

S. No	Participant	Age	Sex	Carer For
1	Pihu	12	Female	Mother, Paternal Uncle, Younger Sisters
2	Nisha	17	Female	Niece, Mother
3	Sameer	15	Male	Mother, Brother
4	Alicia	18	Female	Mother
5	Gazal	17	Female	Mother
6	Ayana	17	Female	Father, Mother
7	Ruksar	17	Female	Mother
8	Suhana	15	Female	Older Brother
9	Kabir	16	Male	Mother, Older Sister, Younger Brother
10	Reshma	15	Female	Father
11	Kavita	15	Female	Father
12	Ganesh	17	Male	Mother
13	Rani	16	Female	Mother, Grandmother
14	Naira	16	Female	Younger Sister, Grandmother
15	Sahil	15	Male	Mother
16	Moto	15	Female	Younger Brother, Younger Sister, Father
17	Bitto	15	Female	Father
18	Yashika	16	Female	Father
19	Nidhi	18	Female	Younger Brother, Younger Sister, Mother
20	Khushi	18	Female	Mother, Father, Younger Sister
21	Payal	15	Female	Father

Key Informants

The information sheet (Appendix 14) describing the study and requirements from the participants was shared with each participant prior to the meeting, along with a brief of the study. The time and venue of the interview was arranged based on the participant's convenience. The venue for these interviews were mostly the key informant's office or the organisation's community centre. Before beginning the interview, I re-introduced myself to the participant. This was done even though I was already working with some of the participants for recruitment of child participants. Thereafter, the purpose of the study was briefly discussed with the participant and then

any doubts or questions were addressed. I also shared a printed copy of the information sheet with my contact details. They were informed that their participation was completely voluntary. After this written consent was gathered from each participant. These interviews were also recorded using a recording device. Table 3 lists the details of key informants who participated in the study.

The interviews with the adult key informants who worked closely with children were not intended to cross check the children's opinion, rather to provide a holistic interpretation of the young carers' social-economic situation and of the data collected. Most of these interviews were conducted in Hindi, except for the interview with Key informant 2, which was conducted in English.

Like, the child participant interviews, the adult participants in these interviews too were reflecting on issues they had not considered before. These interviews were retrospective accounts of the participants experience of working closely with vulnerable children and families. Most participants shared that they had observed children caring for family members as part of their practice but had never considered them to be children in need of care and support. They applauded these children for their commitment, however, the support provided to these children was either episodic or directed towards other needs resulting from their care roles like, educational support when their studies were getting affected. The children were seldom directly supported in their caring responsibilities. As the participants had limited experience of the topic, some digressed into talking about their area of expertise and I had to steer them back, at the same time ensuring to avoid over direction as recommended by Myers and Newman (2007).

Unlike the child participant interviews, the key informant interviews offered fewer non-verbal cues to draw upon. Their responses were direct and assertive. The interviewees were older and more experienced than I was. This stood in marked contrast to the interviews with children, where I was older than the participants.

Barring one interview which lasted for two hours all other interviews were only an hour long. At the end of each interview, the adult participants were also asked for feedback on the interview questions. These participants were also informed that they could contact me on the contact details provided on the information sheet within fourteen days to withdraw from the study. They could also add or remove information if they

change their mind on any conversation within the interview. I did not receive any withdrawal requests.

Table 3- List of Key Informants

Participant	Sex	Location	Designation
Key informant 1	Male	New Delhi	Social Worker
Key Informant 2	Male	New Delhi	Project Lead
Key Informant 3	Male	New Delhi	School Teacher
Key Informant 4	Female	Mumbai	Social Worker
Key Informant 5	Female	Mumbai	Social Worker
Key Informant 6	Male	Mumbai	Social Worker

Translation and Transcription

Transcription of the interviews in this study encompassed translation from Hindi to English. Although this was a long and demanding process, I undertook it myself, and no external transcribers were employed as the participants were ensured complete anonymity. Furthermore, to maintain anonymity, all the field work data, including the recordings and transcriptions, were only accessible to me and my supervisor. My familiarity with the culture and proficiency in the Hindi language ensured that, complications arising due to non-native researchers were kept to a minimum (Davidson, 2009). However, as mentioned above some confusions did arise due to socio-economic differences between me and the child participants. These terms were clarified then and there with the participants. Some of these terms have been retained in the original language as would be seen in the excerpts from these interviews in the following chapters.

On the continuum of transcription practices the interview transcripts inclined towards a denaturalised approach as opposed to a naturalised approach as the research aimed at reflecting on the deeper socio-cultural discourses rather than linguistic markers (Davidson, 2009; Brown and Danaher, 2019). Naturalised transcription prioritises the written conventions of language, often smoothing or omitting features characteristic of spoken discourse. In contrast, denaturalised transcription retains the authentic elements of oral communication, such as fillers like “um” and “er,” to preserve the original speech patterns (Davidson, 2009). The aim was to retain features of the spoken

language while also elaborating on the meanings and perceptions that constructed the everyday realities of the participants. Transcription was also an important aspect of the analytic procedure wherein I engaged with the interviews through reflection for this research (Davidson, 2009).

For the interviews with children, a subset of 10 interviews were chosen based on diversity of perspectives in the sample for verbatim transcriptions. The remaining 10 interviews were reviewed by coding the audio directly using MAXQDA, a qualitative analysis software and through case studies summarising the interviews. The themes identified from these interviews were then compared against the fully transcribed interviews to ensure consistency. This method ensured time efficiency and focus on relevant data for analysis. All the key informant interviews were translated and transcribed.

Analysis of the Interview Data

The interview data collected from the children and key informants were analysed using thematic analysis. The analysis used Braun and Clarke's (2006) guide of thematic analysis. Thematic analysis was selected as a method of analysis for its capacity to identify patterns and describe both implicit and explicit ideas of the research topic (Guest, MacQueen and Namey, 2012; Miller, 2024). Moreover, its theoretical flexibility also allowed for the application of various concepts to guide the analysis (Miller, 2024).

The transcribed interviews and audio recordings were loaded on to MAXQDA. The young carer interviews and the adult key informant interviews were treated as two separate data sets and were therefore treated as two separate projects in the MAXQDA software. This was deliberately done to prioritise the voices of young carers. Such a separation also allowed for meaningful comparisons across the two data sets.

The analysis followed Braun and Clarke's (2006) six-phase guide, while acknowledging their assertion that thematic analysis is not a rigidly linear process but one that requires recursive engagement and iteration. The process involved both descriptive and interpretative layers of analysis. In this analysis the data was firstly organised and summarised, and then patterns and their broader meanings were interpreted and theorised (Braun and Clarke, 2006).

Phase 1: Familiarisation with the Data

Although I conducted the interviews, the process of familiarisation was essential in gaining a holistic understanding of the data. This phase involved reading and re-reading the transcripts and listening to the audio recordings, which enabled me to engage with the data at a deeper level. Notes were taken during this process to capture early impressions and potential analytic observations.

Phase 2: Generating Initial Codes

This involved looking for key-words, trends, ideas or patterns in data sets and then coding or grouping them into codes and sub-codes (Guest, MacQueen and Namey, 2012; Miller, 2024). An inductive or bottom up way of thematic analysis was used meaning that codes were derived directly from the data rather than guided by pre-existing theories (Braun and Clarke, 2006). This was done because the thesis was studying an under-research concept. The young carers' data set was coded first, to give primacy to children's voices in the analysis.

Some of the initial codes generated from the young carer data sets were – 'care-recipients' issues,' 'domestic chores,' 'assistance required by the care-recipient,' etc. Codes like 'impacts' had sub-codes like – 'impact on education,' 'physical impacts,' 'emotional impacts,' etc. While coding, annotations were made using MAXQDA's memo feature, allowing me to jot down analytic notes and reflections that were revisited and refined as coding progressed. The adult key informant data set was coded separately using the same inductive process.

Phase 3: Searching for Themes

After initial coding, I examined how different codes related to one another and began to collate them into broader themes. MAXQDA's mind-mapping tools were used to visualise the connections among codes and explore thematic groupings. This step was aimed at identifying patterns across the data sets which answered the research questions.

At this stage, the children's and adult key informant's data sets were initially coded separately, they were then reviewed together to identify both similarities and differences across the two groups. Children predominantly spoke about their day-to-day caregiving experiences and the impacts these responsibilities had on their education, emotional wellbeing, and physical health. Key informants echoed many of

these themes in their reflections. In addition, the adult participants contributed insights into broader systemic, socio-cultural, and institutional challenges, such as the lack of policy recognition for young carers, limited-service provision, and cultural barriers. This comparative phase helped enrich the thematic framework by highlighting not only shared understandings but also distinct layers of meaning across the two groups.

Phase 4: Reviewing Themes

In this phase, the generated themes were reviewed and refined in relation to the research question, which sought to understand the experiences of being a young carer in India and the challenges they face.

The review process began by revisiting the codes within each theme to evaluate whether they formed a meaningful and internally consistent pattern. Extracts that did not clearly align with the central idea of a theme were reconsidered. While some codes were re-coded, other were reassigned to more suitable themes, or removed if they did not contribute meaningfully. This process ensured that the data within each theme grouped logically and that the themes themselves were clearly distinct from one another.

Through this review three major themes were confirmed. The first theme encapsulated the experiences of being a young carer in the Indian context capturing the daily responsibilities and nature of their care work. The second theme covered the impacts of caregiving on the various aspects of the children's lives like education, physical health, emotional wellbeing, among others and also the exacerbated nature of impacts because of the lack of support systems around them. The third theme which was primarily generated from the key informant data set, highlighted the systemic challenges faced by young carers and also captured some suggestions to address these challenges.

Reviewing the themes across both data sets also highlighted the overlap and divergence in perspectives. While children spoke from lived experience, adult key informants often reinforced these accounts while also identifying wider systemic and socio-political issues. This dual perspective added depth to the thematic structure and ensured that the final themes reflected both personal narratives and structural

insights. Thus, in this phase, the themes were refined into coherent and distinct themes which answered the research questions.

Phase 5: Defining and Naming Themes

In this phase clear definitions and names for each theme was generated. As suggested by Braun and Clarke (2006), the 'essence' and broader meanings of themes were interpreted and theorised in this phase. The overarching themes reflecting the various aspects of the data were titled as follows:

1. I do everything: the everyday realities and nature of care work by children in India
2. No respite: navigating the impacts of the caregiving role
3. Seen yet overlooked: The systemic blindness towards young carers in India

Theme one captures experiences of children who undertake adult-like caring roles in the Indian context and their intricate position in their family's functioning. It also explored how these roles and responsibilities were normalised and naturalised in their lives. Theme two reports on impacts of these responsibilities and how the participants managed various obligations in the absence of formal support systems. Theme three focuses on the structural challenges the young carers face in the Indian context, reflects on policy gaps and offers suggestions for supporting such children in India.

Phase 6: Producing Report

The final phase of Braun and Clarke's (2006) guide involves the production of the report or in this case, the writing of the analytical chapters. As detailed above, the thematic analysis process resulted in three major themes, which have been presented as separate chapters. These are discussed in detail in chapters seven, eight, and nine. These chapters use extracts from the interviews, patterns from the data and my reflections to demonstrate the complex lives of young carers in India, while aiming to address the research questions and convey the core meaning of the data.

Chapter Summary

This chapter discussed the various methodological and practical considerations employed in the qualitative research design. It offered an extended account of the approaches utilised to identify children with caring roles and key informants who worked closely with children. It also explained how the interviews were conducted,

recorded, translated, and transcribed. It concluded with detailing the analysis technique used to thematically code and interpret the data which resulted in the generation of three key themes which this thesis seeks to elucidate on in the following chapters. These themes are- 1. I Do Everything: The everyday realities and nature of care work by children in India, 2. No Respite: The impacts of the caregiving role and 3. Seen Yet Overlooked: The systemic blindness towards young carers in India. The following three chapters will communicate results from the qualitative interviews conducted with 21 young carers and six key informants in New Delhi and Mumbai.

Chapter 7: I Do Everything- The Everyday Realities and Nature of Care Work by Children in India

Introduction

This chapter will elaborate on the first theme from the qualitative thematic analysis of the interview. It will explore the circumstances under which the children in the sample undertook adult-like responsibilities. It will also delve into the tasks they performed on a regular basis and the regimental nature of these tasks which made them young carers, contributing to the understanding of being a young carer in the Indian context.

Antecedents to Caring

This section will elaborate on the reasons children became carers for their family members. The antecedents to their caring role can be broadly divided into- explicit reasons and implicit reasons. The explicit reasons elaborate on the immediate cause for their caring role, and the implicit reasons cover the broader socio-economic conditions which pressured these children into becoming care givers.

Explicit Reasons

The apparent reasons or incidents because of which the children in this study adopted caregiving roles can be further divided into- long term illness, disability, substance abuse, accidents in the family and demise of a family member. These factors had an immediate or cascading effect on the child assuming a carer role.

For 12-year-old Pihu, her mother's long term mental health problems were the cause for her taking on adult roles from a very young age. Since she was the oldest of three sisters in the family, she had to assume her mother's responsibilities. She was unable to explain the exact problem or illness but was only able to say that her mother was, *"sick in the head."*

This lack of information was a common occurrence throughout many interviews, wherein the children did not know the name or reasons for the illness but were only able to explain the symptoms as witnessed by them. 17-year-old Ruksar said that her mother gets *"fits,"* another term for seizures. On being asked if she knew why her

mother got seizures she said, *“I don’t know that much... That time we were young, so we don’t know and neither have we been told as to why it happens.”* According to her observations her mother got seizures when she has some kind of *“tension.”* She also said that it could be because, *“there is a vein in her brain in which a lot of blood has accumulated/frozen.”* 18-year-old Alicia, a carer for her mother, was only able to say that her mother’s, *“head hurts, she gets fever sometimes, her heartbeat increases rapidly.”* 17-year-old Gazal and 16-year-old Kabir were also unaware of the reasons for their mothers’ ill health. Sameer, 15-years-old, knew bits and pieces of information about his mother’s ill health and that his mother had constant pain in her hands due to over consumption of substances like *gutka/paan*⁴. She was operated on her face and neck which resulted in her losing significant function in her hands.

Consequently, in the absence of definitive reasons, some children constructed an understanding of the situation which aligned with their observations. For example, 16-year-old Rani only knew that her mother’s breathing problems and difficulties with mobility were due to weight related issues. She did not know the cause for the same so, she developed an explanation for herself. She shared, *“she is healthy [meaning fat] but in her body, inside, nothing is left...she has been sick for a long time, right, so because of the medicines, her bones, her muscles have left the bones. So, it’s all hanging.”*

Some others like 17-year-old Ayana knew that her father had blood pressure related issues. 15-year-old Suhana explained that her older brother was paralysed from birth. 18-year-old Khushi had been a carer for her mother suffering from tuberculosis and her father with alcohol related issues. 15-year-old Payal’s father was also suffering from issues related to alcohol abuse. 15-year-old Reshma was a carer for her father with liver disease. 15-year-old Sahil said that his mother has a physical disability as she was affected by polio during her childhood.

15-year-old Kavita’s father, 17-year-old Ganesh’s mother, 16-year-old Yashika’s father and 15-year-old Bitto’s father were suffering from physical ailments because of accidents and related diseases. 17-year-old Ganesh explains, *“... [mother] has a bit of a limp while walking... she can’t stand for long. Her hands and legs keep hurting... she*

⁴ chewing tobacco

does not work...she can't even sit properly... her leg starts swelling...and sometimes she sweats where the wound is."

Some caring roles were triggered by changes within the household, for example, 15-year-old Moto had to take on a parentified role towards her younger brother and sister after her mother separated from their father a few years ago. Additionally, her father also had physical and mental health concerns. The children lived with their father.

Others like 16-year-old Naira's care responsibilities were due to the demise of a family member. Her mother passed away during childbirth leaving the baby in Naira's care. Nisha, 17-year-old, was also in a similar situation wherein she was caring for her deceased sister's daughter. She had to take on this responsibility after her sister passed away during childbirth. Nidhi, 18-years-old, became a carer for her younger brother and sister after the death of her father who was the sole bread winner in the family. The absence of a wage-earner meant that the mother had to start working outside the family home for the first time and as a result Nidhi, being the oldest child in the family, then had to free her mother of responsibilities of looking after younger siblings and the household. Therefore, it can be said that these explicit reasons shocked the fixed roles in the family system and created a gap. In the absence of resources or other adults to plug this gap, the children had to step in. Key Informant 2, a development sector professional from Delhi believed children become caregivers when the primary breadwinners become ill.

These were some of the immediate circumstances due to which children in this study found themselves to be in a care giving role for their family members. Factors like long term illness, disabilities, accidents in the family, demise of a family member or substance abuse did have a direct influence on them becoming young carers. However, this is not the whole picture. These were not the only reasons why children in this study became carers. The likelihood of children becoming carers or taking on adult like responsibilities may be greater with inadequate socio-economic circumstances, which may add to the nature and extent of their vulnerabilities. These would be elaborated on in the next section.

Implicit Reasons

While the children only spoke about the explicit reasons, it was evident from the children's and key informant interviews, that other implicit factors like poverty and migration also played a key role in the children becoming carers.

Poverty and Lack of Resources

Literature from the UK associates poverty in the families of young carers as a repercussion of ill health in the family or disability (Bibby and Becker, 2000). This is accurate considering the strain that illness or health care needs may place on a family's resources. Nonetheless, data from this research suggests that poverty could also be a major reason why the children in the sample had to become young carers.

Most children in the sample belonged to families, involved in informal/unorganised employment⁵, earning daily wages. Meaning, if they were unable to work, they did not earn money. Just like many developing countries, informal sector jobs in India do not provide any labour-based social protections, including health insurance, unemployment benefits, paid leave, paid vacations, or old age pensions (UNDP and OPHI, 2020).

Fathers of the participants in the sample were involved in jobs like construction work, mending cycles, welding, POP (plaster of paris) work, tailoring, painting, *jhoolawala*⁶, factory worker, driver, seasonal farmer, etc. The mothers in the family were also involved in similar occupations in the informal/unorganised sector like, domestic work or factory work.

Some families, like those of Pihu, Naira, Rani, Nisha, Moto and Kabir, were involved in unorganised home-based enterprises. Additional details pertaining to this will be presented in later in the chapter.

⁵ The terms informal sector and unorganised sector are used interchangeably in the Indian context. The informal sector workers are defined as a worker with no written contracts, paid leave, health benefits or social security (Murthy, no date).

⁶ Jhoolawala is a person who would walk around the city with a portable mini version of a Ferris wheel. These are usually person sized. This is meant as an entertainment for children. They are paid based on the number of participating children.

At the time of interview, the families of Ayana, Kavita, Rani, Bitto, Reshma, Khushi, were dependent on the incomes of their elder siblings as neither of their parents were working.

Gazal, Suhana, Naira, Moto, Nidhi, had only one parent in the family who was bringing in an income at the time of the interview. On the other hand, Yashika and Kavita had no income coming into the family. As a result of these circumstances, these children themselves had to, in some instances, pitch in to support the family's finances along with their caregiving roles. These would be described in detail in the sub-section titled 'Supporting the Family Financially' later in the chapter.

17-year-old Ganesh revealed that his mother's accident and the resultant medical expenses incurred had put a huge pressure on the family's finances. He shared that after the accident, *"...we took her to the hospital. Those, umm, the train people they took her to the private [hospital] then whatever expenses there were, all that, papa only had to pay, then big brother also gave money. We had also borrowed from other places. The whole lockdown, we were in problems."* This was because finances in these families were limited, and such income shocks could lead to its derailment.

Lack of resources was another aspect of poverty which led to an increase in their workload and its complexity as compared to their less disadvantaged counterparts. For example, some participants shared that they had access to basic amenities like water only once a day at very unsociable times like midnight or 4am.

Most of these families lived in very small spaces. This is clear through 15-year-old Sameer's interview when he shared that his mother sleeps on a bed which needs to be spread every night and then picked up every morning. Suggesting that the space was also used for something else other than sleeping. 16-year-old Naira also mentioned having to pick the bed up, every morning. Limited spaces could also indicate a lack of private space for the young carers.

Additionally, they lacked machinery like washing machines, which implied that they had to invest more time and physical energy in washing clothes by hand. Some participants also shared that the family did not own a refrigerator. This conveyed that they could not buy and store groceries in bulk resulting in them buying groceries every

day and cooking every meal freshly for their families. Lack of storage space and daily-wage-based-incomes also augmented the laborious nature of their chores.

Key Informant 2, a development sector professional from New Delhi adds, *“...reason for taking up the job of caregiver at a young stage, the major compulsion is because of economics only. Otherwise, they could have hired a maid from outside...So in a family with dwindling economy only, such [young] care giving practices come up... Only those families will have to compromise on all these things, make the family members themselves take care of their sick ones ...”* Key Informant 1, a social worker from New Delhi was of the opinion, *“other factors come later, firstly it is the money.”* Other key informants also had similar opinions. Due to economic deprivation these families could not afford external support for the care-recipients, which would be expensive. This meant that the children had to take on carer roles as there was no one else to do it cheaply and affordably, often at a great personal expense as will be elaborated in the next chapter.

Migration

Most of the families in this sample had migrated from rural villages in nearby regions like Uttar Pradesh, Madhya Pradesh, Bihar, etc to the cities of New Delhi and Mumbai. They moved in search of better jobs and opportunities but still maintained strong ties with extended families living in the villages. 18-year-old Khushi's family who had migrated to New Delhi said, *“our family is from Jhansi, MP, Madhya Pradesh...since I was born, we live here only, we don't live in the village...we do visit often.”* 17-year-old Gazal was brought to the city to care for her mother. She migrated to the city, leaving her school and everything she knew to support her mother.

Key Informant 1, a social worker from New Delhi shared, *“firstly there is migration. So, they have lost their joint family. If the grandparents were there then they might have done the care work.”* Other key informants concurred with this connection of young caring practices to migration, however, some families in the sample had extended family members like uncles, aunts and grandparents living in proximity but support from them was limited or episodic in nature. Therefore, the correlation between migration and young caring needs to be studied further.

Started Young

Even though the participants in this study were in the age group of 12-18 years, many of them shared that they had been caring for the care-recipient from a very early age.

For some young carers, the start of their caregiving responsibilities usually coincided with a major event like an accident or a major operation. For example, 15-year-old Sameer, started caring for his mother after her operation, when he was 10 years old. 17-year-old Ruksar associates the beginning of her mother's illness with the birth of her younger brother. She was only 4 years old then. 16-year-old Naira started caring for her sister when she was 14 years old after the demise of their mother. 18-year-old Nidhi had been a carer for 5 years and 17-year-old Nisha for 6 months at the time of the interview. Both started care work after the demise of a family member. Young carers like 17-year-old Ganesh, 15-year-old Bitto, 15-year-old Kavita and 16-year-old Yashika started care work after an accident in the family. Ganesh had been a carer for 2 years, Bitto for 3 years, Kavita for 2 years and Yashika for 2 months at the time of the interview. 15-year-old Moto started care work after her parents separated when she was 8 years old. 17-year-old Ayana associates her care work journey to the covid lockdown, as her parents' health declined after that. She had been a carer for 2 years. 15-year-old Suhana started only a year before the interview because before that she was at a residential school. 17-year-old Gazal was brought from the village to the city to care for her mother when she was 14 years old. 16-year-old Rani said that she started caring for her mother when she was 8 years old because before that her maternal aunt was living with them to care for her mother. After the aunt was married, Rani had to take over from her. 16-year-old Kabir shared that he started around the age of 12 or 13 years and 15-year-old Sahil shared that he started when he was 5 years old.

For others, care work had been a part of their lives as long as they could remember in some capacity. Therefore, they could not remember the exact time when they started. 12-year-old Pihu shared that her mother had always been sick. This meant that she had to start caring for her mother very early on. She is supported in her care work by her two younger sisters who were 9 and 10 years old. 15-year-old Payal had been dealing with her father's substance abuse related issues for a long time. 15-year-old Reshma sums this up very clearly when she says that she had been a carer *"since she remembers."*

Therefore, it can be inferred from above that caregiving could start for children at any time in their lives. It could be as early as 4 years or as late as 17 years, while some others are born into caregiving.

Tasks Performed by the Young Carers

This section will talk about various duties of a young carer. The main responsibilities of the children were – caring tasks and household chores. Additionally, there were also other duties which some of the participants had to perform like - caring for siblings and other vulnerable family members and supporting the family financially.

Caring Tasks

As the children in this study were charged with caring responsibilities of their family members, assisting the care receivers was their primary obligation. This section categorises the various tasks the children undertook into support with mobility, managing medical needs, help with intimate hygiene requirements, emotional support, constantly monitoring the care-receiver, support with nutritional and other needs. As will be evident from chapter 11, many of these tasks were unusual for their age and beyond what would be expected of most children their age. However, for children in this qualitative study, these tasks were part of their daily routine.

Assistance required by the care-receivers in this study was on a spectrum, some required a lot more support than the others, and the care needs also fluctuated making some days tougher for the young carers. In some instances, the person receiving care was reluctant to accept help from anyone else other than the young person, as clearly explained by 16-year-old Yashika, carer for her father who was incapacitated due to an accident. She said, *“when I am around, then papa says you only do it...because mummy does not have strength in her, he says mummy does not do it properly, you do it nicely.”* 15-year-old Reshma’s father also preferred her support over her four brothers. He refused to go to hospital with them. This put additional pressures on the children.

Support with Mobility:

Supporting the care-recipient with physical aspects of the care was one of the central responsibilities of the young carers. For the children in this sample this could range

from help with walking, getting up from bed, sitting down, and in some instances ensuring limited physical exercises to mitigate further decline in their physical condition.

Rani, 16-year-old, a carer for her mother with long term physical ailments, said, *“Because of the breathing [issues] she cannot walk alone... her hand has to be held and [she needs to be] taken along. So, because of this, I only take her.”* Rani was a carer for her grandmother too, who also needed support with walking.

16-year-old Naira, a carer for her grandmother, had to help her grandmother walk to the communal toilet and back, *“grandmother is unable to get up also...help her get up from the bed, hold her hands, and take her to the washroom, helping her sit...”*

16-year-old Yashika, a carer for her father shared that when her father was really unwell and could not get up from bed, she needed to support him with getting up and then help him sit using her own body weight, *“he wasn’t able to get up, so I would first help him get up, someone would sit behind him supporting his back with theirs, then only he used to be able to sit.”* On being asked who supported the father she replied chuckling shyly, *“Me, I would take the phone and sit there using it.”*

12-year-old Pihu, 15-year-old Reshma, 17-year-old Ganesh and 17-year-old Gazal also reported that their care-recipients needed support with general mobility.

Supporting with physical mobility also involved making sure that the care-recipient does not have to move much as this may hurt them. For example, 15-year-old Sahil, carer for his mother with a physical disability, ensured that his mother’s clothes were ready and kept right outside the bathroom for her after her bath. He also made sure that her medicines were kept next to her bed from where she could easily access them.

Some of the children spoke about getting aches and pains potentially due to the physicality of care. This will be discussed in detail in the next chapter.

Managing medical needs:

Catering to the medical needs of the care-recipient was another key aspect of the young carers' responsibilities. However, this meant different things for different children in the sample.

For 17-year-old Ruksar, managing the medical needs of her mother involved asking her mother twice a day, *"have you taken your medicines? Ate medicines?"* This was because the mother tended to forget her medicines especially when she was stressed out. Ruksar's mother needed to take her medicines regularly otherwise there was a possibility of her getting seizures. Ruksar also recalled scolding her mother for forgetting medicines. As a response to this behaviour her mother used to say, *"you are my amma [mother]."* Even though this was a common joke in Ruksar's family, this excerpt shows that the child assumed a 'parentified' role towards the mother.

Managing the medical needs of the care recipient also involved buying and administering medicines on time. As 16-year-old Rani explains this clearly when she said, *"And then there are mummy's medicines that need to be given on time, I give that [to her] time to time.... I bring [buy] them [medicines]."* Rani also mentioned that her mother needs to be administered home remedies for her breathing problems. She also makes sure that her mother is kept warm, by putting a blanket over her, especially during colder months and lighting a fire next to her which kept her warm. She explains, *"...the fire has to be lit in a [special] way. Ajwain [carom seeds], muleti [licorice spice] and all needs to be put in the fire so that, so she keeps getting its vapour."* She did this because the family did not have internal heating arrangements and therefore had to rely on open fires to keep themselves warm.

15-year-old Reshma also helped her father with medicines. When she was asked about her role, she casually diminished her contribution by saying, *"I do bring it for him, but it's not my money that is involved."* She added that her father had different kinds of medicines, *"four leaflets of medicines, three syrups, and this [gesturing with hands] big a powder [packet], that needs to be put in milk and given.... both in the morning and evening."* It was Reshma's responsibility to buy these medicines from the pharmacy and to ensure their timely administration.

16-year-old Yashika, also had to remember to give her father his medicines. She added shyly, *“now there are few [medicines], earlier there were more, earlier I used to forget also (smiling shyly) ...now there are only 2-3, one at 12 o’ clock or so, one at 7 o’ clock, at night... and one in the morning.”*

For 16-year-old Gopal, the need to support his mother with medicines arose because she was not as educated as him, he explained, *“we [he and his younger brother] give her, yes. She has studied till 5th [class only], that’s why... so we have to give her medicines.”*

Young carers also attended to the physical aspects of medical needs, for example, massaging body parts in cases of aches/pain and tending to their wounds.

17-year-old Ganesh, a carer for his mother with physical ailment shared, *“... [her legs] swells up. Meaning, while she is walking it swells up, if she wears footwear it swells, or if it is too hot. If she has to wear footwear and go somewhere then it swells up very much... then coconut oil needs to be massaged into her legs... doctor had shown us how it is to be massaged... I have to do it... that gives her some relief. It takes around half to one and half hours for her to get some relief.”*

For Sameer, massaging his mother’s hands and legs was part of his daily routine now. He said, *“...anyway it’s an everyday thing for me, massaging mother’s hands and legs at night, I massage till 2-2.30 (am).”* 16-year-old Yashika also massaged her father’s legs and helped him with physiotherapy exercises.

15-year-old Kavita’s schedule involved dressing her father’s wound every two days. Kavita’s diabetic father was incapacitated due to a major wound in his leg. He had been unable to move for almost two years before the interview. *“I do [dress the wound]. We are unable to go to the hospital, right, that’s why I do it,” said Kavita.* Additionally, she also spoke about the complex medical decisions she was asked to make on her father’s behalf. She had to sign to consent for a medical procedure. *“The most challenging ... was when papa was ill and was in the hospital and when doctor had asked us to sign, that was a very difficult day.”*

Supporting with medical needs also involved accompanying the care receiver to the hospital and being their bystander ⁷ at the hospital whenever required. Rani, 16-years-old accompanied her mother to the hospital, whenever required. Sometimes she also had to explain her mother's distress to the doctor, whenever her mother was unable to. She says, *"because of breathlessness and because of shortness of breath she is unable to speak then."* If the mother was unable to travel to the hospital, Rani would go to the doctor herself and tell the doctor about the mother's illness and bring the medicine.

Whenever 15-year-old Suhana's brother had to be taken to the hospital, she accompanied her mother to the hospital and she, *"sat looking after brother"* so that her mother was free to deal with hospital paperwork and other formalities. She did this in addition to buying her brother's medicines and administering them on time.

17-year-old Gazal, however, did not have to be at the hospital with her mother but had to visit everyday with food and other requirements. She says, *"when mummy was at the hospital then only papa would be with her, I just had to take food and clothes for her."*

These contributions by the young carers enabled the care recipients to effectively manage their medical needs at home or in the hospital rather than relying on external support which could be expensive.

Intimate Hygiene Needs:

Some children were also responsible for assisting their family members with intimate hygiene requirements of toileting and bathing. 15-year-old Kavita, whose father was confined to the bed, shared that she and her younger sister bathed their father twice a week. She explained the process saying, *"He just lies like that [on the bed] and raises himself a bit and we spread something under him, fill the bucket [with water] ... we bath him... we lather and wipe him...we do it only two days a week, because it is not possible*

⁷ A bystander, or hospital chaperon in the Indian context is a person who accompanies the patient to the hospital. This could be a family member or a friend. It is common for patients to be accompanied by a bystander in hospitals. In addition to supporting the patient emotionally, they are often expected to buy and get medicines for the patient from the pharmacy or buy food and feed the patient too. A bystander has different names in different parts of India.

for us every day.” He wore an adult incontinence pad for his toileting needs when the family had disposable income. But the more frequent occurrence was that he urinated in a small bottle, which was kept beside his bed. When the father needed to defecate, the sisters put a cloth under him, which was later disposed of by the children.

15-year-old Suhana, who is a carer for her brother with paralysis and epilepsy says, *“If it is washroom [urine] I clean it...have to pick up the sheet and clean him...at least 2-3 times a day... he does everything [defecate] at his place only... if he has done potty then I tell mummy, I don’t like it. I feel like vomiting. So, it’s like that...If he feels like vomiting, then I sit in front of him, with a cloth...”*

16-year-old Naira, 17-year-old Nisha and 15-year-old Moto were carers for younger siblings and had to support them with basic toileting and bathing needs.

Naira was also a carer for her grandmother, and she says, *“When grandmother is very sick and grandmother is unable to bath, then I fill water at home and bath her...”* 17-year-old Ruksar also had a similar situation wherein on some days, her mother required help going to the toilet. 17-year-old Gazal also mentioned helping her mother with bathing and with toileting.

Some of these families did not have a toilet inside the house, instead they used community toilets as is the case for a lot of low-income families in these cities. This meant that these toilets could be at a distance from the house and sometimes they would even have to wait in queues for their turn. 16-year-old Rani mentioned taking her mother and maternal grandmother to these community toilets every day. She added that because both needed support walking, she had to take them individually as it was difficult for her to take them together.

Rani also bathed her mother. She said, *“if she wants to take a bath, hot water needs to be made for her because if she baths in cold water then she will have more breathing problems. So, the normal water has to be warmed up ...so she can bath comfortably. I only bath her...in the haudiya⁸ inside the house.”*

⁸ A space inside houses for wet jobs, like washing utensils, washing clothes, bathing, etc.

Yashika, 16-year-old, also helped her father with bathing. She says, “[we] bath him... me and mummy.” She immediately adds that her mother was used to taking a bath in the morning and Yashika took bath in the evening. Therefore, it just happened to be that it was Yashika who helped her father with bathing. She talks about the bathing routine and says, “fill water, then warm it up once, a little water, then in that bucket, make it lukewarm..., then put soap [on papa], then papa puts the rest of the water himself, then after he changes clothes, he goes onto the bed, then give him food, after a bit, massage the foot, then do the exercise [the physiotherapy exercise prescribed by the doctor], then after 1 hour, if it’s not working then papa will say that it needs to be bent again and the medicines need to be remembered [and administered] on time.” Thus, highlighting the relentless and repetitive nature of the care tasks she performed. It evokes a sense of fatigue in the listener (here reader), mirroring the tiredness that Yashika might have experienced. This will be discussed further in the section ‘Regimental Nature of Daily Schedule’ later in the chapter.

15-year-old Reshma’s father needed someone to be with him at all the times, even while bathing, “when he goes to the washroom, then he needs to be held and taken... (while bathing) the water has to be really hot and there has to be someone with him all the time.” While for 17-year-old Ganesh helping his mother with bathing only involved filling water in a bucket and taking it upstairs as their bathroom was upstairs and the family did not have the provision for pipeline or motor to pump water upstairs.

The girls in the sample said that they helped their care-recipients with intimate hygiene needs, while boys like Sameer 15-year-old and 17-year-old Gopal, both carers for their mothers, said that they received support from their female neighbours for their mother’s intimate hygiene needs. The gendered nature of care work was observed here.

These excerpts and the experiences of the children in the sample, explain the extent to which the children in this sample were involved in the care routine of their family members. The care-recipients were dependent on these young carers for their basic needs.

Support with Nutritional Needs:

The responsibilities and tasks of the children with regards to nutrition also differed according to the care receiver's needs. While for 15-year-old Sahil and 15-year-old Sameer, caring for their mothers with physical disabilities, it involved preparing and serving a plate of food to their mothers; for 16-year-old Suhana who was a carer for her brother with paralysis and epilepsy, it meant manually feeding him at his bed side. She also had to make sure that he does not choke and understand his hand gestures as her brother was unable to speak. She says, *“So, like if he wants water, then he will do this [making a curved hand gesture], and if he wants food, then he will do like this [bringing the back of her hand to her cheek].”*

12-year-old Pihu, a carer for their mother with mental health issues, describes her mother's needs saying, *“I feed her (mother) with my own hands and make her drink water. I have to support her head and tilt it slightly to make her drink water.”* She does this with help from her 9-year-old sister. This was also the case for 17-year-old Gazal, who had to feed her mother. 15-year-old Reshma had to, *“break the roti [Indian flat bread] for him [father] and give, then he can eat slowly-slowly”* She says, *“I feed him food and all.”*

Some care-recipients also needed separate diets. Therefore, the young carer had to ensure separate meals and meal plans for the care-recipient. This requirement became particularly acute during periods of severe health deterioration. 17-year-old Gopal a carer for his mother with a physical disability shared that due to his mother's medicines, he had to cook separate meals for his mother and for the rest of his family. This placed additional demands on the young carer as he had to procure separate ingredients and cook the meals separately. Gopal said, *“in the morning and evening there was a lot more work... for mummy separate food had to be cooked.”*

Emotional Support:

Another crucial type of care provided by the participants to the care-recipients was emotional support. The care-recipients, being in a vulnerable position, needed constant reassurance, which was provided by the young carers. The participants did

not explicitly speak about providing emotional support to their care-recipients, as it is difficult to quantify. However, throughout the interviews there was an apparent sense that the young carers supported the care-recipients' emotional health.

The young carers were very aware of the mental state of the parent as articulately explained by 18-year-old, Alicia, carer for her mother, who said, *"mummy is also broken completely from inside."* 15-year-old Moto also shared that her father did not openly share about his health issues with his children, but she knew about it because, *"[our] feelings are linked together."* So, she makes sure that she keeps her father happy. She says, *"I have to keep Papa happy, tell him nice things, joke with him.... not let him know of any of our problems, he should be always happy."* This also meant that she had to be happy or pretend to be happy in front of her father even when she was not. *"We have to keep him happy from our side, if we have any problems, we do not show it in front of him. It hurts him to hear about it, we show him that we are happy, about everything, we believe we should keep him happy."* I could feel the pain in her voice when she was saying this. Her voice was breaking and eyes welling up. This was a lot of pressure on a 15-year-old. However, this was important for the family and their sustenance.

17-year-old Ruksar, a carer for her mother also mentioned supporting her mother at the demise of her grandfather. She says, *"when grandfather's thing happened...she was crying. So, I had supported her a little saying 'that's it, don't cry now, everything is okay. Or else grandfather will feel bad.'"* She did this to emotionally support her mother who could get seizures anytime if she was anxious.

15-year-old Kavita when talking about her father says, *"he can't walk right...he is just like 'do not leave me and go, just stay near me.' It's like that."* Though Kavita might not be aware that this was helping her father psychologically, she unknowingly supported her father's emotional needs by just being near him as much as she could.

Nidhi, 15-year-old mentioned that sometimes her mother cried in front of her because of the troubles the family was facing. 15-year-old Suhana who is a carer for her brother with paralysis said, *"... if he is unwell, then sit next to him only. If he is getting irritated, then keep asking him again and again. Keep coming and going for him."* This is how she reassured her brother.

17-year-old Gazal supported her mother by keeping her engaged in conversations “so that she doesn’t worry, and her mind is away from that [tensed thoughts] ... I mean if she is idle then she worries and if you lull her, keep talking to her, make stupid jokes, talk about useless things, then she smiles...”

The depth of layered thinking demonstrated by Gazal serves as indication to the fact that children are not simply naïve individuals rather, they possess the ability to think critically and exhibit a strong capacity for pro-social behaviour.

Key Informant 2, a project lead from New Delhi was also of the opinion that the young carers also emotionally supported the healthy parent.

Young carers addressed the emotional needs of the family members by keeping them happy, reassuring and comforting them, keeping them company, and encouraging them. In addition to aiding the care-receiver, these activities ensured less tension at home which would otherwise adversely affect the health of the care-recipient and put pressure on the family unit. The emotional support provided by the young carers were less obvious and to some extent they themselves and the care-receivers were unaware of it. Therefore, the emotional support tasks were less obvious than physical support tasks. The above-mentioned excerpts point to the importance of emotional support provided by the young carers in the care-recipient’s lives. Additional research is needed to understand more about young carers contributions to the emotional health of the care-recipient.

Children Caring for Children

There were some children in the sample who were primary carers for other children like a young sibling or niece. In such cases they tended to assume a ‘parentified’ role.

After her mother’s demise during childbirth, 16-year-old Naira assumed a mother’s responsibilities and took care of her infant sister. She shared, “*the things that a mother does for children, when the children are young, all those things I only do. Like if she is hungry then boiling and giving her milk. And feeding her, bathing her, washing clothes, hers. All I only do..... Then picking her up, caring for her, I mean, if she potties, cleaning potty, feeding her, putting her to sleep.*”

15-year-old Moto also had to step into her mother's shoes after the mother separated from the family when her younger brother was an infant. She shared, *"he was small, papa had brought me powdered milk, milk powder, that I would mix and feed him, bath him with soft hand [emphasis on the soft], make him wear clothes, massage him."* There was also a middle child in the family, Moto's younger sister, who needed Moto's support. Moto shared that she helped her siblings stay clean, cooked for them, packed their school lunch, took them to the hospital and got them medicines.

The situation was similar for 17-year-old Nisha and 18-year-old Nidhi. This illustrates the dichotomy of young carers' lives, where they were children with their own care needs, yet had to set aside those concerns to prioritise the well-being of other children.

Other Kinds of Support:

Some young carers also reported supporting their care-receivers with tasks such as dressing, washing clothes and money related needs.

15-year-old Reshma shared that her father needed support with getting dressed. 16-year-old Rani had also been supporting her mothers with money-related requirements like going to the money lender and bringing money from them in the mother's stead. Khushi, 18-year-old helped her mother with loan and banking needs.

Constant Monitoring:

Typically, due to their disease or disability, the care-recipients required constant attention from the young carers. 17-year-old Ruksar, carer for her mother who was prone to epileptic attacks says, *"there has to be someone near her all the time...if she falls while standing, then she can hurt herself anywhere. Once she had hurt her nose very badly, it was bad, there was blood coming..."* She also shared another incident when her mother had a seizure and fell on top of a burning gas stove used for cooking.

The young carers constantly monitored care-recipients because they were aware of their vulnerabilities. This involved, accompanying the care-recipient everywhere, and not leaving them alone at all. This was succinctly explained by 15-year-old Sahil, carer for his mother with a physical disability when he said, *"...if she (mummy) needs to go somewhere then she will take me only (along). She cannot go alone...if she goes to the bank, I only go with mummy.... when she goes to the hospital also, I go with her"*.

18-year-old Khushi, carer for her father with substance abuse issues said that even though her father did not require active support with his daily tasks he needed constant overseeing, *“just have to keep an eye [on him] ...I do it”*.

The children in the sample did this to be prepared for adversities and ensure the comfort of the care-recipient. Before going to school every morning, 16-year-old Rani, undertook strenuous amounts of preparation to ensure her mother’s comfort. She keeps her medicines close by, keeps a bottle of warm drinking water along with a glass, and also cooks and keeps food next to her bed. She makes sure that her mother’s bathing and toiletry needs are fulfilled before she leaves but also keeps a bedpan next to her mother which she cleans after coming back from school. She also keeps extra linen next to her mother’s bed in case of continence incident. Additionally, she also kept checking on her mother using her teacher’s phone from school.

The routine chores of the young carers were intense. They had to be ever prepared to act swiftly. This could be an additional mental load for the young carers who were already managing a comprehensive array of responsibilities.

Dealing with ‘Tough days’:

Along with being on an ever ‘alert mode,’ dealing with tough days was another one of the tasks undertaken by the young carers. When the care-recipients’ health deteriorated, their tasks became onerous.

They had to wake up earlier than normal, as explained by 12-year-old Pihu, *“on those days I have to wake up earlier, around 6 am in the morning and finish the chores.”*

17-year-old Gazal dreaded the days when her mother’s health worsened. Describing her tough days, 15-year-old Reshma says, *“those day, those days, I wish, those days did not exist at all, that’s how I feel, crying the whole day, the whole day is ruined.”*

Whenever her mother got seizures, 17-year-old Ruksar and her younger siblings had to do the following- *“we hold her. We hold her and then make her lie down, so that her head does not hit anywhere. Or she does not get hurt anywhere, we do it very carefully. Then we make her lie down and give her the iron thing in her hand, that gives some control... And give her bed rest.”*

This section on ‘caring tasks’ elaborated on the nature of caregiving tasks performed by the young carers in the Indian context. It demonstrated the extraordinary levels of intense labour that were undertaken by the young carers and the profound dedication involved in the caregiving work. These young carers assisted the care-recipients in almost all aspects of their lives most of the times without any complaints. They displayed levels of maturity which are usually associated with adults and not expected of children in an adult-centric society. The following sections will elucidate the additional obligations of the young carers besides their caregiving work.

Household Duties

These young carers heavily contributed to the running of the household by performing domestic chores along with the previously-mentioned tasks of assisting the care receiver. This section will elaborate on the varied household chores undertaken by the children in this sample.

The young carers in the study described undertaking daily responsibilities for various household chores, including cooking, grocery shopping, washing dishes, doing laundry, cleaning the house, and filling water.

It is important to note that most of the times, the cooking processes entailed daily visits to the market to buy vegetables. This is because, the families relied on the daily wages and lacked sufficient income to shop in bulk. After buying the groceries, the children would cook Indian bread or rice and curries from scratch for every meal as most of the households did not own a refrigerator to store food. 16-year-old Yashika explains, *“there is no fridge and all, it [vegetables] rots that’s why, and it was so hot also, that is why we go every day and bring it [groceries].”*

Similarly, washing dishes did not involve the use of a dishwasher, rather it was done manually. In many households, washing clothes was done by hand using buckets and manually washing clothes with water and detergent. Most of the children in this study spoke about washing clothes as one of their daily chores. 15-year-old Sahil and 15-year-old Sameer were responsible for washing their mothers’ clothes as the mothers were unable to do so. Sameer said, *“So, mother’s clothes and all, I only wash...everything I only do.”* This involved washing the undergarments too. Given the shame associated with undergarments in the Indian context, this chore may have

involved a lot of shame for both the young carers and their care-recipients. This chore was not just confined to the care-recipients but also extended to other members in the family. 16-year-old Rani stressed this, when she said, *“I wash everyone’s [clothes].”*

15-year-old Sahil, a carer for his mother with a physical disability, signalled to the intensity of the physical labour involved in his work which increased in response to weather and festivals when he shared, *“I sweep [the floor], I throw the garbage out, sweeping and mopping all that... Deepavali is coming, the cleaning and all I’ll only have to do [it all] ...my mummy knows that Sahil will only do it. During winters, blankets, and all, they become dirty. Cleaning them, putting them inside the drum, bringing the detergent and all, everything is on me, washing and all. When water fills inside the blanket, you know how heavy it becomes. My grandmother is old, so she isn’t able to do it, my father, he goes to work ...my brother is also young. So, I only have to look after everything.”*

Another significant responsibility of young carers was filling of water for household use. These families, like many communities in these cities, relied on daily water distribution for use through the day. However, given their socio-economic backgrounds, some young carers in the sample reported receiving water at very unsociable times. For instance, 15-year-old Payal had to wake at 5 a.m. to collect water for her household. 15-year-old Kavita had to be ready at 4 a.m., while 12-year-old Pihu’s and 15-year-old Sameer’s water filling duties were undertaken at midnight. These examples illustrate the disruptive nature of this essential task on the sleep patterns and daily routines of these young carers. This added to their burden and had a significant impact on how they were able to engage with the school day.

Similarly, 15-year-old Sahil was tasked with obtaining drinking water from a separate water dispensing machine. He also shared that he and his younger brother used to stand in queues, fill water in big containers from public taps and carry these home.

Additionally, for some participants, household chores also involved cleaning the drainage in front of house, cleaning the entire house during festivals, tending to domestic cattle like goats, hens, and sometimes contributing to the home-based industry.

However, since there was a lack of awareness about young carers in general and consequently among the young carers themselves about the intensity of the tasks they undertake, they seemed confused, when they spoke about their tasks, sometimes, they said they did nothing at all, while during the same interview when asked about their daily routines, they seemed to be doing a lot more than they believed or realised. Occasionally they also said that it was them who did everything in the house. The central role played by the children in the functioning of the family is explained by 18-year-old Khushi when she said, *“In my house, if anyone needs anything, they ask me only, because only I know what is where in the house.”*

The sense of duty for some young carers was so powerful that they did not let anyone else share their workload either. For example, Naira, 16-year-old carer for her step sibling and grandmother, says that her grandmother comes back from work tired, so *“I don’t let her [help with household chores]. Because she anyway comes tired and all, then she will also do the house chores [rhetorically]? So that is why I only do it.”* The young person does this to protect her grandmother from additional burdens, as the grandmother is already sick and ailing, but it seemed as though there was no one to protect her from these chores.

Household chores were also perpetual as explained by 15-year-old Bitto, carer for her father with a physical disability. She said, *“morning, evening and afternoon, I make everything [meals]...be it a holiday or not, be it a Sunday or not, it has to be done.”*

It is imperative to note that in the Indian context some children may be engaging in such domestic chores despite not having a family member to care for as is evidenced through the quantitative findings in chapter eleven. The critical distinction lies in the necessity and inevitability of young carers’ responsibilities. Young carers seldom had alternatives or substitutes for their roles. They are compelled to perform these duties even during challenging circumstances like examination periods or times of illness as evidenced in the next chapter. Moreover, these responsibilities are often carried out in addition to their primary caregiving roles.

Supporting Siblings and Other Vulnerable Family Members

The responsibilities of the children were not limited to the primary care-receiver but also extended to younger siblings and other vulnerable members of the family who required support.

Some young carers were responsible for the safety, nutritional and educational needs of their younger siblings. Kavita, 15-year-old, had two younger siblings. Her father was disabled due to a wound in his leg and her mother was deceased. When her siblings were required to bring books or craft items for school and she was not able to arrange it for them due to financial constraints, it was she who met the teacher in the school and informed them of her inability. This is a parent's role, which Kavita had now taken up. *"... from the school sometimes, some books are required, then craft things are required, then I am not able to do it. Then I go and speak to the teacher, I say 'teacher I am not able to do all this.'"*

During tough times like the parent becoming very ill, it was the young carer who gave courage to their younger siblings. 15-year-old Sameer shares an incident when his mother's health declined, *"And then we saw all this happening to mother and my brother started crying and all, the younger one. So, then I told him, wait mother will come soon. Her health is only slightly bad, she is going to the doctor. He was like 'No, no, mother, mother'. And so, I went and held him, and told my father 'Now you go I will handle.' Father took her, then I held him."* Just like protecting their care-recipient's emotional health, as discussed earlier, the young carers had to put their concerns and anxiety aside to provide emotional support and reassurance to their siblings.

In many instances, the young carers also involved their younger siblings in their duties. They diligently trained the siblings in the caregiving and household responsibilities, ensuring continuous support for the care recipient. The theme of striving to develop a contingency plan wherein they ensured that continuous support was maintained for the care-receiver in case they themselves were somehow unavailable or unable to support them was of significance for many of the young carers. Like 17-year-old Gazal says that if there were situations where she must leave the household and go away for reasons like education, job or marriage, then *"my second sister is there, she will look after...she will be older by then, she also handles mummy very well."* So, they made

sure to teach their younger siblings some skills. This ensured a continuous supply of support for the care recipient, even when the current care giver was not around.

Moto and her younger sister collaborated in taking care of their young brother when he was a baby. Then took turns to go to school and made sure that one of them was present with him all the time. At the same time, she also expected them to return the favour when they got older. She says, *“my brother and sister, now I do things for them, so maybe when they become older, they would also do something for me...I do have that hope from them.”*

Sometimes, this also led to a reduction in the burdens of the young carers eventually. 15-year-old Sahil when talking about his 10-year-old brother proudly says, *“I have taught my brother [carework and household chores]”* At the same time, there was also a protective attitude towards young siblings. As clearly shared by 12-year-old Pihu who said, *“...if I put pressure on my sisters now, they are young, only in 5th class [9-10 years old], then they will also become like this.”*

Some young carers also supported other vulnerable family members. For example, 17-year-old Ayana helped her ageing grandparent, and 12-year-old Pihu supported her visually impaired uncle.

Supporting the Family Financially

In some families, the illness or accident led to serious income shocks in the family because of which some participants had to support their family's financial needs. This was important for the family's sustenance. They took on economic commitments in addition to their care, educational and household responsibilities. This could be a part-time work outside the house, opening a small shop connected to the house, or through assembling products at home for larger industries. Some had to resort to begging or asking neighbours for money. Some reduced family expenses by curtailing their wishes, while others dropped out of school.

Part-time Employment

Sahil, 15-year-old worked part time at a vegetable stall to aid the family's finances. Sometimes, they also had to fill in for other family members, like 15-year-old Sameer, who filled in for his brother. He says, *“...when my brother takes too many holidays... if*

there is some work, I will do it." 16-year-old Naira also substituted for her grandmother when she was sick. Her grandmother was a domestic worker. On such days she had to miss school. She had to consistently prioritise her sister and grandmother's care needs and covering her employed domestic work over school. Naira also mentioned that previously she had worked at a clothes shop and a cosmetic shop.

For these young carers, acquiring marketable skills which may be swiftly monetisable, like tailoring (Naira) and *mehandi*⁹ (Payal) took precedence over acquiring educational certificates and degrees. 18-year-old Alicia was doing a 6-month certificate course in nursing at the time of the interview to be able to support her family. During holidays she also went to a sweet shop and helped with packaging. She mentioned doing this even while suffering from tuberculosis. These jobs were low paying and thus, perpetuating the vicious cycle of poverty (Sultanova, 2024).

Home-Based Enterprises

16-year-old Rani had set up a momo (dumpling) stall next to her house to help the family. She was aware that the profit from the shop was minimal, but she required that for her family's sustenance. She did this in addition to her studies, care work, and household chores as explained very well in this excerpt from Rani's interview, *"Shop and my house are very close, they are joint. So, I look after the house also and run the shop. I do both together...when someone comes to the shop to buy things, I have to leave the inside work and come outside. And when there is no one at the shop, there is no customer, so I go inside and do the housework."*

Rani, Nidhi (18-year-old) and Moto (15-year-old) were also involved in providing tuition classes¹⁰ to younger children from the community for a small fee.

12-year-old Pihu, 17-year-old Nisha, 15-year-old Moto, 16-year-old Naira and 16-year-old Kabir were involved in assembling goods at the home as part of small-scale household industries. In such cases, component parts of various goods like hair clips, chewing tobacco, and clothes (putting sequins on clothes or cutting extra threads of machine-made clothes) was delivered to the homes of these families and their task was to assemble it and make the final product. For example, Pihu shared that smaller

⁹ Henna tattoo

¹⁰ Additional support classes for school going students to improve their academic understanding.

parts of a hair clip were delivered to their house, and they had to construct the final product. They were paid based on total weight of the final products. Their payment increased in direct proportion to the quantity of items they were able to assemble. Thus, children also helped with assembling the goods, as this increased the quantity of final goods and consequently the remuneration they received. Kabir said that doing this was part of his daily schedule and he did it till 11.30pm or midnight. Such home-based enterprises also helped the young carers be near their care-recipients as they did not have to go out of the house to make money.

Key Informant 3, a teacher from New Delhi recalled that a 11-year-old boy, a carer for his visually impaired father, used to sell tea at the family's tea stall at night. As a result of this he was unable to stay awake during school.

Begging

15-year-old Kavita, carer for her father, had to either rely on the kindness of her paternal uncle and aunt or resort to begging. She went to temples and other religious establishments which offered food for poor people. This was her way of helping her family sustain because they did not have enough money for mere survival and because she was under the legal age to work and was not being employed by anyone. She says, *"we bring it [food] from the temple...we don't have breakfast and manage the afternoon meal by asking around...I bring dinner...from paternal aunt's place."*

16-year-old Naira, carer for her sister and grandmother, shared that sometimes she had to ask for money and food from her neighbours.

Reducing Expenditure

Children were well aware of their family's financial situation and therefore curtailed their wishes and desires. 15-year-old Moto shared, *"my heart also comes onto dresses, but I don't tell my father that I want this and this, want to eat this, I want to go for an outing..."*

Other young carers aided their family's financial situation by reducing expenditure on their education and dropping out of school. 17-year-old Ruksar shared that she and her younger sister were pulled out from school due to the inability of the parents to support

their education. 15-year-old Sameer and 17-year-old Nisha had also dropped out of school because of their caring responsibilities.

Regimental Nature of Daily Schedule

The young carers lives were very systematic, given that they were responsible for a variety of daily chores. This regime of chores could be all encompassing and therefore overwhelming. For 17-year-old, Gazal, a carer for her mother, her daily routine looked like the following:

“In the morning like papa has to go to work right, and brother and sister have to go to school... I have to wake up by 6 o'clock, between 6-7, after waking up brush or wash face, then make breakfast for papa, tiffin and breakfast for brother and sister also, and also food for everyone, and then get them ready for school. And then they go to school, then get ready myself...then go by 7.30, by 7.30-8.00. I used to give them the clothes, they used to wear and I used to do my work... like making tiffin, making food, it takes time to make. Till 8.30 I make and then quickly, I have to make two pigtails for school, I don't get time for two pigtails, so I used to tie the hijab¹¹, so I don't have to make the two pigtails, because only mummy can tie them, and her health is not good, so that is why I used to tie hijab and go, teacher couldn't even say anything because of that (laughs). So, without the pigtails and with the hijab, I used to go quickly to school. Then also I used to be late sometimes. I used to be always late (laughs shyly). Even if I get out of the house at 8-8.30, I used to be late because of the traffic...my class was at 9 o'clock, and I used reach late...then I used to get leave by 2 and it used to be 2.30 by the time I reach from there. Sometimes I used to take the rikshaw¹² to make it faster. I used to be home by 3-3.30 very easily. And after coming home, change the dress, and then do the work at home...sweeping the floor, mopping the floor, washing the clothes, then after all that work is over, then it would be 6 or 7 by then, then I had to read the namaz¹³ too, then it is evening, then I have to look after mummy...like what does she need to eat, did she take the medicine or not, when I wasn't there, how did she take the medicine, then bring whatever items she requires, like bringing fruits from the market, bringing vegetables. After doing all the work, then go to bring the vegetables, then by 7 or 8 all

¹¹ Islamic head and neck scarf.

¹² A three-wheeled motorised vehicle used as a taxi.

¹³ Islamic prayer.

the work used to finish. Then at 8 o'clock cook for the night and then cook till 9-10 then give everyone food, then everyone eats, by then it would be 11. Then if I get some time, then I sit for studying, then I study for two hours, then water comes at 12.30, it used to come at 12 earlier, now it comes at 12.30, so study till 12 then fill water. By the time the water fills it would be 1 o'clock. Then after filling water till 1 o'clock, I used to study a bit then I used to be tired, and sleepy, then I used to sleep, then after that the same routine in the morning."

She also added that her mother does not like the house to be dirty, so she makes sure that the house is kept to her mother's liking because otherwise her mother gets angry and annoyed which in turn adversely affects the mother's health.

16-year-old Rani also shared that she woke up early in the morning at 5 o'clock and then went on to describe a staggering day involving cooking, cleaning, caring for her mother, going to school, managing other household chores, running a shop connected to the house, homework and on some days, she also provided tuition classes to young children from her community.

Even though timetables and schedules may be common for a lot of children, the activities that they undertake would be for their own development and may include hobbies, like music classes, sports, etc. However, for the young carers in this sample, it involved household chores and caregiving responsibilities. These chores might help with life-skill development, however, it needs to be acknowledged that they do not conform to the typical definitions of childhood. Additionally, such a regimental day, as can be seen from Gazal's excerpt above, leaves very little time for the children themselves and their self-development. Furthermore, they cannot take a leave of absence from these chores.

Chapter Summary

Children in this sample had to take on the role of a carer for many reasons. The primary facilitators for young individuals assuming caregiving roles included family health issues such as illness, disability, substance abuse, accidents or death, as well as socioeconomic factors like poverty and migration. These young carers also had increased, and complex workloads.

Participants typically cared for at least one family member, often older, though some were primary caregivers for younger siblings. The onset of caregiving responsibilities frequently occurred at a remarkably young age, for some as early as four years old.

In most cases the young carers were unaware of the exact nature of the care-recipients' problems. In the absence of this information some of them constructed meanings to their observations which seemed insensible or unlikely to adults or professionals around them but were enough for these children to make sense of their situation.

The participants' age and cognitive abilities could be a reason for their information dearth. However, this did not translate into a dearth in caregiving tasks and other responsibilities. "*I do everything*" or versions of it was a common sentiment expressed by the young carers in these interviews. This alludes to the intensity of the responsibility that the children felt. The responsibilities of young carers can be broadly categorised into assisting the care recipient, performing household chores, supporting siblings and other family members, and contributing financially to the family. Many of these tasks exceeded typical expectations for their age group but were normalised within their rigid daily routines.

Supporting care recipients was part of young carers' lived realities and they undertook these roles consistently, with persistence and without complaint. The relentlessness of their routines, as illustrated through the excerpts in this chapter, evokes a palpable sense of exhaustion, yet they continued to carry them out with quiet resilience.

A defining feature of their caregiving was the absence of support for these children. In some cases, they even shielded other family members like younger siblings, from participating in care tasks, fully aware of the emotional and physical toll involved. While they took care of nearly everyone in their household, there was a recurring sense of their own care needs being overlooked.

Some young carers demonstrated an awareness of the centrality of their role for the care-recipient and the functioning of the household and actively sought to ensure continuity of care by preparing younger siblings to take on similar responsibilities in their absence.

At the same time, these children were often unaware of the extent and significance of their own contributions, despite undertaking the majority of the caregiving tasks. This lack of recognition can be attributed to the broader societal devaluation of feminised labour, such as caregiving and domestic work, within patriarchal and capitalist structures. The absence of collective hermeneutical resources that affirm the value of such labour further contributed to their internalisation of its perceived insignificance.

The study sample comprised predominantly of female participants potentially indicative of the gendered nature of care work or the societal norms that may obscure male carers from the mainstream gaze. A lot of what they did was gendered in nature as has been explored in other studies and thus has not been discussed here.

This chapter illustrates the intricate position that the young carers held in the secure functioning of their families. This was often because of the lack of available adults to undertake these tasks, leaving the young carer responsible for majority of these duties. They were in a situation wherein if they did not do the tasks, no one else would, as there was no one else to relieve them of their duties. They were aware that any oversight could detrimentally affect the care-recipient and the overall well-being of the family.

Chapter 8: No Respite- Navigating the Impacts of the Caregiving Role

Introduction

This chapter will explore the second theme from the thematic analysis of the 21 young carer interviews and the six adult key informant interviews. It will discuss the implications of the carer role on the young carer. It examines the consequences of caregiving on education, physical health, emotional well-being, time, social lives and the future of the young carers. It also describes the risks associated with being a young carer and some positive impacts of the role. The chapter also focuses on how these impacts were intensified by the absence of support systems and therefore the limited availability of respite for the young carers.

Impacts on Children

This section will elaborate on the implications of the tasks and responsibilities mentioned in the previous chapter. The impacts of the carer role manifested in the children's life as- educational deprivation, physical health issues, emotions and behavioural issues, limited time, relationship struggles, uncertain future and significant risks. While all these were generally negative impacts, some positive impacts were also noted.

It is important to note that this may be the first time many of these children are being asked about their experiences. Thus, may not have been fully aware of all the impacts of their caregiving roles yet.

Impact on education

The impacts of care work on young carers' education involved- not being able to concentrate at school, getting limited or next to no time to do their homework or study at home, missing classes to support the care-recipient and dropping out of school.

Thinking about Home All the Time

Some children in the study shared that when they went to school, they were unable to concentrate because they kept thinking about the wellbeing of the care-recipient

whom they had left at home. The children felt like they were abandoning their family members when they went to school.

16-year-old Rani felt very guilty and anxious about leaving her mother at home on school days. She says, *“When I go to school leaving mummy at home, I feel very bad from inside. I feel nervous, ...what if something happens to her.”* She then resorts to using her teacher’s phone to check on her mother and sometimes comes back home in the middle of the school day.

16-year-old Naira had to leave her 2-year-old sister under the supervision of her neighbours when she went to school. She says, *“I will be worried about my sister...what will my sister be doing? I mean half my brain will be in school and half at home.”* As a result of this she did not go to school very often... She adds, *“On days that I go to school to study, on those days, my brain is at home only, thinking, what would she be doing? How would she be? Would she be crying? Would she be outside? Would she be inside? Would she be sleeping?”* Just like Rani, on some days Naira got so anxious about her sister while at school that she left her classes and went home. And on days that her teachers did not allow her to do so she took her teacher’s phone and called her neighbour to check on her sister.

Naira further adds that, the distraction from studies was not only because of care-recipient, but also the chores at home. She kept thinking, *“And now, this work is left, I have to do this after going home, or this is the problem. Or like, I have to go home and wash clothes, have to feed grandmother, I have not even cooked food... I have to go home and cook food also... I keep sitting and thinking.”*

These distractions were detrimental to the child’s concentration in the classroom and eventually to their education. 15-year-old Bitto explained this very well when she said, *“I cannot concentrate on studies, I keep thinking that I have to study, study, study... I keep reminding myself that if I am in class then I [her mind] should be there only, I should not go anywhere else.”* However, a lot of times she was unable to do so because she was worried about her father’s health. She says, *“I am worried about the house, more than half the time... that something might have happened at home. Then I can’t pay attention to studies... I am just worried about home, hoping that papa is well, what is he doing, hoping that nothing has happened to him. When they are teaching, I just*

keep hoping that nothing happens at home...It affects my education...I don't understand anything... that ma'am teaches." Others, like 12-year-old Pihu, 16-year-old Kabir, 18-year-old Khushi and 15-year-old Moto also shared similar experiences.

This section highlights how young carers remain mentally engaged in their caregiving responsibilities even when physically away from the care-recipient. Their thoughts were persistently occupied with concerns for the care-recipient, reflecting a constant state of vigilance and lack of respite from their role even in environments like school. Therefore, this section underscores the relentless and uninterrupted nature of their caregiving roles.

Homework or study at home:

The young carers in this sample spoke about care work and household responsibilities affecting their studies. They shared instances where they did not get enough time to finish homework due to their responsibilities at home. 15-year-old Bitto shared, *"I keep thinking that I will study, I will study in a bit, but in looking after papa I don't realise when the time passes."*

Some others shared that they were too tired to study after a long day of chores. 18-year-old Alicia said, *"do this, do that...so then I wasn't able to do my homework and then I would think to myself that I should write it (homework) but then I wouldn't feel like doing it."* As a result, she, *"would study on the bus to school...or sometimes in the library. I would start early from home to get some time to study."* 17-year-old Gazal and 16-year-old Naira also shared that they had to stay up late at night, after everyone was asleep to finish their homework and study. 18-year-old Alicia studied along with cooking, especially during exams. She says, *"I would keep the food cooking on one side and stand with my book next to it."* This demonstrates that they were literally juggling multiple roles at the same time, a trait usually associated with adults and unexpected from children.

The constant demands of the tasks throughout the day impeded their ability to focus on studies. 16-year-old Naira said, *"on education, it does have an effect. Because during exams, there are household chores also.... here I am learning, and there some work comes up, then whatever I have studied, I forget that."* This excerpt reinforces the notion that there was no alternative support available for them.

The repercussions of this were- punishments from teachers, lack of trust from teachers after repeated lapses in homework, incomplete schoolwork, less marks, and less time for rest.

These excerpts suggest that there are clear implications of care work on the young person's ability to do homework, and study at home. They had to balance care work, household chores and their education.

Missing classes and school days:

Missing school for emergencies is common among school children. However, this would generally be for the child's own need and seldom for the need of an adult or family member. Taking leave for the need of another family member is a very 'adult' like responsibility. However, for children in this sample, missing classes, or school days to cater to the needs of the care-recipient was a common occurrence.

16-year-old Naira, carer for her toddler stepsister, said, *"I don't go to school that often because I feel scared to leave [my] sister alone...that is why I stay at home only... I go to school very few times in a month...rest I take leave."* She also shared that a couple of years ago, when her sister was just born, and their mother had died because of complicated childbirth she had completely stopped going to school. She said, *"my school [going] had been permanently stopped... I didn't go to school at all. I had left school altogether."* At the age of 14, Naira had to step into the role of the mother to take care of the ailing and weak newborn. At the time of the interview, she had rejoined school, however it was still interrupted due to her care work and other household responsibilities. Naira also had to take leave from school whenever her grandmother was ill, as she had to fill in for the grandmother at her workplace. The young person had multiple responsibilities and therefore her education was completely sidelined. She felt that her education was getting affected because of her duties at home. She says, *"...during exams also, I did have a bit of problem...in school, teacher explains everything, even though friends come and give me their copies, [and] I do the work, I learn it also, but I am unable to understand whatever is explained in class. So that is why I feel like, yes, it is affecting my education..."* The young person felt a sentiment of disadvantage when compared to her friends who had the opportunity to learn in class

while she had to study from their notes. Naira held her education in high regard and wanted to study but her circumstances deterred her from doing so.

15-year-old Suhana also had to miss school and tuition lessons when her brother was having bad days. She says, *“when [my] brother is unwell, then I neither go to tuition, nor do I go to school. I only sit at home and take care of him.”*

15-year-old Moto recalled that she had to regularly miss school as there was no one else to look after her brother when he was an infant. 12-year-old Pihu also shared that on days her mother was really unwell, she had to miss tuition classes to take care of her mother. Rani, 16-year-old carer for her mother, had to miss school at least 2-3 times a month to accompany her mother to the hospital or to get her medicines.

These excerpts clearly suggest that the children in this sample, prioritised their family member’s health and care needs over their own education. As a result, their studies were severely affected. Key Informants also suggested that school attendance was adversely affected by caregiving responsibilities as duties towards the family member and household were prioritised over education. Furthermore, in the absence of alternative forms of support, they had to keep going.

Dropping out of School:

Some children had to completely abandon their education as they were unable to meet the demands of schoolwork along with their care work. When asked why she left school, 15-year-old Kavita said, *“because there is no one at home the entire day right, then papa needs looking after... That is why.”* She went to school till 8th class. In Indian schools, children cannot be held back till 8th class and are passed to the next level. Because of the scarcity of cognitive and physical resources to dedicate to schoolwork, Kavita left school after she completed 8th class.

15-year-old Sameer, who also dropped out after 8th class (approximately 13-years-old) shared, *“I used to go [to school] till 8th, then at that time, there was mummy’s operation, so I left, then they cut my name...”*

17-year-old Ruksar’s family also faced major financial crises as result of which she and her younger sister had to drop out of school. It also aided the family’s financial situation

as their education was no longer an expense for the family. Moreover, they were able to dedicate more time to the care-recipient and the household chores.

16-year-old Rani mentioned that her older brother had to drop out of school when he was in 7th class (approximately 12-years-old) *“because of the problems at home.”* 17-year-old Gazal also had to leave school to care for her mother.

Key informant 1, a social worker from New Delhi shared, *“Even if they are going to school, they face a lot of challenges. They don’t go regularly. They drop out slowly.”* He was also of the opinion that school becomes challenging for such children after 8th class and start failing once they reach 9th class which exacerbates the pressures on them and therefore, they drop out. This is exactly what happened with 15-year-old Kavita as explained in the excerpt above.

The children in the sample had passively accepted the circumstances wherein they were unable to go to school or prioritise their education. This was their way of navigating their caregiving role.

Physical Impacts

This section examines the various physical impacts of caregiving responsibilities and household duties as reported by the young carers. The common physical impacts mentioned by the children included feeling tired and lacking in energy, pain in the body, breathlessness, and unexplained pain in different parts of the body. Less time for sleep was another implication of care work mentioned by the children. These may have long-term physical health impacts.

Fatigue and weakness resulting from the intensity of chores was a common concern of the young carers in this sample. 15-year-old Kavita complained of fatigue saying, *“I used to have a lot of weakness, it still happens... Weakness outright, hands and legs start hurting... once... I had vomited blood, and I was getting dizzy.”* 15-year-old Sahil and 18-year-old Khushi also felt fatigued. In addition to fatigue, Khushi also had breathing issues. 18-year-old Nidhi wished *“if someone else could do one time’s work. I feel like resting, sleeping a bit.”*

In addition to tiredness, 17-year-old Nisha said she had constant body pain because of doing heavy chores at home, like lifting heavy drums of water. 12-year-old Pihu, had

to physically help her mother get up from bed which resulted in back pain for her. 16-year-old Rani also had to lift heavy things in the house that led to leg, hand and back pain. She says, *“...if I lift a heavy thing, then sometimes, my back starts hurting or my hand.”* 15-year-old Sameer also complained of pain in the shoulders and hands when picking up heavy things. 17-year-old Ganesh also suffered from pain in his hands and legs.

16-year-old Yashika suffered from pain in her hands, especially when she had to massage and exercise her father’s legs. She said, *“when one makes papa exercise then hands start aching. Because you have to massage like this sometimes, like that sometimes, do this to him sometimes, so hand does hurt. And use really hot water to do sikai¹⁴.”*

16-year-old Naira said, *“I keep getting dizzy, headaches, and pain here [in the stomach] is always there.”* 16-year-old Kabir complained of a similar unexplained pain in his stomach. Nidhi, 18-year-old also complained of intense pain in the legs. She did not know the reason for the same. However, she shared that whenever she went to the doctor, *“they give medicine, but it does not become better even then, it is fine for two days, then again, it’s the same”*.

15-year-old Bitto said that she had headaches all the time, she didn’t know the reason for the same. 12-year-old Pihu also said, *“I keep having these headaches from time to time, just out of the blue. My head hurts a lot.”* Naira, 16-year-old, also had headache all the time. These could be physical manifestations of the stress that the children are under. 15-year-old Reshma also points to this when she said, *“when there are a lot of problems at home, then I have a weird headache.”* These aches and pains could be attributed to stress and anxiety that these young carers experienced. Headaches and bellyaches are commonly identified somatic symptoms in children and have been associated with anxiety (Muris and Meesters, 2004). Anxiety about the well-being of the care-recipient and by extension about their own circumstances was a common concern amongst the young carers in the sample. This will be discussed in detail in the next section.

¹⁴ Hot fomentation therapy.

Most of the participants had an early start to their day owing to number of tasks and prep tasks that needed to be undertaken for the family. As, 15-year-old Bitto, a carer for her father with physical disability due to an accident, says, *“in the morning I wake up at 5’ o clock to make tea and breakfast ...”* Her school started at noon before which she needed to finish all her chores. 15-year-old Sameer had to wake up at 5am to be able to finish his chores, before his brother went to school and his father went to work. 18-year-old Khushi’s day also started at 5am as she had to prepare lunch for her older sister.

Early start to the day and long hours of work meant that the children received limited sleep. 16-year-old Rani mentioned that she slept only after putting the rest of the family to bed and 15-year-old Sahil felt that he was always sleep deprived. Key Informant 5, a social worker from Mumbai said, *“the child is unable to take rest also the whole time. Because even after they sleep, someone calls them, then get up and give them water, take them to washroom, or help them with it [toilet], so their sleep is also not complete. Healthwise there is a chance that they also get sick. Because...their immunity power is not that strong so maybe in the future or while treating the ill person they also can become ill.”*

Key Informant 1, a social worker from New Delhi suggested that the young carers duties may also have an impact on their leisure and consequently their physical health. He shared, *“...and health-wise too they would be weak. They are not playing...it definitely would be affecting [their physical health] because they don’t play, there is no exercise for the body.”* Key Informant 2, a project lead from New Delhi also believed that recreation would be a major issue for such children. 16-year-old Kabir said that he did not get enough time to play because of his busy schedule and chores at home. The only time he got to himself was when he used to, *“sit at home and use the mobile,”* reflecting how his movements were restricted, and he was largely housebound due to his caregiving duties.

These exemplars show the physical impact that care work and additional housework tasks can have on the children. However, caregiving can also be mentally demanding. The next section will discuss some of the emotional and behavioural impacts on the young carers.

Emotional and Behavioural Impacts of Care Work

Key Informant 2, a project lead from New Delhi shared, “...it’s very difficult to deal with emotional trauma and strains of taking care...” The young carers in this sample expressed emotions such as fear and anxiety, self-blame and guilt, quite sadness, destructive behaviours, self-neglect, helplessness and despondency. They also mentioned that they felt different from their peers and had ambivalent feelings towards their carer roles. This section will examine the emotional and behavioural impacts of the caregiving roles of young carers in this study.

Fear and Anxiety

Participants presented an overarching sense of fear and anxiety. This could be for their care-recipients’ well-being or their own.

They were apprehensive about the potential death of the care-recipient. Around a week before the interview, 15-year-old Reshma had been informed by the doctors of the imminent demise of her father. She shared, “doctor had said that there is no chance for him, anything can happen anytime.” 15-year-old Sahil and 15-year-old Sameer had also been told the same about their mothers during their caring journeys. 17-year-old Ruksar also shared that she felt scared about her mother’s condition. These young carers had to cope with the possibility of a serious decline in their care-recipients health or their death, daily.

Therefore, they kept thinking about the well-being of the care-recipient as explained earlier in the section ‘Thinking About Home all the Time.’ This was also the case when they were out with friends. 16-year-old Kabir says that he feared that something would happen to his mother. He shared that the thought could surface into his mind anytime. It was a constant emotion for him.

Fear of losing the parent was accompanied by fears for their own future as well. 15-year-old Reshma feared losing a guiding force in her life. She shared, “the person who used to care for us, who used to stay with us, used to tell us about all right and wrong, if he is no more with us then how will we live in the future, ...I could only see weeping and I could not understand what else to do.” 15-year-old Bitto, 16-year-old Yashika and 16-year-old Rani also shared similar fears.

For 17-year-old Gazal, the fear of losing her mother was also associated with fear of losing her opportunity to study. She says, *“mummy will let me go for studies, ...it’s because of mummy that I am able to study...because the rest of the family they say things like don’t teach girl children, if mummy is not there then who will make papa understand? ...papa listens to other people easily and the people are like, get her married, don’t let her study, she is a girl....in the family also there were some girls who were studying and then ran away and got married.”*

Gazal also shared, *“there is mental stress, if studies are happening then tension of studies is there, then there is house’s tension and then other than that there is mummy’s tension also...then if something happens with friends that tension is there, then if family members say something that tension is also there...then one becomes emotional.”* Gazal’s excerpt is a poignant example of the multifaceted nature of stressors experienced by young carers. In addition to the typical stressors of being a teenager, these children also have added pressures of caregiving responsibilities and household duties. This differentiated young carers from their non-caring counterparts.

Some young carers like 15-year-old Kavita and 16-year-old Rani had already lost a parent to illness and feared being orphaned. 15-year-old Kavita whose mother had passed away when she was very young shared *“I want to improve my papa’s health. Because mummy is not there, [if] papa will also not be there, then who will take care of us?”* Naira, 16-year-old carer for her stepsister, had lost her mother in childbirth only around 2 years before. 18-year-old-Khushi who had been a carer for her mother with tuberculosis, had also lost her younger sister a few years before the interview. While grief is common among adolescents, for young carers who had already experienced loss, their caregiving roles amplified their emotional burden, intensified concern for the care recipient, and potentially restricted their capacity to process grief effectively.

Setting aside the mental load of potentially losing a parent, these children also had to deal with the practical aspect of it which may involve dealing with a stepparent, being institutionalised, moving to a new city or to the village with extended family leaving everything they knew among other possibilities.

Self-blame and Guilt

Some children in the sample held themselves responsible for their care-recipient's condition. This was especially true in the case of 17-year-old Ganesh who had traumatic memories associated with his mother's accident. He explained the incident viscerally. *"When the lockdown was about to begin, so at that time we were about to go to the village. Both my brothers were already on the train. Mummy, papa and me. Papa was about to come later, but mummy and I were there. So, mummy was about to get on [the train] and I was to give her the luggage from behind. And at time the train had started, so papa said do it fast, do it fast, train is about to start/move, so mummy's leg slipped. There is this [gesturing with hands] much space, here is the [train] track and this much space is there, mummy went into that. So here, [pointing to his ankle] her entire leg got cut. Heels are there right, her heels got scrapped completely, by the train."* This was the longest Ganesh had spoken in the interview, having only given one-line answers before. He felt guilt as this was a life changing event which he witnessed closely and could not do anything about.

Some of them felt that their care-recipient's health deteriorated because of them. For example, 15-year-old Moto shared that the reason for her father's worry and consequential health decline was his worry for Moto and her siblings, their future and well-being. 17-year-old Ruksar believed that her mother's seizures were linked to stress about her and her siblings' needs. She shared, *"she [mother] was bringing my sister from the hospital... So, she forgot to take her medicines. Whenever we have a fever or something she just forgets to take her medicines... then on those days she is not able to care for herself. On those days her entire attention is on us."* This created a sense of self-blame in the children. Consequently, the children were extremely careful around their care-recipients. 17-year-old Gazal also thought that her mother was sick because she worried about the family too much, and therefore ensured that her mother was always in a good mood. She did this by always being a 'good girl' around her mother. This was so that her mother did not have to scold her because *"if she scolds then her health declines, [even] if she talks a bit loudly."*

Some young carers also dealt with guilt especially when they were doing something for themselves, like going to school or spending time with friends. Rani, 16-year-old shared that she felt sad when she had to leave her mother at home and go to school.

Ayana, 17-year-old mentioned that when she was out with her friends, she was worried about something happening at home. That is why she spent less time with her friends and even in that little time, worry about her parents' health deterred her from fully enjoying her leisure time.

Quiet Sadness

Frequent feeling of sadness which was manifested as crying behaviours were reported by the children in the sample.

15-year-old Nidhi mentioned feeling sad about her mother's condition, especially when her mother cried in front of her. When asked about his feelings 16-year-old Kabir, said *"I feel bad"* and that he did feel like crying sometimes, but when asked to elaborate or tell me a little more about that. He outrightly refused.

"I cry a lot at night" said 18-year-old Alicia. That was her method of venting. 15-year-old Kavita also said, *"I spend days, like I keep crying the entire day."* 16-year-old Rani also said, *"when I feel bad, I become completely silent for a while. After becoming silent, I feel like crying also a little bit. After crying my heart becomes lighter... I cry so silently that even if someone is lying next to me, they will not know."* 17-year-old Gazal was also in a similar situation. She also said that there was no one with whom she could share everything and that she cried thinking about her mother, studies, and future. 12-year-old Pihu mentioned that she put her head down on the table and cried when she was overwhelmed while at school.

16-year-old Naira used words like *"depression"* and *"sadness"* to describe the difficult days. Naira also mentioned not sharing her feelings even with her grandmother because the grandmother would feel sad and hurt and might cry which she didn't want. She shared *"I keep it in my heart only, all things."*

This explains how many children in the sample suppressed their feelings and emotions. Some children had never shared their feelings or their circumstances at home with anyone else before the interview. Sometimes they were unable to share their feelings with family members or even the parent they were caring for because they knew that this would make the parent sad and in turn affect their health. Therefore, their display of emotions was very restricted, and this put them under a lot of emotional pressure. Sometimes they had to resort to crying only when everyone else at home was asleep.

Key Informant 3, a schoolteacher from New Delhi also observed, *“those children are a bit suppressed; they are not responsive in the classroom all the time.”* This is also the reason why these children need to be brought to limelight so that they have some kind of vocabulary to explain their feelings and situations instead of suffering in silence.

Destructive Behaviours

As opposed to quiet sadness, some young carers in the sample were so overwhelmed with their lives that they inclined towards destructive behaviours. This ranged from anger outbursts to self-harming thoughts.

15-year-old Sameer said, *“when I get angry, I am a little crazy, I break things (laughs).”*

15-year-old Payal shared, *“I feel like going away, very far from here...where there is peace.”* 18-year-old Khushi felt that no one in the family cared for her. Her mother was the only one who checked on her. She had lost her appetite and only ate when prompted by others. She said *“I don’t eat food...I don’t feel hungry....no one asks me, and I don’t eat till anyone asks me...I don’t eat, I like it when someone asks, I eat one extra roti [Indian flat bread], no one cares.”*

15-year-old Moto shared that she had thought of suicide because she felt distressed about her life. 15-year-old Kavita also had similar thoughts of self-harm, and she tried to spend some time away from home at her paternal aunt’s house.

Self-Neglect

Young carers spent a lot of time and energy on their care-recipients and other household chores. As a result, a lot of times they neglected their own requirements and needs.

18-year-old Alicia shared that she went to work even when she had typhoid. 15-year-old Moto shared, *“I eat only if I get time.”* 16-year-old Rani said, *“even when I am unwell, I do not pay attention to myself.”* This was echoed by 15-year-old Kavita who was carer for her father, *“then also I only have to look after. No matter how sick I am, I only have to do.”*

15-year-old Sahil, 16-year-old Rani, 16-year-old Naira and 12-year-old Pihu neglected their bodily pains and aches by either resorting to home remedies or self-medications.

They didn't have time for their own medical needs. For 15-year-old Sameer his aches and pains had become a *"habit."*

Some of them visited the doctor only when their condition was very critical. 16-year-old Naira shared that she feared being diagnosed with a major health issue, which would put her family's sustenance at jeopardy. This deterred her from seeking medical help. Naira said, *"there are already so many problems in my house. Then that problem would be added to my other problems...If there is something, take some normal medicines (over the counter medicines), and if it becomes okay then it will, otherwise let it go however it is going."*

Some young carers ate only after everyone in the family had eaten. They were the last to sleep, at the same time, they were mostly the first to wake up in the morning.

Helplessness and Despondency

Some young carers shared that they felt helpless. Even after doing so much for their care-recipients, they felt like they were unable to do enough and felt helpless as they were unable to make their care-recipients' troubles go away. 18-year-old Nidhi said, *"I wish I could help her [mother], if I could take half the responsibilities off her...I feel like I do nothing now, only if I could help her, she keeps sad, so I don't like it."* Nidhi felt like this after taking on the full responsibilities of her two younger siblings and the entire household chores. As mentioned in the earlier in this thesis, this is also closely linked to the gendered and undervalued nature of care work.

They got little support from their extended family members, even though they might be living in close proximity. The support they received was short-lived, conditional and sometimes humiliating. 15-year-old Kavita, sharing about her difficult relationship with her father's brother who was also their neighbour, said, *"paternal uncle and all, I mean, earlier they used to help. Now no one does... now they don't. They say 'till when would we look after yours [expenses]. We also have kids.'" She also shared having constant fights with her paternal uncle for her father and his needs.*

Because of the challenges they faced recurrently, some of the young carers had resigned to their circumstances. 15-year-old Sahil shared, *"there is no other adult in the house ma'am. So, I have to do it. If I do from now itself, then it will become a habit ma'am."* 15-year-old Sameer also used the word 'habit' to describe his struggles with

housework and his mother's care. He added further, *"it was written in my destiny, all this work for mother, housework, looking after parents. There is nothing other than that."*

16-year-old Rani shared that she had 'convinced her mind' of her situations. She had accepted her circumstances for her mother's welfare. When asked if there was something she did not like about the role Rani shared that there was nothing that she did not like. She then added, *"If I start thinking like that then who would do that work."*

15-year-old Moto concurred, *"what's the use of thinking all this, I have to do what I have to do"*.

Describing a young carer's situation, Key Informant 6, a social worker from Mumbai said, *"now the situation is such that there is nobody else and that is why it's their [young carers'] turn."*

Care work and household chores had become a part of the young carers' routine. They had normalised their circumstances.

Feeling Different from Peers

Most of the children reported feeling different from their peers. They felt that their chores, duties, troubles, and emotional status were very different from their friends and peers.

15-year-old Reshma said, *"people of my age do not have to do so much work, moreover sometimes I feel like my life is very different... for example, people of my age only concentrate on studies they are not tensed about anything, no depression of anything, I have so much tension and also the entire work at home, in the family, caring for father, all this work, it feels very heavy."*

12-year-old Pihu shared, *"my life is not different at all, but it also is. They [peers] have to do little work I have to do more work... I don't like telling. I start crying because only my life is like this, no one else's. I look at my friends. Everyone's mummy is better. My mummy is also okay, but I have to work. I don't like working. I want my life to be such that I live on my own and I don't have to work. I don't like it...Everyone talks very fondly [about their lives/family]."* Ostensibly, Pihu didn't want to say much as this would present her mother and her parenting abilities in a negative light.

Other children like 18-year-old Nidhi, wished there was another adult at home so that she could *“be like other children”*. 16-year-old Kabir, 15-year-old Kavita, 15-year-old Sameer, 17-year-old Ruksar, 17-year-old Ayana, 16-year-old Naira, and 16-year-old Rani also felt different from their peers and that their peers had more time to themselves, for play and rest. Young carers also felt that they had to do more care work and housework than their peers. Rani also shared that sometimes she did compare her family with other families. She said, *“I feel like, I wish in my family everyone was well, ...I feel bad from inside. I wish these problems were not there...My friends, in their families, there are other people to do [the work]. So, they are not taking so many responsibilities. As much burden is there on me, that much is not there on my friends. Our childhood was spent differently from all other kids. We are different from others.”*

15-year-old Payal felt that her father’s behaviour after he consumed alcohol was unwarranted when she compared him to her friend’s father who also used alcohol. She said, *“My friend’s father is also nice. I mean he also drinks but he does not do so much drama...Her’s [life] is better, when her father does not see her at home, he asks where she is... when she comes, he will talk to her and all, our father is not like that.”*

There were some young carers who felt that they were better than their peers because they were more skilled than children of their age. 17-year-old Ganesh shared, *“my friends, they only eat, drink and study, they don’t know anything other than that. Only playing and all, they don’t know anything else other than that. And now here I am, I know how to cook food, right, I know how to do the household chores. Now I cannot depend on anyone else. If anyone goes somewhere, I will cook according to my will and eat according to my will. That’s there.”* Ganesh felt that the carer role made him self-reliant when compared to his peers.

18-year-old Khushi shared that even her neighbours endorsed this difference and thought that her contributions were superior to her peers. She shared, *“A lot of people say that, looking at your age it does not feel like you can do all this, but you do. The aunty on my street also says, that in today’s time, no one will agree that the girl who is studying will also be doing so much housework... she says this only, that you do housework also, study also, take care of your brothers and sisters, cook food and all also, so I do feel like, yes, my life is a bit different from other people.”* This is also a glimpse into the fact

that there is no societal expectation on children to do so much work in the Indian context.

Key informants observed that young carers behaved more maturely as compared to their peers. Key Informant 3, a schoolteacher from New Delhi shared, *“They don’t adjust with people their own age that much, as much as they are able to with other people, alright, like with older people...their way of talking changes.”*

Ambivalent Feelings about the Carer Role

Young carers in this sample had mixed feelings about their carer role. They were unhappy that they had so many responsibilities, however, they also felt happy that they were able to help their care-recipients.

16-year-old Rani felt bad that she had to support her mother. She shared, *“I do not feel good that I am bathing mother, I wish mummy could bath herself. I wish she would have been fine.”* She also shared that she and her older brother had to sacrifice their childhood because of their carer role. She also added, *“I like caring for people who are older than me. I feel happy about it. I love my family the most...I like it, handling the family, caring for them, I like it a lot.”*

18-year-old Khushi felt like leaving home because of her carer role. 12-year-old Pihu shared that she got irritated when she had to do the chores. 18-year-old Alicia shared that she felt angry sometimes. 16-year-old Kabir felt bad about his role but was not ready to say anything more about it. 15-year-old Suhana shared that she didn’t like her role, especially the toilet bits but liked feeding her brother. 16-year-old Naira described her role as difficult, upsetting, and depressive, especially on tough days. 15-year-old Moto had very strong feelings about her carer role. She shared, *“what is this life, ...there is no happiness, no nothing... I have to live for papa.”* Implying that she lived for her father and not for herself. These are strong feelings for a 15-year-old.

17-year-old Ayana felt that by being her father and mother’s carer she was reciprocating the care and love they provided her with when she was an infant. So, she felt good about it. 15-year-old Sahil also felt good about his carer role as he felt proud of himself for being responsible. 15-year-old Sameer also shared that he felt nice that he was able to help his mother. However, earlier he used to feel bad about his responsibilities because he was unable to do what other children did. But now he had

brought himself to like his work because this was his reality, at least till his older brother got married and the sister-in-law took over duties of care and domestic work from him. This alludes to gender hierarchies in care-work.

16-year-old Yashika, shared that she struggled with her role but felt good when her mother appreciated her. She shared, *“One day, mummy was also saying. We were in the hospital. So, she was saying, ‘you have to do a lot of work, don’t you?’ ... I said now it has become a habit mummy.”*

16-year-old Naira summed up the feelings of young carers when she said, *“So sometimes, I feel like, yes, this thing that I am doing, I should not have done. But then later I realise, that mummy is not there, so I have to do it...I feel like, more than my age there are responsibilities on me, that I have to shoulder. The responsibilities, which I should have got in the future, I have got them now itself. That is why I don’t get the opportunity to live my life.”*

This section gives insights into the tumultuous feelings of the young carers about their carer role.

Limited Time for Oneself

The children had little relief from their caregiving duties because of which they reported having very little time to themselves because of their hectic schedule of care work and household responsibilities. 18-year-old Khushi felt that her entire time was spent in caregiving responsibilities and household chores. She said, *“my entire day goes by in this...this is how all my days pass... I am not able to take time out for myself.”* She also added that sometimes she doesn’t get time even to eat food.

15-year-old Rani said that apart from the time she was in school, she was always caring for her mother. She says, *“There is no timing for mummy’s care, because she can need me anytime...when I am not in school my entire time is hers.”* Rani was never off duty. She was always taking care of her mother, which left little time for herself. The situation was similar for 15-year-old Reshma, who said that *“all the time after school”* was spent in the care of her father. Even if she had to study, she sat next to her father and studied.

18-year-old Nidhi shared that she didn’t even get one minute to herself. 18-year-old Alicia shared getting time only at night, after everyone was asleep. 15-year-old Moto

also felt that it was, *“difficult to take out time for oneself.”* 15-year-old Sahil, 15-year-old Suhana, 15-year-old Sameer and 16-year-old Rani also had similar feelings about their time.

Key Informant 6, a social worker from Mumbai also said, *“such children get very little time for themselves. The biggest challenge for such children is that they are not able to do anything for their own development.”*

Impact of Care Work on Relationships

Care work also impacted the relationships of these children. They isolated themselves and rarely made friends. They also mentioned losing friends because of their role. 17-year-old Gazal was brought to the city from her village, where she used to live with her grandparents, to look after her mother. She had to uproot her life from the village and separate herself from everyone she knew because of her mother’s care needs.

18-year-old Khushi also reported having fights with her friends due to her caregiving responsibilities. She said, *“yeah a couple of time, have had fights with friends, it was my birthday only, and on my birthday, they had made plans to go out, but I wasn’t able to go, I said mummy is unwell, I won’t be able to go, so they got angry...then I had to make peace with them over phone.”*

As noted earlier, caring activities affected the children’s time for leisure and thus their time with friends. 17-year-old Ayana felt that she was able to spend more time with her friends before she started caring for her parents. 15-year-old Sameer also said that he got to spend time with his friends only on days when there was not a lot of housework. Nidhi, 18-year-old, also said, *“I get very little time with friends, I stay at home only mostly. I don’t get time to go out a lot.”* She also added *“I don’t have any special friends... even if I want to make, they don’t want to become my friends.”*

They were very careful in peer relationships as some children reported that they’ve had to face ridicule from friends. Additionally, a certain level of stigma was also associated with the young carer role. Although more needs to be studied about it in the Indian context.

Key Informants suggested that social isolation, limited social interactions and weaker social circles also affected their job prospects as most jobs required social

connections. It also affected their ability to access support services as they remained unaware of their availability.

Key Informant 1, a social worker from New Delhi shared, *“Their friend-circle remains small. Sometimes limited to family only. Their social life is also limited, so they know little about other religions and cultures. They don’t mingle with them [people from other religions and cultures] ...”*

Thus, it can be inferred that care work has cascading impacts on the children’s relationships and social life.

Future Impacts

Care work could also have an impact on the future of these children as some had to change their own aspirations for the benefit of the family. At school, they chose presumably simpler subjects to study which gave them more time for caring activities. 16-year-old Naira shared, *“because in commerce¹⁵.... that will become hard, because of the problems at home, I won’t be able to concentrate a lot... arts, I would be able to handle it.”*

Their decisions were made keeping the family in mind. This also involved career choices which would help them financially support their families in a timely manner, choosing colleges/universities closer to the house and even decisions to not get married too soon to be able to support the family member longer, especially among girls.

At the time of the interview, 17-year-old Gazal had secured admission to a university a bit far from their home twice but was unable to join due to her mother’s care needs and her father’s insistence that she went to the nearest university. The other option for her was to join night college. Her ability to study was also dependent on the well-being of her mother. She was worried that after her mother’s demise, her father wouldn’t let her continue her education and would insist she gets married.

¹⁵ In the Indian education system, students choose between Science, Commerce, and Humanities/Arts streams after Class 10 national exams. This is similar to GCSEs in the UK. Stream selection is merit-based, with Science requiring the highest marks, followed by Commerce and then Humanities, reflecting a perceived hierarchy of difficulty in learning too.

15-year-old Reshma also believed her future will be affected because of the carer role. She said, *“I want to do something in the future, but I feel like, given the situation of the family, would I be able to do it or not?... this is papa’s condition now, don’t know what will happen then...I want to become a doctor.”*

16-year-old Yashika was not sure if she would be able to go to university after finishing her schooling. 18-year-old Khushi wanted to become a teacher, but she was aware that the situation at her house would not allow this. Khushi’s eyes were welling up when she said this, and we had to take a break in the interview.

Then there were others like 15-year-old Bitto, for whom finishing school looked like a difficult task. During the interview she said, *“if I pass 12th that itself would be a big thing...I have told mummy that it’s my dream to become a doctor, mummy is like keep the dream in your dreams only.”* This was because the family was facing major financial crisis after her father’s accident. Her father’s health kept deteriorating and the family wished to marry Bitto off before the father’s demise. This meant that she would have to stop school.

Caregiving also affected the young carers’ ability to think about their future as Key Informant 3, a schoolteacher from New Delhi shared, *“Their ambitions, they don’t show that much. I mean, they can’t think ahead very much. Because now, for them the question is of life and death. So how will they think? What will they do? So, their ambitions that are there, they stop...Once they are out of that circumstance, only then they can think ahead.”*

As seen from literature and from the findings of this study young carers have a limited social circle. Key informant 1, a social worker from New Delhi, while reflecting on the socio-economic situation of India says that it would be difficult for young carers to get jobs because, *“a lot of jobs especially in the private sector, are got through friend circles [connections]... so if there is no friend circle then there are no jobs.”* Key Informant 2, a project lead from New Delhi was of the opinion, *“there is no future for her [young carer].”*

Risks Associated with being a Young Carer

Some young carers also had to face risky situations due to their carer role. This could either be the tasks they were undertaking or the situations they were in.

For example, 15-year-old Rani, who ran a small shop to support her family had to carry a heavy and flammable materials like a gas cylinder to and from the shop every morning and evening. She had to do this because the shop was not a permanent set up. Rani also undertook extremely dangerous chores when she heated water on a stove top and carried the hot water to the bath place, for her mother. Sometimes she also did this on an open fire using a mud stove and firewood to curtail expenses on gas. Here the bath water is boiled in a large container after which it is manually picked up and taken to the bathing spot.

12-year-old Pihu's visually impaired paternal uncle also lived with the family. He needed support with various things, especially, going to the community toilet. Pihu often helped her uncle with this, however the uncle preferred taking her 10-year-old younger sister because Pihu was *"grown up"* and the community toilet was where drunkards and other anti-social elements spent time. The sexualisation of a 12-year-old and the physical risks of helping her uncle with basic hygiene needs is visible here.

17-year-old Ruksar shared one instance where the young carer was physically at risk when the mother got seizures. She said, *"at our old home... so there she [mother] had got it [seizures]. So, she just fell on my body, completely. So, I had to hold her. I was not able to hold her."*

Another example of risks associated with carer role is the case of 15-year-old Payal who was a carer for her father with alcohol related issues. She mentioned that sometimes her father became very violent towards her and other members of the family. She shared, *"...when I was alone [at home] ...he wanted money, so he was asking me. I said I don't have money, ...so he picked up the tongs and hit me on the thighs...it got swollen...once my sister had not given him curry, so he had hit her, I mean he threw a bowl at her head, so blood had come. I mean if you don't give him something then he resorts to hitting."* She shared that she used to be in a constant state of fear when her father was at home. So, she, and her sister preferred spending time at their neighbour's house. They only went home when their mother came back from work. She

also shared that her father had threatened to stop her education because he didn't like the smell of pen ink. This was distressing for Payal. She had also witnessed her mother and sister being physically abused by her father and therefore had to do things for him because she feared him.

Key Informant 5, a social worker from Mumbai shared that some young carers were at risks of infections especially if they were supporting the care-recipients with medical needs and if the care-recipients had communicable diseases.

Thus, it can be inferred that for these young carers, their responsibilities posed significant risks to their well-being. Nevertheless, they carried out their roles with resilience and without complaints, fully aware of the centrality of their position and the absence of alternative options.

Positive Impacts

Even though the carer role demanded a lot from the children, some shared that they had also learnt new life skills like cooking, basic knowledge about medicines, how to manage a household among others because of their role. Some felt that they had acquired more skills and were better than their peers. They felt proud of themselves. They also enjoyed the appreciation they garnered from family and neighbours because of the tasks they performed.

17-year-old Gazal, used to live at her village before she was brought to Mumbai to care for her mother. As a result of her carer role, she was able to spend more time with her mother. She said, *"[earlier] I didn't feel like I had a mother, she was always away, now I feel very good that I am with mummy."*

18-year-old Nidhi shared, *"[I have learnt] to become responsible, I mean I can manage the house, I have learnt now, earlier I didn't know how to do anything, any household chores."* 16-year-old Yashika said that she had become a little more empathetic towards victims of accidents after she experienced it with her father.

Key Informant 2, a development sector professional from New Delhi shared that early maturation of young carers was also a positive impact as, *"the earlier you become more responsible, you will become a more responsible citizen also. So that's one way of thinking, but again, [that] is at the cost of losing the individual's opportunities of*

learning and growth and proper development and all. We shouldn't be so selfish in that way. So certainly, it [comes] more with the challenges rather than the benefits."

Key Informant 1, a social worker from New Delhi was also of the opinion that there were some positive impacts of a child's caring role which may take the form of appreciation from neighbours/relatives and favourable comparisons with other children their age. However, he was quick to add, "...but this is only the 'starting level.' Later the child has to face a lot of troubles...Positives are there only initially..."

Therefore, as evident from the above excerpts, the negative impacts of caregiving roles were much more than its positive impacts. Therefore, the aim should be to acknowledge the positives and to reduce the negatives.

Lack of Support and Hidden Nature

The major challenge that young carers in this study had to face was a serious lack of support. Some children in the sample shared receiving monetary support, emotional support, and support with caregiving duties from extended family members, neighbours, friends, teachers, NGOs and government programs. However, these were inconsistent and unstructured. This minimal support was also mostly directed towards the care recipient, but it indirectly helped the young carer by reducing their stress. It can be argued that the well-being of the care-recipient was directly proportional to the well-being of the young carer.

This lack of support could be linked to the lack of awareness amongst policy makers and civil society about the existence of such a group of vulnerable children and the resultant lack of programs. This would be discussed in detail in the next chapter.

Chapter Summary

The young carers in this study reported various detrimental impacts of their caregiving role on their education, physical and emotional health, time, future, relationships, and overall well-being. However, it is noteworthy that some participants also reported positive impacts, such as, improved empathy, and the development of practical life skills. The negative impacts, however overshadowed the positive impacts. These outcomes provide a nuanced understanding of the challenges faced by young carers in the Indian context.

Young carers indicated to various support systems like family, relatives, friends, neighbours, school and teachers, NGO, government, and religion. However, these were episodic and unstructured in nature leaving the young carers in a state of self-reliance and isolation. At the time of writing, there were no government regulations targeting young carers and their families. The lack of awareness about their mere existence was a leading factor contributing to their hidden nature.

The impacts of their caregiving role were often exacerbated by the lack of any formal or informal support systems, leaving children to navigate their responsibilities in isolation. This chapter reflects the pressure to continue caregiving without rest, and the absence of safe spaces for young carers to express or process their emotional and physical strain.

Due to lack of awareness about their challenges and support systems, the young carers were compelled to continue their duties no matter the costs. Furthermore, in the absence of formal support systems, they became the safety nets on which the sustenance of the entire family was dependent. From the outset, the duties that they were undertaking were beyond what was expected of children their age, and in addition to that, these children had no respite from them due to systemic challenges and the invisibility of their contributions. Therefore, this chapter underscores the urgent need for recognition and support of young carers in the Indian context and subsequently the constitution of policies and support systems for them.

Chapter 9: Seen Yet Overlooked- The Systemic Blindness Towards Young Carers in India

Introduction

While young carers described their everyday struggles, the broader systemic issues contributing to their invisibility were highlighted by adult key informants. This chapter will present an analysis of data obtained from six key informants' interviews, highlighting the systemic challenges encountered in developing support systems for young carers. The key informants in this study were social workers, teachers and professionals working closely with children and young people. Their experience of working with children in areas such as child labour, school education, children living with HIV/AIDS, health, housing, disability, and more spanned between 10 years to 26 years. They drew on their years of professional engagement with children and social systems and identified key structural challenges which young carers in India were facing which will be detailed in this chapter. This chapter will also explore potential support structures that could be established or leveraged from existing frameworks, as identified by the informants.

Reflections about Young Carers as a New Concept

Key informants in this study found it difficult to reflect on the idea of children caring for adults, and their focus was primarily on children looking after other children like younger siblings. They needed some prompting during interviews to reflect on the issue of children taking on caregiving roles for adults, which was a completely new concept for all of them. This challenge is evident in the suggestions they provide later in the chapter, which are mostly for children caring for other children. The key informants in this study were professionals working closely with children and were predominately trained to address distressing events in children's lives such as child labour where there were external aggressors. This, however, was not a perpetrator-victim situation, rather, the child's challenges stemmed from the illness of a family member. There was no one to blame and the situation involved multiple nuances. These scenarios have not been widely recognised in the Indian setting; it was unfamiliar to them and

therefore difficult to process. Had I spoken to professionals from adult-focused support services or disability rights I may have received different insights.

Although most key informants were reflecting on the issue for the first time, all of them agreed that children with caring responsibilities were a vulnerable group, pulling more than their weight. Key Informant 2, a project lead from New Delhi, believed children with caring responsibilities to be a very vulnerable group. He said, *“becoming a caregiver... is much much much much much much worse than the normal kids. So, one side you see they are being ignored of the school education...second thing, they are financially always dependent on the adults. They are voiceless primarily for the reason that there are no big forums, they are not able to express themselves, their concerns, there are no avenues where they can come forward and express themselves and express their trauma and their concerns. So, basically, I would say that they are the most voiceless groups in the entire spectrum of people who are infected, affected or at risk...”*

Key informant 5, a social worker from Mumbai shared, *“no child, no matter who the patient is, children should not be doing the work of handling patients...which might cause him to be maybe physically infected or mentally disturbed.”*

They also recognised that the magnitude of this underexplored and underdiscussed issue would be immense, as clearly articulated by Key Informant 3, a schoolteacher from New Delhi, *“In Delhi if there are 2500-3000 schools... and in each school if there 10-20 [such] cases, then also the number goes up to more than 40 thousand.”*

The motivations for children to take on caring roles according to the key informants could be boiled down to two main reasons. Firstly, lack of support from the extended family due to break up of the joint family owing to migration. Secondly, poverty in the family. These issues have been discussed in detail in chapter seven. However, it needs to be emphasised here that the overarching theme emerging from interviews with both the key informants and the young carers is the lacuna in support for poor households with ill family members from both the state and civil society. Some other reasons mentioned by key informants include- women’s employment, substance abuse in the family, ill health of the parents and parental separation.

Some key informants also believed that the need for children to become carers arose only when the mother in the family became ill. Key Informant 6, a social worker from Mumbai said, *“we have seen that the children mostly care for the mother...”* This could be attributed to the gendered construction of care work as a feminine role. While mothers are expected to care for ill fathers, societal norms often discourage men from engaging in caregiving or domestic tasks. Consequently, the children in the family, who as discussed throughout this thesis are considered part of the feminine sphere until adulthood, assume caregiving roles for their mothers. This also alludes to a certain level of systemic normalisation and therefore hidden nature of young carers in India.

Systemic Challenges Faced by Children with Caring Responsibilities

While the children in the young carers sample spoke about their day-to-day challenges, the larger systemic challenges which resulted in their hidden nature was brought to light by the adult key informants in the study. Their social location as people working closely with children and as people who were closely working with social justice systems put them in a position to see the gaps in these systems and to reflect on them. They mentioned cultural norms and gendered expectations, lack of awareness and support and stigma associated with illnesses to be the main systemic challenges faced by children with caring responsibilities in India.

Cultural Norms and Gendered Expectations

Cultural norms of filial piety and institutionalisation of caregiving within the families, as elaborated on in chapter two, that are prevalent amongst Indian families, dictate that taking care of family members especially parents, is their child’s duty or *kartavya*. Key Informant 4, a social worker from Mumbai said that she has observed this expectation in some communities, *“our children will only have to take care of us. This mindset is there.”*

Key Informant 2, a project lead from New Delhi added, *“...caregiving has been part of the Indian culture, be that for the younger ones, be that for the elderly...”* He was also of the opinion that more than children in cities, children in villages, are encouraged to follow such cultural practices which prescribe specific norms and responsibilities of being part of a family. He said, *“responsibilities are being imposed on them by... imposing upon culture and practices. [they are told] this is how we are ...this is how*

family should be, this is how a family member should be." Here they refer to early social conditioning within families, wherein traditional norms are instilled in children from a very young age, with the expectation that these norms will be adhered to. Key Informant 3, a schoolteacher from New Delhi, also alludes to this when he observes that, children watch their parents and other adults taking care of vulnerable members which results in development of a "culture" where you *"have to take care of your elders... a child sees these things, so his sense of belonging is maintained. So, then [in turn] he tries to maintain that system, that unit [of family]."* He goes on to equate caregiving for elders with language spoken in the house, which is picked up instinctively by a child even without formal education.

Key Informant responses emphasised that when in crisis, cultural compulsions required children to take on adult roles of caregiving and that there was a tendency amongst children to emulate older adults' adherence to filial piety and consider caregiving as their duty.

Any kind of external institutional support sought to perform this duty of caregiving, is socially condoned even for adults. As rightly illustrated by Key Informant 1, a social worker from New Delhi, *"if the grandfather is unwell and if the son keeps him [in an institution], then the society will know that the son had put him in a home [which is looked down upon]. So, would the son keep him there? Now if the son does not, then ultimately the granddaughter or the grandson will only have to look after [the grandfather]."* Additionally, the socio-economic status of the families suggests that availing such services, which are usually privatised, would be expensive and beyond the financial capacity of many such families.

Key informants also re-emphasised the gendered nature of care work. Key Informant 1, a social worker from New Delhi says, *"there is a cultural aspect. Girls are able to cook, and boys don't."* He emphasises on the cultural expectations from girls to contribute to the family's reproductive labour from early on. He then goes on to connect this family expectation to structural choices that shape girls' lives for instance their education. He elaborated that *"parents enrol girls in government schools, where her name will not be taken off the [admission] list, even if she does not go to school for two months."* This enables the girls to continue to contribute to the family's reproductive labour. While on the other hand boys are enrolled in private schools

where there are stricter rules around attendance and of schoolwork. This indicates to the socio-cultural expectations from girls to be the caregivers.

Key Informant 2, a project lead from New Delhi added, *“the male-female gender difference are there, caregivers when we talk about.”* He claims that in instances of crisis, *“the elder girl child... has to become the caregiver there. So, she particularly, will have to leave schooling first of all, and make sure that the younger ones are taken care of...mostly these caregivers are considered to be the female elder children...never we have seen a male elder child becoming a caregiver...male child becomes a caregiver...[but] that is very rare...”* He alludes to the importance of birth order in care work.

This pattern was evident in the qualitative sample, where eight of the 21 children were firstborns. Seven out these were girls and only one was a boy. Among the four boys in the sample, three were second-born sons whose older brothers typically handled responsibilities outside the home, leaving them to manage domestic caregiving tasks. The remaining girls were either the only daughters, with brothers who did not engage in caregiving, or the sole daughters available to support the family, as their older siblings were either employed or had moved away after marriage.

However, these intersections of birth order, gender and caregiving practices in India needs to be studied further. Because it is highly possible that male carers remain largely invisible, owing to the gendered nature of care work. Additionally, the reliance on community contacts for identifying young carers may have introduced a selection bias, potentially leading to a greater representation of girls in the sample.

Key Informant 2 was also of the opinion that girl children in particular, ensure that the family is held together and not *“derailed”* in times of crisis. Key Informant 4, a social worker from Mumbai was also of a similar opinion. Key Informant 2 claimed that in cases where there are no female caregivers in the family, other females from the extended family are called in to take on caregiving roles, highlighting on the gendered nature of care work.

While cultural norms do emphasise filial piety, it is to be noted that this expectation is typically directed towards adult children who are capable themselves. However, the lived realities of some families as seen in the previous chapters require non-adult

children to bear these responsibilities. This combination of quotidian circumstances and socio-cultural norms contributes to the hidden nature of young carers in India. This could be because of a collective understanding that young carers just started repaying their filial debts a 'bit' early and did a 'bit' more than their peers. These children are therefore applauded for their compassion and for fulfilling these duties earlier than their peers, however, they are rarely supported because it is their 'duty,' resulting in the negative consequences of their care-giving roles as observed in chapter eight.

Lack of Awareness and Support

Key informants also suggested that another major challenge for young carers in the Indian context, which also correlates to the previous point of cultural compulsions, is a significant lack of awareness amongst the general population about such children. Even amongst social workers, teachers and professionals who have been working with children under various capacities for many years, this was a novel concept. Most were hearing about something like this for the first time. Key Informant 3, a schoolteacher from New Delhi shared, *"there have been no conversations about this ever. I have also never thought [about young carers]."* They thought that the topic of this study was *"peculiar"* because they had not heard of any research on such a topic before.

Key Informant 1, a social worker from New Delhi added, *"I have come across them [young carers] a lot of times, but I have not looked at them from your perspective. I just used to think that the child is working at home. Working in the sense taking care of parents and siblings...But I had not, like you are saying, caregiver, I had not looked at them from that perspective."* Thus, emphasising that people saw them but also did not consider them to be vulnerable children in need of care. Therefore, their contributions and resultant implications stayed hidden in plain sight.

Alluding to the selective attention of state, civil society and academia, Key Informant 5, a social worker from Mumbai said, *"Our focus was very clear, firstly child labour, [and then] children with special needs... apart from that such vulnerable children are also there, they were never focused on."* Key informant 2, a project lead from New Delhi added, *"... something like this has never been explored or never been adequately documented and advocated with the government for a programme like this."* Key

Informant 5, a social worker from Mumbai also noted, “...we do not have any programs for such children. We don't have any activities. Or even the government does not have any provisions. That if there are such children, if there are such families, then rehabilitate them in some way, there are no provisions like that.” Such lack of attention from both governmental and non-governmental bodies contributed to a perception that such an issue is either non-existent or are isolated incidents. The experiences of such children were largely absent from collective consciousness. At the time of data collection there were no organisations, governmental or non-governmental working with young carers in New Delhi or Mumbai. Such a lack of awareness in practice amongst people working closely with children extends to policy makers as well.

As a result, children with caring responsibilities were treated as anomalies and received only provisional support if they or their family fell within the scope of the organisation's mandate in some other capacity. Key Informant 6, a social worker from Mumbai shared, “there are organisations with a certain target group. Some organisations have limited scope of work. Some work only with women. Some work with only girls, some work with children only. So, in that, I think some [vulnerable groups] get missed.” They also received some support because of personal initiatives of individuals like social workers or teachers as they were perceived as isolated cases.

Therefore, due to the lack of awareness and identification young carers fell through the cracks of the child protection systems in the country. They were not acknowledged as part of a systemic problem requiring comprehensive solutions and broader interventions. Lack of awareness further aggravated the issue of lack of support available to children with caring responsibilities and consequently their families. Key Informant 5, a social worker from Mumbai believed “there are other provisions, but they are not reaching them [young carers]”. For these children to receive any kind of support, even to be made part of the existing provisions granted by the state for vulnerable children, their existence needs to be widely recognised by gatekeepers. For example, Key Informant 1, a social worker from New Delhi, believed that infants and toddlers could be supported through the pre-existing *Anganwadi* system. *Anganwadis* are government-run early childhood care and education centres in India that provide free pre-school education and nutritional support to children under the age of six. Key Informant 1 believed enrolment of toddlers into *Anganwadis* could ease the burden on

older children who care for them and enable them either to do schoolwork or undertake household responsibilities with ease. However, this support remains inaccessible either because the system is unaware of these children with such responsibilities or because the families themselves are unaware of, or unable to access, such services. As a result, the children with caring responsibilities continue to face difficulties.

Stigma

As is often the case in many households, there is a strong inclination to keep family matters private. Key Informant 3, a schoolteacher from New Delhi, mentioned that there is a tendency amongst young children to hide their circumstances. He says, *“normally, that tendency is there in us. We don’t share our problems with everyone that easily. That’s what these kids do.”* According to them this tendency to conceal crises within the family is further exacerbated due to fear of judgment, bullying or ridicule from others.

There is also the issue of stigma associated with illness which could be due to the cultural tendency of viewing *“everything as infectious”* as shared by Key informant 2, a project lead from New Delhi. It often forces families to hide such issues to avoid losing their social standing and being judged by others. This is especially true in families suffering from stigmatic diseases like HIV/AIDS and tuberculosis. Such a tendency would have only exacerbated after the COVID-19 pandemic.

All the above-mentioned challenges of cultural compulsions, lack of awareness and stigma, worked along with antecedents to caring roles mentioned in chapter nine, to create challenging environments for the young carers in India and deterred them from seeking support.

Suggestions to Support Young Carers in India

When asked for suggestions to address this issue, and support children with caring responsibilities, the common suggestion amongst all key informants was raising awareness about young carers. Following which they also suggested measures to support the young carers either through involvement in existing policies and programmes or through creation of new provisions targeting them in particular. Other

suggestions such as appealing to philanthropic efforts or seeking individual-based support, were also proposed.

Raising Awareness and Identification

All the key informants unanimously expressed the need for raising awareness about children with caring responsibilities. Key informant 3, a schoolteacher from New Delhi argued, *“I feel, the first thing is identification... until identification does not happen, how will it work?”*

Key Informant 1, a social worker from New Delhi shared, *“If they are able to identify, then there would be benefits.”* Methods of identification as suggested by key informants involved surveys or collection of data about young carers in the families through existing networks of Accredited Social Health Activist (ASHA) workers or Anganwadi workers, who are community based frontline workers focused on women and child health. This data was not being collected at the time of the study.

Key informant 2, a project lead from New Delhi suggested collecting data about young carers through the census. It was recommended that based on this collected data, evidence can be created, and the gravity of the issue understood. This would further aid in establishment of laws and policies for children with caring responsibilities.

Key informant 2 also observed, *“India has to travel a long way to realise that this is really a fact. And there is a need for interventions and adequate budgetary and man-force support...”*

Involvement in Existing Programs

One of the main support measures for young carers as suggested by the key informants was that after awareness generation and identification these children should be made party to existing programs of the government and/or the NGOs from which they can get support. For example, Key Informant 2, a project lead from New Delhi proposed incorporating young caregivers as a separate category of vulnerable children into the Integrated Child Protection Scheme. This could help young carers and their families receive financial support from the government.

Key Informant 1, a social worker from New Delhi suggested encouraging continued education for young carers by registering them under the *Ladli* Scheme. Under this

program, financial contributions are made by the state into a fixed deposit account held in a girl child's name, based on certain eligibility criterion. These deposits are made when the child attains key academic milestones- ₹5,000 upon entering grade 1 and subsequently in grades 6, 9, 10, and 12. These funds become accessible upon the scheme's maturity, which depends on the child's entry point into the initiative. It is to be observed that this suggestion stems from an assumption that young carers are only girl children and do drop out of school. However, we have observed in the previous chapters that this might not always be the case.

During the interview, Key Informant 1, recalled that, children who were responsible to take care of younger siblings were often allowed to bring them to the NGOs centre when the older ones came there for education support. This was also extended to youth or children's meetings organised by the NGO. He believed that this approach could be systematised and expanded to include young carers responsible for looking after younger siblings, thereby providing older children with greater space and time for themselves. This was also an example of young carers being supported by civil society, albeit unknowingly.

Key Informant 1 also proposed bringing back night schools, a discontinued government initiative. He believed that these evening classes could provide a pathway for young carers, who care for vulnerable members of their families during daytime hours while other adults are at work, to continue their education. This idea when connected to his earlier observation about the social isolation faced by young carers and consequent lack of job opportunities, might offer a chance for social interaction and broader opportunities. However, it needs to be acknowledged that this approach would not be viable for those with full time caregiving duties. He also suggested connecting such children to open schools, which are organisations which provide opportunities for flexible education for children who are unable to attend traditional schools. Such non-formal systems of education were also advocated for by Key Informant 2, a project lead from New Delhi. Although these could be helpful for some young carers, their effectiveness would be limited for those with highly regimented and lengthy daily routines as illustrated in chapter seven.

Key Informant 1 and Key Informant 2, also advocated for providing support to young carers with poor health by integrating them into existing nutritional support programmes of the government.

Key Informant 5, a social worker from Mumbai suggested, linking up the young carers to *Bal Sanghapan Yojna*, a Maharashtra government scheme which provides financial support to children who suffer neglect or are at a risk of separation from their families. They also suggested linking the families to organisations that distribute free ready meals.

As mentioned earlier, Key Informant 1 also proposed the use of government-run crèche facilities or those linked to *Anganwadis* for the care of infants and toddlers. This, he suggested, would help support families by ensuring appropriate care for young children while reducing the caregiving burden on young carers. Although he did not specifically refer to it, this provision can be availed under the Indian government's *Palna* Scheme. He further noted that such crèche-based solutions are only feasible when the young carer is responsible for younger siblings who can be placed in these crèches. However, in cases where the young carer is looking after an adult family member, he admitted that he could not identify a viable solution. He speculated that an institutional arrangement for the sick person might be a possibility but immediately acknowledged that this might not be culturally acceptable. As mentioned above, this further intensifies the pressures on the young carer. He also added that he was not aware of any existing government schemes addressing such situations.

New Provisions

Key Informants also proposed some new provisions for supporting young carers. Key Informant 2, a project lead from New Delhi, suggested viewing families with young carers as 'ill families.' They also described three approaches of care for these vulnerable families - 1. Family Centred Approach, 2. Community Centred Approach and 3. Institution Centred Approach. The family centred approach should focus on capacity building of the caregiver and on resilience building. It should also aim at improved quality of life of the vulnerable members. This could be done through financial support, access to education, health and mental health services, nutrition support and livelihood support. The community centred approach involves building

safety networks within community groups by mobilising the local community to care for the vulnerable family. This could be done through training community groups or volunteers within the community. The institution centred approach should focus on improving infrastructure like foster care, or residential shelter homes which can function as permanent or temporary abodes for the young carers, if necessary.

Key Informant 3, a schoolteacher from New Delhi, felt that there should either be trained professionals who can be trusted by children and identify those in caregiving roles, or that schoolteachers themselves should be equipped with appropriate training to carry out this identification. Post identification, they suggested, that the parents of the young carers should receive counselling with a focus on the child's future well-being and development. He also suggested mental health support for young carers. Counselling support for young carer was also recommended by Key Informant 2, a project lead from New Delhi.

Key Informant 1, a social worker from New Delhi suggested institutionalising young carers as a potential solution. The underlying goal of this measure was to ensure that young carers could focus on their education and, in turn, secure a better future. This idea was supported by Key Informant 5, a social worker from Mumbai, who additionally recommended the institutionalisation of care recipients and/or other vulnerable members in the family. Key Informant 6, a social worker from Mumbai, recommended the concept of part-time shelter homes for care-recipients where they can be placed while the young carer goes to school or is at work.

Key Informant 1 also suggested providing skill-based or technical education to children as this may help them with early employment. He pointed out that government does have provisions currently available, but these are during the day and therefore inaccessible for young carers. Key Informant 2, a project lead from New Delhi supports this idea of vocational training for young carers which can provide them with skills and certifications to become employable and in turn support their families.

Key Informant 6, a social worker from Mumbai also suggested setting up a food programme for such families through which they could receive free food supplies, which would reduce some financial burden on the family.

Key Informant 5 mentioned that, following the introduction of this topic to the NGO through this research project, they had begun considering programs that could provide some form of respite to young carers. She shared, *“even if for 1 hour they come out of that environment, so they would be able to get some time for themselves. We are thinking along those lines.”*

Key Informant 3, a schoolteacher from New Delhi also suggested supporting the family financially but immediately elaborated on that statement by saying, *“where you bring in money matters, then there you will have to strengthen the identification process a lot. Because just for the sake of money, many people will lie...”* He then goes on to say, *“Economically I feel that that much need won’t be there, if you develop the policy in a way that things would be handled there. It can be done.”*

Other key suggestions included, creating training programs to help young carer support the care-recipient better, creating opportunities for recreation for young carers and generating philanthropic support which could translate into financial or material aid for the family. Key Informant 2, a project lead from New Delhi advised that when provisions are created for young carers, they should be gender and geography specific. He is also of the opinion that social parameters like caste and religious identity-based differentiations should be addressed while these provisions are created.

Chapter Summary

Once the issue was brought to their attention, the key informants acknowledged that the issue of young carers was a significant concern and agreed that the chores carried out by children with caring responsibilities were beyond what is normally expected of children their age.

The hidden nature of the young carers can be attributed to cultural messaging around family roles and the effects of social conditioning. Additionally, the lack of awareness about such a group of children also added to this challenge. The chapter also indicated that the unwillingness of families to receive support due to stigma around diseases such as HIV/AIDS or communicable diseases like tuberculosis also contributed to the hidden nature of young carers.

The major challenges facing young carers in India right now is lack of awareness about them. As discussed in chapter five there was also a general lack of collective hermeneutical resources to understand young caregiving practices and its implications. Most of the participants in this study were reflecting on the issue for the first time. Furthermore, this led to lack of helpful vocabulary to describe such a situation. It also discouraged the children performing these roles from recognising that their situation was not normal, and that seeking support is acceptable and not a betrayal of their duty.

This lack of awareness also translates into lack of long-term support or only episodic support for these children. Therefore, raising awareness and identification of young carers was suggested as a key recommendation and a crucial immediate step towards mobilising support for them and advocating for their rights. This, in turn, could lead to the development of new programs and policies tailored to the needs of young carers, or their formal recognition and inclusion within existing child welfare initiatives.

Section 4

Quantitative Methods and Findings

Chapter 10: Quantitative Study Methods

Introduction

This chapter discusses the methodological choices made to formulate the survey questionnaire, and collect data from the children and young people to answer the quantitative research question of this mixed-methods study:

What are the daily tasks undertaken by children and young people in India to support family functioning?

As mentioned in chapter five, this research question was included in this study to contextualise the information received from the young carers in the qualitative study, their experiences and responsibilities. The objective was to understand the typical levels of children's engagement in the various household tasks that contribute to the reproductive labour of their households. This chapter will begin by describing procedures involved in the development of a survey tool. It will also explain the procedures undertaken to recruit participants to this study following which the survey tool was administered. Towards the end of the chapter the reader will be introduced to the data analysis techniques used in this study and the hypotheses generated to understand the data.

Development of Survey Tool

A review of literature indicated that two tools – (1) Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and (2) Positive and Negative Outcomes of Caring Scales (PANOC-YC20) were widely utilised to measure caring activities undertaken by young people and to measure the positive and negative outcomes of caring (Joseph *et al.*, 2009). Then there was also the Carers' Alert Thermometer for Young Carers (CAT-YC) which was designed to be used primarily for the identification of previously unknown young carers by professionals (Kettell *et al.*, 2021). Other measures contributing to knowledge about young carers were also available (Ireland and Pakenham, 2010). However, these instruments were primarily developed in the United Kingdom where there are well-defined understandings of young carers and their roles. India, as evident from chapter one, did not have an understanding about young carers or the tasks they undertook. Additionally, the understandings around childhood

and cultural practices around participation of children in household chores differed in the western and Indian context. Moreover, measures developed for a given concept in one particular cultural context may not assess the concept in the same manner in other groups (Harachi *et al.*, 2006). Therefore, the use of psychometrically sound and culture specific measures were deemed imperative. To the best of my knowledge, no existing measures in the Indian context served the same purpose, thereby creating the need to develop novel measures to operationalise key concepts related to young carers in India. These measures will also assist in future investigation of young carers.

This section will elaborate on the procedures involved in choosing the caring domains or attributes to be measured using the survey tool. It will also explain the processes involved in selecting items or questions that would examine the domains of interest. Additionally, the procedures involved in translation and piloting of the survey tool will be discussed.

Scale Development Guidelines

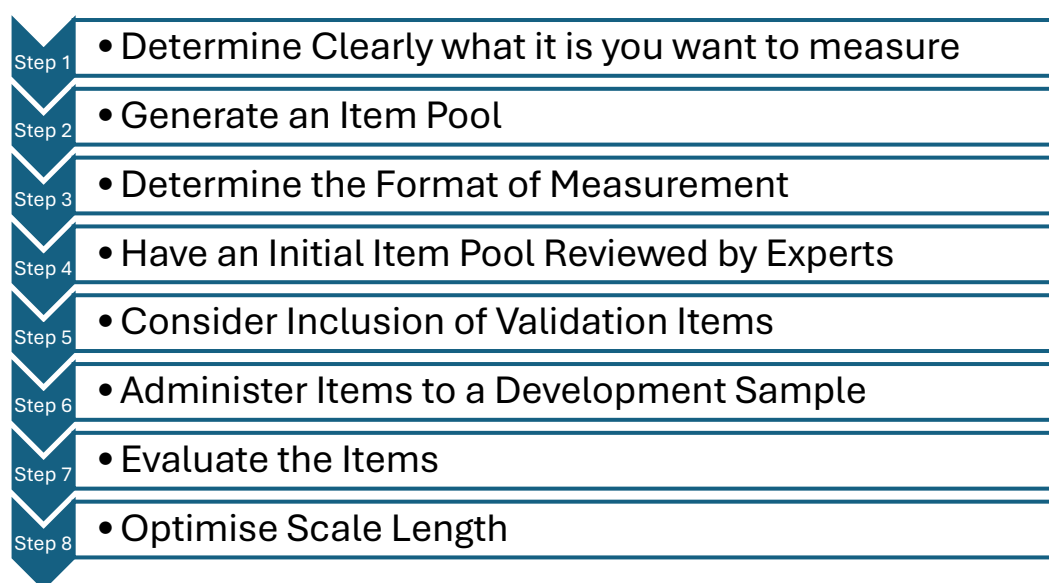


Figure 2: Steps of Scale Development as per DeVellis (2012)

Figure 2 illustrates the guidelines to be followed for development of scale according to DeVellis (2012). Steps 1-6 will be detailed in this chapter. Chapter eleven will elaborate on Steps 7 and 8.

Domain Finalisation

The qualitative interviews conducted with the young carers and adult key informants, revealed that young carers were undertaking a wide array of household and caring tasks and contributed heavily to the functioning of their families. As evident from previous chapters, the labour provided by such children were often crucial for the families' survival. However, drawing comparisons between their responsibilities and those of their non-caring counterparts was challenging because of limited literature on the typical household tasks undertaken by children within India. Therefore, the aim of this survey tool was to understand the typical engagement of children, regardless of their caring roles, in daily tasks within their households and to use that information to contextualise the tasks undertaken by young carers and its intensity.

As per Dillman (1978: 80) quoted in de Vaus (2013) the content of a questionnaire can be divided into five distinct types namely, "behaviour, beliefs, knowledge, attitudes and attributes." This survey tool was precisely interested in understanding the 'behaviours' of children in New Delhi and Mumbai with regards to their engagement in tasks that assisted in functioning of the family. Therefore, questions were formulated to establish what they 'do' (de Vaus, 2013). Additionally, the impacts these behaviours had on the children were also explored because, young carers in the qualitative sample spoke about the negative consequences of their caring activities on their time, education, physical health etc.

Therefore, the main domains or constructs to be measured through the quantitative component of this study were:

1. The engagement of children in household tasks to support the functioning of their families and
2. The impacts these tasks had on the children. Impacts measure captures physical, psychological and time-based impacts.

Additionally, demographic 'attribute' questions like age, gender, family information, religion, caste etc., were also included as part of the questionnaire to collect information about characteristics of the participants (de Vaus, 2013).

Item Generation and Response Format

To measure the domains of ‘household tasks undertaken by children’ and ‘impacts on children,’ question items were developed based on the information-rich responses of young carers and key informants in the qualitative interviews. Broad information from the questions in the interview schedule like *“Can you talk me through a normal day in your life?”* and *“Tell me about the kind of things/tasks you do at home, especially for the person requiring care”* informed the kind of tasks that children were engaged in. Additionally, information from questions from the ‘impacts’ section of the interview schedule like – *“Has helping your relative affected your physical health/ mental health/education/ social relationships?”* was used to generate items to understand the impact of children’s engagement in household tasks and caring role.

The appropriate items for this study were identified using an inductive method, also known as “grouping” or “classification from below” (Boateng *et al.*, 2018). Common chores or impacts across the interviews were identified and discussed with the supervisory team. The common themes for chores undertaken by the children were- cooking meals, cleaning dirty utensils and clothes, keeping the house clean by sweeping and mopping, buying groceries, filling water for domestic use, financially supporting the family through part-time work, helping an ill family member with bathing and toileting, helping with walking or exercising, administering medicines, taking the family member to the doctor or to the hospital, helping with dressing, helping siblings with schoolwork and supervising siblings. This, facilitated in generation of 17 items to measure the frequency of engagement of children in tasks to support household functioning.

The common themes for impacts of caring were- pain in various body parts, limited time for socialising with friends, missing school, limited time for schoolwork, constant worry about money, and constant worry about the wellbeing of someone at home. This resulted in 9 items to measure impacts. In total across both domains the survey tool had a total of 26 items which have been listed in table 4. The data was to be collected using paper and pencil interviewing method (PAPI) (Boateng *et al.*, 2018). The complete survey tool is attached in Appendix 3.

Table 4: List of original Items finalised through Grouping from Qualitative Interviews

Item No	Item Name
<i>Tasks Undertaken by the Children</i>	
1	I cook full meals at home
2	I wash clothes at home
3	I sweep and mop the house
4	I bring/shop groceries and vegetables for the house
5	I fill water at home
6	I wash utensils at home
7	I work part-time to support my family financially
8	I assist a family member with bathing
9	I assist a family member with toileting
10	I help a family member with dressing
11	I help a family member with eating food
12	I help a family member with mobility/ exercise
13	I help a family member with medicines
14	I accompany a family member to the hospital or to a doctor
15	I supervise my siblings (make sure they are safe, clean, and healthy)
16	I help my siblings with schoolwork
17	I have to make my family members happy when they are sad
<i>Impacts or Effects of the Tasks</i>	
18	I get enough sleep
19	I arrive late to school
20	I get enough time to do my homework
21	I miss (school) classes
22	I get time to play with my friends out of school hours
23	I suffer from body ache, headache, back pain, pain in hands and legs
24	I keep thinking about home/ worry about the well-being of someone at home when at school
25	I feel like crying or keep sad
26	I worry about my family's finances

As the survey tool was designed to be a self-report measure aimed at children, questions were worded simply and unambiguously. Care was taken to phrase the statements in everyday spoken language instead of using complex, formally correct written grammar. Use of jargon and technical terms were avoided. The questions were kept as short and simple to avoid confusion as far as possible. Leading questions and negative questions using 'not' which can be difficult to understand, were also avoided. Moreover, as the questions were about the children's behaviours they were phrased in the first person for example – "*I wash clothes at home*" (de Vaus, 2013). Cultural anchoring of the words and phrases was also ensured. The questions were also kept to a minimum to reduce response fatigue (DeVellis, 2012).

The questionnaire predominantly had close-ended questions (Reja *et al.*, 2003), especially when measuring for engagement in household tasks and impacts. This was beneficial because the questionnaire was designed for self-administration, making it easier for the participants to respond (de Vaus, 2013). To provide the participants with sufficient response alternatives when asked about the frequency of engagement in various chores or the impacts of their engagement, a 5-point Likert scale was utilised: 1- Never, 2-Occasionally (a few times a year), 3-At least once a month, 4- At least once a week, 5- Daily, instead of dichotomous variables (Yes/No).

Questions assessing for attributes of the participants like their religion or caste were also close-ended (Reja *et al.*, 2003). A sufficient range of response options were provided, in addition to the categories like 'other' and/or 'don't know.' At the same time questions inquiring age, family composition, etc were open-ended. The survey tool also had dichotomous variables (Yes/No) like- "*Do you know any child or young person who looks after a critically ill or disabled family member?*" and "*Do any of your siblings do any of the tasks mentioned above?*"

Furthermore, the survey tool also had a question in which the participants were requested to report on the composition of family members in their household. They were provided with a two-column table: in the first column, they indicated each family member's relationship to them (e.g., mother, brother), and in the second column, they entered the family member's age. They were told that no names need to be mentioned. the survey tool ended with open ended questions like – "*Is there anything else you would like to share with me on this topic?*" "*What are some of your hobbies?*" and

“What do you want to become when you grow up?” This was done to give the respondents a chance to add any additional comments and to end on a lighter note.

DeVellis (2012) suggests inclusion of few extra validation items (Step 5 in scale development guidelines), to test for answers due to biases like social desirability. However, this was avoided in this study as the items were generated using an inductive approach grounded in real participant responses from the qualitative sample. Construction of quantitative items based on conceptual constructs from the qualitative interview data also aided construct validity and content validity, i.e. ensuring that the items were truly measuring what we wanted them to measure (Olshansky *et al.*, 2012). Additionally, this would also have affected the length of the questionnaire. However, inclusion of such validation items can be considered in future iterations of the instruments if social desirability was considered to be an issue.

Translation

The survey tool was designed in English for the researcher’s and supervisors’ convenience. Even though the qualitative interviews with the young carers and the key informants were conducted in Hindi, they were also transcribed to English before coding. Therefore, as the survey tool was created in English, it needed to be translated to Hindi and Marathi. Hindi was the main spoken language in New Delhi, while both Hindi and Marathi were spoken in Mumbai.

As the survey tool was designed within the cultural context of India, only direct translations were undertaken, and cultural adaptations of the instrument were not required. The study used the most common methods of forward and back translation design (Epstein, Santo and Guillemin, 2015). Figure 3 illustrates the procedure followed for translation of the items in the survey tool to Hindi and Marathi. For this procedure I took support from friends who were proficient in the source and target languages. For both Hindi and Marathi translation, two bilingual individuals each fluent in the source and the target language were engaged for forward translation. I am fluent in English and Hindi and can read and understand Marathi. So, consensus between the two translated versions was obtained by me and then translated back to English. This was done to ensure that the translation reproduced the original text and to reveal or amplify mistakes in the forward translation (Epstein, Santo and Guillemin, 2015).

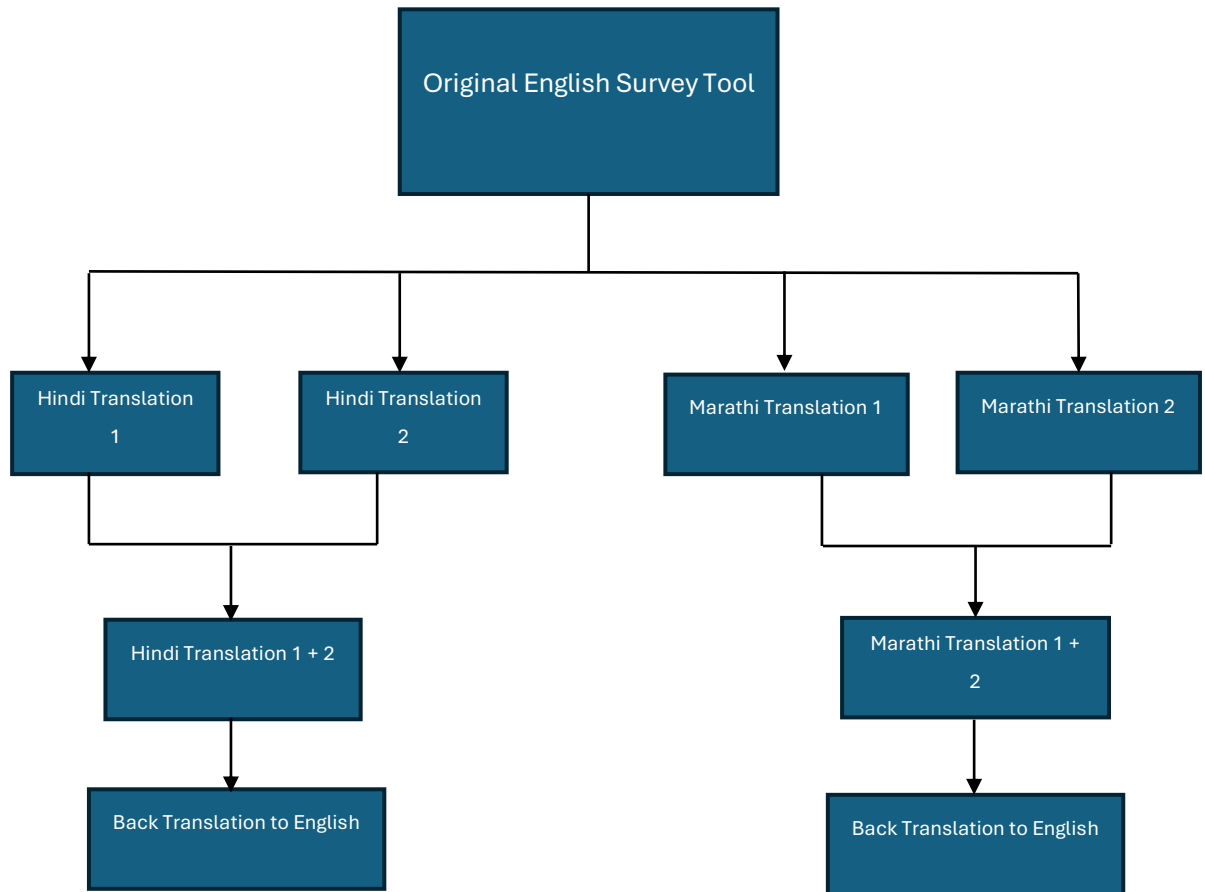


Figure 3: Diagram of Translation Process

This approach was also reviewed and confirmed during the pilot study discussed in the next section. The language used followed a casual and spoken style of Hindi and Marathi as much as possible. Both in Hindi and Marathi, verbs and adjectives change based on the gender of the person. Therefore, to make the survey tool inclusive, both the male and female verbs were used in the survey tool. For example, the Hindi translation of Item No. 1, 'I cook full meals at home' for the male gender is मैं घर पर पूरा खाना बनाता हूँ (mai ghar par poora khana banata hu) and मैं घर पर पूरा खाना बनाती हूँ (mai ghar par poora khana banati hu) for the female gender, thus in the survey tool it was presented as मैं घर पर पूरा खाना बनता /बनती हूँ (mai ghar par poora khana banata/banati hu). This was also important because such household tasks can be presented as gendered in nature with an implicit assumption that they are generally undertaken by females

Pilot Study and Results

Post translation, to help ensure that the items are meaningful to the target population a pilot testing was administered. This was done to minimise misunderstandings and non-responses which could lead to subsequent measurement errors. This was also important because translators and researchers cannot anticipate all problems encountered by the participants (Epstein, Santo and Guillemin, 2015).

For the pilot testing, six children were recruited through one of the community-based organisations in Mumbai, and this organisation was previously involved in recruitment for the qualitative study. These six participants were different from the participants of the qualitative study. Mumbai was chosen as the site for the pilot study as both Hindi and Marathi speaking populations were present here. This was an external sample, independent of the main study. The participants were offered English, Hindi and Marathi versions of the survey tool.

This sample was also from a similar background as the young carers. Their parents were domestic and daily wage workers, who belonged to low socio-economic backgrounds. All the participants were female. A mix of males and females had been requested but unfortunately, they were only able to recruit females. The participants of the pilot study were in the age range of 15-18 years. Median age was 16 (*IQR*: 15,17.25). In terms of religious composition, three participants (50%) were Hindus and three were Muslims. While two participants said that they did not know or did not want to share their caste details, two participants said they belonged to the general category, and two said they were from Other Backward Classes (OBC) (see chapter three).

The six pilot surveys were administered to each participant separately, one at a time and were recorded for analysis purposes. All the participants requested for the Hindi version of the survey tool. The entire exercise of introducing myself, explaining the research objective, clarifying doubts, attempting the survey tool, and discussing feedback took less than 30 minutes for each participant. The participants took an average of 15 minutes to complete the survey tool. This confirmed that the survey tool was short and time efficient.

While attempting the survey tool, the participants were not disturbed but could ask me any questions as I was present in the same room. One participant shared that they did

not know the right age of their parents and therefore they were asked to leave that section blank. I noted that in the introduction, participants needed to be told that if they were unsure about any answer, they did not have to worry and could leave the section blank. One participant was confused about Question 18- *Do any of your siblings do any of the tasks mentioned above?* This could have been because this question was towards the end of the survey tool initially, so it was moved up with the tasks-based questions. Another participant requested me to read out the consent form. Therefore, each statement was read out to the participant and the participant was given time to decide on their answer. I noted that this approach could be easier for the children.

After finishing the survey tool, each participant was asked about the clarity and length of the survey tool. None of the participants expressed concerns on the language and said that it was easy to understand and quick to do. One participant advised numbering the family composition table. This change was made in the finalised survey tool.

No new items were generated after the pilot and no items were dropped; however, minor adjustments were made to the approach and the structure of the survey tool based on the suggestions of the children and my observations mentioned above. This pilot testing process aided to check for misunderstandings and inconsistent interpretations of the survey tool (Epstein, Santo and Guillemin, 2015). Additionally, it also ensured sound comprehension of the survey tool by the participants as neither I nor the translators belonged to the socio-economic strata of the target population. I was, however, unable to pilot the Marathi version of the questionnaire which may therefore contain issues that remain unknown to me. The finalised items included in the questionnaire can be found in Appendix 3.

Each of the pilot participants were offered a small backpack as a thank you for their time. This was the same as the gift that the participants of the qualitative interviews received.

Questionnaire Implementation

After the survey tool was finalised, it needed to be administered to a sample of children and young people to determine the daily tasks performed by them within their households, i.e. to answer the second research question. This section will take the

reader through the procedures followed to implement the survey tool with the children and young people in the study.

Participant Recruitment

With 26 items in the scale, the ideal minimum sample size to test a new survey tool using factor analysis¹⁶ is 10 respondents per scale item, therefore a minimum of 260 participants were required for this study as recommended by Boateng *et al.*, (2018). Furthermore, considering an approximate class size of 50 students, there were expected to be approximately 150 students (50 x 3 streams) in class 11 of a school. Therefore, rounding off from 260, a total sample of 300 school-going children was to be gathered, 150 from one school in New Delhi and 150 from one school in Mumbai. Nunnally (1978) as cited in DeVellis (2012) also suggests that in order to eliminate variance as a significant concern in scale development, a sample of at least 300 should be recruited.

As mentioned in chapter five, the participants of this study were recruited from four public and state aided schools in New Delhi and Mumbai. I approached the participants only after gaining the required permission as elaborated in chapter five, and only when the school authorities were happy with the survey tool. I was introduced to the students in each class by the schoolteacher, who was present in the classroom throughout the process. Then I gave the participants a brief introduction of the topic and the purpose of the study. Following that, each participant was given a copy of the information sheet with my contact information including my local contact number, my email and the email address of my PhD supervisor, the consent form, the survey questionnaire with a unique ID and a help sheet. The help sheet was a customised list of NGOs and support organisations in their city with whom they could connect in case of any distress.

They were also given time to read the information sheet before participating in the study. The participants were assured that their participation was not compulsory and their refusal to participate would not have any consequences on their relationship with the school or their academic outcomes. They were informed that there were no right,

¹⁶ Factor Analysis is a term used to describe a family of techniques, often used in development or evaluation of measures. For this study Principal Component Analysis (PCA) was used as a data reduction technique. This is explored and explained further in chapter eleven.

or wrong answers and they could leave the sections blank if they did not know the answer. To reduce the effects of peer pressure and support their choice not to participate the participants were informed that they were free to return the questionnaire blank or to not return the questionnaire at all. Few students across the participating schools exercised this option and chose not to take the questionnaire at all while some others returned blank surveys.

Each questionnaire had a unique ID, and the participants were encouraged to note down the unique ID. They were informed that they could contact me using the contact details on the information sheet and withdraw from the study by quoting their unique ID without any questions or consequences. They were encouraged to do this within fourteen days. This was also mentioned on the information sheets. I did not receive any withdrawal requests. In the event of any emotional distress, they were encouraged to contact the schoolteacher.

Additionally, the survey form did not require the participants to write their names or any other identifying details. The participants were also discouraged from writing their names anywhere on the survey forms. Following this brief, the consent form was read out and explained to the participants. They were then invited to fill out the self-report survey form.

They were also requested to direct any questions or points of clarifications to me. I was in the room with them as they completed the survey. In the first school, participants raised questions specifically around filling the family composition table, which appeared unfamiliar to them. In response, for subsequent schools, I took a few minutes during introduction to draw the table on the blackboard and provide an example on how to complete the table. My presence in the room would likely have facilitated participants' completion of the form, enabling them to seek clarification and complete it more efficiently.

As mentioned in chapter five, 577 survey responses were collected in this study. Out of the 577, 48 participants had filled the survey form but did not provide full consent. These participants either left certain sections of the consent form incomplete or marked a cross next to specific boxes, indicating their disagreement with the statements presented in those sections. Some of these were ambiguous as to whether

the child was indicating a lack of consent or had made an oversight on the paper. Each of these were discussed with the supervisory team and it was agreed that as full consent was required for participation, these would not be included in this study. Therefore, only 528 forms were used in the study.

Data Analysis and Hypothesis

After the questionnaires were collected, they were quantitatively tested and analysed using IBM SPSS Statistics version 29. Relevant descriptive statistics and inferential statistical methods were used to answer the research question and to draw meaningful conclusions from the data.

The range of items in the questionnaire were then evaluated and combined into composite measurable scales. “A scale is a composite measure of a concept, a measure composed of information derived from several questions or indicators” (de Vaus, 2013:179). Principal Component Analysis (PCA), a data reduction technique in the development or evaluation of measures used to summarise the data (Pallant, 2016), was used to cluster items through factor analysis and inform the construction of the measures. The two measures developed were – Children’s Engagement in Household Tasks Measure and Impacts of Children’s Engagement in Household Tasks Measure. The processes involved in their development have been discussed in-depth in the chapter eleven.

It is to be noted that, during the process of refining the measure for this study, some items were removed as they did not contribute meaningfully to the measurement. This could be attributed to the fact that the questionnaire was implemented with a group of children who were predominantly non-carers and was used to understand the typical levels of children’s involvement in household tasks. These items could be reintroduced when applying the measure with young carers and subsequently tested for reliability and validity.

Following this, hypotheses were formulated to test specific assumptions regarding children's contributions towards the reproductive labour within the household. The hypotheses and rational for hypotheses have been elaborated below:

Literature suggests that work within the household is gendered in nature, with females bearing the majority responsibilities (Backer and Cairns, 2021). This trend has also been observed in children who are caregivers (Dearden and Becker, 2004; Santini *et al.*, 2020; Ytterhus *et al.*, 2024). Additionally girls in India were found to spend more time on household chores and caregiving especially during adversities (Vikram, Ganguly and Goli, 2024). Most of the young carers who participated in qualitative interviews of this study were also girls. Furthermore, key informants who participated in the qualitative interviews of this study were also of the opinion that girls participate in caregiving and household tasks more than boys. Therefore, the first hypotheses associated with the quantitative research question was:

Hypothesis 1: Engagement of girls in household tasks is higher than boys.

In addition to being females, many participants in my study were also the oldest females in the family. Key informants who participated in the qualitative interviews of this study also indicated the importance of the female elder child in times of crisis. Therefore, through the following hypothesis I wanted to understand if there was an influence of birth order and sex on the engagement of children in household tasks:

Hypothesis 2: The oldest female in the family engages in household tasks more frequently.

Webbink, Smits and de Jong, (2012:640) suggest that “Asian children are less involved in housework if extended family members are living in the household.” This was also implied by key informants in the qualitative interviews of this study who suggested that migration of people into cities and their consequent break-away from their extended families was a reason for children to take on additional responsibilities. To understand the patterns of engagement of children in household tasks and presence of extended family members the following two hypotheses were formulated:

Hypothesis 3: Higher number of members in the family, would be associated with less engagement of children in household tasks.

Hypothesis 4: The presence of grandparents or extended family members in the household is associated with a reduced engagement of children in household tasks.

As elaborated in chapter one, and from the findings of the qualitative interviews of this study (chapter eight) caregiving responsibilities have a range of impacts on the children. This includes but is not limited to their physical health, mental wellbeing, education, time and socio-economic opportunities. Therefore, to explore the relationship between household tasks undertaken by children and the impacts it has on them, the following hypothesis was formulated:

Hypothesis 5: *Higher frequency of engagement in tasks is associated with higher impacts on the children.*

Literature also suggests that girls tend to report experiencing greater impacts from caregiving responsibilities than boys (Becker and Becker, 2009; Santini *et al.*, 2020; Lewis *et al.*, 2023). This gendered difference was also noted by some key informants who participated in the qualitative interviews of this study. To examine whether similar patterns emerge in this sample, the following hypothesis was formulated:

Hypothesis 6: *There is greater impact of engagement in tasks on females as compared to males.*

The quantitative survey data (see chapter eleven) indicated that children in India frequently contributed to certain types of household tasks like domestic tasks and family assistance tasks, while did not contribute frequently to certain others like intimate care tasks. This raised the question of whether certain types of tasks were more strongly associated with greater impacts on the children. To explore which household tasks were associated with higher impacts, the following hypothesis was formulated:

Hypothesis 7: *When we control for the possible effect of sex, the variables - domestic tasks, intimate care tasks and tasks to support family members, would still be able to predict a significant amount of variance in impacts of engagement in household tasks on the children.*

Chapter Summary

In mixed methods studies, the combination of quantitative and qualitative research techniques aids in a nuanced understanding of the research problem. This chapter describes in detail how the qualitative interviews with the young carers and key

informants facilitated the generation of a quantitative measure to understand the participation of Indian children in household tasks and its impacts on their well-being. It also elaborates on the sampling procedures followed to recruit participants to the quantitative study. The challenges and methodological decisions taken have also been reported. This chapter also introduces the reader to the analysis techniques and hypothesis generated which will be further elaborated in the next chapter.

Chapter 11: Quantitative Study Findings

Introduction

As the expectations regarding the tasks performed by children vary across regions, it is essential to understand the normative roles and responsibilities of children in the Indian context while attempting to define or examine the specific activities undertaken by young carers. Therefore, this chapter will respond to the second research question of this study:

What are the daily tasks performed by children aged 13-19 years in India, to support their family functioning?

In the absence of baseline literature or instruments to determine the typical level of responsibilities undertaken by children within Indian families, this study aimed to formulate measures to answer the research question. This chapter will describe the findings from the survey implemented with 528 children and young people, in two cities of India, New Delhi and Mumbai. The chapter is broadly divided into three sections: Descriptive Data of the Participants, Scale Development and Results.

The first section will describe the descriptive data collected from the participants including information concerning age, gender, religion, caste and other family demographics. It will elaborate on the frequency of participants' engagement in various chores and the various impacts as reported by them. The second section will provide a detailed description of the procedures used to develop the two measures – 1. Children's Engagement in Household Tasks and 2. Impact of Children's Engagement in Household Tasks. It will also include the finalised versions of the measures. The third section of the chapter includes results from the measures. This section also includes analysis driven by hypotheses stemming from the research question and literature around young carers.

Descriptive Data of the Participants

This section will describe the characteristics of the data obtained from the 528 children and young people who participated in the survey.

Age

The participants in the sample were aged between 13 and 19 years ($M = 16.07$, $SD = 1.00$) with 91.4% of the sample between 15 and 18 years of age. Majority of the participants in this study were 16 years (40.2%) and 17 years old (33.2%). It was decided that data from the participants below the age of 15 years will be retained as they had provided proper consent and were studying in the same classes the 15-year-olds and therefore were expected to be mature and competent enough to participate in the survey. Since 19-year-olds were already adults, their data was also included.

Sex

The breakdown of the sample by sex of the respondents reveals that there were more girls in the sample than boys. 43% ($n = 218$) were males and 56.4% ($n = 286$) were females, while 0.59% ($n = 3$) said that did not want to reveal their sex. This reflects the broader trend in India, where girls are commonly enrolled in public schools (Kushwaha, 2020) and boys are enrolled in private schools.

Religion and Caste

In terms of religious division of the sample, data showed that 79.3% ($n=402$) of participants were Hindus, 14.99% ($n=76$) of the sample were Muslims, 0.8% ($n=4$) of the sample were Christians and 4.1 % ($n=21$) identified as Buddhist. While none of the respondents identified as Sikhs or Jains, the remaining 0.8 % ($n=4$) said that they did not want to reveal their religious identity or belonged to other religions. This is illustrative of the population of India, wherein Hindus form the majority.

Majority of the sample, which is 49.8% ($n=233$) belonged to the General category, 20.9% ($n=98$) were from Other Backward Classes (OBC), 16% ($n= 75$) belonged to Scheduled Castes (SC), 3.4% ($n=16$) belonged to Scheduled Tribes (ST) and 9.8% ($n= 46$) said that they didn't know or preferred not to reveal their caste identity. Table 5 contains a summary of participants' biographical information.

Table 5: Demographic Characteristics of Participants (N= 528)

Variable	<i>n</i>	Percentage
Age		
13	4	0.80
14	36	7.40
15	75	15.50
16	195	40.20
17	161	33.20
18	12	2.50
19	2	0.40
Sex		
Female	286	56.41
Male	218	43.00
Other	0	0.00
Don't Want to Say	3	0.59
Religion		
Hindu	402	79.29
Muslim	76	14.99
Christian	4	0.79
Buddhist	21	4.14
Sikh	0	0.00
Jain	0	0.00
Others/ Don't want to say	4	0.79
Caste		
Scheduled Tribe	16	3.42
Other Backward Castes	98	20.94
General	233	49.79
Scheduled Caste	75	16.02
Don't Know/Prefer not to say	46	9.83

Family Composition

This section presents data collected from the family composition table in the survey questionnaire, where participants were asked to report on the members of their household. They were provided with a two-column table: in the first column, they indicated each family member's relationship to them (e.g., mother, brother), and in the second column, they entered the family member's age. The average family size in the sample was 5.14 members ($SD = 1.68$, $N=450$). This is higher than the national average of 4.4 members and also of the average of 4.2 members in urban areas (IIPS, 2021).

Table 6 presents the details of families living with and without extended family members. Here, families living 'with' extended family members include relatives like grandparents, daughter-in-law (or the sister-in-law of the participant) and other relatives like paternal/maternal uncles and aunts, nephews-nieces, and cousins. It is important to note that family compositions varied, with some households including grandparents together with cousins, or other extended relatives. On the other hand, families living 'without' extended relatives included only parents and children, i.e. a nuclear family. While the majority (77.33%) lived in nuclear families, a total of 22.67% ($n=102$) of the participants lived in extended multigenerational households. This suggests that majority of the sample lived in nuclear families comprising of father, mother and children. This data is reflective of the national statistics of urban areas, where 61.3% families were nuclear and 38.7% were non-nuclear (IIPS, 2021).

Table 6: Nuclear and Non-nuclear Families in the Sample

	<i>n</i>	Percentage of all responses
Nuclear families (families without extended relatives)	348	77.33
Total families living with extended relatives	102	22.67
<i>Grandparents</i>	78	17.25
<i>Daughter-in-law</i>	9	2.00
<i>Other relatives</i>	40	8.89

The family composition table from the survey was also used to determine each participant's birth order ($N=428$). This was done by comparing the participant's age

with the ages of their siblings, allowing the identification of whether they were the oldest, middle, youngest, or an only child. Majority (32.01%, $n=137$) of the participants in the sample were the oldest child in the family. 30.14% ($n=129$) were youngest and 24.30% ($n=104$) were the middle children in the family. 13.55% ($n=58$) children were only children in the family.

Data from the table was also used to determine the sibling networks ($N=443$) that the participants lived in, and they were grouped into mixed-gendered sibling networks, single-gender sibling network and single children. The majority 62.75% ($n=278$) lived in mixed gender sibling networks, while 24.15% ($n=107$) lived in single gender sibling households and 13.09% ($n=58$) were single children, i.e. they did not have siblings.

Other Data

Majority of the participants reported to have lived in the respective cities their whole lives (80.8%). Only 19.2% said that they had migrated to the city later on. This shows that very few children had newly migrated to the cities.

What work did majority of the participants do daily?

Figure 5 illustrates descriptive statistics (frequencies) regarding children's involvement in household chores. To simplify the analysis of daily task engagement, the original five-point Likert scale (which included the categories: daily, at least once a week, at least once a month, occasionally, and never) was collapsed into a three-point scale: daily, sometimes, and never. Here, the 'sometimes' category includes the participants who responded - at least once a week, at least once a month, and occasionally (a few times a year) - to the questions enquiring about their engagement in various chores. This adjustment was made to better focus on participants' engagement in daily household tasks. An elaborate description of the engagement in chores as reported by the participants on the five-point Likert scale has been presented in Appendix 4,5 and 6.

Based on figure 4 it can be inferred that the typical tasks in which children engaged in on a daily basis were: keeping the house clean (sweeping and mopping), filling water, washing utensils, supervising siblings and supporting sibling with schoolwork. 50.5% of children stated they sweep and mop the house, 47.5% supervise their siblings,

47.4% fill water at home and 38.7% wash utensils daily. Although not the majority, a notable 36% reported supporting siblings with schoolwork on a daily basis.

The other tasks were typically not undertaken by children in this sample. These were: cooking full meals at home, washing clothes at home, shopping for groceries, working a part time job, trying to make a family member happy, assisting with bathing, assisting a family member with toileting, assisting a family member with dressing, assisting a family member with eating food, assisting a family member with mobility or exercise, assisting a family member with medicines, and assisting a family member with doctor appointment or hospital visits. Children in this sample reported that they either ‘never’ or only ‘sometimes’ engaged in these tasks.

However, it is to be noted that although a minority, some children in the sample reported to be engaged in the less typical tasks on a daily basis, thus suggesting the likelihood of some young carers being present in the sample. There were children who were, trying to make a family member happy (33.4%), shopping for groceries (32.2%), assisting a family member with medicines (23.2%), washing clothes at home (22.1%), assisting a family member with eating food (20.8%), cooking full meals at home (17.9%), assisting a family member with mobility or exercise (12.6%), assisting a family member with dressing (11.3%), assisting with bathing (10.3%), assisting a family member with toileting (6.3%), working a part time job (6.1%), and assisting a family member with a doctor appointment or hospital visits (7.1%), all on a daily basis. It is less likely that children would have to assist a family member with doctor appointments or hospital visits on a daily basis. Therefore, future iterations of the measures could reframe this question. On the other hand, the qualitative study findings indicate that the other tasks are part of young carers’ regular day-to-day responsibilities. This thesis is about such young carers as they were frequently engaging in tasks which majority of their peers either did not engage with or engaged in only sometimes.

This data also reinforces the argument that children are not merely recipients but also contributors to reproductive labour within the household. These contributions, as mentioned in chapter four, are often overlooked by society and thus calls for the recognition of children’s active role in supporting family functioning.

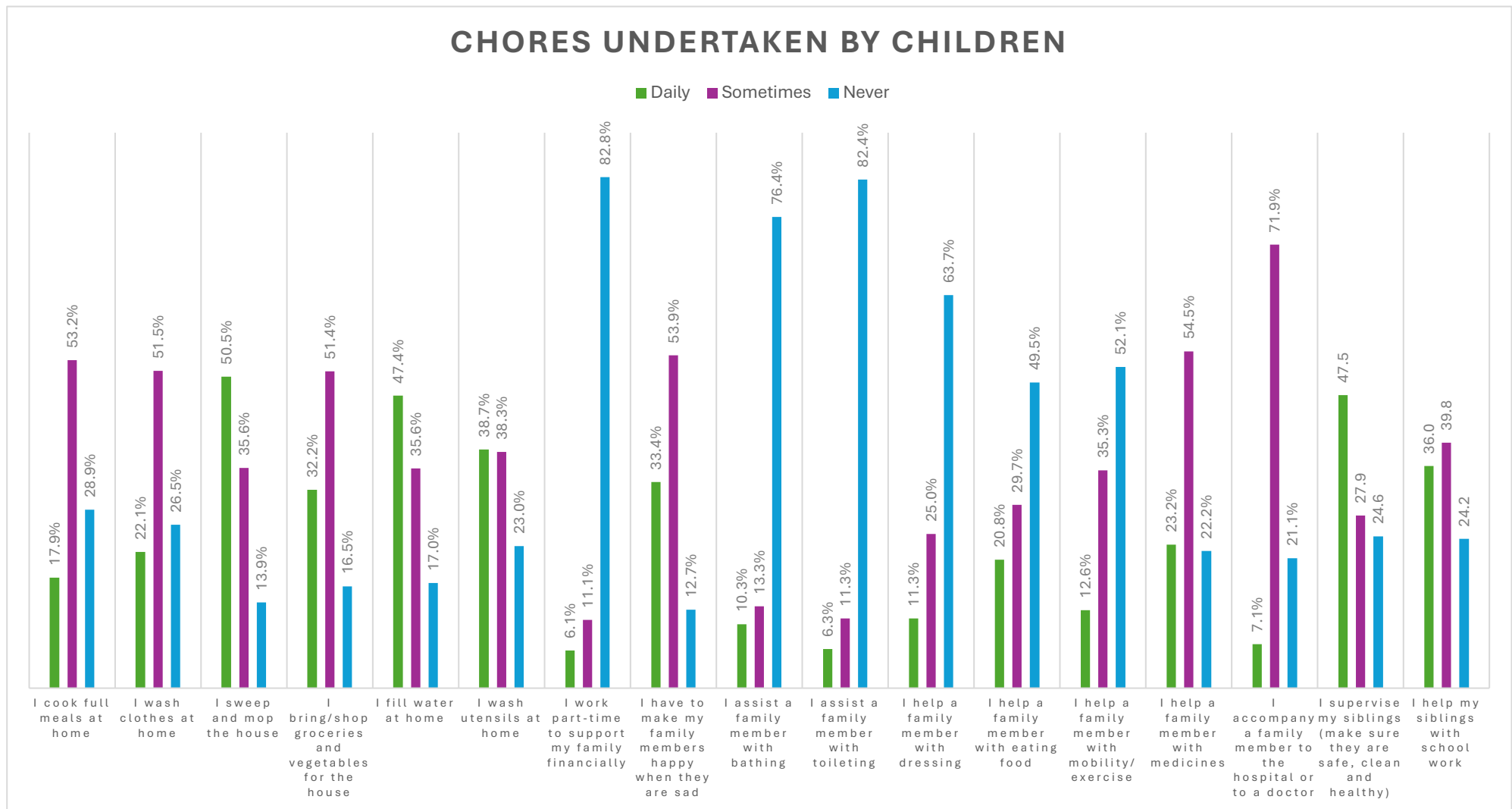


Figure 4: Chores Undertaken by Children and Young People

What are the daily impacts on the participants?

Just like the frequencies of daily task engagement, the frequencies of impacts were also collapsed into a three-point Likert scale. The results from the analysis have been depicted in figure 5. A detailed description of the impact of engagement in chores as reported by the participants on the five-point Likert scale has been presented in Appendix 7 and 8.

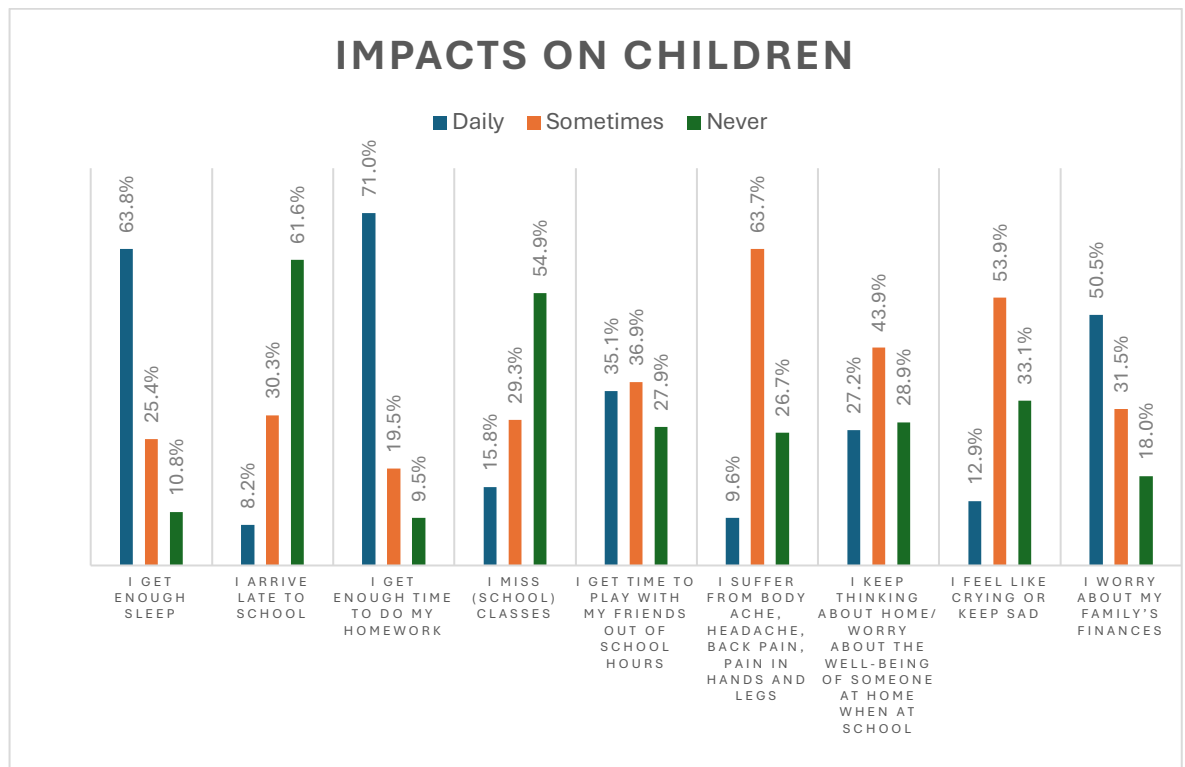


Figure 5: Impacts on Children

Reports of daily physical distress, such as aches and pains, were low (9.6%). Similarly, psychological distress symptoms like feeling like crying or feeling sad, was also relatively low, with only 12.9% experiencing it daily. While 27.2% of children reported worrying about someone at home while they were at school on a daily basis, which is a considerable proportion and warrants further attention, this number was still lower compared to those who reported experiencing this worry only 'sometimes' or 'never'.

Other indicators, such as getting enough sleep, arriving on time to school, having enough time for homework, and attending school regularly, were generally reported positively. Very few children said they lacked sleep, arrived late, or missed classes on a daily basis, therefore suggesting that these are not widespread problems in this

group. Participant responses around time for play or leisure were more balanced, with most children reporting they had this time either daily or sometimes.

Overall, most participants indicated positive daily behaviours across various impact areas, with one notable exception of being concerned about the family's finances. A significant number of children (50.5%) reported worrying about their family's finances daily. This persistent concern likely reflects the socio-economic context of the children surveyed.

Therefore, it can be inferred that apart from worrying about the family's financial situation, the other concerns were not daily occurrences for majority of the children in this sample.

This contrasts with findings from the qualitative sample, i.e. among children who were young carers. Because of their caregiving duties, the young carers reported greater physical and emotional strain. As a result of dedicating their time to care for others, young carers failed to care for themselves and reported to having very little time to sleep, play with friends and do their schoolwork or study at home owing to their responsibilities at home. The young carers in the qualitative sample, on the other hand, shared that they were thinking about their family members more frequently when at school or any place away from the care-recipient. Thus, highlighting a clear distinction in experiences between general participants and those with added responsibilities at home.

Figure 5 also reveals that a small proportion of children reported experiencing persistent challenges - such as never getting enough sleep, arriving late to school daily, missing classes daily, lacking time for play or leisure, suffering from daily body aches, constantly worrying about someone at home, or feeling like crying every day. While these numbers are relatively low, they are still concerning and may indicate the presence of children with caregiving responsibilities within the sample. This pattern warrants closer attention and further investigation.

Scale Development

This section will describe the process of developing and evaluating:

1. A new measure to assess the engagement of children in reproductive tasks within the household, and
2. A new measure to assess the impacts of this engagement on the children.

The measures were developed using Principal Component Factor Analysis (PCA). This is a data reduction technique in development or evaluation of measures used to summarise the data. This is done by looking for intercorrelations amongst a smaller set of factors or components and looking at how they cluster together (Pallant, 2016). The main goal of factor analysis is to see if we can find a smaller number of underlying patterns or factors based on how people answered the questions, i.e. to see if some question items cluster together (de Vaus, 2013).

As mentioned earlier, the 26 items in the questionnaire were designed to measure two main domains. However, the items do not assess a single phenomenon, but rather reflect multiple aspects within each domain (Marjorie A Pett, Lackey and Sullivan, 2003). PCA was used to identify the number of distinct dimensions represented by these items.

Checking Assumptions and Suitability for PCA

This section will elaborate on the pre-analysis steps taken to ensure that the data is suitable for running a PCA and that the results are interpretable.

1. Sample Size

Considering that the questionnaire had a total of 26 items as illustrated in table 3, the sample size of 528 had enough power to perform PCA. The ratio of participant to items, 20.31:1, was more than the recommended ten to one, i.e., there were more than twenty cases for each item to be factor analysed (Nunnally, 1978). Tabachnick and Fidell, (2013:705) also suggest that “over 300 cases provide a good sample size for factor analysis.”

2. Missing Data

The dataset was examined for missing values across the 26 questionnaire items. Using listwise deletion, which excludes any case with missing data on one or more of the included variables, a total of 407 complete cases were identified. Therefore, 121 cases were removed due to incomplete responses on at least one item. The resulting sample size ($N = 407$) exceeded the recommended minimum for PCA and provided sufficient statistical power, with more than 15 participants per variable. Therefore, PCA was conducted using only the 407 cases with complete data on all 26 items.

3. Normality

Before conducting PCA, the 26 items were assessed for violations of normality. The result of the Kolmogorov-Smirnov (K-S) statistic was significant, i.e. $p < 0.05$, indicating violation of the assumption of normality. As this is common in large samples (Pallant, 2016) and because “the stability or repeatability of the PCA results does not depend heavily on the normality of the data” (Bispo and Marques, 2023:1061), the analysis proceeded using all 26 items.

4. Outliers

Each of the items were also checked for outliers or cases which are very different from the majority of other cases, as they can distort the results. Even though outliers reflect the natural variations in the sample, they can have major influence on the analysis (Newbold, Carlson and Thorne, 2023). Outliers in this study might also indicate to the presence of young carers in the sample.

Initially each of the 26 items was checked for outliers using boxplots. Inspection of the graphical representations suggested that outliers were present in eight items listed in table 7. It is to be noted here that these are also the tasks, or the impacts of the tasks, that young carers in the qualitative samples also reported to have undertaken frequently in the previous chapters.

Table 7: Outliers

Item No.	Item	Mean	Trimmed Mean
7	I work part-time to support my family financially	1.40	1.23
8	I assist a family member with bathing	1.71	1.57
9	I assist a family member with toileting	1.49	1.33
10	I help a family member with dressing	1.96	1.85
14	I accompany a family member to the hospital or to a doctor	2.45	2.39
18	I get enough sleep	4.20	4.33
19	I arrive late to school	1.89	1.76
20	I get enough time to do my homework	4.33	4.48

After making sure that the outliers were not recording errors, the mean value of the items and their 5% trimmed mean were investigated. Table 7 also provides information on the mean value and 5% trimmed mean of each of these items. The statistic 5% trimmed mean excludes the top and bottom 5% of the cases and calculates a new mean value. This new value when compared to the original mean helps determine if the extreme cases in the sample have a strong influence on the mean (Pallant, 2016). As can be inferred from table 7, the difference between the two means of each of the items was small. Therefore, these outlier cases were retained in the data.

Additionally, to check for multivariate outliers which may affect the total observation in the data set, Mahalanobis distance was calculated across the 26 items (Liu, 2025). Multivariate outliers are extreme cases created as a result of a combination of two or more data points (El-Masri *et al.*, 2021). The critical chi-square value for 26 degrees of freedom at $p < 0.001$ is 54.052 (Tabachnick and Fidell, 2013). Results indicated that four cases exceed this threshold suggesting multivariate outliers. These cases were removed from the dataset to minimise influence on PCA. Thus, finally the PCA was conducted with 403 cases.

Development of Children's Engagement in Household Tasks (CEHT)

Measure

The question items 1-17, for this measure were grouped together conceptually as they reflected the tasks undertaken by the children to support the family. These have been listed in table 8.

Table 8: Initial items measuring Engagement of Children in Household tasks

Item No	Item Name
<i>Tasks Undertaken by the Children</i>	
1	I cook full meals at home
2	I wash clothes at home
3	I sweep and mop the house
4	I bring/shop groceries and vegetables for the house
5	I fill water at home
6	I wash utensils at home
7	I work part-time to support my family financially
8	I assist a family member with bathing
9	I assist a family member with toileting
10	I help a family member with dressing
11	I help a family member with eating food
12	I help a family member with mobility/ exercise
13	I help a family member with medicines
14	I accompany a family member to the hospital or to a doctor
15	I supervise my siblings (make sure they are safe, clean, and healthy)
16	I help my siblings with schoolwork
17	I have to make my family members happy when they are sad

Initial screening of data

Prior to performing PCA, to verify that the data set was suitable for factor analysis, factorability of the data was also assessed using the overall Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy, which was 0.86, exceeding the minimum recommended value of 0.6 (Kaiser, 1970, 1974). The Bartlett's Test of Sphericity also

reached statistical significance ($p < 0.001$). These results suggest that PCA was appropriate and could produce common factors.

Inspection of correlation matrix, which checks for the strength of the relationships among the items, revealed the presence of many coefficients of 0.3 and above. For PCA, correlations of 0.30 or higher between items indicate that the items share enough variance to justify the analysis. If many item correlations fall below this threshold, it may suggest that PCA is not appropriate for the dataset (Pallant, 2016).

Factor Extraction

The 17 items were then subjected to PCA for factor extraction. “Factor extraction involves determining the smallest number of factors (components) that can be used to best represent the interrelationship amongst the set of variables (question items)” (Pallant, 2016:184). This step examined how the 17 question items grouped together or not, based on how people answered them (de Vaus, 2013). These groups are called components.

To determine the number of components to be extracted, the data was subjected to three tests- Kaiser’s criterion or eigenvalue rule, scree test and parallel analysis.

The eigenvalue is a statistic linked to each component and shows how much of the total variance in the original variables is explained by the component. A higher eigenvalue means the component accounts for more variance. Only components with an eigenvalue greater than 1 are retained (de Vaus, 2013). The PCA for this data set yielded five components with eigenvalues greater than 1.0 (5.01, 1.90, 1.38, 1.16 and 1.04) explaining 29.49%, 11.17%, 8.14%, 6.79% and 6.12% of the variance respectively. These five components explain a total variance of 61.71%. The Kaiser’s criterion has a tendency to extract too many components (Pallant, 2016) and therefore the scree plot was considered. The pattern matrix from the PCA has been reported in Appendix 10.

The second approach to determine the number of components to be retained is the scree test. A scree test involves plotting the eigenvalues of the components and examining the graph to identify the point where the curve changes direction or breaks. The factors above this point contribute most to the variance in the dataset and are therefore selected (Pallant, 2016). Figure 6 illustrates the scree plot for the components generated from the 17 items. Component 1 and 2 accounted for the largest proportion of variance. After component 3 the slope of the scree plot begins to flatten, suggesting a possible two or three component solution. However, as the elbow was not sharply defined in the plot, parallel analysis of the data was considered.

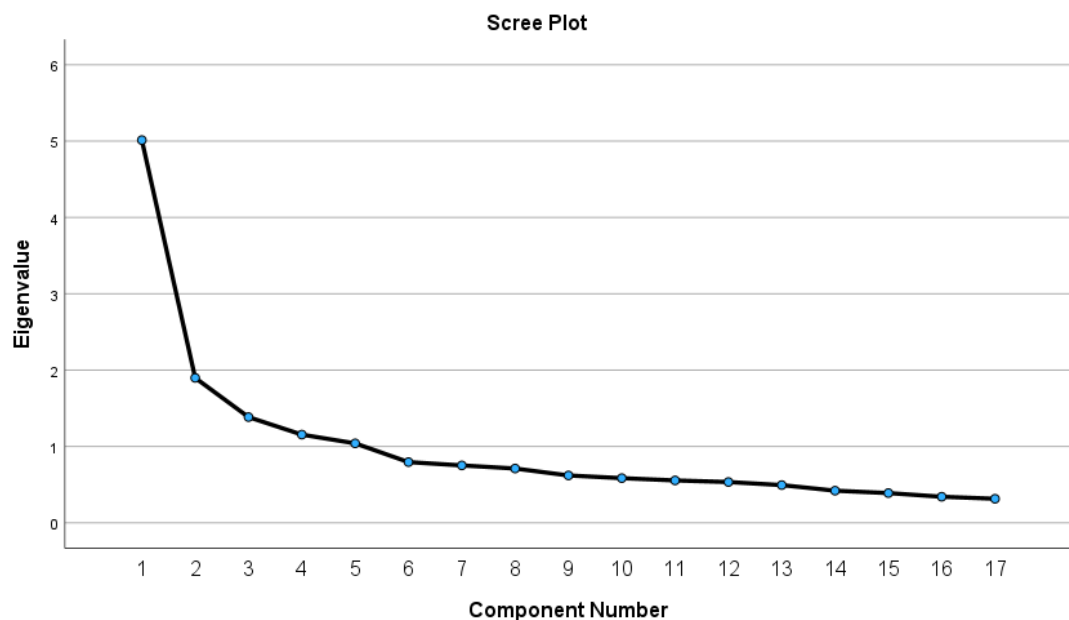


Figure 6: Scree plot from Principal Component Analysis- Engagement of Children Scale

Parallel analysis compares the eigenvalues from the actual data with those from a randomly generated dataset of the same size. Only the eigenvalues that are larger than the corresponding values from the random data are kept (Pallant, 2016). The results of Parallel Analysis have been illustrated in table 9.

Table 9: Monte Carlo PCA for Parallel Analysis

Number of Items: 17

Number of subjects: 403

Number of replications: 100

Eigenvalue #	Random Eigenvalue	Standard Dev
1	1.3730	0.0418
2	1.2966	0.0277
3	1.2395	0.0293
4	1.1893	0.0229
5	1.1431	0.0196
6	1.1006	0.0191
7	1.0625	0.0201
8	1.0248	0.0210
9	0.9863	0.0200
10	0.9512	0.0188
11	0.9158	0.0193
12	0.8801	0.0176
13	0.8449	0.0187
14	0.8090	0.0210
15	0.7723	0.0224
16	0.7300	0.0229
17	0.6809	0.0264

Table 10: Comparison of Eigenvalues from PCA and Criterion Values from Parallel Analysis

Component number	Actual eigenvalues from PCA	Criterion value from parallel analysis	Decision
1	5.0130	1.3730	Accept
2	1.8983	1.2966	Accept
3	1.3844	1.2395	Accept
4	1.1549	1.1893	Reject
5	1.0404	1.1431	Reject

Table 10 compares the actual eigenvalues obtained from the data set to those from the parallel analysis. Results show three components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (17 variables x 403 respondents), suggesting a three-component solution.

Thus, for this data set a three-component solution was finalised for the 17-items on the engagement of children in tasks measure. The three-component solution explained a total of 48.80% of the variance, with Component 1 contributing 29.49%, Component 2 contributing 11.17%, and Component 3 contributing 8.14%.

Initial unrotated component loadings of each of the items (table 11) also revealed that Components 4 and 5 had fewer strongly loading items compared to Components 1, 2, and 3. This also suggests that a three-component solution is likely to be more appropriate.

Table 11: Component Matrix- Engagement of Children Measure

	Component				
	1	2	3	4	5
I help a family member with dressing	.701				
I help a family member with eating food	.646				
I assist a family member with toileting	.636		-.477		
I help a family member with medicines	.603	-.338			
I assist a family member with bathing	.591		-.487		
I help a family member with mobility/ exercise	.582	-.404			
I cook full meals at home	.550	.498			
I accompany a family member to the hospital or to a doctor	.550				
I wash clothes at home	.548	.466			
I fill water at home	.475			.457	
I have to make my family members happy when they are sad	.468				
I wash utensils at home	.491	.627			
I sweep and mop the house	.513	.596			
I supervise my siblings (make sure they are safe, clean and healthy)	.514		.581		
I help my siblings with schoolwork	.482		.525	-.353	
I bring/shop groceries and vegetables for the house	.362			.616	
I work part-time to support my family financially	.358				.772

Factor Rotation and Interpretation

Factor Rotation is a process used to aid in interpretation of the components after their extraction in PCA. After finalising the number of components to use, the 17 question items were then ‘rotated’ to determine which items belonged together and to which component (de Vaus, 2013; Pallant, 2016).

The 17 items were then subjected to a further PCA (with direct oblimin rotation), with a forced three-factor solution. Oblique rotation was used here, rather than orthogonal, because the factors were expected to be moderately correlated (Pallant, 2016). This assumption was supported by the component correlation matrix (table 12), which showed strong correlations (above 0.3) between Component 1 and 3, and between Component 2 and 3, despite a weaker correlation between Components 1 and 2. Therefore, the use of oblique rotation is reported.

Table 12: Component Correlation Matrix

Components	1	2	3
1			
2	0.27		
3	0.37	0.30	

Table 13 illustrates the communalities table which indicates the proportion of each item’s variance that is explained by the extracted components in the PCA (Pallant, 2016). Low values (below 0.3) may suggest that the item does not fit well with the other items in the component. In this table, 3 items- Item 4 (I bring/shop groceries and vegetables for the house), Item 5 (I fill water at home), Item 7 (I work part-time to support my family financially) have a low value, suggesting that these items are not well represented by the retained components.

Table 13: Communalities- Children's Engagement in Household Tasks Measure

Item No	Items	Initial	Extraction
1	I cook full meals at home	1.000	0.574
2	I wash clothes at home	1.000	0.474
3	I sweep and mop the house	1.000	0.660
4	I bring/shop groceries and vegetables for the house	1.000	0.154
5	I fill water at home	1.000	0.276
6	I wash utensils at home	1.000	0.655
7	I work part-time to support my family financially	1.000	0.166
8	I assist a family member with bathing	1.000	0.586
9	I assist a family member with toileting	1.000	0.696
10	I help a family member with dressing	1.000	0.619
11	I help a family member with eating food	1.000	0.487
12	I help a family member with mobility/ exercise	1.000	0.465
13	I help a family member with medicines	1.000	0.543
14	I accompany a family member to the hospital or to a doctor	1.000	0.474
15	I supervise my siblings (make sure they are safe, clean and healthy)	1.000	0.608
16	I help my siblings with schoolwork	1.000	0.479
17	I have to make my family members happy when they are sad	1.000	0.378
Extraction Method: Principal Component Analysis.			

For the three-factor solution, these three items also have the lowest loadings. Item 4 (I bring/shop groceries and vegetables for the house) failed to load adequately on any component. Item 5 (I fill water at home) had the lowest loading on Component 1 (0.36) and item 7 (I work part time to support my family financially) had the lowest loading on Component 2 (0.43). Therefore, to improve the overall structure and increase the total variance explained, these three items were removed from the final analysis. Poor loadings of these items on to the components could also be because majority of the sample were not young carers. Therefore, when developing this measure for use with young carers, these items could be added back to the measure.

After removing the three items, the remaining 14 items were again subjected to PCA with oblique rotation (direct oblimin). Two tables were examined - Pattern Matrix and Structure Matrix (table 14). It was evident from both the tables that the output was not an example of a 'simple structure,' i.e. an output where each item strongly loaded (<0.3) onto only one component (Pett, Lackey and Sullivan, 2003; Pallant, 2016). Here, there were multiple items which loaded onto more than one component, which is not unusual, particularly with an oblique rotation which allows for the components to be correlated (Pett, Lackey and Sullivan, 2003).

As recommended by Pett, Lackey, and Sullivan (2003), items were assigned to the components with which they were most conceptually aligned. Additionally, Cronbach's alpha coefficients were examined to assess the internal consistency of each component and to inform decisions regarding the placement of items that loaded onto multiple components (Pett, Lackey and Sullivan, 2003). Table 14 presents the outputs of the solution from the pattern and the structure matrix for the PCA with oblimin rotation of the three-factor solution for the measure to determine the frequency of children's engagement in household tasks. The items in bold are the ones selected to form the final measure.

The three-factor solution revealed meaningful components and accounted for 56.127% of the total variance. Components 1-3 were assigned the following labels: *family assistance tasks, domestic tasks, and intimate care tasks*. The total 14-item measure was labelled- 'Children's Engagement in Household Tasks (CEHT) Measure.' Table 15 presents the eigenvalues, percentage of variance accounted for by each component and rotated component loadings.

Table 14: Pattern and Structure Matrix- Children's Engagement in Household Tasks (CEHT) Measure

Item No	Item	Pattern Coefficients (factor loading of item to component)			Structure Coefficients (correlation between items and factors)		
		Component	Component	Component	Component	Component	Component
		1	2	3	1	2	3
15	I supervise my siblings (make sure they are safe, clean and healthy)	0.768	0.196	0.230	0.741	0.354	-0.063
16	I help my siblings with schoolwork	0.680	0.192	0.193	0.665	0.333	-0.070
13	I help a family member with medicines	0.643	-0.065	-0.234	0.705	0.143	-0.439
14	I accompany a family member to the hospital or to a doctor	0.618	-0.058	-0.186	0.665	0.135	-0.383
17	I have to make my family members happy when they are sad	0.598	-0.048	-0.074	0.610	0.119	-0.266
12	I help a family member with mobility/ exercise	0.493	-0.150	-0.377	0.581	0.045	-0.516
6	I wash utensils at home	-0.069	0.851	-0.045	0.166	0.841	-0.173
3	I sweep and mop the house	0.098	0.795	0.063	0.283	0.809	-0.111
1	I cook full meals at home	-0.010	0.725	-0.125	0.220	0.745	-0.251
2	I wash clothes at home	0.040	0.635	-0.127	0.247	0.668	-0.253
9	I assist a family member with toileting	-0.030	0.047	-0.834	0.263	0.187	-0.832
8	I assist a family member with bathing	-0.105	0.184	-0.759	0.198	0.292	-0.757
10	I help a family member with dressing	0.224	0.116	-0.654	0.474	0.290	-0.750
11	I help a family member with eating food	0.319	0.081	-0.516	0.512	0.255	-0.638

Bold indicates highest factor loadings and correlations

Table 15: Results of Principal Component Analysis- Children's Engagement in Household Tasks (CEHT) Measure

Item No.	Item Labels	3 Component Solution		
		1	2	3
Family Assistance Tasks				
15	I supervise my siblings (make sure they are safe, clean and healthy)	0.768		
16	I help my siblings with schoolwork	0.680		
13	I help a family member with medicines	0.643		
14	I accompany a family member to the hospital or to a doctor	0.618		
17	I have to make my family members happy when they are sad	0.598		
12	I help a family member with mobility/ exercise	0.493		
Domestic Tasks				
6	I wash utensils at home		0.851	
3	I sweep and mop the house		0.795	
1	I cook full meals at home		0.725	
2	I wash clothes at home		0.635	
Intimate Care Tasks				
9	I assist a family member with toileting			-0.834
8	I assist a family member with bathing			-0.759
10	I help a family member with dressing			-0.654
11	I help a family member with eating food			-0.516
Eigenvalue		4.63	1.85	1.38
% of Variance		33.10%	13.21%	9.83%

Reliability

To assess the internal consistency of each component, both Cronbach's alpha and mean inter-item correlations were calculated. This was done because the scales had fewer than ten items. These evaluated the extent to which items within a component measured the same underlying construct. A Cronbach's alpha value of 0.70 or above is generally considered acceptable for psychological scales (Pallant, 2016). For mean inter-item correlations, values between 0.20 and 0.40 are recommended, as they indicate an optimal level of item specificity without redundancy. Values above 0.5 indicate that the items on the scale are overtly redundant (Piedmont and Hyland, 1993; Pallant, 2016).

As presented in table 16, the Intimate Care Tasks component demonstrated strong internal consistency (Cronbach's $\alpha = .78$), i.e. the items were measuring the same underlying construct, with a mean inter-item correlation of 0.49, suggesting strong but non-redundant coherence among items. The domestic tasks component also showed strong reliability (Cronbach's $\alpha = 0.78$), with a mean inter-item correlation of 0.48. The Family Assistance Tasks component demonstrated moderate internal consistency (Cronbach's $\alpha = 0.75$), with a mean inter-item correlation of 0.34, indicating acceptable coherence among the items.

Given that the mean inter-item correlations for two components – Intimate Care Tasks and Domestic Tasks, approached the upper end of the recommended range, future studies may consider reviewing and refining item content to reduce potential redundancy.

Table 16: Mean scores and Internal Consistency reliability of the 14 items- Children's Engagement in Household Tasks (CEHT) Measure

	Range	Mean (SD)	Cronbach's Alpha	Mean Inter-item Correlation
Intimate Care Tasks	4-20	7.51 (4.38)	0.78	0.49
Domestic Tasks	4-20	12.78 (4.79)	0.78	0.48
Family Assistance Tasks	6-30	17.57 (6.00)	0.75	0.34
Total ECHT Score	14-70	37.86 (11.83)	0.84	

For each of the item groupings, sub-scale (component) raw scores were computed by summing the items. Raw scores were also computed for the total 14-item Children's Engagement in Household Tasks (CEHT) Measure. The range of each of the sub-scales and the total 14-item CEHT measure have been reported in table 16, along with the mean and standard deviation results.

Validity

Pearson product-moment correlation coefficient (r) was computed between the total scores on the measure- Children's Engagement in Household Tasks (CEHT) Measure and three subscales- Domestic Tasks, Intimate Care Tasks and Family Assistance Tasks, to assess the internal structure of the scale. r values, indicate the strength of the relation between the variables. The r values between 0.10 to 0.29 indicate low strength, between 0.30 to 0.49 indicate moderate strength and between 0.50 to 1.0 indicate high strength (Pallant, 2016). Preliminary analyses were performed to ensure no violation of the assumptions of normality linearity and homoscedasticity. Table 17 summarises the correlations among the three sub-scales and the total measure scores.

Table 17: Correlation among the subscales- Children's Engagement in Household Tasks (CEHT) Measure

	Intimate Care Tasks	Domestic Tasks	Family Assistance Tasks	Total ECHT Score
Intimate Care Tasks				
Domestic Tasks	0.361**			
Family Assistance Tasks	0.525**	0.336**		
Total ECHT Score	0.782**	0.708**	0.837**	

** $p < 0.001$ (2-tailed)

All three subscales were strongly and positively correlated to the total score, indicating that each subscale contributes meaningfully to the overall construct of the CEHT measure.

Inter-component correlations among the three subscales were all positive and significant. In this instance the correlation between the subscales is low to moderate. Thus, suggesting that although the subscales are related, they represent different dimensions of the domain, thereby supporting validity of the measure.

Additionally, it is important to note that the scale was not administered to a young carer population in the present study. Therefore, future studies involving young carers should consider re-running the PCA as part of ongoing scale validation.

Summary

The initial 17 items to measure engagement in children in household tasks were subjected to principal component analysis (PCA). These 17 items were related to various tasks that children undertook within their households. Prior to performing PCA, the suitability of the data for factor analysis was assessed. Cases with missing data were excluded listwise resulting in a final sample of 403 participants.

Inspection of the correlation matrix revealed the presence of many coefficients of 0.3 and above. The Kaiser-Meyer-Olkin value was 0.86, exceeding the recommended value of 0.3 and above (Kaiser, 1970, 1974) and the Bartlett's Test of Sphericity (Bartlett, 1954) reached statistical significance, supporting the factorability of the correlation matrix.

PCA revealed the presence of five components with eigenvalues exceeding 1, explaining 29.49%, 11.17%, 8.14%, 6.79% and 6.12% of the variance respectively. An inspection of the scree plot suggested either two or three components for further investigation (Cattell, 1966). Results from Parallel analysis showed three components with eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (17 variables x 403 respondents).

Additionally, three items were removed as they either did not load sufficiently on any component or exhibited low communalities, indicating that these items did not share enough variance with other items to be retained in the factor solution. The final analysis was therefore conducted on 14 items.

The three-component solution explained a total of 48.80% of the variance with Component 1 contributing 29.49%, Component 2 contributing 11.17% and Component 3 contributing 8.14%.

To aid in the interpretation of these three components, oblimin rotation was performed. The rotated solution did not reveal the presence of simple structure (Thurstone, 1931) and items cross-loaded onto more than one component. Following guidelines by Pett, Lackey and Sullivan, (2003), the items were assigned to components based on conceptual relevance. Components 1-3 were assigned the following labels: *family assistance tasks*, *domestic tasks*, and *intimate care tasks*.

Reliability analyses showed acceptable internal consistency for the three components: Intimate Tasks ($\alpha = .78$), Domestic Tasks ($\alpha = .78$), and Family Assistance Tasks ($\alpha = .75$). The Children's Engagement in Household Tasks (CEHT) Measure also had a good internal consistency with a Cronbach alpha coefficient of 0.84.

Inter-correlations among the subscales indicated low to moderate associations between Intimate Care Tasks and Domestic Tasks ($r = 0.361$, $p < .001$), Family Assistance Tasks and Domestic Tasks ($r = 0.336$, $p < .001$), and a stronger correlation between Family Assistance Tasks and Intimate Care Tasks ($r = 0.525$, $p < .001$). All subscales correlated strongly with the total scale score: Intimate Tasks ($r = 0.782$), Domestic Tasks ($r = 0.708$), and Family Assistance Tasks ($r = 0.837$), $p < 0.001$, supporting both the multidimensionality of subscales and the meaningfulness of an overall score.

Development of the Impact of Children's Engagement in Household Tasks (ICEHT) Measure

For this measure, the question items 18-26 were grouped together conceptually as they reflected the impacts of tasks undertaken by the children within the household. These have been listed in table 18. These nine items were subjected to Principal Component Analysis (PCA).

Table 18: Initial items measuring impacts of engagement of children in household tasks

Item No	Item Name
<i>Impacts or Effects of the Tasks</i>	
18	I get enough sleep
19	I arrive late to school
20	I get enough time to do my homework
21	I miss (school) classes
22	I get time to play with my friends out of school hours
23	I suffer from body ache, headache, back pain, pain in hands and legs
24	I keep thinking about home/ worry about the well-being of someone at home when at school
25	I feel like crying or keep sad
26	I worry about my family's finances

Initial screening of data

Prior to performing PCA, the scores on Items 18 (I get enough sleep), 20 (I get enough time to do my homework) and 22 (I get time to play with my friends out of school hours) were reversed so that all Likert ratings were in the same direction.

Thereafter, the suitability of data for factor analysis was assessed. The overall Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was 0.65, exceeding the minimum recommended value of 0.6 (Kaiser, 1970, 1974) and the Bartlett's Test of Sphericity reached statistical significance ($p < 0.001$), supporting the factorability of the correlation matrix. Although these results suggest that PCA could be performed, as the KMO value here was between 0.50 and 0.69 more care was taken as recommended by de Vaus (2013). Inspection of the correlation matrix revealed the presence of only a few items with coefficients of 0.3 and above, suggesting weak correlations between the items.

To further evaluate the suitability of the data for PCA, the anti-image correlation matrix (Appendix 11) was inspected (Sürücü, Maşlakçı and Yıkılmaz, 2024). This matrix provides the individual measures of sampling adequacy (MSA) for each item, which evaluates how appropriate each item is for inclusion in the factor analysis (Dziuban

and Shirkey, 1974). The diagonal of the matrix represented the MSA value for each of the items. The values were all more than the recommended 0.5, indicating that the items have high partial correlation and are suitable for PCA.

Factor Extraction

The 9 items were then subjected to factor extraction. The Kaiser's criterion or eigenvalue rule yielded three factors with eigenvalues greater than 1.0 (2.15, 1.42 and 1.19) explaining 23.93%, 15.81% and 13.19% of the variance respectively. These three components explain a total variance of 52.93%.

It was evident that a one component solution was not ideal as data clearly indicated multi-factorial solutions. A two- component solution was indicated by the scree plot (figure 8) and seemed to offer a logical solution.

The unrotated loadings (table 19) of each of the items on the three components in the Component Matrix table indicated that most of the items load quite strongly on the first two components. This also suggests that a two-factor solution is likely to be more appropriate. The Pattern matrix from the PCA has been reported in Appendix 12, which also indicated to a two-factor solution.

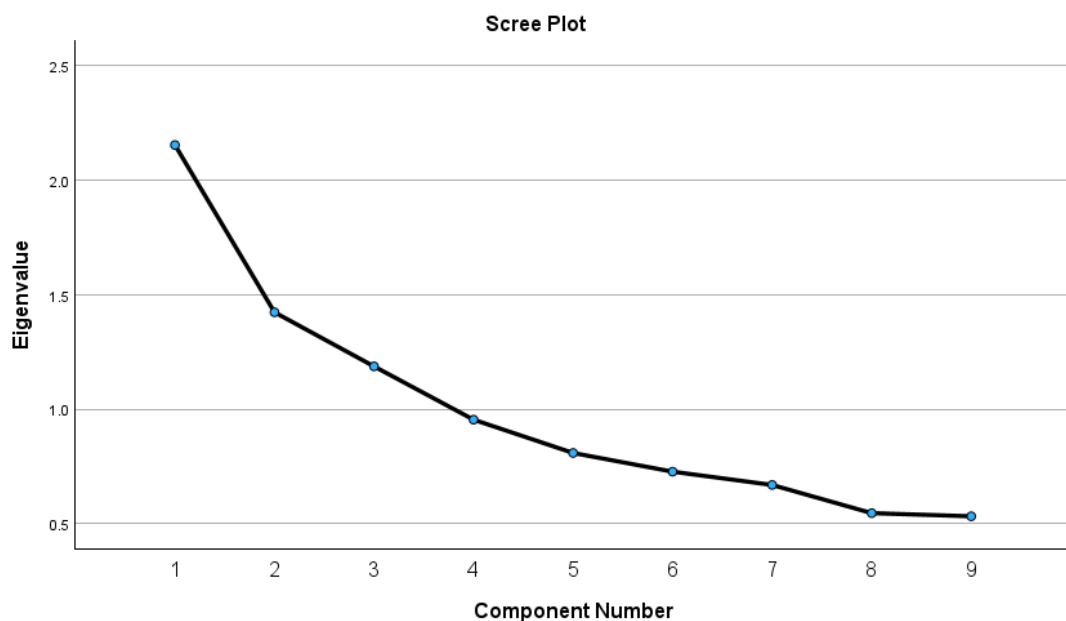


Figure 8: Scree plot from PCA- Impacts of Engagement of Children in Household Tasks Measure

Table 19: Component Matrix- Impacts of Engagement of Children Measure

	Component		
	1	2	3
I keep thinking about home/ worry about the well-being of someone at home when at school	.734		
I feel like crying or keep sad	.683		
I suffer from body ache, headache, back pain, pain in hands and legs	.596		
I worry about my family's finances	.583		-.361
I get time to play with my friends out of school hours_Reversed		.617	
I get enough time to do my homework_Reversed		.612	.409
I get enough sleep_Reversed	.349	.553	.348
I arrive late to school		-.405	.620
I miss (school) classes	.402	-.326	.552

Factor Rotation and Interpretation

After finalising the number of components to use, the 9 items were 'rotated' to determine which items belonged together with which component (de Vaus, 2013; Pallant, 2016).

The 9 items were then subjected to a further component analysis (with direct oblimin rotation), with a forced two-factor solution. Oblique rotation was used here, rather than orthogonal, because the factors were expected to be moderately correlated (Pallant, 2016). This assumption, however, was not supported by the component correlation matrix (table 20), which showed weak correlations (below 0.3) between Component 1 and 2. Therefore, the analysis was re-run using varimax rotation.

Table 20: Component Correlation Matrix

Components	1	2
1		
2	-0.001	

Table 21 illustrates the communalities table which indicates the proportion of each item's variance that is explained by the extracted components in the PCA (Pallant, 2016). Low values (below 0.3) may suggest that the item does not fit well with the other items in the component. For the two- factor solution, item 19 (I arrive late to school), and item 21 (I miss classes) showed very low variance values, of 0.11 and 0.18 respectively (table 21). Hence, these items were removed from the measure to refine the measure. But again, when developing this measure for use with young carers these items could be added back to the measure.

Table 21: Communalities- Impacts of Engagement of Children in Household Tasks

Item No	Items	Initial	Extraction
18	I get enough sleep_Reversed	1.000	.458
22	I get time to play with my friends out of school hours _Reversed	1.000	.442
20	I get enough time to do my homework _Reversed	1.000	.508
19	I arrive late to school	1.000	.114
21	I miss (school) classes	1.000	.176
23	I suffer from body ache, headache, back pain, pain in hands and legs	1.000	.405
24	I keep thinking about home/ worry about the well-being of someone at home when at school	1.000	.571
25	I feel like crying or am sad	1.000	.531
26	I worry about my family's finances	1.000	.372
Extraction Method: Principal Component Analysis.			

The remaining 7 items were subjected to further PCA with orthogonal rotation (varimax). The rotated solution revealed the presence of a 'simple structure,' with "each item strongly loading on only one component and each component was represented by a number of strongly loading variables" (Pallant, 2016:200). Table 22 presents the outputs of the solution from the rotated component matrix Principal Component Analysis with orthogonal rotation of the two-factor solution of the Impacts of Engagement of Children in Household Tasks Measure.

The two-factor solution accounted for 49.49% of the total variance. Components 1 and 2 were labelled as follows: Psychological/Physical Impacts and Impacts on Time. The total 7-item measure was labelled Impact of Children's Engagement in Household Tasks (ICEHT) Measure. Table 23 presents the eigenvalues, percentage of variance accounted for each component and the rotated component loadings.

Table 22: Rotated Component Matrix - Impact of Children's Engagement in Household Tasks (ICEHT) Measure

Item No	Item	Component Loadings	
		Component 1	Component 2
24	I keep thinking about home/ worry about the well-being of someone at home when at school	0.754	0.090
25	I feel like crying or keep sad	0.733	0.187
26	I worry about my family's finances	0.659	-0.019
23	I suffer from body ache, headache, back pain, pain in hands and legs	0.655	-0.067
20	I get enough time to do my homework _Reversed	-0.043	0.750
18	I get enough sleep _Reversed	0.107	0.693
22	I get time to play with my friends out of school hours _Reversed	0.038	0.624

Note- Bold indicates highest factor loadings

Table 23: Results of Principal Component Analysis- Impact of Children's Engagement in Household Tasks (ICEHT) Measure

Item No.	Item Labels	2 Component Solution	
		1	2
Psychological & Physical Impacts			
24	I keep thinking about home/ worry about the well-being of someone at home when at school	0.75	
25	I feel like crying or keep sad	0.73	
26	I worry about my family’s finances	0.66	
23	I suffer from body ache, headache, back pain, pain in hands and legs	0.66	
Impacts on Time			
20	I get enough time to do my homework _Reversed		0.75
18	I get enough sleep _Reversed		0.69
22	I get time to play with my friends out of school hours _Reversed		0.62
Eigenvalue		2.06	1.40
% of Variance		29.47%	20.02%

Reliability

To assess the internal consistency of each component, the Cronbach's alpha values were calculated. These evaluated the extent to which items within a component measured the same underlying construct.

Cronbach's alpha values were lower than the threshold values of 0.7 for Psychological and Physical Impacts ($\alpha = 0.66$) subscale, for Impacts on Time subscale ($\alpha = 0.45$) and the Total Impact of Children's Engagement in Household Tasks (ICEHT) Measure ($\alpha = 0.57$) (table 24). The low alpha values for the measures also suggest that measures demonstrate poor internal consistency and that they may require further refinement in future research.

Given the that subscales had less than 10 items, the mean inter-item correlation value is also reported which serves as a guide of item homogeneity in a unidimensional scale (Pallant, 2016). These values fall within the optimal level of homogeneity of 0.2 to 0.4 for short measures (Piedmont and Hyland, 1993).

Table 24: Mean scores and internal consistency reliability of the items- Impact of Children's Engagement in Household Tasks (ICEHT) Measure

	Range	Mean (SD)	Cronbach's Alpha	Mean Inter-item correlation Value
Psychological and Physical Impacts	4-20	6.27 (2.96)	0.66	0.33
Impacts on Time	3-15	11.57 (4.19)	0.45	0.22
Total IECHT Score	7-35	17.89 (5.52)	0.57	

For each of the item groupings sub-scale scores were computed by summing the items. Thus, sub-scale of Psychological and Physical Impacts has a potential range of 4-20 and the sub-scale of Impacts on Time has a range of 3-15. The total 7-item scale has a potential range of 7- 35.

Validity

The relationship between the subscales- Psychological and Physical Impacts and Impacts on time was investigated using Pearson's product-moment correlation coefficient (r). Preliminary analyses were performed to ensure no violation of the assumptions of normality linearity and homoscedasticity. Table 25 summarises the correlations between the two components. Inter-factor correlation between the two subscales was positive and significant. Correlations between the sub-scales was small ($r = 0.15$), supporting their empirical separability.

The r values for correlation between the subscales and the total Impact of Children's Engagement in Household Tasks (ICEHT) Measure were strong, indicating that they contributed meaningfully to the overall construct of the ICEHT measure.

Table 25: Correlation among the Sub-scale- Impact of Children's Engagement in Household Tasks (ICEHT) Measure

	Psychological and Physical Impacts	Impacts on Time	Total Measure Score
Psychological and Physical Impacts			
Impacts on Time	0.119**		
Total Measure Score	0.841**	0.638**	

** $p < 0.001$ (2-tailed)

Summary

The initial 9 items on to measure the impact of children's engagement in household tasks were subjected to PCA. These 9 items were related to the impacts of the various tasks that children undertook within their households. Prior to performing PCA, the suitability of the data for factor analysis was assessed. Cases with missing data were excluded listwise resulting in a final sample of 403 participants.

Inspection of the correlation matrix revealed the presence of few coefficients of 0.3 and above. Therefore, to further evaluate the suitability of the data for PCA, the anti-image correlation matrix (Appendix 10) was inspected (Sürücü, Maşlakçı and Yıkılmaz, 2024). The values were more than the recommended 0.5, indicating that the items

have high partial correlation and are suitable for PCA. Thereafter, the suitability of data for factor analysis was assessed. The overall Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was 0.65, exceeding the minimum recommended value of 0.6 (Kaiser, 1970, 1974) and the Bartlett's Test of Sphericity reached statistical significance ($p < 0.001$), supporting the factorability of the correlation matrix.

PCA revealed the presence of three components with eigenvalues exceeding 1, explaining 23.93%, 15.81% and 13.19% of the variance respectively. An inspection of the scree plot suggested a two-component solution for further investigation (Cattell, 1966).

Additionally, two items were removed from the measure as they exhibited low communalities and had low loading on the components. The final analysis was therefore conducted using seven items. The two-component solution explained 49.49% of the variance with Component 1 contributing 29.47% and component 2 contributing 20.02%.

To aid in the interpretation of these two components, varimax rotation was performed. The rotated solution revealed the presence of simple structure (Thurstone, 1931) with both components showing a number of strong loading and all variables loading substantially on only one component. Component 1 was labelled *psychological and physical impacts* and component 2 was labelled *impacts on time*.

Reliability analysis illustrated values were lower than the threshold values of 0.7 for Psychological and Physical Impacts ($\alpha = 0.66$) subscale, for Impacts on Time subscale ($\alpha = 0.45$) and the Impact of Children's Engagement in Household Tasks (ICEHT) Measure ($\alpha = 0.57$) (table 24). The low alpha values for the measures also suggest that measures demonstrate poor internal consistency and that they may require further refinement in future research. However, the mean inter-item correlation values fell within the optimal level of homogeneity for both the measures.

Inter correlations among the subscales, Psychological and Physical Impacts and Impacts on Time indicated low associations ($r = 0.119$, $p < .001$). However, both the sub-scales strongly correlated with the total measure score: Psychological and Physical Impacts ($r = 0.841$, $p < 0.001$) and Impacts on Time ($r = 0.638$, $p < 0.001$),

supporting both the multidimensionality of subscales and the meaningfulness of an overall score.

Results

For this study, the samples from both the cities New Delhi and Mumbai, were considered together. This was because by design this study was conducted in metropolitan cities with a diverse population from all over India. The backgrounds of the school chosen for the study were also similar, making sure that children from similar socio-economic backgrounds came to study in the school. Additionally, to test for variance or inconsistencies between groups of participants from New Delhi and Mumbai, a one way between-groups multivariate analysis of variance was performed to investigate difference in cities' engagement and impact scores. Two dependent variables were used: total amount of tasks undertaken by the young person for the family and total impact. The independent variable was city. Preliminary assumption testing was conducted to check for normality linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices and multicollinearity with no serious violations noted. The difference between New Delhi and Mumbai on the combined dependent variables, $F(2,428) = 2.47, p = 0.09$; Wilk's Lambda = 0.99; partial eta squared = 0.011, was not statistically significant. As it was concluded that there was no statistically significant difference between the samples from New Delhi and Mumbai with respect to engagement in household chores or its associated impacts, the data was treated as a whole and city- specific differences were not taken into consideration for subsequent analyses.

Results from the Children's Engagement in Household Tasks (CEHT)

Measure

This section elaborates on the graphical examination of the subscales of the Children's Engagement in Household Tasks (CEHT) Measure. Histograms were constructed for the three sub-scales for the visual representation of the distribution of the data.

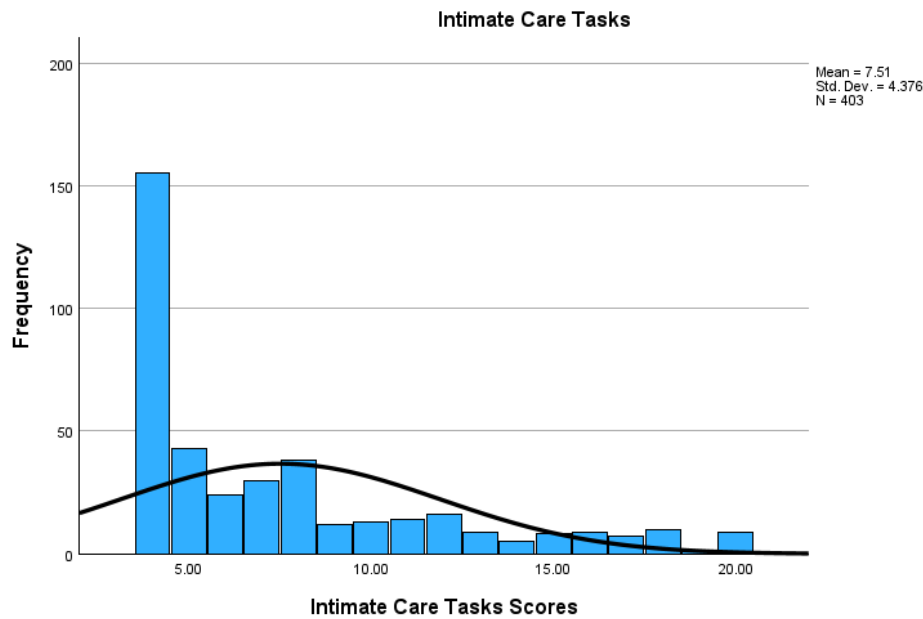


Figure 9: Histogram showing the distribution of Intimate Care Task scores

A histogram was constructed to examine the distribution of scores on the Intimate Care Tasks sub-scale (figure 9). Visual inspection of the histogram indicated a non-normal distribution. The distribution was positively skewed, i.e. the scores were clustered to the left/lower values. This illustrates that most participants reported relatively low engagement in intimate care tasks. The mean score was 7.51 ($SD = 4.38$), based on a sample of 403 respondents. The mean and median scores for this sample were 6 and 4 respectively. A small number of participants reported high engagement levels.

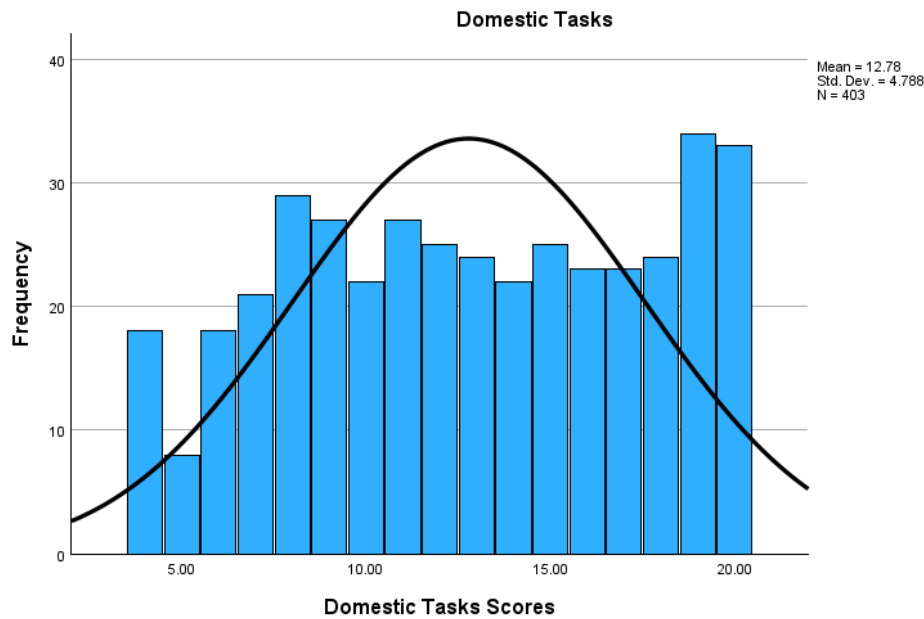


Figure 10: Histogram showing the distribution of Domestic Tasks scores

Figure 10 illustrates the distribution of children's engagement in domestic tasks in this sample. Visual inspection of the histogram indicated a bell-shaped curve and thus a possible normal distribution. The mean values of the data was 12.78 ($SD=4.79$) for 403 participants. This implies that most participants in this sample, engaged in an average level of domestic tasks. Few participants reported extreme scores, i.e. undertaking too many or too few tasks. The median and mode were 13 and 19 respectively.

To assess the normality of the data statistically, the Kolmogorov–Smirnov test was conducted. The results indicated a significant deviation from a normal distribution, $D(403) = 0.094$, $p < .001$, suggesting that the assumption of normality was violated, despite visual approximation.

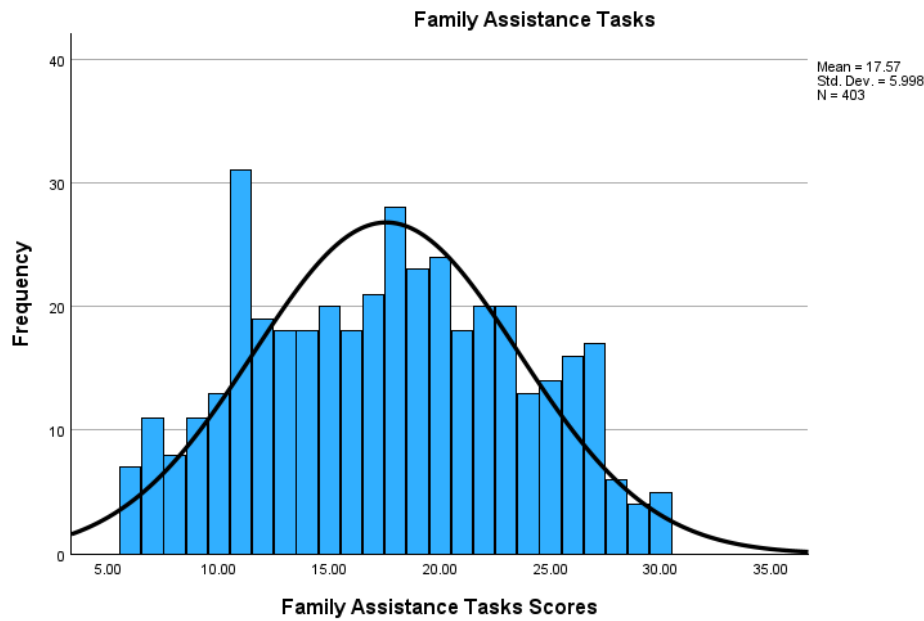


Figure 11: Histogram showing the distribution of Family Assistance Tasks scores

Figure 11 illustrates the distribution of children's engagement in family assistance tasks in this sample. Visual inspection of the histogram indicated a bell-shaped curve and thus a possible normal distribution. The mean value for this sample is 17.57 ($SD = 6.00$) for 403 participants. This implies that most participants in this sample, engaged in an average level of family assistance tasks. Few participants reported extreme scores, i.e. undertaking too many or too few tasks. The median and mode values were 18 and 11 respectively.

To assess the normality of the data the Kolmogorov–Smirnov test was conducted. The results indicated a significant deviation from a normal distribution, $D(403) = 0.072, p < .001$, suggesting that the assumption of normality was violated, despite visual approximation.

Consequently, it can be inferred that majority of children in this sample participated primarily in domestic and family assistance tasks but did not engage in intimate care responsibilities for family members. In contrast, young carers in the qualitative sample reported frequent involvement in intimate care tasks in addition to domestic and family support tasks. These findings suggest that young carers in the qualitative sample were assuming a broader and more demanding range of household and caregiving responsibilities compared to most of their peers.

Results from the Impacts of Children's Engagement in Household Tasks (ICEHT) Measure

This section elaborates on the graphical examination of the subscales of the Impacts of Children's Engagement in Household Tasks (ICEHT) Measure. Histograms were constructed for the two sub-scales for the visual representation of the distribution of the data.

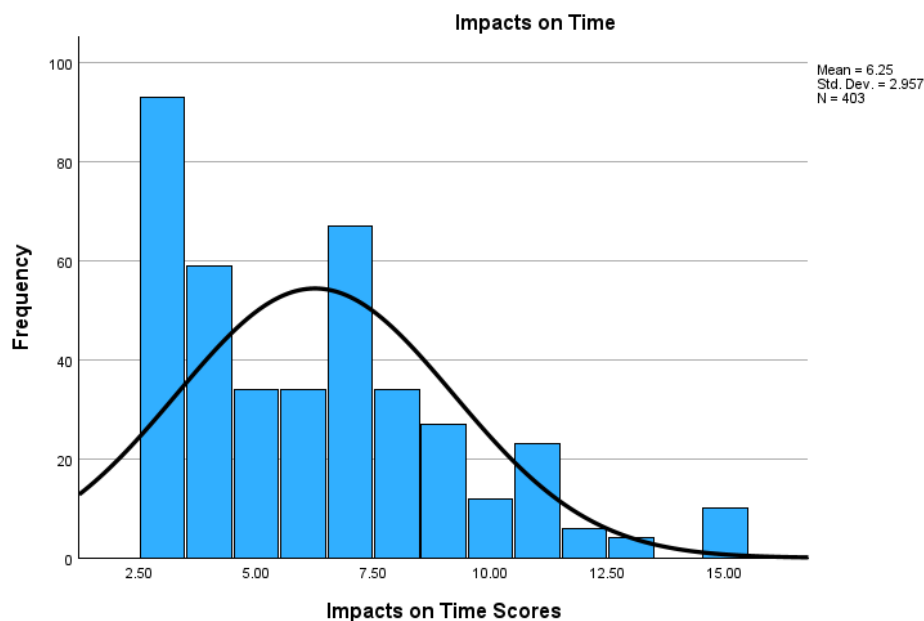


Figure 12: Histogram showing the distribution of Impacts on Time scores

Figure 12 illustrates the distribution of children's engagement in family assistance tasks in this sample. Visual inspection of the histogram indicated a non-normal distribution. The distribution was positively skewed, i.e. the scores were clustered to the left/lower values. The mean value for this sample is 6.25 ($SD = 2.96$) for 403 participants. This implies that most participants in this sample, reported less frequent impacts on their time. The median and mode values were 17 and 16 respectively.

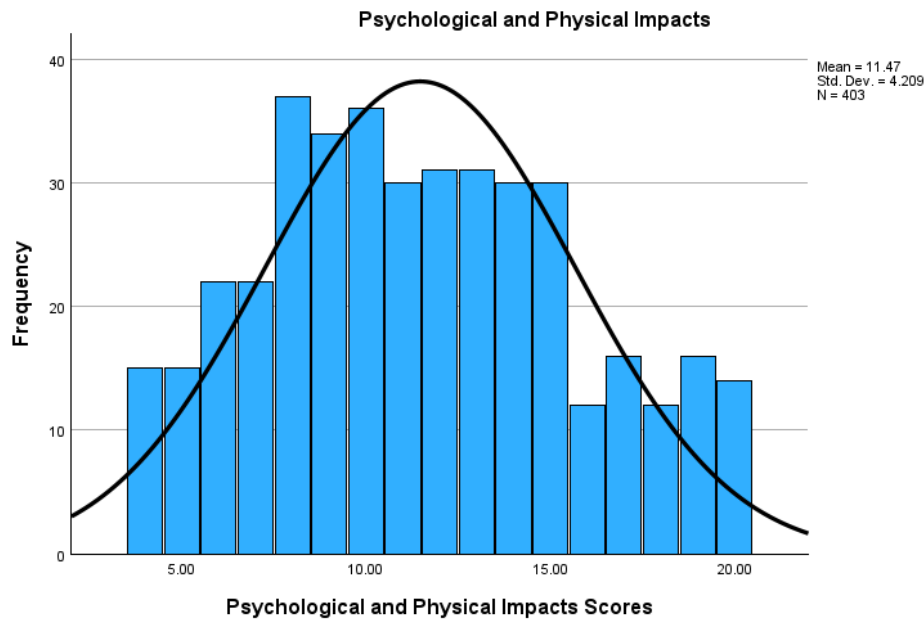


Figure 13: Histogram showing the distribution of Physical and psychological impacts scores

Figure 13 illustrates the distribution of physical and psychological impacts on children in the sample. Visual inspection of the histogram indicated a bell-shaped curve and thus a possible normal distribution. The mean value for this sample is 11.47 ($SD = 4.21$) for 403 participants. This implies that most participants in this sample, had average levels of physical and psychological impacts. Few participants reported extreme scores, i.e. having too few or too many physical and psychological impacts. The median and mode values were 11 and 8 respectively.

To assess the normality of the data the Kolmogorov–Smirnov test was conducted. The results indicated a significant deviation from a normal distribution, $D(403) = 0.086$, $p < .001$, suggesting that the assumption of normality was violated, despite visual approximation.

Consequently, it can be inferred that majority of children in this sample reported low to moderate levels of frequency of impacts on them. In contrast, young carers in the qualitative sample described frequent impacts owing to their household responsibilities. They reported frequent physical impacts like headaches and body pains, frequent psychological impacts like constant worry about a family member or feeling sad, and time-related impacts like getting very little time to sleep or do their schoolwork or leisure time with friends. These findings indicate that, in addition to

undertaking a broader and more demanding range of household and caregiving responsibilities than most of their peers, young carers in the qualitative sample were also disproportionately affected in terms of their time, physical well-being, and psychological health.

Analysis and Hypothesis Testing

This section will elaborate on the hypothesis associated with the research questions.

Hypothesis 1: Engagement of girls in household tasks is higher than boys.

To test this hypothesis a one-way between-groups multivariate analysis of variance was performed to investigate sex differences in engagement of children in reproductive tasks. This was done to reduce potential of Type 1 errors by carrying out multiple tests on the same data. Three dependent variables were used: Intimate Care Tasks, Domestic Tasks and Family Assistance Tasks. The independent variable was sex.

Before performing the analysis, as MANOVA is sensitive to missing data, the sample was checked for missing data. 11 cases did not have information on sex of the participant, and two participants had ticked the option 'prefer not to say' in the survey form. As analysis was testing for the impact of sex on the frequency of tasks undertaken by the participants, these cases were removed for this analysis which brought the sample size to 390. The sample sizes were different for the sex of the participant, with 163 males and 227 females

Thereafter, preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices and multicollinearity, with no serious violations noted.

On a linear combination of the dependent variables there was a statistically significant difference amongst males and females with, $F(3,386) = 64.48$, $p < 0.001$; Wilks' Lambda = 0.67; partial eta squared = 0.33. This means when considering the combination of the three sub-scales males and females scored differently overall.

When the results for the dependent variables were considered separately, the only differences to reach statistical significance, using a Bonferroni adjusted alpha of 0.017 were domestic tasks, $F(1,388) = 179.09$, $p < 0.001$, partial eta squared = 0.32 and intimate care tasks $F(1, 388) = 14.24$, $p < 0.001$, partial eta squared = 0.04. This means

that there was a statistically significant difference between males and females in their engagement in domestic chores and intimate care tasks. However, difference in scores of engagement in family assistance tasks were not statistically significant, i.e. they were similar for males and females.

An inspection of the mean scores indicated that females reported higher levels of engagement in domestic tasks ($M = 15.03$, $SD = 4.15$) than males ($M = 9.58$, $SD = 3.71$). Females also reported somewhat higher levels of engagement in intimate care tasks ($M = 8.21$, $SD = 4.74$) than males ($M = 6.53$, $SD = 3.70$). Table 26 elaborates on the results from this test.

Table 26: Mean Scores on the engagement in household tasks by Sex

	Mean (SD)		<i>F</i>	<i>p</i>	η^2
	Females	Males			
Domestic Tasks	15.03 (4.15)	9.58 (3.71)	179.09	<0.001	0.32
Intimate Care Tasks	8.21 (4.74)	6.53 (3.69)	14.23	<0.001	0.04
Family Assistance Tasks	17.89 (5.93)	17.07 (5.98)	1.83	0.177	0.05
Total Score			64.48	<0.001	0.33

Mean scores for females were generally higher than males for all types of tasks. The partial eta squared statistic (η^2) represents the proportion of variance in the dependent variables (Intimate care tasks, domestic tasks, and family assistance tasks) that can be explained by the independent variable (sex). The guideline for interpreting this value is as follows: 0.01= small effect, 0.06 = moderate effect, 0.14 = large effect. This can be expressed as percentage by multiplying the value by 100 (Pallant, 2016). Therefore, it can be inferred that 33% difference in overall engagement of children in household tasks scores can be explained by gender. There was 32% difference in scores for domestic tasks for males and females. This indicates that the participation of females

in domestic tasks was significantly higher than males. This is in concurrence with the larger literature around the gendered nature of household chores.

For the intimate care tasks performed by the children in the sample, there was a significant difference in scores for males and females. However, the magnitude of the difference was only 5%. Participation of females in intimate care tasks was only moderately higher than males in this sample. It is to be noted that very few participants reported to be frequently involved in these tasks in this sample, and that these results could vary with a sample who were frequently involved in intimate care tasks.

An analysis of children and young people's involvement in overall household tasks showed that a higher proportion of females participated in domestic tasks compared to males, supporting the hypothesis that females are highly engaged in such activities. The hypothesis was also supported for intimate care tasks, with females reporting slightly higher participation than males. However, the hypothesis was not supported for family assistance tasks, suggesting that both males and females participated at similar levels in this category.

Hypothesis 2: The oldest female in the family engages in household tasks more frequently.

To test this hypothesis a two-way between groups multivariate analysis of variance was conducted to explore the impact of sex of the participant and their birth order on domestic tasks, intimate care tasks, and family assistance tasks.

The data was first checked for missing data. Of the total sample ($N = 390$, after removal of missing data cases for sex), 61 participants (15.6%) did not provide information on birth order and were excluded from analyses involving this variable. The final sample size for birth order and sex related analyses was 329. Thereafter the birth order was recoded into binary variables of 'oldest' and 'not oldest' as this analysis was examining the impact of being the oldest girl child on their engagement in various household chores. The interaction effect between gender and birth order was not statistically significant on the combined dependent variables, $F(3, 323) = 0.920, p = .431$; Wilks' Lambda = 0.99. So, this was not explored further. These results suggest that hypothesis two was found to be unsupported for this sample of children. Being the oldest female in the families did not have a significant effect on their engagement in household tasks.

Hypothesis 3: Higher number of members in the family, would be associated with less engagement of the children in household tasks.

To test this hypothesis, the relationship between the total number of family members and total amount of tasks undertaken by the children (as measured by the Engagement of Children in Household tasks Measure) was investigated using Pearson product-moment correlation coefficient. Preliminary analyses were performed to ensure no violation of the assumption of normality, linearity and homoscedasticity. There was a small positive correlation between the two variables, $r = 0.22$, $n = 353$, $p < 0.001$, with high number of family members associated with higher frequency of tasks for the children. Therefore, the hypothesis was not supported for this sample.

This finding could indicate an increased number of younger children in larger families and consequent pressures on other children to engage in more household tasks. This aspect could be explored further in future studies.

Hypothesis 4: The presence of grandparents or extended family members in the household is associated with a reduced engagement of children in household tasks.

An independent samples t-test was conducted to compare scores on total Children's Engagement in Household Chores Measure between participants who lived with extended relative like grandparents, uncles, aunts, daughter-in-law, etc and participants who did not (i.e. in nuclear families). There was no statistically significant difference in scores between participants who lived with extended relatives ($M = 38.85$, $SD = 11.68$) and participants who did not ($M = 37.31$, $SD = 11.65$); $t(df) = 1.07$, $p = 0.288$. Therefore, for this sample, the presence of extended relative did not significantly associate with children's engagement in household tasks in this sample.

Hypothesis 5: Higher frequency of engagement in tasks is associated with higher impacts on the children.

To test this hypothesis, the relationship between total amount of tasks undertaken by the children as measured by the Children's Engagement in Household Tasks Measure and total scores on the Impacts of Children's Engagement in Household Tasks Measure was investigated using Pearson product-moment correlation coefficient.

Preliminary analyses were performed to ensure no violation of the assumption of normality, linearity and homoscedasticity. There was a medium positive correlation between the two variables, $r = 0.34$, $n = 403$, $p < 0.001$, with high levels of engagement in household tasks associated with greater levels of impacts on the children. Therefore, the hypothesis is supported for this sample.

Hypothesis 6: There is greater impact of engagement in tasks on females as compared to males.

A one-way between-groups multivariate analysis of variance was performed to investigate sex differences in Impacts of Children's Engagement in Household Chores. Two dependent variables were used: Psychological and physical impacts and Impacts on Time. The independent variable was sex.

Before conducting the test, the data was checked for missing cases. Cases without information on sex were removed and the analysis was run with 390 cases.

After this, preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and multicollinearity, with no serious violations noted.

There was a statistically significant difference between males and females on the combined dependent variables (i.e. total ICEHT measure), $F(2, 87) = 11.604$, $p < 0.001$; Wilks' Lambda = 0.94; partial eta squared = 0.06.

When the results for the dependent variables were considered separately, the only difference to reach statistical significance, using a Bonferroni adjusted alpha level of 0.025, was Psychological and Physical Impacts on the young person, $F(1, 388) = 20.84$, $p < 0.001$, partial eta squared = 0.05. This means there was a statistically significant difference amongst males and females in this sample with respect to the psychological and physical impacts of their engagement in household tasks. However, the difference on the impacts on time scale was not statistically significant.

An inspection of the mean scores indicated that females reported slightly higher levels of psychological and physical impacts ($M = 12.33$, $SD = 4.19$) than males ($M = 10.42$, $SD = 3.93$). The results from this test have been provided in table 27.

Table 27: Difference in impact between males and females

	Mean (SD)		<i>F</i>	<i>p</i>	η^2
	Female	Male			
Psychological and Physical Impacts	12.33 (4.19)	10.42 (3.93)	20.84	<0.001	0.05
Impact on time	6.51 (2.89)	5.90 (2.95)	4.14	0.043	0.01
Total Impact score			11.60	<0.001	0.06

Table 27 illustrates that females reported more overall impacts than males. Eta squared values of 0.06 indicates that females reported 6% higher overall impacts than males. Similarly, females reported 5% more physical and psychological impacts than males. Therefore, the hypothesis is supported for the composite score (total ICEHT score) and for scores on the psychological and physical impacts subscale but is not supported for impacts on time subscale.

Analysis of children and young people's involvement in overall household tasks with their gender in Hypothesis 1 has already revealed that higher proportion of females participated in domestic tasks compared to males. This in association with this analysis may suggest that females report more impacts because they undertake more household tasks.

Hypothesis 7: When we control for the possible effect of sex, the variables-domestic tasks, intimate care tasks and family assistance tasks would still be able to predict a significant amount of variance in impacts of engagement in household tasks on the children.

To test this hypothesis with total impacts of engagement of children, hierarchical multiple regression was used to assess the ability of the various engagements of children (domestic tasks, intimate care tasks and family assistance tasks) to predict the total impacts of the engagement, after controlling for the influence of sex.

Preliminary analyses were conducted to ensure no violation of assumption of normality, linearity, multicollinearity and homoscedasticity. Cases missing

information on sex were removed. With 390 respondents and 4 independent variables the number of cases is well above the minimum requirement ($N \geq 104 + m$, where N is the total number of cases and m is the number of independent variables) (Tabachnick and Fidell, 2013). Table 28 displays the correlations between the variables.

Sex was entered at Step 1, explaining 5.3% of the variance in total impacts. After entry of the domestic tasks, intimate care tasks, and family assistance tasks scales at Step 2 the total variance explained by the model as a whole was 13.8%, $F(4, 385) = 15.42, p < 0.001$. The three tasks' variables explained an additional statistically significant variance of 8.5% on the impacts on the children, after controlling for sex, R squared change = 0.085, F change (3, 385) = 12.64, $p < 0.001$.

In the final model, in addition to sex ($\beta = 0.16, p = 0.007$), only one tasks' measure, intimate care tasks, was statistically significant ($\beta = 0.22, p < 0.001$). Table 29 provides details of this analysis.

Therefore, it can be concluded that in addition to the sex, the intimate care tasks, that were undertaken by the children in the sample would be able to predict a significant amount of variance in the total impact on the children. However, domestic tasks and family assistance tasks were not able to predict significant impacts. This could be because intimate care tasks were more typical of the tasks performed by young carers and not typical for other children.

Table 28: Correlation between Variables for Hierarchical Regression

	Total Impact Score (<i>p</i>)	Sex (<i>p</i>)	Intimate Care Tasks (<i>p</i>)	Domestic Tasks (<i>p</i>)	Family Assistance Tasks (<i>p</i>)
Total Impact Score					
Sex	0.231 (<.001)				
Intimate Care Tasks	0.316 (<.001)	0.188 (.000)			
Domestic Tasks	0.243 (<.001)	0.562 (.000)	0.363 (.000)		
Family Assistance Tasks	0.231 (<.001)	0.069 (.088)	0.526 (.000)	0.333 (.000)	

Table 29: Hierarchical Multiple Regression Analyses Predicting the Impacts of the Engagement of Children with Control for Sex and Domestic, Personal and Supporting Family Member Tasks

Predictor	Total Impact/Outcome Score			
	R^2	R^2 Change	Standardised regression coefficient (β)	p
Step 1				
Sex	0.053	0.053	0.231	<0.001
Step 2				
	0.138	0.085		<0.001
Sex			0.158	0.007
Domestic Tasks			0.044	0.481
Intimate Care Tasks			0.223	<0.001
Family Assistance Tasks			0.089	0.123

Chapter Summary

As evident from the chapters eight, nine and ten, young carers in the Indian context performed many tasks to support the proper functioning of their families. However, there was no baseline data available to compare or contextualise their engagement with that of their non-caring peers. Therefore, for a greater understanding of the intensity of their experiences, an understanding of responsibilities undertaken by their non-caring peers was deemed beneficial.

Few studies have specifically examined the typical engagement of children in Indian households that contributes to the reproductive labour within the household and also the overall functioning of the family system. Therefore, the purpose of this quantitative study was to assess the typical tasks that children and young people performed within the domestic sphere. It provided information about the nature and extent of the tasks typically engaged in including domestic tasks, intimate care tasks and family assistance tasks. This data was essential to contextualise the insights obtained from the interviews of young carers in the qualitative study.

The quantitative findings addressing the research question on the daily tasks performed by children in India indicate that they were typically engaged in - keeping the house clean (sweeping and mopping), filling water, washing utensils, supervising siblings and supporting sibling with schoolwork. This reinforces the argument for inclusion of children within social reproduction theory, as they were not merely recipients of reproductive labour but also active contributors to it.

Other tasks like - cooking full meals at home, washing clothes at home, shopping for groceries, working a part time job, trying to make a family member happy, assisting with bathing, assisting a family member with toileting, assisting a family member with dressing, assisting a family member with eating food, assisting a family member with mobility or exercise, assisting a family member with medicines, and assisting a family member with doctor's appointment or hospital visits- were not typically undertaken by children in India. This highlights that young carers were undertaking a wider range of tasks and doing so more frequently than most of their peers.

However, a minority of children reported to have been engaged in the aforementioned tasks on a daily basis, like the young carers identified in the qualitative study. This may indicate that some children who completed the survey were young carers as would be expected.

In this sample, participants generally reported positively on the question items which evaluated impacts of children's engagement in household tasks, with the exception of frequent worries about the family's financial situation, which could be attributed to the socio-economic background of the sample. This finding was also in direct contrast to the experiences of young carers who reported frequent impacts of their role on various aspects of their lives including schoolwork, sleep, leisure, mental and physical health. Thus, highlighting a clear distinction between the experiences of young carers and majority of their peers.

Additionally, to gain a deeper understanding of the data two new measures were developed to empirically measure the frequency of engagement of children in household tasks and its impacts on them. These were: 1. Children's Engagement in Household Tasks (CEHT) Measure and, 2. Impacts of Children's Engagement in

Household Tasks (ICEHT) Measure. Scores on both the measures were reported on a five-point Likert scale.

CEHT is a 14 item self-report measure consisting of three subscales – Domestic Tasks, Intimate Care Tasks and Family Assistance Tasks. Results from this measure indicate that children in this sample were frequently involved in Domestic Tasks and Family Assistance Tasks than Intimate Care Tasks.

ICEHT is a 7-item self-report measure consisting of two-subscales – Psychological & Physical Impacts and Impacts on Time. Results from this measure indicated that children in this sample reported less frequent impacts on their time and average levels of psychological & physical Impacts.

Quantitative data from the children in New Delhi and Mumbai provides crucial insights into the contributions of children towards their family's functioning. It also provides a benchmark for the typical levels of children's engagement in various household tasks enabling contextualisation of the tasks performed by young carers.

Results from the analysis of CEHT measure and ICEHT measure reemphasise the gendered nature of household tasks and its impacts as females reported higher engagement and higher impacts of engagement in household tasks.

In contrast to commonly held assumptions, for this sample, being the oldest female in the family did not mean more engagement in household tasks. However, more members in the family meant more demand on the children to engage in household tasks. Additionally, in this group of children, living with extended family members like grandparent, uncles, aunts, nephews or nieces, daughter-in-law, did not make a clear difference on their engagement in household tasks.

Intimate care tasks, alongside gender, significantly predicted the overall impact on children, whereas domestic and family assistance tasks did not. This is most likely because intimate care is more a characteristic feature of being a young carer.

Limitations of the present study include a relatively small and convenience sampling which limits the generalisability of the findings. Additionally, the sample did not contain known-carers and a similar study with known-carers may offer different results. This emphasises the importance of further research into the area. Also, this

measure was developed with children in an urban setting. More items may have to be added to the measures if implementing them with children belonging to the rural setting and to fully comprehend their contributions towards their families. Further, the validity of the measures needs to be tested with age ranges of children other than the one specified in the sample.

Despite, these limitations, the current study has advanced the literature on children's contributions towards their family systems and quantitative research with young carers in the Indian context, by developing an empirically derived measure of the engagement of children in household tasks and its impacts on them.

The CEHT measure and ICEHT measure can be further developed to be used for identification of young carers in the Indian context in future studies. In future iterations of these measures to be used with young carers the items removed for this study can be added back as these removed items are likely to identify young carers.

Section 5

Discussion and Conclusion

Chapter 12: Discussion

Introduction

This thesis began with the story of *Shravan Kumar*, a boy who took care of his parents until his dying breath, to introduce this research study of modern-day Shravan Kumars and Kumaris, i.e. children in India who were taking care of a family member who was ill, disabled or had a care need that required them to seek external support and for which, these children were primarily responsible. These children are called young carers.

This chapter will discuss the findings and arguments that this study intends to highlight. It will also integrate the qualitative and quantitative study findings and synthesise the overall picture for the reader, while linking the contributions of this study to the larger literature around young carers. It will also discuss policy recommendations for young carers in India and the limitations of the study before presenting conclusions from this thesis.

Research Aims

At the time of writing, there were few studies in India which offered insights about children caring for family members affected by HIV/AIDS (D'Cruz, 2004; Mehta and Gupta, 2005; Visvanathan and Rani, 2015a, 2015b) but there were only two studies which specifically focused on young carers (Sahoo and Suar, 2010; Pande, 2022). These studies focused on the impacts of the caregiving roles undertaken by children, and there remained a gap in the understanding of the characteristics and experiences that constitute this role. Therefore, the first research question this project aimed to address was:

What are the specific experiences of children who undertake caring roles in New Delhi and Mumbai? What are the challenges they face and how supportive are the social systems around them?

Although, literature acknowledged that children from the majority world countries were more likely to participate in household chores compared to their minority world counterparts (Nieuwenhuys, 2020) and that Indian children's contributions to household tasks are often shaped by gender norms that placed greater expectations

on girls (IIPS, 2007; Lin & Adserà, 2013; Gibby, 2022), there was little understanding of the typical daily tasks undertaken by children in India. Throughout the course of this study, I also encountered frequent remarks, particularly by individuals from majority-world contexts, questioning whether ‘such tasks’ had not been a common aspect of childhood for all of us. Therefore, it was important to differentiate between the typical levels of engagement of children in household tasks and the tasks performed by young carers. This understanding was essential to contextualise the extent of responsibilities undertaken by young carers. Therefore, the second research question of this study was:

What are the daily tasks performed by children aged 15-18 years in New Delhi and Mumbai, to support their family functioning?

To study these questions, this research employed an exploratory sequential mixed methods approach. Qualitative semi-structured interview schedules with 21 young carers and six key informants, followed by a survey implemented with 528 children and young people (irrespective of their caring roles) were the tools used to answer the research questions.

Contributions of this Research Project

This section will elaborate on the main arguments and findings that this research project intends to highlight. This study, using the CEHT and ICEHT measures, has illustrated that children are not merely passive recipients of care and reproductive labour within households in India. They undertake a range of domestic tasks. However, there are a group of children in India who undertake more intense domestic and care tasks for their families. These tasks are different from those which typical children and young people engage in. In fact, these are more ‘adult-like’ tasks. Therefore, calling for the inclusion of children, especially young carers, as active participants in reproductive labour debates, from which they are currently absent. These young carers experience intense implications to their well-being as a result of their role. However, epistemic injustices towards children and a collective lack of hermeneutical resources about young carers in India contribute to their hidden nature. This also accounts for the limited support they receive. This study also indicates that poverty and lack of welfare

provisions in the country are the key factors contributing to their role in the Indian context. These arguments have been discussed in detail in the subsequent sections:

Children's contributions to typical domestic chores in India

This finding is an answer to the second research question which seeks to determine the typical tasks that children in India engage in. This is a novel finding which suggests that children and young people in the age range of 13-19 years in India are regularly engaged in tasks like – keeping the house clean by sweeping and mopping it, filling water for family use, washing utensils, supervising siblings and supporting siblings with schoolwork. Therefore, creating a baseline for understanding the typical tasks that children in India engaged in.

This study also found that children and young people's engagement in tasks such as cooking full meals at home, washing clothes at home, shopping for groceries, working a part time job, trying to make a family member happy, assisting with bathing, assisting a family member with toileting, assisting a family member with dressing, assisting a family member with eating food, assisting a family member with mobility or exercise, assisting a family member with medicines, and assisting a family member with doctor's appointment or hospital visits, was not typical. Majority of the participants responded that they seldom participated in these tasks. However, there were some children who reported that they engaged in these tasks more frequently suggesting that they might be young carers.

CEHT and ICEHT Measures for Children in India

This study also led to the development of two new measures namely- 1. Children's Engagement in Household Tasks (CEHT) Measure and 2. Impact of Children's Engagement in Household Tasks (ICEHT) Measure.

CEHT is a 14-item measure of the tasks that children and young people engage in within their household. CEHT measure has three distinct dimensions of tasks undertaken by children namely- Intimate Care Tasks, Domestic Tasks and Family Assistance Tasks. Results from this measure indicate that children in this sample were frequently involved in Domestic Tasks and Family Assistance Tasks than they were in Intimate Care Tasks.

ICEHT is a 7-items measure of the impacts of the tasks that children and young people engage in within their household. ICEHT measure has two distinct dimensions namely- Impact on Time and Psychological & Physical Impacts. Results from this measure indicated that children in this sample reported less frequent impacts on their time and average levels of psychological & physical impacts.

Results identified a relationship between the household tasks and the gender of the children, which is consistent with findings from earlier research (Vikram, Ganguly and Goli, 2024) showing greater household tasks are undertaken by girls.

Another significant result from this study showed that being the oldest female in the family did not have a significant effect on their engagement in household tasks. This is in contrast to the claims by key informants in this study who suggested that older daughters in the family are more likely to be engaged in household tasks. However, these results could differ when the study is undertaken with families who are in crisis or with young carers.

Results have also identified that in this sample; large family sizes led to greater engagement of children in household tasks. Additionally, the presence of extended family members in the household like grandparents, uncles, aunts or daughters-in-law, did not have a statistically significant relationship with the children's engagement in household chores. This is in contradiction to earlier claims (Webbink, Smits and de Jong, 2012) that the presence of more extended relatives i.e. more members in the family, may reduce the burden of household chores on the children especially, in Asian families.

As would be expected, higher scores on CEHT were related to higher scores on the ICEHT. This implies that children who were engaged in household tasks had significant impacts on their time and also their physical and psychological health. Additionally, these impacts were found to be greater among girls. This is consistent with earlier research with young carers (Becker and Becker, 2009; Santini *et al.*, 2020; Lewis *et al.*, 2023).

Another significant finding of this study is that in addition to the gender of the children, the main variable that predicted higher impacts was their engagement in intimate care tasks. Children who regularly assisted a family member with toileting, bathing,

dressing or with eating food experienced higher levels of impacts on the time they had for homework, sleep and with friends. They suffered from frequent body pains, frequently felt like crying or sad, frequently worried about a family members when at school and frequently worried about their family's finances. These tasks and consequent impacts are consistent with the experiences of young carers, thus indicating to the presence of young carers in the sample. Therefore this study corroborates Warren's (2007) claim that helping others with personal and intimate care most certainly distinguishes young carers from other children who may be just helping out at home.

Young carers performed a range of indispensable tasks for the care-recipient and their families and were different from children who were not carers

This study found that young carers in India, performed a range of tasks for their immediate family members which have been categorised into- assistance to the primary care-recipient, household duties, support to other vulnerable members in the family and financial support.

Assisting the care-recipient was the primary responsibility of the young carers. They did this by supporting them with basic mobility, managing their medical needs, looking after their intimate hygiene needs like bathing toileting and dressing, supporting them with their nutritional needs, providing them with emotional support, constantly monitoring them and dealing with their tough days.

Carrying out household chores and ensuring the smooth functioning of the home in the absence of an adult constituted routine and essential responsibilities for these young carers. They were involved in tasks like cooking, grocery shopping, washing dishes, doing laundry, cleaning the house, and filling water for daily use. Young carers in this study were usually the first ones to get up and the last to go to bed. In addition to these other seasonal duties like cleaning blankets or festival-based arrangements were also their responsibility. Given their underprivileged socio-economic background, these responsibilities were particularly demanding, as they lacked access to machinery which could help reduce their labour and could not afford readymade food. Daily grocery shopping was often necessary, as most families subsisted on daily wages.

Furthermore, the daily water supply to their houses often arrived at unsociable hours, a challenge which could be linked to their marginalised socio-economic status. These domestic responsibilities were undertaken alongside their caregiving duties. A key point of divergence from their western counterparts was this intense nature of the household tasks undertaken by young carers in India.

Another important task for these young carers was supporting their young siblings or any other vulnerable family member. Support for siblings could take the form of keeping them safe, catering to their nutritional needs, helping them with schoolwork, and emotional support especially when the care-recipient was ill. In addition to these some young carers also collaborated with their siblings to cater to the needs of the care-recipient. In doing this, they made sure to teach the required skills to the younger siblings, thus setting up a contingency plan, for the future, in case of their own incapacity to support the care-recipient. They also supported other vulnerable family members like ageing grandparents and other relatives who were ill or incapacitated.

While many of the tasks undertaken by young carers in India are similar to those performed by their counterparts in minority world countries like the UK, a significant distinction lies in the additional financial responsibilities assumed by Indian young carers. In this study, such responsibilities were met through part-time employment, engagement in home-based enterprises, begging, or by actively minimising household expenditure by dropping out of school or sacrificing their own needs. This tendency of young carers in India to discontinue their education in order to support their families has also been documented elaborately by Pande (2022). Research with young carers from African countries (Evans and Becker, 2009b; Andreouli, Skovdal and Campbell, 2013; Joseph *et al.*, 2023) have also highlighted that the presence of poverty and absence of welfare provision required young carers to be involved in some form of income generation activities. The findings of this study reflect a similar pattern in the Indian context.

When assessed alongside the typical tasks in which non-caring children engaged in, as discussed in the previous section, the range of tasks undertaken by young carers were significantly more intense and demanding. Thus, distinguishing the young carers in India from their non-caring counterparts. The labour that these young carers provided was extensive and critical to the functioning of the household, and the

family's daily life would not have been sustainable without their contributions. They carried out these roles with passive acceptance and without much resistance. Such acquiescence among children providing care for their parents has also been documented in previous studies (Blake-Holmes, Maynard and Brandon, 2023). In many cases these young carers were in a peculiar situation wherein they were the main individuals accountable for these tasks and there were no alternatives even when they themselves were incapacitated like in cases of illness or an important school exam. Many young carers in this study performed all these tasks in addition to their educational responsibilities. They clearly undertook many more intense tasks than their non-caring Indian counterparts.

It was also important to make this distinction from non-carers, because of the limited understandings about young carers in the Indian context. It was important to underline that not all children who supported with reproductive tasks within the household were young carers. As illustrated from the findings of the qualitative study of this research, for these children, caregiving was not just an additional task, it became a central aspect of their identity and daily lives, often taking precedence over their own well-being as discussed in detail in chapter eight.

Thus, the generalised assumption that all children in the Indian context perform 'such tasks' is both inaccurate and dismissive of the distinct experiences of the children who would be considered young carers. This misunderstanding could be the result of a tendency to conflate household chores with caregiving responsibilities. While household tasks are indeed a significant component of the work undertaken by these young carers, they do not fully capture the scope of their responsibilities. As seen in chapter seven, young carers engaged in a much broader and more demanding set of duties for their families. Their roles extended well beyond routine domestic chores performed by children.

Joseph et al.'s (2023) conceptualisation of children with caregiving responsibilities as situated within three concentric circles, as described in chapter one, offers a valuable lens for understanding the young carers in India and the extent of their contribution. The young carers in this study's qualitative sample were situated firmly within the innermost circle as those undertaking intensive caregiving duties that include specialised medical tasks, emotional labour and more. These responsibilities affected

their participation in social and educational activities. Young carers had to fulfil these duties on days they themselves were suffering from ill health as well. They had no respite from their duties and had to manage other things like schoolwork, nationalised exams, etc along with their caregiving duties. This positioning distinguishes them from children who may perform household chores, but whose responsibilities do not substantially interfere with their schooling or social lives.

This study significantly adds to the minimal literature on children with caring responsibilities in the Indian context. It evidences the fact that young carers are not just a phenomenon prevalent in the minority worlds. These children are present in the majority world too and are the lynch pin in the sustenance of their families.

Young carers need to be recognised as active contributors to the social reproduction of labour within families

Chapter four of this thesis critically examined the effects of adultism (Liebel and Philip, 2024) and its role in perpetuating epistemic injustices (Fricker, 2007) against children. It questioned the dominance of adult-centric perspectives in interpreting children's experiences, highlighting how such views often marginalise children's voices and agency.

The discussion also addressed how adult-centric assumptions are embedded within theoretical frameworks such as social reproduction theory, which traditionally centres on the experiences of adult women. Many studies (Nieuwenhuys, 2020; Rosen, 2023b, 2023a) have questioned this capitalist and adult-centric social constructions of labour and argued for the inclusion of children as competent social actors whose contributions to reproductive labour are significant and deserving of scholarly attention.

The findings of this study also illustrated that, children especially those facing unfavourable socio-economic conditions, do undertake informal and unpaid labour roles within households which are beyond capital generation, and which assist the social reproduction of labour. They are not merely children 'learning' adult chores or 'helping' around the house.

As already discussed, the participants of the qualitative study of this thesis undertook many tasks within the household. Their informal labour included intense caregiving roles, general household chores and supporting younger and vulnerable members of the family. These children also freed other adults to perform capital generating activities outside the household, by taking on majority of the work inside the household. Thereby, contributing to the social reproduction of labour within the families.

The majority of participants of the quantitative study, who were not young carers, were also engaged in household tasks like cleaning the house, washing utensils and filling water for the family's needs daily. Looking after the wellbeing of their siblings and supporting them with schoolwork were also some of the tasks that the children were engaged in. It can be argued that these chores undertaken by the children reduced a considerable amount of burden of the adults and contributed to the social reproduction of labour.

Therefore, along with earlier studies (Tisdall and Punch, 2012), the findings of this study also challenge the sanitised idea of the 'providing' parents and the 'receiving' children. Although this may be true for some privileged children, many others may not be so lucky. This thesis supports the claim that children are competent social actors, who contribute meaningfully to the reproductive labour within family units and are not just passive recipients of it. As seen from the findings of this study children do contribute to the household economy and to the social reproduction of labour, more so in families affected with adult illness or disabilities.

Children's contributions to the family systems are influenced by the needs of the families that they are a part of. Consistent with literature on young carers around the world as discussed in chapter one, results from this study also illustrated that young carers' contributions to their families' functioning were not negligible. In fact, their contributions were crucial for the sustenance of their families, without whom the family unit would fall apart. This underscores the need for recognition of children especially, young carers, as active participants in the social reproduction of labour, a focus that is notably absent from the existing body of research.

Young carers in India face many consequences of their caregiving role which are exacerbated due to the lack of support available to them

Chapter eight of this thesis discussed the significant negative consequences of the intense roles undertaken by young carers on their education, physical health, emotional and behavioural well-being, time, social relationships and their future. Although not a novel finding, as previous research (Sahoo and Suar, 2010; Visvanathan and Rani, 2015a, 2015b; Pande, 2022) from India has mostly concentrated on the impacts of the caregiving role, it echoes the earlier research findings and underlines the need for raising awareness and providing support to young carers in India. The interviews also highlighted significant risks associated with the caregiving role. Some positive outcomes arising from young carers' experiences were also identified, however, these were found to be fewer and less influential than the negative impacts. These negative impacts intensified due to the complete lack of awareness about young carers, their contributions and its consequent implications on public discourses in India.

Education: This study found that the most direct impact of care work was on the children's education and schoolwork. This is in line with findings from global literature (Gowen *et al.*, 2022). Pande's (2022) study with young carers in India also found that the caregiving roles have profound effects on the education of the young carers. Although not focussed on young carers in particular, previous studies (Mehta and Gupta, 2005; Visvanathan and Rani, 2015a, 2015b; Dhanaraj, 2016) in India have also found that living with an ill parent or family members has considerable impacts on children's school performance.

Young carers in this study reported that they faced concentration issues while in school as they were constantly worried about the wellbeing of their care-recipient or the chores at home. They also had limited time to complete schoolwork and had to take time off from school to cater to the needs of the care-recipients. Some even mentioned that they had to drop out of school to fully concentrate on the household or the care-recipient's needs.

Pande, (2022) reports that the opportunity costs for families to send children to school are high in comparison to continuing in unsupportive school environments, where their

needs and challenges are not understood. Such unsupportive school environments were reported by some young carers in this study too. Just like the findings from Pande's (2022) study, children in this study also faced distrust, lack of support and even punishments from school as a consequence of their caregiving role. However, there were some participants who reported being supported by the schoolteachers once the teachers were made aware of their circumstances. This is evidence to the fact that a deeper understanding of the circumstances faced by young carers can facilitate the provision of support, rather than leaving them to manage their responsibilities in isolation. Consequently, this study advocates for increased awareness of their roles.

Physical Health: This is the first study in India to report on the physical health impacts of caregiving role amongst young carers. Children in this study reported feeling tired and energy less, pain in the body, breathlessness, and unexplained pain in different parts of the body. Such unexplained aches and pains in children have been identified as somatic symptoms of anxiety and stress (Muris and Meesters, 2004). International research (Nap *et al.*, 2020; Gowen *et al.*, 2022) has also suggested that these roles may have long-term physical health consequences. Less time for sleep was another implication of care work mentioned by the children. Another reason for these physical impacts can be attributed to the regimental and relentless nature of their daily schedule which offered minimal time for rest and respite.

Emotional and behavioural impacts: Emotional and behavioural impacts of young carers in this study ranged from fear and anxiety of losing the parent and about their own future, self-blame and guilt, quiet sadness to even destructive behaviours like suicidal ideation and self-neglect. They also felt helpless and despondent. These feelings were amplified by the fact that many young carers were not given enough information about their care-recipients situation. Patronising attitudes towards children prevalent in society also lead to children being left in the dark about the actual nature of the care-recipient's illness. As a result, many children in this study did not know or did not seem to understand the conditions of their care-recipients.

This also the first study in the Indian context to report on thoughts of self-harm and suicidal ideation amongst children signalling to high levels of distress amongst children who are carers. As mentioned in chapter one, although there is some evidence of such behaviours in international literature (Cree, 2003; ME-WE, 2021; Lewis *et al.*,

2023) this is still a significantly under-researched area. The lack of information on young carers' self-harming behaviours can be attributed to the pivotal role young carers play in their family's survival, coupled with the awareness that the well-being and in some cases, the very existence of their care-recipient depends on the young carer themselves. However, as noted, this role is also accompanied by considerable mental strain and psychological distress, which may contribute to self-harming behaviours, and therefore warrants further enquiry.

Emotional and behavioural implications amongst young carers were also reported by Sahoo and Suar's (2010) study. They reported feelings of anxiety, sadness, diminished concentration levels, aggression, internal conflict, worthlessness, insecurity, distrust, and depression. The findings of this study also corroborated these findings. Sahoo and Suar (2010) also found that young carers experienced greater pressures and more complex needs than the non-carers, further underscoring the distinction between the two groups and highlighting the need for supporting young carers.

Additionally, many young carers in this study were more educated than their parents or care-recipients, which put additional psychological pressures on the children to undertake the caring roles more precisely like giving the right medicines on time, failing which they and the family may have to bear terrible consequences. Such a psychological pressure on the young carer has not been reported in earlier studies. However, these pressures of knowing more than your parents is similar to the findings of studies with BAME young carers in the UK, which reports that children who had better understanding of English language than their parents had to translate and interpret complex medical information which increased risk of miscommunication and misdiagnosis (James, 2019).

Limited Time: The young carers in this study had very limited time for themselves and for attending to their own well-being. As discussed earlier, caregiving activities often competed directly with time needed for schoolwork and education. This was a crucial finding in Pande's (2022) study. In addition, caregiving responsibilities encroached on time for other activities such as socialising with friends, play, and adequate sleep, all of which are activities essential for children's well-being and development. It was, in many cases, as though their time was no longer their own. Similarly, Sahoo and Suar's (2010) study also reported that young carers often spend long hours engaged in care

work. Limited time for oneself also led to neglect of one's own physical and mental health.

Social Relationships and Future Aspirations: Other major impacts of caregiving responsibilities and the all-consuming nature of the role was on the social relationships and consequently future aspirations of the young carers in this study. As their attention and energy were primarily directed towards the well-being of the care recipient, the time available for social interaction, friendships, and other competing needs was substantially reduced. This finding aligns with Pande's (2022) article which indicates that young carers often have limited friendships.

Participants mentioned being so tired at the end of day that they did not have enough energy for their own tasks like studies or socialisation. These reduced social interactions were also found to have long-term implications, particularly in the Indian context, where access to many jobs and opportunities is often influenced by one's social connections and networks. Lacking such social leverage, young carers were consequently disadvantaged in accessing future opportunities. Similar concerns regarding the future wellbeing of young carers have also been reported by Sahoo and Suar (2010).

Risks: The caring role of the young carers in this study also put them in some risky situations. Earlier studies (Visvanathan and Rani, 2015a) have indicated to this risky nature of the role. This study advances the understanding of the types of risks associated with the caregiving role for young carers in India. In this study, the young carers were at risk of - physical harm due to lifting heavy items or the care-recipient falling on them while having seizures, burning themselves due to operating open fires, sexual assault as a result of helping a care-recipient use common public toilets, and being a victim of domestic violence due to alcohol dependency of the care-recipient.

Positive Impacts: This study also reported on some positive aspects of being a young carer in India. These included learning new life skills like cooking and managing a household, knowledge of medicines and their uses. Their role was also key in enhancing the self-worth of the young carers, as they felt good about being able to help their family members. For one young carer, the role enabled her to live with her mother as she was previously living with her grandparents before she took on the role. Sahoo

and Suar (2010) also found that young carers developed feelings of sympathy, affiliation, nurturance, endurance, heightened awareness, and harm-avoidance more than non-carers.

However, as detailed in this thesis and international literature, the positive impacts almost seemed inconsequential when compared to the negative impacts.

For young carers in India, the implications of their role, especially the negative consequences were exacerbated in nature due the limited awareness about the existence of such a group of vulnerable children in the mainstream and the consequent lack of support.

Young carers in India are a hidden group of vulnerable children who require acknowledgement and attention

Congruent with the findings of previous studies (Sahoo and Suar, 2010; Pande, 2022) with young carers in India, findings of this study also emphasises that young carers are a hidden group of vulnerable children in India. There was limited research and awareness about the presence of such a group of children. They were there in front of everyone's eyes taking on 'adult-like' responsibilities and facing consequences of the same. But recognition or acknowledgment for their contributions was minimal, sometimes even from their own families and family members for whom they were carers. They were hidden in plain sight.

Sahoo and Suar (2010) are of the opinion that young carers are a hidden group in society because of their parent's fear of being misconstrued as incompetent to parent and/or manage the household. Another reason they mention is that the children themselves feel embarrassed about their caregiving activities as this would mean their parents are perceived by other people in society as inadequate in their roles as parents. Additionally bullying by friends and others in society is reported as another reason (Sahoo and Suar, 2010). Literature from other countries also suggest that a fear of social services interfering with the family and taking children away, could be another aspect which leads to their hidden nature (Thomas *et al.*, 2003). However, this is only when they are a known group and need to be hidden from the systems for the family's need. In India, there seems to be lack of awareness about the existence of such a group of children altogether which leads to more responsibility being placed on the children

without any support provisions. Furthermore, any help seeking behaviour from the children or their families may also go unheeded.

As mentioned previously, children from majority world countries like India, engage in a wider range of household chores when compared to their minority world counterparts (Nieuwenhuys, 2020). So, when young carers engage in caregiving activities, these can be easily misconstrued as children performing only 'slightly' more than what is conventionally expected of them. Lack of awareness about the consequences of the young carers' tasks adds to these misconceptions.

As indicated by previous studies, there is a tendency in patriarchal societies to relegate such caregiving roles to the feminine spheres (Kashyap, 1989; D'Cruz and Bharat, 2001). And as detailed in chapter four, feminine roles and experiences have a tendency to be subjected to testimonial injustice (Fricker, 2007). In the Indian context, children who are young carers have to face testimonial injustice as children, which is exhibited as lack of trust in what they have to say or not being asked for opinions. This injustice only multiplies with the deprived socio-economic status of these children. Young carers also have to deal with hermeneutical injustice in the face of lack of language and vocabulary enabling an understanding of their situation.

These factors contribute to their hidden nature. Such a hidden nature results in lack of research and consequently lack of supportive policies and programs for these young children. This deficiency in understanding also leads to teachers and other influential adults in society failing to comprehend the children's circumstances and reprimanding them instead. The previously mentioned consequences of their tasks were also pronounced due to the limited awareness and support systems and programmes available to them as detailed in chapters eight and nine of this thesis.

This study challenges the prevailing tendency to associate young carers in the majority world countries mostly to families affected by HIV/AIDS. While such households undoubtedly require attention and support, this is a skewed understanding of the young carers and their realities. There are a range of other circumstances including long term illness, disabilities, mental illnesses, substance abuse and age-related illness which can lead to caregiving practices by young children, who need recognition and support.

Poverty and lack of welfare provisions are strong indicators for being a young carer in India

Although, causes for caregiving practices amongst children in India can be multifaceted and may include, poverty, lack of welfare provisions for the underprivileged, migration, small family sizes, cultural norms emphasising filial piety, or women's involvement in paid work, I argue that it is poverty and lack of welfare provisions that play a key role in the prevalence of young caregiving practices.

Poverty emerges as a key determinant of such caregiving practices among children in India, a country which suffers from rampant poverty as discussed in chapter two of this thesis. Compounding this is the lack of adequate welfare provisions or the poor implementation of existing ones for families affected by illness, disability, or other care needs (Panda, 2015; Das, Ghosh and Paria, 2022). As a result, these families are often compelled to incur high out-of-pocket expenditures, as discussed in chapter two of this thesis, which in turn perpetuates the cycle of poverty.

Both Pande (2022) and Sahoo & Suar (2010) indicated to poverty in families being a major indicator for children becoming young carers. Further findings from this study suggest that poverty and the resultant lack of resources also increases the amount, intensity and nature of tasks that these children have to perform.

Poverty and health issues are deeply interconnected (Sangar, Dutt and Thakur, 2019). In the Indian context, poverty determines the amount of nutrition, access to timely health care services, engagement in ill paid or hazardous jobs, and access to neighbourhoods with clean water and air (M.D. and S.K., 2019; Sangar, Dutt and Thakur, 2019; Das, Ghosh and Paria, 2022; Pandey, Mishra and Singh, 2022). These factors can make people susceptible to detrimental health conditions, as discussed in chapter two. The socio-economic circumstances in India suggest that people who have access to sufficient economic resources have access to safe and well-paid jobs, optimal nutrition, access to quality healthcare, clean water and air. They may also have the means to employ paid external help for caregiving activities in case of ill health, household chores, child-care needs or any other requirements. However, families who live in poverty are unable to employ external help. They, therefore, have to turn to family members for support, regardless of their age. This meant that children had to step-in

when the adults are unable to perform these tasks, because labour by family members is free and also reduces additional expenses for the family. Therefore, it can be inferred that young carers in India, mostly belonged to low socio-economic backgrounds and this also augmented the intensity of the tasks they performed.

It is important to note that a lot of middle to low-income families in India may also not have household appliances for support, but they may also not have an ill family member to care for and may have the resources to employ external help to cater to these needs. The mere presence or absence of such appliances is not the determinant, but the circumstances which puts additional pressures on the children.

Poverty also meant that these children lived in areas where basic resources like water is limited to certain times a day, during which the children had to ensure its collection in large storage containers for use throughout the rest of the day. This sometimes involved carrying large containers from the water collection points to their homes. Underprivileged neighbourhoods also received water supply at unreasonable hours of the day like midnight, which meant that the children had to sacrifice their sleep for their family's basic needs. Additionally, this also affected their ability to concentrate in school the next day.

Poverty and engagement in the unorganised sector jobs also implied that at times of ill-health and inability of the adult to engage in employment the family faced income shocks, as jobs in unorganised sector do not have any safety nets like paid leave. This led to some young carers needing to supplement their families' incomes by either working outside the family homes or by undertaking small scale initiatives like providing tuition classes to other children, running a shop or engaging in home-based industries. This placed additional demands on their time. It is to be noted that helping the family financially was a task they had to undertake in addition to their caregiving roles and household chores. None of the participants in this sample left school for paid employment but some did mention that their older siblings had to do this.

The dialogues with the young carers gave the impression that they and their families were being penalised for being poor and simultaneously displaying the impudence to be ill.

This is not to say that lack of wealth would not be a problem in high income countries, it would still be a problem for families there. As suggested by Lynch (2007), care work is highly gendered and hierarchical in nature, i.e. people who have money, irrespective of their location, do not have to perform care work and can delegate it. However, the rampant nature of poverty in low-income countries makes the problem more widespread in such countries and therefore requires more attention.

Other reasons like small family sizes or the separation of the family from the extended family system as a result of migration have also been cited as reasons for young caregiving both in this study and in previous research with young carers. Sahoo and Suar (2010, 2009) suggest that small family sizes are a reason for children becoming carers. Pande (2022) also suggests that migration of people from villages to larger cities away from extended family networks has led to the creation of ‘labouring children.’ However, quantitative study findings from this study suggest that the family size was directly proportional to the frequency in engagement in tasks by the children in the family. I am aware that engagement in tasks may not be same as undertaking caregiving roles, however, there might be more to it than meets the eye. Equating smaller family sizes to care or labour by the children is an easy explanation but it does not take into account, unsupportive extended family relations, fatigue of helping or reluctance by extended family members. This has also been suggested by some participants in this study who had extended family members living nearby. Support from such family members were episodic and limited. Some even reported blatant rejections of their support pleas by relatives. Therefore, this needs to be examined in greater detail.

As noted in chapter eleven, many key informants in this study attributed children’s caregiving roles to prevailing cultural norms in India of filial piety as is the case in many Asian countries (Kashyap, 1989; D’Cruz and Bharat, 2001; Gupta, Pillai and Levy, 2012; Kumar and Saini, 2012; Goyal-Honavar *et al.*, 2025). Chapter two also described that caregiving is situated within families and is mostly considered to be a feminine role in India. Pande (2014) also highlights young carers’ moral obligations and duties towards their families. The embedded nature of such norms in the cultural fabric of India is also evident from the story of *Shravan Kumar*. However, I would like to argue that situating caregiving solely within the family context reflects a broader failure of the patriarchal

welfare system. Caregiving is an unpaid onerous responsibility for anyone who undertakes it, yet it has received limited recognition in India. This is largely because it occurs within the domestic sphere and, as previously discussed, the capitalist systems undervalue such unpaid work. Furthermore, it could be contended that the enduring prominence of *Shravan Kumar*'s story is linked to his gender. If *Shravan Kumar* had been a girl, it is questionable whether her caregiving for elderly disabled parents would have achieved comparable cultural significance and popular appeal. This is a question that merits critical reflection. Therefore, while the cultural practice of caring for family members can indeed be of positive value for the care-recipient, when compounded with structural factors such as poverty and weak welfare systems, it places immense pressure on the family unit and the member providing the care. When this situation intersects with entrenched inequalities such as gender-based discrimination, caste-based hierarchies, adultism, and epistemic injustices, the challenges become significantly more severe.

Another factor often cited in both the literature (Dearden and Becker, 2004) and by some key informants in this study as a reason for children assuming caregiving roles is women's engagement in paid employment outside the home. While this may appear plausible at face value, I contend that such an explanation is overly simplistic and rooted in an intrinsically patriarchal understanding of the issue. It disregards the deeper, systemic issues of poverty and inadequate welfare provisions previously discussed. Global literature (Dearden and Becker, 2004; Metzging *et al.*, 2020; Lewis *et al.*, 2023) and evidence from this study indicates that the majority of young carers were, in fact, caring for their mothers. Although there were instances in this study where mothers engaged in paid work and the young carer assumed responsibility for fathers or other family members, these situations arose primarily when fathers were incapacitated or following their death, wherein the young carers freed their mothers from domestic and care responsibilities to undertake paid employment for the sustenance of the family. Similarly, in some cases, young carers were looking after their fathers, in the absence of the mother, either due to her death or separation from the family. Key Informants in this study also felt that children often assumed caring roles for their mothers. If one were to imagine a hierarchy in the allocation of caregiving roles within families, the responsibility would first be assigned to the adult woman, followed

by the girl children and then boy children. The father or adult male figure, in most cases, is noticeably absent from this arrangement. Thus, questioning the notion that children become carers because of their mother's paid employment. Instead, I argue that they were becoming carers because their fathers did not or could not undertake these roles.

Policy and Practice Measures to Support Young Carers in India

As discussed in this study, children with caregiving responsibilities or young carers represent a group largely hidden from policy discourses and as result of which, the support they receive is minimal. This section will elaborate on the policy and practice implications of this study which could lower barriers for young carers in India.

Key informant interviews clearly indicate a significant gap in awareness regarding the existence and unique needs of young carers. Young carers often remain an invisible population, overlooked due to a combination of socio-economic challenges and competing national priorities, given the country's broader developmental concerns including poverty, unemployment, and inadequate healthcare.

However as stated in *Gaurav Kumar Bansal v. Union of India & Ors* (2014), India's commitment to functioning as a welfare state, although not explicitly stated in these exact terms in policy documents, is evident when the Indian Constitution's assurance of justice, liberty, equality, and fraternity to all citizens, are read with the Directive Principles of State Policy, especially Article 38 and 39 (Constitution of India, 1950, Part IV). For the purpose of this study, Article 39 (e) and 39 (f) are key. Article 39 (e) suggests that the state should ensure that 'the health of workers, men and women and the tender age of children are not abused and that citizens are not forced by economic necessity to enter avocations unsuited to their age or strength.' Article 39 (f) of the directive principles directs the state to 'ensure that children are given opportunities and facilities to develop in a healthy manner and in conditions of freedom and dignity and that children and youth are protected against exploitation and against moral and material abandonment.'

The situation of young carers as evidenced by this study is in clear violation of these principles of state policy, whereby the children were forced to enter roles unsuited for their age and strength which in turn affected their opportunities to develop in a healthy manner. Thus, underscoring the state's failure to adequately safeguard the welfare of

this particularly vulnerable group and calling for the need to recognise and respond to their needs.

Therefore, the first step towards supporting young carers in India, as has also been suggested by the key informants in this study, is recognition and raising awareness about children below the age of 18 years who are primarily responsible for providing care to family members who are ill, disabled or have any other care need and the role is affecting the child's day to day activities like their education or their physical and mental health. Such a definition of young carers in the Indian context can help distinguish them from other children who contribute to the socially reproductive activities within the household but do not have major repercussion of these activities.

UNICEF's (2007) definition of child labour which includes housework undertaken for four or more hours per day or 28 or more hours per week, can also be a helpful starting point to identify young carers. Although this definition does not include care work specifically and concentrates on household chores, as household chores are an important aspect of young carer's tasks as evidenced in this study, such an approach could be useful. Pande's (2014) approach to identifying young carers is also useful which includes children who drop out of school, either to supplement the family's income or enable another family member to earn an income. These approaches are valuable and can aid the case for recognition of children's contributions to socially reproductive labour, however they have limitations. Firstly, it would be difficult to log the time spent in housework or care work, especially when young carers are juggling multiple chores like studying while cooking or managing a family shop, as the young carers in this study were. Secondly, while conflating young carers with child labourers could be useful as it negates capitalist understandings of labour and emphasises that not all forms of labour generate income, it also runs the risk of diluting the unique contributions of young carers and leaving their specific needs unaddressed. Therefore, it is important to maintain a clear conceptual distinction between the two, particularly in contexts such as India, where children's contributions within the household are often considered normative as discussed previously. Thirdly, as evidenced from this study, not all young carers drop out of school or engage in income generating activities. Therefore, a more effective initial approach to identifying young carers could be to examine the nature and frequency of the chores they perform and the impacts these

have on their day-to-day lives. The presence of a family member who needs care would be another crucial factor in identifying young carers. Further development and application of CEHT and ICEHT measures are recommended, both for the identification of young carers and for assessing the impacts of their caregiving roles.

Civil society organisations, child rights advocates, social workers, and policymakers need to acknowledge and recognise the existence of this distinct group of children. It is only when individuals in positions of power recognise the existence of these children that effective response strategies can be developed, beginning with their identification and subsequently moving to make provisions for appropriately supporting young carers. Additionally given the adult centric nature of society, it is only through such recognition that collective hermeneutical resources about young carers in India can be created and would subsequently encourage development of vocabulary for young carers to recognise their own experiences and claim support.

Development of vocabulary can start with terms to address young carers in Indian languages. For, example, in Hindi, young carers can be addressed as *bal dekhbalkarta*. Here, *bal* means child and *dekhbalkarta* means carer. This term is currently not in use to the best of my knowledge. The term *bal dekhbalkarta* has been influenced by the Hindi term for child labourers, which is *bal kamgar* (child labourer/worker). Similarly, other terms in other Indian languages need to be developed which could be a direct translation of the term ‘young carer’ or a term which encapsulates the definition of being a young carer.

Recognition, however, should avoid pathologising this group. This is a risk that is particularly high given that, as this study demonstrates, young carers often belong to underprivileged communities already grappling with multiple socio-economic disadvantages, including poverty, and intersecting class, gender, and caste-based inequalities.

Response strategies should focus on supporting the family as a whole, rather than resorting to institutionalisation or family separation. Support for young carers should focus on a whole family approach, which aims at developing services based on the needs and challenges of each family member and also on the basis of shared needs of the family. It also aims at developing strengths and addressing risk factors (Gentile and

Clapton, 2022). Such an approach would be helpful in the Indian context wherein for many care-recipients, as evidenced from this study, the family was the primary and, in most cases, the only source of support for the individual. This approach will also avoid stigmatising the family or ‘blame’ the parent who needs support. Therefore, minimising resistance to seek support.

As discussed in chapter three, India already has several policies and programmes that could be leveraged to support young carers. Existing frameworks and schemes could potentially be expanded or adapted to include the specific needs of young carers, ensuring that they receive the support, and opportunities they deserve. As elaborated in chapter three of this thesis, the definition of ‘children in need of care and protection’ in the Juvenile Justice Act of India (2015), already has a clause that involves children whose parent or guardian is deemed unfit or unable to ensure their safety and well-being. These children may assume the role of young carers. In such a scenario, young carers can be included in the Mission Vatsalya or ICPS Scheme (MWCD, 2022 a) which could help the families receive monetary support. Additionally, the extension of the *Bal Sanghopan Yojna* (WCD, 2013), which is currently implemented in only some regions of India, to all over India could also garner financial aid to families with young carers.

NGOs and civil society organisations can create spaces for young carers where they could spend some time away from their responsibilities, giving them some relief from their roles. It goes without saying that this provision would also need to cater to the care-recipients needs during the unavailability of the young carer. For example, an NGO member could be stationed at the house during the specific time. As otherwise, the young carers minds would not be at ease. Additionally, establishing peer support groups for young carers could help reduce feelings of isolation, difference, and loneliness by providing a sense of shared experience and belonging. These groups could also be extended to online platforms for young carers where they could exchange ideas, share experiences, and express their thoughts and emotions in a supportive environment. Such spaces could facilitate the development of friendships, particularly for young carers who often feel different from their peers.

Government and civil society organisations could also invest in training programs for teachers for identification of young carers and their educational needs in school. The

CEHT and ICEHT measures could be developed to be used with young carers and could be useful in their identification.

Creation of flexible and non-formal learning opportunities, as suggested by key informants in this study and by Pande (2022), could also be useful for some young carers. Additionally, involvement of young carers in skill development programs of the government could also help them gain paid employment.

Some young carers in this study expressed the need for assistance with household chores and intensive care tasks. One potential approach could be the creation of a cadre of trained personnel capable of providing in-home support to sick or disabled family members, thereby alleviating some of the caregiving burden on children.

Strengthening India's healthcare system, which currently relies heavily on family-based care, is essential for the well-being of young carers. Such improvements must prioritise accessibility for underprivileged communities and aim to reduce out-of-pocket expenditures, which exacerbate poverty. However, the effectiveness of all these measures ultimately depends on the formal recognition and systematic identification of young carers which is a crucial first step towards addressing their needs.

Limitations and Areas for Further Research

A major limitation of the study is a relatively small sample which limits generalisability of the findings. The study also engaged with children in the urban setting and may offer very different results from the rural setting in India. For reasons mentioned previously, this study could not involve young carers who were not already associated with organisations. This study was limited to a review of literature published in English and did not include studies available in other languages, which may have excluded valuable regional or local perspectives.

Despite, these limitations, the current study has advanced the literature on children's contributions towards their family systems. It also added to the limited literature on experiences of children who are carers for an immediate family member in the Indian context. It elaborates on the limited and unstructured support systems around them which makes them unable to rely on anyone, but themselves.

The needs of young carers and their families have not been systematically investigated within the Indian context. The extent and nature of their caregiving responsibilities remain largely under-researched and poorly understood. As emerging evidence suggests, caregiving activities can have significant and far-reaching impacts on young carers and more research into the young carers in the Indian context is the need of the hour.

A key area for further examination is young carers who drop out of schools especially after class 8 when their educational demands start intensifying. Research with young-adult carers or adults who were young carers may also offer a more holistic perspective on the issue.

Additionally, future use of CEHT measure and ICEHT measure, developed for use with young carers could facilitate the identification of young carers and distinguish between carers and non-carers within the Indian context. Such a screening tool could also address the problem of invisibility of young carers in India. It needs to be highlighted here that future administration of the measures should include the items removed from this study as they would be crucial in identification of young carers.

Although this study shows that poverty is a significant indicator of children becoming young carers, it is important not to completely deny the presence of children with caregiving responsibilities amongst the privileged socio-economic strata in India. Emotional and behaviour impacts of caregiving like the fear of losing a family member and resultant mental stress may not be limited to a particular social class. Therefore, warranting further investigation of subject.

Conclusion

For most of us, we are the protagonists of the movie of our lives. However, the life, needs and choices of the young carers in this study was seldom centred around them. Their narratives placed them in the position of supporting characters, as their lives mostly revolved around the care-recipient. This, however, was neither the child's fault nor their families'. Social, economic and cultural circumstances around them put these children in vulnerable position wherein they were primarily responsible for the care needs of their immediate family members.

The young carers performed numerous onerous tasks for a family member which were beyond filial obligations and supererogatory (Xu, 2021). The caring responsibilities they performed made them indispensable to their families, without whom the survival of the family would be threatened. Often, these responsibilities were performed at a significant personal cost to the young carer.

Despite their indispensable nature, young carers in India were a group of children who were hidden in plain sight. Their dual marginalisations as children and as carers amplified their hidden nature. These children often operate in isolation, without sufficient support. Therefore, this study points to the serious lack of awareness about the presence of children who are carers for immediate family members and calls for the recognition of young carers as children in need of care and protection.

The dominant public discourse in India tends to prioritise visibly vulnerable children, such as those who are abandoned, orphaned, working, or abused. In contrast, young carers' intense physical, emotional, and psychological burdens are hidden behind the doors of their family homes and therefore relegated to the background. Young carers are drawn into a wide range of caregiving roles which have serious implications, both on their present and future. Their invisibility from public and policy discourses only exacerbates these implications. Additionally, young carers in India who may disproportionately represent marginalised backgrounds, face layered disadvantages related to caste, gender, region, or socio-economic status. The additional responsibility of caregiving aggravates these inequalities and also distances them from opportunities accessible to their peers. Lack of welfare services only amplified their marginalisation.

This study does not intend to pathologise the experience of a group of children or stigmatise families with disabilities and illnesses. The study highlights that the families were victims of systemic injustices. Therefore, through this study I wanted to bring attention to the existence of such a group of children in the Indian context, especially outside the context of families affected with HIV/AIDS and the integral contributions that they make to their family unit. Additionally, I also wanted to highlight their circumstances and challenges so that they can be appropriately supported. This support, as this thesis has illustrated, can be provided within the existing child welfare systems present in the country without the requirement of making drastic or novel changes.

Appendices

Appendix 1- Interview Schedule (Young Carers)

The first few minutes of the interview would be spent in rapport building and ice breaking with the participants. As per the comfort of the participant, the schedule will be implemented in one or multiple sittings.

Step 1: Introduction and re-cap of the purpose of the interview.

Step 2: Addressing the questions/doubts of the participant.

Step 3: Reading out the consent form and recording written/ verbal consent. Verbal consent will be recorded on a recording device.

Step 4: Initiation of the interview.

Part A: Background Information

1. Age
2. Where is your family from? (village/town)
3. Father's age and occupation
4. Mother's age, Occupation
5. Do you go to school/college?
 - i. If yes, which class are you in?
 - ii. If no, why?
6. Do you work for an income?
7. Can you tell me a little more about your family and members of your household?
8. Is there anyone in your family with a long-term illness, disability, or other care need?

Part B: Information about the care receiver

9. Relation to the care-receiver _____
10. What kind of care do they require? Since when have they required this kind of help?
11. Do you help your relative?
12. How and when did you start helping your relative?

Part C: Types of caring

13. Can you talk me through a normal day in your life?

Probe: From the time you wake up to the time you go to sleep

14. If this is a normal day, what does a difficult day look like?

15. How much time do you spend helping (care receiver) in a day?

16. Tell me about the kind of things/tasks you do at home, especially for the person requiring care.

17. If you don't do these tasks who will do them?

Probe: If you decide to move away for education or work who would do these tasks?

18. Do you think you have to help (care-receiver) because you are a boy/girl?

Probe: would you be doing the same task if you were not boy/girl?

Part D: Impacts

19. Have you faced any challenges? Can you tell me more about it?

20. What do you like about caring?

Prompt: Have you learnt anything? Impacts on the relationship with the relative.

21. Are there any things that you do you not like about caring?

22. Has helping your relative affected your education in any way? Give examples.

Probe: Have you missed school? Were you unable to do your homework? Too tired to do school work?

23. Has helping your relative affected your physical health?

24. Has helping your relative affected your mental/emotional health?

25. Has helping your relative affected your social relationships?

Probe: friendships, romantic relationships, etc

26. Do you think your role will affect your future prospects?

Probes: Decisions about higher education, marriage, career, etc.

Part E: Feelings about the carer role

27. How do you feel when you have to do these tasks for your relative?

28. Do you think your life is different from that of other children and young people your age? If yes/no, why?

Probe: Do you compare yourself with other children/young people your age?

29. Do you talk about your family situation with your friends, teachers, other people? If yes/no, why?

30. If no, do you feel you will be treated differently if you share about your family circumstances?

31. Do you feel embarrassed/stigmatised/ judged because of your family situation?

Probe: Do you get thoughtless or pitying remarks from peers, teachers, neighbours

etc.? how do these remarks make you feel?

Part G: Support Systems and COVID-19

32. If you need any help with your relative, whom do you ask for help?

33. Have you received any external support (cash benefits, care services, etc.) to take care of your relative?

Probe: Has the government helped you? Do you receive support from local nongovernmental organisations? Have your extended family members helped you?

34. How did COVID-19 pandemic affect your family circumstances and your ability to help out at home?

35. How do you think children and young people who help out at home like you do can be supported?

Probes: Policies, programs, support groups, welfare schemes

Step 5: Concluding questions to the participants

- Is there something that you would like to say that has not been already covered?
- Do you have any comments or suggestions for the interview process? Should I be doing anything differently?
- Asking the participants for a pseudonym for their interview.

Step 6: Handing the help sheet and information sheet to the participants

Step 7: I will chat with the young person about their friends and school or what the rest of their day would look like. I can also speak to them about the recent movies they saw or the actors they like or any other topic that is not related to their caring tasks. This will make sure that the interview is ended on a lighter note and that the young person is not distressed when they leave the interview. I will also ask the young person if they would like to choose a pseudonym for their data to be anonymised.

--X--

Appendix 2- Interview Schedule (Key Informants)

Young carers in India: A study of the prevalence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai.

Interview Schedule – Key Informants

Research Objective: What are the specific experiences of children who undertake caring roles in New Delhi and Mumbai? What are the challenges they face and how supportive are the social systems around them?

The first few minutes of the interview would be spent in rapport building and ice breaking with the participants. As per the comfort the participant, the schedule will be implemented in one or multiple sittings.

Step1: Introduction and re-cap of the purpose of the interview.

Step2: Addressing the questions/doubts of the participant.

Step3: Reading out the consent form and recording written/ verbal consent.

Step4: Initiation of the interview.

Part A: Background Information

1. Age
2. Occupation
3. Languages spoken
4. Professional background: Experience of working with vulnerable children, education (years, locations, areas of expertise)

Part B: Information/knowledge about the carers

5. Please tell me about your work with children who are carers.
6. Have you worked with children who take care of family members with a long-term illness, disability, or other care need?
7. Whom do these children usually care for?
Prompts: parents, grandparents, siblings
8. How do you think they start caring for their family members?
Prompt: At what age? Under what circumstances?
9. Why do children take up caring roles and not someone else?
10. If children do not/ did not take up these roles what will happen to the family?
11. Do you think gender of the child has a role to play in children doing caring tasks?
12. Do you think there are other demographics factors like religion, caste, economic status have an influence in children becoming carers?

Part C: Impacts

13. What are the challenges that such children face?

Prompt: Education, mental health, physical health, social relationships, future prospects.

14. Do you think there are any good aspects to being a child carer?

Part D: Support Systems and COVID-19

15. Do you think such children receive any support?

Prompts: government support, civil society, extended families

16. Did COVID-19 pandemic affect such families? If yes, how? If no, why do you think that is the case?

Prompts: lockdown, medicines, access to hospitals, increasing pressure on the child carer

17. How do you think children who are carers can be/ should be supported?

Probes: Policies, programs, support groups

Step 5: Concluding questions to the participants

- Is there something that you would like to say that has not been already covered?
- Do you have any comments or suggestions for the interview process? Should I be doing anything differently?

Step 6: Handing the thank you voucher to the participant.

Step 7: I will make sure that the participant is not distressed at the end of the interview and will try to chat with them about their plans for the rest of the day/week. I will also ask them if they would like to choose a pseudonym for themselves.

--X--

Appendix 3- Survey Questionnaire

Please answer the following questions to the best of your knowledge:

1. Age: _____
2. Sex: ☐ Male ☐ Female ☐ Other ☐ Prefer not to say
3. Religion:

☐ Hindu ☐ Muslim ☐ Sikh ☐ Christian

☐ Buddhist ☐ Other/ Prefer not to say
4. Caste:

☐ Scheduled Tribe (ST) ☐ Other Backward Caste (OBC)

☐ General ☐ Scheduled Caste (SC) ☐ Don't Know/ Prefer not to say
5. Have you lived in Mumbai/New Delhi all your life? ☐ Yes ☐ No

 If No, at what age did you move to Mumbai/New Delhi? _____.
6. Please list all the family members you currently live with:

	Your Relation to the family member (mother, father..)	Age of family member (approx.)
1.		
2.		
3.		
4.		
5.		

	Your Relation to the family member (mother, father..)	Age of family member (approx.)
6.		
7.		
8.		
9.		
10.		

7. Please tell us what your Father's Occupation is (if he has more than one occupation, please tell us all occupations.:

8. Please tell us what you Mother's Occupation is (if he has more than one occupation, please tell us all occupations:

9. Who brings in the main income for the household? _____

Please tell us how often you do the following tasks. Please note that there are no right or wrong answers.

1. I cook full meals at home:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

2. I wash clothes at home:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

3. I sweep and mop the house:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

4. I bring/shop groceries and vegetables for the house

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

5. I fill water at home:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

6. I wash utensils at home:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

7. I work part-time to support my family financially:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

8. I worry about my family's finances:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

9. I assist a family member with bathing:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

10. I assist a family member with toileting:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

11. I help a family member with dressing:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

12. I help a family member with eating food:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

13. I help a family member with mobility/ exercise:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

14. I help a family member with medicines:

☐ Never	☐ Occasionally (a few times a year)	☐ At least once a month
☐ At least once a week	☐ Daily	

15. I accompany a family member to the hospital or to a doctor:

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

16. I supervise my siblings (make sure they are safe, clean and healthy)

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

17. I help my siblings with school work:

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

18. Do any of your siblings do any of the tasks mentioned above?

☐ Yes ☐ No

If No, who does these tasks at home? _____

19. I get enough sleep:

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

20. I arrive late to school:

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

21. I get enough time to do my homework:

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

22. I miss (school) classes:

- ☐ Never ☐ Occasionally (a few times a year) ☐ At least once a month
- ☐ At least once a week ☐ Daily

23. I get time to play with my friends out of school:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

24. I suffer from body ache, headache, back pain, pain in hands and legs:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

25. I keep thinking about home/ worry about the well-being of someone at home when at school:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

26. I have to make my family members happy when they are sad:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

27. I feel like crying or keep sad:

- ☐ Never

 ☐ Occasionally (a few times a year)

 ☐ At least once a month
- ☐ At least once a week

 ☐ Daily

28. Do you know of any child or young person who looks after a critically ill or disabled family member?

☐ Yes ☐ No

If Yes, how is this person related to you _____.

29. Is there anything else that you would like to share with me on this topic?

30. What are some of your hobbies?

31. What do you want to become when you grow up?

Appendix 4- Household Chores Undertaken by Children

	Never		Occasionally (a few times a year)		Atleast once a month		Atleast once a week		Daily		Total		Mean (SD)	Median (IQR)
	percent age	n	perce ntage	n	percenta ge	n	percent age	n	perce ntage	n	perce ntage	n		
I cook full meals at home	28.90	150	22.74	118	12.72	66	17.73	92	17.92	93	100	519	2.73 (1.49)	2 (1-4)
I wash clothes at home	26.50	137	21.66	112	9.09	47	20.70	107	22.05	114	100	517	2.90 (1.54)	3 (1-4)
I sweep and mop the house	13.87	72	14.84	77	5.97	31	14.84	77	50.48	262	100	519	3.73 (1.53)	5 (2-5)
I fill water at home	17.02	88	11.61	60	6.38	33	17.60	91	47.39	245	100	517	3.67 (1.56)	4 (2-5)
I wash utensils at home	23.02	119	14.51	75	8.32	43	15.47	80	38.68	200	100	517	3.32 (1.63)	4 (2-5)

Appendix 5- Personal/ Intimate tasks Undertaken by Children

	Never		Occasionally (a few times a year)		Atleast once a month		Atleast once a week		Daily		Total			
	percenta ge	n	percenta ge	n	percenta ge	n	percenta ge	n	percenta ge	n	perc enta ge	n	Mean (SD)	Median (IQR)
I assist a family member with bathing	76.39	385	5.16	26	1.79	9	6.35	32	10.32	52	100	504	1.69 (1.37)	1 (1-1)
I assist a family member with toileting	82.38	416	4.55	23	1.98	10	4.75	24	6.34	32	100	505	1.48 (1.16)	1 (1-1)
I help a family member with dressing	63.69	321	12.50	63	2.38	12	10.12	51	11.31	57	100	504	1.93 (1.44)	1 (1-2)
I help a family member with eating food	49.50	250	13.47	68	4.16	21	12.08	61	20.80	105	100	505	2.41(1. 65)	2 (1-4)
I help a family member with mobility/ exercise	52.07	264	16.17	82	7.30	37	11.83	60	12.62	64	100	507	2.17 (1.48)	1 (1-3)

Appendix 6- Tasks to Support Family Members Undertaken by Children.

	Never		Occasionally (a few times a year)		Atleast once a month		Atleast once a week		Daily		Total		Mean (SD)	Median (IQR)
	percen tage	n	percen tage	n	percen tage	n	percen tage	n	percen tage	n	percen tage	n		
I help a family member with medicines	22.24	113	25.00	127	10.83	55	18.70	95	23.23	118	100	508	2.96 (1.50)	3 (2-4)
I accompany a family member to the hospital or to a doctor	21.06	107	38.19	194	20.08	102	13.59	69	7.09	36	100	508	2.48 (1.18)	4 (2-4)
I supervise my siblings (make sure they are safe, clean and healthy)	24.55	123	12.57	63	5.39	27	9.98	50	47.50	238	100	501	3.45 (1.71)	4 (2-5)
I help my siblings with schoolwork	24.20	121	13.80	69	8.80	44	17.20	86	36.00	180	100	500	3.28 (1.63)	4 (2-5)
I have to make my family members happy when they are sad	12.68	63	28.17	140	8.65	43	17.10	85	33.40	166	100	497	3.29 (1.49)	3 (2,5)

Other Tasks (removed from the instrument)

	Never		Occasionally (a few times a year)		Atleast once a month		Atleast once a week		Daily		Total			
	percenta ge	n	percen tage	n	percenta ge	n	percenta ge	n	percen tage	n	perc enta ge	n	Mean (SD)	Median (IQR)
I bring/shop groceries and vegetables for the house	16.47	85	15.50	80	9.40	49	26.36	136	32.17	166	100	516	3.42 (1.48)	4 (2-5)
I work part-time to support my family financially	82.81	419	6.52	33	1.58	8	2.96	15	6.13	31	100	506	1.43 (1.09)	1 (1-1)

Appendix 7- Impacts on Time

	Never		Occasionally (a few times a year)		Atleast once a month		Atleast once a week		Daily		Total		Mean (SD)	Median (IQR)
	percent age	n	perce ntage	n	percenta ge	n	percent age	n	perce ntage	n	perce ntage	n		
I get enough sleep	10.80	54	4.6	23	3.4	17	17.4	87	63.80	319	100	500	4.19 (1.34)	5 (4-5)
I get enough time to do my homework	9.54	48	5.17	26	1.99	10	12.33	62	70.97	357	100	503	4.30 (1.31)	5 (4-5)
I get time to play with my friends out of school hours	27.94	140	11.18	56	6.19	31	19.56	98	35.13	176	100	501	3.23 (1.67)	4 (1-5)

Appendix 8- Physical and Psychological Impacts

	Never		Occasionally (a few times a year)		Atleast once month		Atleast once a week		Daily		Total		Mean (SD)	Median (IQR)
	percent age	n	perce ntage	n	perce ntage	n	percent age	n	perce ntage	n	perce ntage	n		
I suffer from body ache, headache, back pain, pain in hands and legs	26.69	134	27.49	138	18.92	95	17.33	87	9.56	48	100	502	2.56 (1.31)	1 (1-4)
I keep thinking about home/ worry about the well- being of someone at home when at school	28.86	142	20.53	101	8.54	42	14.84	73	27.24	134	100	492	2.91 (1.61)	3 (1-5)
I feel like crying or keep sad	33.13	164	24.85	123	12.12	60	16.97	84	12.93	64	100	495	2.52 (1.43)	2 (1-4)
I worry about my family's finances	18.00	88	14.72	72	7.36	36	9.41	46	50.51	247	100	489	3.60 (1.62)	5 (2-5)

Other Impacts (removed from the instrument)

	Never		Occasionally (a few times a year)		Atleast once a month		Atleast once a week		Daily		Total		Mean (SD)	Median (IQR)
	percent age	n	perce ntage	n	perce ntage	n	percent age	n	perce ntage	n	perce ntage	n		
I arrive late to school	61.55	309	13.94	70	5.38	27	10.96	55	8.17	41	100	502	1.90 (1.36)	1 (1-2)
I miss (school) classes	54.89	264	13.51	65	10.60	51	5.20	25	15.80	76	100	481	2.14 (1.51)	1 (1-3)

Appendix 9 – Risk Assessment

Risk Assessment for the Child Participants- Interview

Potential Hazards	Actions to be taken to Minimise the Hazards
Interviews have the potential to unearth painful memories of traumatic events, shame, embarrassment, and anxiety. Participants may open-up to me under the reassurance of confidentiality and an impartial stranger willing to listen. There may arise a risk of over-disclosure and children may disclose more than they may be comfortable with or can be managed in the setting. Incidences of illegal behaviour, incidences of abuse, health-compromising behaviour, health problems unknown to adults, etc. may be uncovered. This may cause distress to the participants during the interview.	• My prior experiences working with vulnerable children and families will aid in such situations. • At the beginning of the interview, the participants will be informed that it is their choice how much they say. I will avoid undue intrusions and any undue pressure on the participants to disclose more than they are comfortable with. • The interviews will be conducted at an unpressurised pace, and they will have time to think. I will ensure the participants feel comfortable and at ease, valued and respected not intimidated or judged. • In the event of a distressing disclosure, I will support the participants to help themselves and will direct them to support services. They will also get a list of emergency contacts they can approach in distress. I will ensure that interaction with the participant does not finish until there is some solution to the emotional distress. At the end of the interviews, I will also conduct a small debriefing and ensure that the child leaves in a similar physical and emotional state as they arrived. • If the child reveals something concerning which implies a risk to their safety, then I would need to consider breaking the confidentiality agreement to safeguard their wellbeing. However, the decision on disclosure will be made in consultation with my supervisor and if possible, the participant themselves.
My status as an adult researcher from the United Kingdom, may inadvertently influence the participant and coerce them into participation.	• I will work through gatekeepers with whom the children have a prior relationship to ensure a sensitive and non-coercive approach to participation. However, I am aware that gatekeepers may also be in a position of power over participant groups which may also lead to unconscious coercion. • I will inform the participant that they will be able to opt-out or withdraw from the research at any time during the interview. • They will be reminded that they are free not to answer questions or to say that they do not want to discuss a topic further. I will give participants exact wordings to use if they want to withdraw from a particular question or the interview as a whole. For example, if they don't want to answer a particular question they can say 'I do not want to answer that.' This is to ensure that the participants feel that they have the permission to say what they might otherwise feel is a rude or socially awkward demand during an interview.

	I will also be alert to signs of discomfort or potential withdrawal of consent during the engagement.
The participants who might be socially isolated may become attached to me after they discuss their private experiences with me.	- I will ensure that the participant knows the boundaries of the researcher-participant relationship and illustrate in simple child-friendly terms about my role as a researcher and the purpose of it. - I will make it clear that I will not be giving them any kind of medical/therapeutic/social/ education advice. - A help sheet with a list of emergency contacts and support organisations will also be provided to the participants.
Participants may agree to the research without fully understanding the information.	- I will verbally brief the gatekeepers beforehand and the staff will be requested to communicate important information about the purpose of the research along with the time-frame, ethical principles, contact details, and complaints procedure to the participants before they arrive at the interview location. - After they arrive at the location, this information will be relayed to them by me taking into consideration the level of understanding that each child has. I will not use jargon and will keep the language simple. - All the verbal briefings would be supplemented with to-the-point and child-friendly written information.
The participants might think that I will help them improve their current situation.	- I will be clear about the research aims and will not overstate individual benefits in a way that misleads participants about the potential benefits and outcomes. I will inform them that there will not be any 'direct' or 'concrete' benefits to them but that their views are important to inform policies and programs that may affect them, and other children like them. I will ensure that the participants feel that their contribution is valuable and worthwhile. - At the end of the research process and when withdrawing from the relationship, I will provide information about organisations offering advice and support in a written help sheet.
Detailed personal accounts may raise issues about potential identifiability in	To keep the children safe and to reduce their vulnerability all the names and any information that can be traced back to the participants will be changed.

reporting and deductive disclosure	Any specific circumstances that can be easily identified back to the participants will be carefully amended and reported ensuring protection of the participant's identity.
There might arise a conflict of consent among the participants and their parents where one party may consent to participation while the other might not.	- In a scenario where the parent consents to the study but the child do not, I will immediately terminate the session and data will not be collected from that child. - However, if the child consents to the study but the parents are not sure about the same, I will respect the participant's right to participate and to be heard. I will try to convince the parents through gatekeepers or by myself. - If the conflict persists I will, in consultation with my supervisor and the community contact, make a judgement based on the child's age and maturity.
The children might not be able to open-up about their experiences in front of the care-receiver	I will choose a neutral place of comfort for the child for the interview, like the community-based organisation's office or a community center in the same location, or a park/ mall. The participant's privacy and safety will be given utmost importance while deciding the venue. This venue will be shared with the guardians and/or organisational representatives.
Catching the participant on a bad day, a day when they might have received some bad news or something bad might have happened to them.	I will try to avoid making emotional stress the focus of the discussion as much as possible. If the participants are still distressed, I will offer to pause the interview, or to terminate and/or rearrange it.
The findings of this research can show the parents of the young carers in a negative light. This may cause stress to the participants and their families and the wider group. It may fuel pejorative stereotypes about the parents who may be already marginalised.	There will be an unbiased and accurate reporting of the research. I will not suppress the findings of the research but will be mindful about how they are reported and avoid judgmental language in any written/published literature.
COVID-19 Infection	- I am double vaccinated and have received a booster dose. - I will test myself using a Lateral Flow self-test before meeting the participant and will proceed only with negative results. - I will make sure that the participants and I are wearing masks during the interaction. I will also be carrying extra masks and sanitisers with me to the location of the interview. - If required, the interviews will be conducted using online platforms like Zoom, WhatsApp call, Google meet, etc.

Risk assessment Adult Participants- Interview

Due to some direct or indirect pressure participants might feel obligated to participate.	• I will remain alert for indications that someone is not participating completely freely. • I will inform them that participation is completely voluntary and if they decide to withdraw from the interview, this is normal and will not affect their job, or relationship with their employer.
Participants might feel that data collection is a test of their knowledge and might feel judged by the researcher.	• I will ensure the participants feel comfortable and at ease, valued and respected not intimidated or judged.
Personal information about child carers including their names and other information might be shared by the adult key informants in the process of the interview.	• Before the interview begins, the interviewees will be informed that any information which may enable the disclosure of the identity of young carers should be avoided. • If such information happens to be recorded, it will be edited out of the transcripts and pseudonyms will be given to such details.
COVID-19 Infection	• I am double vaccinated and have received a booster dose. • I will test myself using a Lateral Flow self-test before meeting the participant and will proceed only with negative results. • I will make sure that the participants and me are wearing masks during their interaction with me. • I will also be carrying extra masks and sanitizers with me to the location of the data collection. • If required, the interviews will be conducted using online platforms like zoom, WhatsApp call, google meet, etc.

Risk assessment for the Survey Participants

My status as an adult researcher from the United Kingdom, may inadvertently influence the participant and coerce them into participation, especially as I would be approaching them through the school.	• I will inform the participant that they will be able to opt out or withdraw from the research at any time during the survey. • They will be informed that they are free not to answer questions. • Students will be able to stay in the room and not write anything on the survey form.
Some participants might be reminded of painful memories of	• The participants will be informed that I will be available at the school premises for sometime if someone wishes to speak to me after the survey.

traumatic events, shame, embarrassment, and anxiety while answering the survey. They might also write something on the form which may be distressing.	• Participants will also be handed information sheet and help sheet informing them of the risks and benefits of the survey along with contact details of emergency and support services.
COVID-19 Infection	• I am double vaccinated and have received a booster dose. • I will test myself using a self-test before meeting the participant and will proceed only with negative results. • I will make sure that the participants and I are wearing masks during their interaction with me. • I will also be carrying extra masks and sanitisers with me to the location of the data collection.

Risk Assessment for the Researcher

Unsafe neighborhoods can pose threats of physical abuse and/or violence to me.	• I will do a field analysis of the neighbourhood before going to the field. • I will conduct the research in daylight whenever possible. • I will not give out personal information and be cautious while leaving the field to ensure that I am not being followed. • I will try to travel in the community with a community contact from the gatekeeper organisation. • I will conduct the interviews in neutral and public spaces like the community-based organisation's office or a community centre in the same location, or a park. • I will carry an identity card and a mobile phone at all times and inform my family about my whereabouts. • I will wear culturally relevant clothes and not stand out in the community. • I will carry enough cash on me for expected and unexpected circumstances. • I will have taxi apps installed on my phone and will use personal transport whenever possible. • My family will have a designated time to contact the police if I don't report back.
The food and water in the community may be unsanitary.	• I will carry my water and food and will try not to consume anything from the community.

It can be difficult to stay detached or distance myself from the distressing circumstances of the participants. I might feel overwhelmed and may find it hard to balance empathy and the urge to help against professional neutrality.	• I will be self-reflexive and be aware of my emotional responses. • I will share my experiences with my supervisor routinely and raise any challenges arising in the field.
When interviewees reveal sensitive personal experiences, it has the potential to cause emotional or psychological distress to me leading to vicarious trauma, burn out and/or desensitisation.	• I will use my prior experiences of working as a social worker and a researcher to deal with issues of vicarious trauma, burn out and desensitisation. • I will acknowledge the stress and other symptoms so self-care and care by others can be implemented, if necessary. • I will regularly share my thoughts and challenges with my supervisor.
Participants might become hostile or aggressive during the data collection process. Some participants may even have a history of mental illnesses which may lead to unanticipated behaviours.	• I will find out about the background and history of the participants from the gatekeeping organisation before I meet them. • I will remain calm, listen carefully use correct body language to try and diffuse the situation. • I will use my judgement on whether to continue, curtail, or terminate the interview in a way that does not compromise my safety. • I will keep myself informed of the escape route and position myself accordingly while on the field. • If the situation gets too tense, I will leave the premises immediately.
Substance use/abuse by the participant.	• If I think that the participant is under the influence of alcohol or any other substance, I will discontinue the data collection immediately.
COVID-19 Infection	• I am double vaccinated and have received a booster dose. • I will test myself using a self-test before meeting the participant and will proceed only with negative results. • I will make sure that the participants and I are wearing masks during their interaction with me. • I will also be carrying extra masks and sanitisers with me to the location of the data collection. • If required, I will carry out data collection through online platforms.

Appendix 10 - Pattern Matrix- Engagement of Children Measure

Component					
	1	2	3	4	5
I assist a family member with toileting	.831				
I assist a family member with bathing	.767				
I help a family member with dressing	.728				
I help a family member with eating food	.573				
I wash utensils at home		.861			
I sweep and mop the house		.806			
I cook full meals at home		.675			
I wash clothes at home		.625			
I help my siblings with schoolwork			.820		
I supervise my siblings (make sure they are safe, clean and healthy)			.779		
I help a family member with medicines				.677	
I bring/shop groceries and vegetables for the house				.648	
I accompany a family member to the hospital or to a doctor				.623	
I help a family member with mobility/ exercise	.399			.526	
I have to make my family members happy when they are sad				.455	
I work part-time to support my family financially					.844
I fill water at home					.527

Appendix 11 – Anti- image Correlation Matrix

	I arrive late to school	I miss (school) classes	I suffer from body ache, headache, back pain, pain in hands and legs	I keep thinking about home/ worry about the well-being of someone at home when at school	I worry about my family' s finances	I get enough sleep _Reversed	I get time to play with my friends out of school hours _Reversed	I get enough time to do my homework _Reversed	I feel like crying or keep sad
I arrive late to school	0.548								
I miss (school) classes	-0.18	0.631							
I suffer from body ache, headache, back pain, pain in hands and legs	-0.085	-0.005	0.708						
I keep thinking about home/ worry about the well-being of someone at home when at school	-0.054	-0.153	-0.184	0.697					
I worry about my family's finances	0.118	-0.051	-0.019	-0.299	0.674				
I get enough sleep _Reversed	-0.033	-0.036	0.061	0.037	-0.055	0.589			
I get time to play with my friends out of school hours _Reversed	0.087	0.127	0.015	-0.085	0.081	-0.093	0.554		
I get enough time to do my homework _Reversed	0.018	-0.105	0.013	-0.05	0.034	-0.26	-0.192	0.551	
I feel like crying or keep sad	-0.04	-0.013	-0.274	-0.22	-0.172	-0.169	-0.106	0.047	0.698

Note: Bold indicates MSA values

Appendix 12- Pattern Matrix- Impacts of Engagement of Children in Household Tasks Measure

	Component	
I keep thinking about home/ worry about the well-being of someone at home when at school	.738	
I worry about my family's finances	.701	
I feel like crying or keep sad	.689	
I suffer from body ache, headache, back pain, pain in hands and legs	.631	
I get enough time to do my homework _Reversed	.785	
I get enough sleep _Reversed	.733	
I get time to play with my friends out of school hours _Reversed	.502	-.388
I arrive late to school		.773
I miss (school) classes		.721

Appendix 13- Information Sheets (Young Carer Interviews)

If you have any concerns or complaints about my conduct or the research
Please contact:

Dr. Kate Blake-Holmes
Lecturer in Social Work
University of East Anglia
Norwich
NR4 7TJ
Email: Kate.blake-holmes@uea.ac.uk

If you have any further queries about the research
Please contact me:

Teemol Thomas
t.thomas@uea.ac.uk
+919968419871




YOUNG CARERS IN INDIA



A study of the
caring practices
among adolescents
aged 15-18 years in
New Delhi and Mumbai.

Information for Participants (Interviews-Young People)

Introduction

My name is Teemol, and I am a researcher at the University of East Anglia, United Kingdom. I am looking to talk to children and young people in New Delhi and Mumbai who live with and take care of family members who are critically ill, have a mental illness, disability or are in a situation where they require regular care from another family member.

What does the research involve?

If you agree to talk to me, I will interview you. We will speak about your daily routine, how you help the family member who requires regular care and about the impact it has on your education, health and other aspects of their lives. I would also like to know how COVID-19 affected your lives and your support systems. You will not be pressurized to tell me more than what you want to. We will speak in a place convenient to you away from the person you care for.

Is it necessary for me to participate?

No, it is not necessary for you to participate. No one will question you if you decide to not participate. Any services you receive from Pratham will remain unaffected.

Are there any risks to me if I agree to participate?

During the interview, you may feel sad or overwhelmed when we talk about your experiences. If so, we can stop the interview or take a break.

What happens to the information collected from me?

Any information you give me will be electronically stored on a password protected device and only me and my supervisor will have access to it. I will write about what you tell me in my PhD thesis and associated publications. I will not use your name or any other personal details you give me.

Will anything I say be passed on?

I will not share anything that you tell me with anyone else. However, if there is any serious harm to your well-being or the well being of anyone around you, it may be necessary for me to get help for you. In the first instance, I will refer the issue of concern to _____ (name and phone no. of the community contact). If this need should arise I will, if possible, discuss it with you before I take any further action.

How long will it take?

It will take close to 1- 1.5 hours for the entire interview to complete.

Will the study cost me anything?

No, it will not cost you anything. For the interview, I will come to a place convenient to you so you will not have any additional travel costs.

What are the benefits of participating in this study?

You will not directly benefit from talking to me. However, you will help me understand the experiences and needs of children who care for immediate family members. With your help, awareness and support can be created for children who do jobs that are mostly associated with adults. To thank you for your time and valuable contribution, I will (non-monetary tokens of appreciation offered to the participant to be decided in consultation with the gatekeeping organisation)

What if I agree and then change my mind later?

You can change your mind at any point before or during the interview and I will not use your information. After the interview, you can request to withdraw your data for a period up to and including two weeks afterwards by contacting me on the email/ phone no. provided on this pamphlet. You need not give any reason for wanting to withdraw from the research, and you will not be asked for your reasons.

Appendix 14- Information Sheet- (Key Informant Interviews)

If you have any concerns or complaints about my conduct or the research
Please contact:

Dr. Kate Blake-Holmes
Lecturer in Social Work
University of East Anglia
Norwich
NR4 7TJ
Email: Kate.blake-holmes@uea.ac.uk

If you have any further queries about the research
Please contact me:

Teemol Thomas
t.thomas@uea.ac.uk
+918652195911




YOUNG CARERS IN INDIA



A study of the
caring practices
among adolescents
aged 15-18 years in
New Delhi and Mumbai.

Information for Participants (Interviews-Adults)

About me and what I am doing

My name is Teemol, and I am a researcher at the University of East Anglia, United Kingdom. I am conducting a research study on children and young people who live with and take care of family members who are critically ill, have a mental illness, disability or are in a situation where they require regular care from another family member.

What does the research involve?

If you agree to talk to me, I will interview you about your experiences of coming in contact with such children. We will speak about the impact of their caring roles on their education, health and other aspects of their lives. I would also like to know how COVID-19 affected their lives and also about the support systems available to young people who provide informal care to family members.

Are there any risks to me if I agree to participate?

During the interview, you may feel sad or overwhelmed when we talk about difficult experiences. If so, we can stop the interview or take a break.

Is it necessary for me to participate?

No, it is not necessary for you to participate. No one will question you if you decide not to participate.

What happens to the information collected from me?

Any information you give me will be electronically stored on a password protected device and only me and my supervisor will have access to it. I will write about what you tell me in my PhD thesis and associated publications. I will not use your name or any other personal details you give me.

Will anything I say be passed on?

I will not share anything that you tell me with anyone else. However, if there is any serious harm to your well-being or the well-being of anyone around you, it may be necessary for me to get help for you. In the first instance, I will refer the issue of concern to your immediate superior. If this need should arise I will, if possible, discuss it with you before I take any further action.

How long will it take?

It will take close to 1- 1.5 hours for the entire interview to complete.

Will the study cost me anything?

No, it will not cost you anything. For the interview, I will come to a place convenient to you so you will not have any additional travel costs.

What are the benefits of participating in this study?

You will not directly benefit from talking to me. However, you will help me understand the experiences and needs of children who care for immediate family members. With your help, awareness and support can be created for children who do jobs that are mostly associated with adults. To thank you for your time and valuable contribution, I will offer you a voucher of INR 1000/- (approx.10 pounds).

What if I agree and then change my mind later?

You can change your mind at any point before or during the interview and I will not use your information. After the interview, you can request to withdraw your data for a period up to and including two weeks afterwards by contacting me on the email/ phone no. provided on this pamphlet. You need not give any reason for wanting to withdraw from the research, and you will not be asked for your reasons.

Appendix 15- Information Sheet – Survey

If you have any concerns or complaints about my conduct or the research
Please contact:

Dr. Kate Blake-Holmes
Lecturer in Social Work
University of East Anglia
Norwich
NR4 7TJ
Email: Kate.blake-holmes@uea.ac.uk

If you have any further queries about the research
Please contact me:

Teemol Thomas
t.thomas@uea.ac.uk
+919968419871




YOUNG CARERS IN INDIA



A study of the
caring practices
among adolescents
aged 15-18 years in
New Delhi and Mumbai.

Information for Participants (Survey)

About me and what I am doing
My name is Teemol, and I am a researcher at the University of East Anglia, United Kingdom. I want to speak to young people in the age group of 15-18 to understand things they do to help their families and the impact it has on their well being

What does the research involve?
In this study you have to fill in the questionnaire which comes with this pamphlet. Please remember that there are no right or wrong answers.

Do I have to give my name?
No, you do not have to put your name on the questionnaire. You will, however, have to note down the Unique ID of the questionnaire for any future reference.

How long will it take?
It will take you no longer than 15 minutes.

Is the study confidential?
Yes, the study is confidential. All individual questionnaires will only be seen by the researcher. Your answers will not be seen by your teachers or any other school staff.

Will the study cost me anything?
No, it will not cost you anything. For the survey, I will come to your school so you will not have any additional travel costs.

What happens to the information collected from me?
Any information you give me will be electronically stored on a password protected device and only me and my supervisor will have access to it. I will write about what you tell me in my PhD thesis and associated publications. I will not use your name or any other personal details you give me.

Is it compulsory for me to participate in the study?
No, you need not participate in the survey if you choose to.

What is in it for me?
You will not directly benefit from talking to me. Your participation will help me learn about the things that young people do to help their families and also how it affects them.

What if I agree and then change my mind later?
You can choose not to participate or leave the questions blank in the questionnaire and I will not use your information. After the survey, you can request to withdraw your data for a period up to and including two weeks afterwards by contacting me on the email/ phone no. provided on this pamphlet. Please keep your Unique ID handy for this purpose. You need not give any reason for wanting to withdraw from the research, and you will not be asked for your reasons.

Appendix 16- Help Sheets (New Delhi)

S. No	Organisation	Services Offered	Timings	Contact Details
1.	Child Line	All India 24*7 helpline for all children in need.	24*7	1098
2.	All India Women's Helpline	Women in distress	24*7	1091
3.	Domestic Abuse National Helpline	Domestic Violence/ Intimate Partner Violence	24*7	181
4.	Jagori	Domestic Violence/ Intimate Partner Violence Counselling and support services for women	Mon – Sat 09:03 am - 05:30 pm	(011)26692700 (+91) 8800996640 (Call/SMS)
5.	Shakti Shalini	Domestic Violence/ Intimate Partner Violence	Mon- Fri 10:00 pm – 6:00 pm	(011)24373737, (+91) 9654462722 (+91) 7838957810
6.	Nazariya	LGBTQIA support	Mon-Fri 11:00 am – 6:00 pm	(+91) 9818151707 (Call/SMS)
7.	Aasra	Suicide Prevention Helpline	24*7	(+91) 9820466726
8.	Sumaitri	Suicide Prevention Helpline, Crisis Intervention for Depression	Mon-Sun 2:00 pm – 6:30 pm	(011) 23389090 (+91) 9315767849
9.	Sneha	Psycho-social support, mental health care, Suicide Prevention	Mon-Sun 10:00 am – 10:00pm	(+91) 9582208181
10.	Fortis	Stress Helpline	24*7	(+91) 8376804102
11.	Ministry of Home Affairs Cybercrime Portal	Reporting Online Abuse & Child Sexual Abuse Material	24*7	https://cybercrime.gov.in/Webform/Helpline.aspx
12.	Aarambh India IWF Hotline (English)	Reporting Online Abuse & Child Sexual Abuse Material	24*7	https://report.iwf.org.uk/in
13.	Aarambh India IWF Hotline (Hindi)	Reporting Online Abuse & Child Sexual Abuse Material	24*7	https://report.iwf.org.uk/in_hi

Appendix 17- Help Sheets (Mumbai)

S.No	Organisation	Services Offered	Timings	Contact Details
1.	Child Line	All India 24*7 helpline for all children in need.	24*7	1098
2.	Arpan	Phone counselling and psycho-social support	24*7	+91 98190 86444
		Live chat for children in need	24*7	https://www.arpanel.earn.com/
3.	All India Women's Helpline	Women in distress	24*7	1091
4.	Domestic Abuse National Helpline	Domestic Violence/ Intimate Partner Violence	24*7	181
5.	Sneha	Domestic Violence/ Intimate Partner Violence Counselling services to women and children in distress	24*7	(+91) 9167535765 (+91) 9833052684
6.	One Stop Crisis Centre	Domestic Violence/ Intimate Partner Violence	24*7	(022) 24100511
7.	CEHAT	Domestic Violence/ Intimate Partner Violence	24*7	(+91) 9029073154 (Call/SMS)
8.	Aasra	Suicide Prevention Helpline	24*7	(+91) 9820466726
9.	Vandrevalla Foundation	Suicide Prevention Helpline	24*7	(022) 25706000
10.	Hitguj	Psycho-social support, mental health care, Suicide Prevention	24*7	(022) 24131212
11.	icall	Emotional and psychological distress	Mon- Sat 10:00 am – 8:00 pm	(+91) 9152987821 icall@tiss.edu
12.	The Samaritans Mumbai	Suicide Prevention Helpline	Mon – Sun 5:00 pm – 8:00 pm	(+91) 8422984528 (+91) 8422984529 (+91) 8422984530
13.	NIMHANS	Psycho-social support and mental health services	24*7	08046110007
14.	Ministry of Home Affairs Cybercrime Portal	Reporting Online Abuse & Child Sexual Abuse Material	24*7	https://cybercrime.gov.in/Webform/Helpline.aspx
15.	Meri Trustline	Reporting Online Abuse & Child Sexual Abuse Material	24*7	6363176363

Appendix 18- Email to Community Organisations

Email to the Community Based Organisations

Sub: Proposed Partnership with (name of the organisation) for the PhD Project ‘Young carers in India: A study of the prevalence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai’

To,

Director/CEO

(Name of the Organisation)

Dear _____,

Greetings,

I am Teemol Thomas, a doctoral researcher at the University of East Anglia, United Kingdom. This email is regarding a proposed partnership with (name of the organisation) on my PhD project ‘Young Carers in India: A study of the prevalence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai.’ The main element of this project is to study the informal caring roles and responsibilities undertaken by children for family members who have long term physical illnesses, mental illnesses, disability or any other care requirement. For further information about the study, please see the attached brief of the project.

Under this project, I will conduct in-depth interviews with 20 children and four key informants across New Delhi and Mumbai. The main objective of the interviews will be to understand the nature and extent of children’s caring roles and responsibilities, the positive and negative impacts of this role on the children, and identify the support systems available to the family, especially after the COVID-19 pandemic (See Attached Interview Schedule). Based on the findings from the interviews, a survey will be conducted with 300 school going children in the age group of 15-18 years to determine the proportion of children providing care and learn about their demographic characteristics (sex, religion, caste, etc.). The survey will help us identify the proportion of carers to non-carers in the sample, which can then be used to extrapolate and estimate across the wider Indian contexts.

The information collected through this process will be helpful to understand the competencies and needs of young people in India who provide informal care to family members. It will also help develop appropriate arguments for social support and policy formulations catering to the well-being of children and young people who find themselves in informal caring roles in India.

The unprecedented consequences of the COVID- 19 health crisis add to the intensity of the issue and claim active responses.

Expectations from the partner:

1. Facilitate access to adolescents (as many as possible) from New Delhi and Mumbai (if the organisation works in both cities or else one city) aged 15-18 years who provide informal care to family members with long term care requirements- like critical illness, physical or mental disability, substance abuse, etc. Each interview will take 1-1.5 hours.
2. Facilitate access to key informants (maximum two from each city) from New Delhi and Mumbai (if the organisation works in both cities or else one city) who work closely with children and young people like -case workers, teachers, or other professionals. Each interview will take 1-1.5 hours.
3. Gather consent from parents/ guardians of the adolescent participants. The adolescents participating in the study will be provided with a non-monetary token of appreciation (like diary, bag, other stationary) for their time and valuable contributions. The key informants will receive a voucher of Rs.1000/- (approx.10 pounds) each. (Name of the organisation) will get a summary of the findings from the study at the end of the project.

If you are interested to participate in the study, you could contact me at t.thomas@uea.ac.uk or +919968419871. I would be happy to answer any queries or concerns you may have.

I look forward to hearing from your end.

Warm regards

Teemol Thomas

Ph.D. Researcher

School of Social Work

University of East Anglia

Norwich, Norfolk

United Kingdom

NR47TJ



Appendix 19- Consent Form- Young Carer



Consent Form (Interview Participants- Young Person)

Young Carers in India: A study of the prevalence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai.

Please respond to the following by placing ✓ a ✗ or in the answer box.

1. I confirm I have read and understood the information sheet for the above study, and I have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to stop the interview at any time, without having to give a reason.	
3. I understand that the interview will be audio recorded.	
4. I understand that all the information I give will be treated confidentially, under the United Kingdom's Data Protection Act 2018.	
5. If anything is published/ presented with regards to this study, I am aware that my name/ identity will be kept private.	
6. I understand that if I disclose any information which leads to concerns regarding the safety of a vulnerable adult or child this will be reported to relevant authorities at (name of the community based organisation).	
7. After the interview I can choose to withdraw my interview and information within 2 weeks.	
8. I agree to take part in the above study.	

Name of participant Date Signature

This is to confirm that I am aware of my child's participation in the aforementioned study:

Name of the parent Date Signature

This is to confirm that the required consent has been gathered for participation of the young person in the study:

Name of the counter signatory Date Signature

Appendix 20- Consent Form- Key Informant

**Consent Form (Interview Participants- Key Informants)**

Young Carers in India: A study of the prevalence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai.

Please respond to the following by placing ✓ a or ✗ in the answer box.

1. I confirm I have read and understood the information sheet for the above study, and I have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to stop the interview at any time, without having to give a reason.	
3. I understand that the interview will be audio recorded.	
4. I understand that all the information I give will be treated confidentially, under the United Kingdom's Data Protection Act 2018.	
5. If anything is published/ presented with regards to this study, I am aware that my name/ identity will be kept private.	
6. After the interview I can choose to withdraw my interview and information within 2 weeks.	
7. I agree to take part in the above study.	

Name of research Participant

Date

Signature

Appendix 21- Consent Form- Survey

Unique ID:



Young Carers in India: A study of the prevalence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai.

Consent Form (Survey Participants)

Please respond to the following by placing ✓ or ✗ in the answer box.

1. I confirm I have read and understood the information sheet for the above study, and I have had the opportunity to ask questions.	
2. I understand that the answers to the following questions will be kept confidential and will not be seen by anyone from the school staff.	
3. I understand that my participation is voluntary and that I am free to not answer the questionnaire.	
4. I understand that all the information I give will be treated confidentially, under the United Kingdom's Data Protection Act 2018.	
5. If anything is published/ presented with regards to this study, I am aware that my identity will be kept private.	
6. I agree to take part in the above study.	

Appendix 22- Consent Form- School



Informed Consent Agreement (Schools/Junior College)

Young Carers in India: A study of the presence of caring practices among adolescents aged 15-18 years in New Delhi and Mumbai.

I agree to provide access to _____ (Name of the School/Junior College) to collect data related to caring activities among children. I understand the following aspects of participation in the study:

- The data collected will be stored in an anonymous format. The name of school or students will not be stored in any digital format.
- The raw data will not be shared with any government or non-governmental organisation.
- The data will be used and analysed only for the current PhD Project.
- Participants will be given two weeks' time to withdraw from the study.

I understand that the following data will be collected:

- Demographic details like age, sex, religion, caste, no. of family members, occupation of parents, etc.
- Tasks performed by the young people at home to support family functioning.
- Impacts these tasks have on the young people.

I agree to facilitate the exercise by providing some class time for the briefing session and for students to complete the questionnaire. I understand that the school will be compensated Rs. _____ for participation in the study. I also understand that the students may receive a nominal non-monetary token of appreciation for their participation.

I hereby certify that I am authorised to give consent for participation, and that I agree to participate in the study.

Signature/ Stamp

Name and Designation
Date

Appendix 23- UNCRC Article 12, 13 and 17

Article 12 stipulates:

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

Article 13 stipulates:

1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.
2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
 - (a) For respect of the rights or reputations of others; or
 - (b) For the protection of national security or of public order (*ordre public*), or of public health or morals.

Article 17 stipulates:

States Parties recognise the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.

To this end, States Parties shall:

- (a) Encourage the mass media to disseminate information and material of social and cultural benefit to the child and in accordance with the spirit of Article 29;

- (b) Encourage international co-operation in the production, exchange and dissemination of such information and material from a diversity of cultural, national and international sources;
- (c) Encourage the production and dissemination of children's books;
- (d) Encourage the mass media to have particular regard to the linguistic needs of the child who belongs to a minority group or who is indigenous;
- (e) Encourage the development of appropriate guidelines for the protection of the child from information and material injurious to his or her well-being, bearing in mind the provisions of Articles 13 and 18

Glossary

- BAME: Black African, Asian and Minority Ethnic Groups
- BPL: Below Poverty Line
- Collective hermeneutical resources: The collective 'pool of ideas' for making sense of events or aspects of human experiences in a society (Fricker, 2007)
- Epistemic injustice: a kind of injustice in which someone is wronged in their capacity as a knower.
- Hermeneutical injustice: structural injustice/prejudice which occurs when there is a gap in collective understanding of a situation/experience.
- Majority world countries: are low- and middle-income countries, where majority of the world's population lives which were previously known as developing countries or countries from the global south.
- Minority world countries: are high income countries which were previously known as developed countries or countries from the global north.
- NGO: Non-governmental Organisation
- OBC: Other backward class
- OOP payments: Out of pocket payments
- SC: Scheduled castes
- ST: Scheduled tribes
- Testimonial injustice: prejudice which causes the hearer to give a deflated level of credibility to the speaker's words.
- UNCRC: United Nations Convention on the Rights of a Child

References

- Aarambh India Initiative (2020) *Homeless & Hiding: Mumbai Street Children During the Lockdown*. Available at: <http://aarambhindia.org/homeless-hiding-mumbai-street-children-during-the-lockdown/> (Accessed: 7 October 2021).
- Ahuja, J. (2019) 'Protecting holy cows: Hindu vigilantism against Muslims in India', in T. Bjørgo and M. Mareš (eds) *Vigilantism against Migrants and Minorities*. London: Routledge, pp. 55–68.
- Ajay, S. et al. (2017) 'Association of impairments of older persons with caregiver burden among family caregivers: Findings from rural South India', *Archives of Gerontology and Geriatrics*, 68, pp. 143–148.
- Aldridge, J. (2006) 'The experiences of children living with and caring for parents with mental illness', *Child Abuse Review*, 15(2), pp. 79–88.
- Aldridge, J. (2018) 'Where are we now? Twenty-five years of research, policy and practice on young carers', *Critical Social Policy*, 38(1), pp. 155–165.
- Alexander, C. (2021) 'Unequal Conditions of Care and the Implications for Social Policies on Young Carers', *Child and Adolescent Social Work Journal*, 38(5), pp. 505–518.
- Anderson, C. and Kirkpatrick, S. (2016) 'Narrative interviewing', *International Journal of Clinical Pharmacy*, 38(3), pp. 631–634.
- Andreouli, E., Skovdal, M. and Campbell, C. (2013) "It made me realise that I am lucky for what I got": British young carers encountering the realities of their African peers', *Journal of Youth Studies*, 16, pp. 1038–1053.
- Babu, T.S. and Iyer, S.R. (2024) 'Human Rights of Persons With Disabilities: Indian Perspective', *INSPIRA*, 4(1), pp. 5–14.
- Backer, D.I. and Cairns, K. (2021) 'Social reproduction theory revisited', *British Journal of Sociology of Education*, 42(7), pp. 1086–1104.
- Balarajan, Y., Selvaraj, S. and Subramanian, S. (2011) 'Health care and equity in India', *The Lancet*, 377(9764), pp. 505–515.
- Balla, S. et al. (2022) 'Distress financing in coping with out-of-pocket expenditure for maternity care in India', *BMC Health Serv Res*, 22:288.
- Ballal, D., Navaneetham, J. and Chandra, P.S. (2019) 'Children of Parents with Mental Illness: The Need for Family Focussed Interventions in India', *Indian Journal of Psychological Medicine*, 41(3), pp. 228–234.
- Barnardo's (2019) *Caring alone: the young carers who struggle to get support*, *British Journal of Healthcare Assistants*. MA Healthcare London. Available at: <https://www.magonlinelibrary.com/doi/10.12968/bjha.2019.13.6.304> (Accessed: 1 July 2025).

- Bartlett, M.S. (1954) 'A Note on the Multiplying Factors for Various ?2 Approximations', *Journal of the Royal Statistical Society. Series B (Methodological)*, 16(2), pp. 296–298.
- Batra, R. and Reio, T.G. (2016) 'Gender Inequality Issues in India', *Advances in Developing Human Resources*, 18(1), pp. 88–101.
- Becker, F. and Becker, S. (2009) *Young adult carers in the UK: Experiences, needs and services for carers aged 16-24*. The Princess Royal Trust for Carers.
- Becker, S. (2007) 'Global Perspectives on Children's Unpaid Caregiving in the Family: Research and Policy on "Young Carers" in the UK, Australia, the USA and Sub-Saharan Africa', *Global Social Policy*, 7(1), pp. 23–50.
- Becker, S., Dearden, C. and Aldridge, J. (2001) 'Children's labour of love? Young carers and care work', in P. Mizen, C. Pole, and A. Bolton (eds) *Hidden Hands: International Perspectives on Children's Work and Labour*, pp. 70–88.
- Benzaken, T., Palep, A.H. and Gill, P.S. (2011) 'Exposure to and opinions towards sex education among adolescent students in Mumbai: A cross-sectional survey', *BMC Public Health*, 11.
- Berrick, J.D., Gilbert, N. and Skivenes, M. (2023) 'Child Protection Systems Across the World', in J.D. Berrick, N. Gilbert, and M. Skivenes (eds) *Oxford Handbook of Child Protection Systems*. Oxford, UNITED STATES: Oxford University Press, Incorporated, pp. 16–39.
- Bhangaokar, R. and Kapadia, S. (2019) 'Gendered Boundaries, Cultured Lives: The Underexplored Dimensions of Duty (Kartavya) in the Indian Family Context', *Psychology and Developing Societies*, 31(2), pp. 252–282.
- Bhatia, S. (2000) 'Can We Return to the Concept of Duty in a Culture of Rights? Implications for Morality and Identity', *Culture & Psychology*, 6(3), pp. 303–316. Available at: <https://doi.org/10.1177/1354067X0063002>.
- Bhatt, S. and Sanyal, S. (2023) 'The Child Protection System in India: An Overview', in J.D. Berrick, N. Gilbert, and M. Skivenes (eds) *Oxford Handbook of Child Protection Systems*. Oxford: Oxford University Press, Incorporated, pp. 855–881.
- Bibby, A. and Becker, S. (2000) *Young carers in their own words*. Edited by A. Bibby and S. Becker. London: Calouste Gulbenkian Foundation.
- Bispo, R. and Marques, F. (2023) 'Stability of principal components under normal and non-normal parent populations and different covariance structures scenarios', *Journal of Statistical Computation and Simulation*, 93(7), pp. 1060–1076. Available at: <https://doi.org/10.1080/00949655.2022.2125971>.
- Blake-Holmes, K. (2019) 'Young adult carers: making choices and managing relationships with a parent with a mental illness', *Advances in Mental Health*, 18(3), pp. 230–240.

- Blake-Holmes, K., Maynard, E. and Brandon, M. (2023a) 'The impact of acquiescence: a model of coping developed from children of parents with mental illness', *Mental Health*, 21, pp. 199–217.
- Blake-Holmes, K., Maynard, E. and Brandon, M. (2023b) 'The impact of acquiescence: a model of coping developed from children of parents with mental illness', *Advances in Mental Health*, 21(3), pp. 199–217.
- Boateng, G.O. et al. (2018) 'Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer', *Frontiers in Public Health*, 6.
- Boddy, J. (2014) 'Research across cultures, within countries: Hidden ethics tensions in research with children and families?', *Progress in Development Studies*, 14(1), pp. 91–103.
- Borga, L., D'Ambrosio, C. and Lepinteur, A. (2022) 'It's a Family Affair: Family Health and Child Well-being', in A. Heinen et al. (eds) *Wohlbefinden und Gesundheit im Jugendalter: Theoretische Perspektiven, empirische Befunde und Praxisansätze*. Wiesbaden: Springer Fachmedien, pp. 151–172.
- Boszormenyi-Nagy, I. and Spark, G.M. (1973) *Invisible loyalties: reciprocity in intergenerational family therapy*. Maryland: Harper and Row.
- Boumans, N.P.G. and Dorant, E. (2018) 'A cross-sectional study on experiences of young adult carers compared to young adult noncarers: parentification, coping and resilience', *Scandinavian Journal of Caring Sciences*, 32(4), pp. 1409–1417.
- Bradbury-Jones, C., Isham, L. and Taylor, J. (2018) 'The complexities and contradictions in participatory research with vulnerable children and young people: A qualitative systematic review', *Social Science & Medicine*, 215, pp. 80–91. A
- Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2).
- Braun, V. and Clarke, V. (2012) 'Thematic analysis', *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological*. Washington, DC, US: American Psychological Association (APA handbooks in psychology), pp. 57–71.
- Brinda, E.M. et al. (2014) 'Cost and burden of informal caregiving of dependent older people in a rural Indian community', *BMC Health Services Research*, 14(1), p. 207.
- Brinkmann, S. and Kvale, S. (2018) *Doing interviews*. Second edition. London: SAGE Publications Ltd.
- Brown, A. and Danaher, P.A. (2019) 'CHE Principles: facilitating authentic and dialogical semi-structured interviews in educational research', *International Journal of Research & Method in Education*, 42(1), pp. 76–90.
- Bryman, A. (2016) *Social Research Methods*. 5th edn. Oxford: Oxford University Press.

- Burr, V., Dick, P. and Gough, B. (2017) 'Social Constructionism', *The Palgrave Handbook of Critical Social Psychology*. London: Palgrave Macmillan, pp. 59–80.
- Burton, L. (2007) 'Childhood Adultification in Economically Disadvantaged Families: A Conceptual Model', *Family Relations*, 56(4), pp. 329–345.
- Campbell, S. et al. (2020) 'Purposive sampling: complex or simple? Research case examples', *Journal of Research in Nursing*, (8), pp. 652–661.
- Carel, H. and Györfy, G. (2014) 'Seen but not heard: children and epistemic injustice', *The Lancet*, 384(9950), pp. 1256–1257.
- Carers Trust (2016) *Invisible and in Distress: Prioritising the Mental Health of England's Young Carers*. London: Carers Trust. Available at: <https://carers.org/downloads/resources-pdfs/invisibleandindistressreport.pdf> (Accessed: 25 March 2025).
- Carers Trust (no date) *Young carers and the school census*. Available at: <https://carers.org/campaigning-for-change/young-carers-and-the-school-census> (Accessed: 1 July 2025).
- Carter, S. and Henderson, L. (2005) 'Approaches to qualitative data collection', in A. Bowling and S. Ebrahim (eds) *Handbook of health research methods : investigation, measurement and analysis*. Maidenhead: Open University Press, pp. 215–229.
- Cattell, R.B. (1966) 'The Scree Test For The Number Of Factors', *Multivariate Behavioral Research*, 1(2), pp. 245–276.
- Chakraborty, R., Jana, A. and Vibhute, V.M. (2023) 'Caregiving: a risk factor of poor health and depression among informal caregivers in India- A comparative analysis', *BMC Public Health*, 23(1), p. 42.
- Chakraborty, R.K. and Waraich, S.B. (2023) 'Stress and Well-Being amongst Young Adults with Chronically Ill Parents', *International Journal for Research in Applied Science & Engineering Technology (IJRASET)*, 2(5), pp. 4918–4942.
- Chakraborty, S. and Bohara, A.K. (2021) 'The Cost of Being "Backward" in India: Socio-religious Discrimination in the Labour Market', *Indian Journal of Human Development*, 15(2), pp. 252–272.
- Chakramakkil, A.T. (2017) 'The Polemics of Real and Imagined Childhood(s) in India', *International Research in Children's Literature*, 10(1), pp. 74–88.
- Chan, S. and Heidi, Y. (2010) 'Growing up with a parent with schizophrenia: what children say they need', *Journal of Children's Services*, 5(4), pp. 31–42.
- Chaturvedi, B.K. (2023) *Research methodology* (1 online resource. vol). First Edition. Delhi: Laxmi Publications Pvt Ltd.
- Chauhan, M. and Pramanik, R. (2021) 'Contribution of Gond Children towards Family Economy: An Overview from Madhya Pradesh', *Social Vision*, 8(1), pp. 27–43.

- Chauhan, U.M. et al. (2021) 'Caregiver's perception of barriers to implementation of the "Rights of Persons with Disabilities (RPWD) Act, 2016 in India"', *Vulnerable Children and Youth Studies*, 17(3), pp. 248–258.
- Clabburn, O. and O'Brien, M.R. (2015) 'Exploring the impact on young people who are caring and grieving for a parent with motor neurone disease', *British Journal of Neuroscience Nursing*, 11(5), pp. 243–248.
- Clandinin, D.J. et al. (2016) 'Engaging in narrative inquiries with children and youth / D. Jean Clandinin, Vera Caine, Sean Lessard, and Janice Huber.'
- Cluver, L. et al. (2013) 'The hidden harm of home-based care: Pulmonary tuberculosis symptoms among children providing home medical care to HIV/AIDS-affected adults in South Africa', *AIDS Care*, 25(6), pp. 748–755.
- Corbin, J. and Morse, J.M. (2003) 'The Unstructured Interactive Interview: Issues of Reciprocity and Risks when Dealing with Sensitive Topics', *Qualitative Inquiry*, 9(3), pp. 335–354.
- Cree, V.E. (2003) 'Worries and problems of young carers: issues for mental health', *Child & Family Social Work*, 8(4), pp. 301–309.
- Creswell, J.W. (2022) *A Concise Introduction to Mixed Methods Research*. 2nd edn. SAGE Publications Ltd.
- Das, J. et al. (2022) 'Two Indias: The structure of primary health care markets in rural Indian villages with implications for policy', *Social Science & Medicine*, 301, p. 112799.
- Das, P., Ghosh, S. and Paria, B. (2022) 'Multidimensional poverty in India: a study on regional disparities', *GeoJournal*, 87(5), pp. 3987–4006.
- Dash, B.B. (2013) 'Approaches to Strategies of Non-Verbal Communication', *Anvikshiki: The Indian Journal of Research*, 7(2), pp. 57–64.
- Davidson, C. (2009) 'Transcription: Imperatives for Qualitative Research', *International Journal of Qualitative Methods*, 8(2), pp. 35–52.
- D'Cruz, P. (2004) 'The Family Context of Care in HIV/AIDS: A Study from Mumbai, India', *The Qualitative Report*, 9(3), pp. 413–434.
- D'Cruz, P. and Bharat, S. (2001) 'Beyond Joint and Nuclear: The Indian Family Revisited', *Journal of Comparative Family Studies*, 32(2), pp. 167–194.
- Dearden, Chris and Becker, S. (2004) 'Growing up caring: Young carers and vulnerability to social exclusion', in M. Barry (ed.) *Youth Policy and Social Inclusion*. Routledge, pp. 202–217.
- Dearden, C and Becker, S. (2004) *Young Carers in the UK*. London: Carers UK.
- Denzin, N.K. (2015) 'Triangulation', in G. Ritzer (ed.) *The Blackwell Encyclopedia of Sociology*. John Wiley & Sons, Ltd.

- Desai, M. et al. (2022) 'Overview and way forward for child-centred social work practice', in M. Desai and N. Mehta (eds) *Child-Centred Social Work in India: Journeys and the Way Forward*. Oxford, UNITED KINGDOM: Taylor & Francis Group, pp. 304–329.
- Desai, M. (2022) 'Preface', in Murli Desai and N. Mehta (eds) *Child-Centred Social Work in India: Journeys and the Way Forward*. Oxford, UNITED KINGDOM: Taylor & Francis Group, pp. 12–18.
- Deshpande, A. and Ramachandran, R. (2020) 'Which Indian Children are Short and Why? Social Identity, Childhood Malnutrition and Cognitive Outcomes'. Ashoka University, Department of Economics.
- DeVellis, R.F. (2012) *Scale Development: Theory and Applications*. 4th edn. Sage Publications.
- Dhanaraj, S. (2016) 'Effects of parental health shocks on children's schooling: Evidence from Andhra Pradesh, India', *International Journal of Educational Development*, 49, pp. 115–125.
- Dziuban, C.D. and Shirkey, E.C. (1974) 'When is a correlation matrix appropriate for factor analysis? Some decision rules', *Psychological Bulletin*, 81(6), pp. 358–361.
- Economic and Social Research Council (2015) *Framework for Research Ethics (FRE)*. Available at: https://www.gla.ac.uk/media/Media_326706_smxx.pdf.
- Edmonds, E.V. (2007) 'Child Labor'. Rochester, NY: Social Science Research Network. Available at: <https://papers.ssrn.com/abstract=969364> (Accessed: 20 May 2025).
- El-Masri, M.M. et al. (2021) 'Multivariate Outliers: A Conceptual and Practical Overview for the Nurse and Health Researcher', *Canadian Journal of Nursing Research*, 53(3), pp. 316–321.
- Epstein, J., Santo, R.M. and Guillemin, F. (2015) 'A review of guidelines for cross-cultural adaptation of questionnaires could not bring out a consensus', *Journal of Clinical Epidemiology*, 68(4), pp. 435–441.
- Evans, R. and Becker, S. (2009a) *Children caring for parents with HIV and AIDS: Global issues and policy responses*. 1st edn. Bristol University Press.
- Evans, R. and Becker, S. (2009b) 'Global and local processes influencing young people's caring roles in families affected by HIV and AIDS', *Children Caring for Parents with HIV and AIDS*. Bristol University Press, pp. 227–268.
- Fatima, H. et al. (2022) 'Religious coping in the time of COVID-19 Pandemic in India and Nigeria: Finding of a cross-national community survey', *International Journal of Social Psychiatry*, 68(2), pp. 309–315.
- Federici, S. (2019) 'Social reproduction theory: History, issues, and present challenges', *Radical Philosophy*, 204, pp. 55–57.

- Fricker, M. (2007) *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Gawde, N.C., Sivakami, M. and Babu, B.V. (2016) 'UTILIZATION OF MATERNAL HEALTH SERVICES AMONG INTERNAL MIGRANTS IN MUMBAI, INDIA', *Journal of Biosocial Science*, 48(6), pp. 767–796.
- Gentile, A. and Clapton, G. (2022) 'Thinking family, acting family: A case study of “the whole family” approach'. *Children in Scotland's Annual Conference 2019*.
- Ghai, Y. (1998) 'Rights, Duties and Responsibilities', in J. Cauquelin, Paul Lim, and B. Mayer-König (eds) *Asian Values: Encounter with Diversity*, pp. 20–42.
- Ghate, B. (2022) 'Protecting child rights through family-based services', in M. Desai and N. Mehta (eds) *Child-Centred Social Work in India: Journeys and the Way Forward*. Oxford, UNITED KINGDOM: Taylor & Francis Group, pp. 39–59.
- Ghosh, S. (2022) 'Religiosity and bank performance: How strong is the link?', *Journal of Behavioral and Experimental Finance*, 33.
- Gibby, A.L. (2022) 'Gendered Housework Among Adolescents in India', *Journal of Family Issues*, 43(11), pp. 2933–2953.
- Gillick competence and Fraser guidelines* (2022) *NSPCC Learning*. Available at: <https://learning.nspcc.org.uk/child-protection-system/gillick-competence-fraser-guidelines> (Accessed: 7 August 2025).
- Goel, S. and Husain, Z. (2018) 'Gender, caste, and education in India: A cohort-wise study of drop-out from schools', *Research in Social Stratification and Mobility*, 58, pp. 54–68.
- Goldblatt, H., Granot, M. and Zarbiv, E. (2019) ““Death Lay Here on the Sofa”: Reflections of Young Adults on Their Experience as Caregivers of Parents Who Died of Cancer at Home', *Qualitative Health Research*, 29(4), pp. 533–544.
- Gouda, J. et al. (2013) 'Government versus Private Primary Schools in India: An Assessment of Physical Infrastructure, Schooling Costs and Performance', *International Journal of Sociology and Social Policy*, 33(11/12), pp. 708–724.
- Gowen, S.M. et al. (2022) ““..It takes a lot of brain space”: Understanding Young Carers' lives in England and the Implications for Policy and Practice to Reduce Inappropriate and Excessive Care Work', *Children and Society*, 36(1), pp. 118–136.
- Goyal-Honavar, A. et al. (2025) 'The Cost of Compassion: Caregiver Fatigue Associated with Caring for Persons with Disability in a Rural Population in India', *Indian Journal of Community Medicine*, pp. 1–6.
- Graham, H. (1991) 'The Concept of Caring in Feminist Research: The case of Domestic Service', *Sociology*, 25(1), pp. 61–78.

- Graham, H. (1993) 'Social Divisions in Caring', *Women's Studies Int. Forum*, 16(5), pp. 461–470.
- Guest, G., MacQueen, K.M. and Namey, E.E. (2012) 'Introduction to Applied Thematic Analysis', *Applied Thematic Analysis*. SAGE Publications, Inc., pp. 3–20.
- Gupta, R., Pillai, V.K. and Levy, E.F. (2012) 'Relationship quality and elder caregiver burden in India', *Journal of Social Intervention: Theory and Practice*, 21(2), pp. 39–62.
- Gupta, Rashmi, Rowe, N. and Pillai, V. (2009) 'Perceived Caregiver Burden in India', *Journal of Women and Social Work*, 24(1), pp. 69–79.
- Hamilton, M.G. and Adamson, E. (2013) 'Bounded agency in young carers' lifecourse-stage domains and transitions', *Journal of Youth Studies*, 16(1), pp. 101–117.
- Hanna, A. (2022) 'Silent Epistemologies: Theorising Children's Participation Rights', *The International Journal of Children's Rights*, 31(1), pp. 40–60.
- Harachi, T.W. *et al.* (2006) 'Examining equivalence of concepts and measures in diverse samples', *Prevention Science*, 7(4), pp. 359–368.
- Hazarika, G. and Sarangi, S. (2008) 'Household Access to Microcredit and Child Work in Rural Malawi', *World Development*, 36(5), pp. 843–859.
- Hemming, P.J. (2008) 'Mixing qualitative research methods in children's geographies', *Area*, 40(2), pp. 152–162.
- Herring, J. (2023) *Adulthood and the Rights of Children*, *Oxford Law Blogs*.
- Hinton, R. (2008) 'Children's Participation and Good Governance: Limitations of the Theoretical Literature', *The International Journal of Children's Rights*, 16(3), pp. 285–300.
- Hounsell, D. (2013) *Hidden from View: The experiences of young carers in England*. London: Children's Society.
- Huang, X. *et al.* (2016) 'Ethical and methodological issues in qualitative health research involving children: A systematic review', *Nursing Ethics*, 23(3), pp. 339–356.
- International Institute for Population Sciences (IIPS) (2007) *National Family Health Survey (NFHS-3)*. 5. International Institute for Population Sciences.
- International Institute for Population Sciences (IIPS) (2021) *National Family Health Survey (NFHS-5)*. 3. International Institute for Population Sciences.
- International Labour Organisation (ILO) (2016) *Women at Work Trends 2016*. Available at: www.ilo.org/publns.
- Ireland, M.J. and Pakenham, K.I. (2010) 'The Nature of Youth Care Tasks in Families Experiencing Chronic Illness/Disability: Development of the Youth Activities of Caregiving Scale (YACS)', *Psychology and Health*, 25(6), pp. 713–731.

- Jalali, F.S., Bikineh, P. and Delavari, S. (2021) 'Strategies for reducing out of pocket payments in the health system: a scoping review', *Cost Effectiveness and Resource Allocation*, 19(1), p. 47.
- James, E. (2019) *Caring alone: Why Black, Asian and Minority*. Barnardo's. Available at: https://scholar.google.com/scholar_lookup?hl=en&publication_year=2019&author=E.+James&title=Caring+alone.+Why+black%2C+Asian+and+minority+ethnic+young+carers+continue+to+struggle+to+access+support (Accessed: 1 July 2025).
- Jha, J. (2017) 'Education and gender: a critical analyses of policies in India', in T.S. Saraswathi, S. Menon, and A. Madan (eds) *Childhoods in India: Traditions, Trends and Transformations*. London and New York: Routledge, pp. 248–270.
- Joseph, S. et al. (2009) 'Assessment of caring and its effects in young people: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers', *Child: Care, Health and Development*, 35(4), pp. 510–520.
- Joseph, S. et al. (2020) 'Young Carers Research, Practice and Policy: An Overview and Critical Perspective on Possible Future Directions', *Adolescent Research Review*, 5(1), pp. 77–89.
- Joseph, S. et al. (2023) 'Young carers research, practice and policy: an overview and critical perspective on possible future directions', *Issue topic: Young Carers (Part II), Intergenerational Justice Review*, 5, pp. 40–51.
- Kaiser, H.F. (1970) 'A second generation little jiffy', *Psychometrika*, (35), pp. 405–415. Available at: <https://doi.org/10.1007/BF02291817>.
- Kaiser, H.F. (1974) 'An index of factorial simplicity', *Psychometrika*, (39), pp. 31–36. Available at: <https://doi.org/10.1007/BF02291575>.
- Kashyap, L. (1989) 'Family's role in providing support to disabled persons in India's changing times', *International Journal for the Advancement of Counselling*, 12(4), pp. 261–271.
- Kaushik, V. and Walsh, C.A. (2019) 'Pragmatism as a Research Paradigm and Its Implications for Social Work Research', *Social Sciences 2019, Vol. 8, Page 255*, 8(9), p. 255.
- Kavanaugh, M.S., Henning ,Franclo and Mochan, A. (2020) 'Young carers and ALS/MND: exploratory data from families in South Africa', *Vulnerable Children and Youth Studies*, 16(2), pp. 123–133.
- Kettell, L. et al. (2021) 'Development of the Carers' Alert Thermometer for Young Carers (CAT-YC) to Identify and Screen the Support Needs of Young Carers: A Mixed Method Consensus Study', *Child and Adolescent Social Work Journal*, 38(5), pp. 559–570.

- Khare, S. *et al.* (2019) 'Antibiotic Prescribing by Informal Healthcare Providers for Common Illnesses: A Repeated Cross-Sectional Study in Rural India', *Antibiotics*, 8(3), p. 139.
- Khurania, V., Singal, M. and Singh, I. (2023) 'Exploring the Operational Framework of Child Welfare in Haryana - Issues and Challenges', *International Journal for Research Publication and Seminar*, 14(4), pp. 1–11.
- Kingdon, G.G. (2007) 'The progress of school education in India', *Oxford Review of Economic Policy*, 23(2), pp. 168–195.
- Krishna, P. and Raj, A. (2022) 'Health Condition of Internal Migrants in India: A Review', *Indian Journal of Human Development*, 16(1), pp. 169–179.
- Kumar, D. *et al.* (2022) 'Corporal punishment and praise in Indian schools: Caste-based heterogeneity on children's cognitive skills', *International Journal of Educational Development*, 89, p. 102554.
- Kumar, P. *et al.* (2023) 'Determinants of School dropouts among adolescents: Evidence from a longitudinal study in India', *PLOS ONE*, 18(3), p. e0282468.
- Kumar, R. (1999) *Research methodology : a step-by-step guide for beginners*. London: SAGE Publications Ltd.
- Kumar, R. (2019) *Research methodology : a step-by-step guide for beginners*. 5th edn. London: SAGE Publications Ltd.
- Kumar, R., Balasubramanian, S. and Loungani, P. (2022) 'Inequality and locational determinants of the distribution of living standards in India', *Structural Change and Economic Dynamics*, 61, pp. 59–69.
- Kumar, R. and Saini, R. (2012) 'Extent of Burden and Coping Strategies among Caregivers of Mentally-ill Patients', *Sage Publications*, 8(4), pp. 274–284.
- Kushwaha, M. (2020) 'GENDER DISCRIMINATION MASKED IN SCHOOL ENROLMENT GROWTH: EVIDENCE FROM INDIA', *Conflux Journal of Education*, 8(2).
- Laver-Bradbury, C. *et al.* (2021) *Child and Adolescent Mental Health: Theory and Practice*. 3rd edn. Boca Raton: Routledge.
- Leu, A. *et al.* (2022) 'The 2021 Cross-National and Comparative Classification of In-Country Awareness and Policy Responses to "Young Carers"', *Journal of Youth Studies*, 26(5), pp. 619–636.
- Lewis, F.M. *et al.* (2023) 'The first cross-national study of adolescent young carers aged 15–17 in six European countries', *International Journal of Care and Caring*, 7(1), pp. 6–32.
- Liebel, M., Overwien, B. and Recknagel, A. (eds) (2001) *Working Children's Protagonism: Social Movements and Empowerment in Latin America, Africa and India*. Frankfurt am Main: IKO Verlag fur Interkulturelle Kommunikation.

- Liebel, M. and Philip, M. (2024) 'Intersectional Tensions in Theorizing Adulthood - ProQuest', *Taboo*, 22(1), pp. 96–123.
- Lin, T. and Adserà, A. (2013) 'Son Preference and Children's Housework: The Case of India', *Population Research and Policy Review*, 32(4), pp. 553–584.
- Liu, G.L. (2025) 'Revisiting and measuring foreign language confidence from a World Englishes perspective: Scale development and validation', *International Journal of Applied Linguistics*, 35(1), pp. 291–307.
- Lomax, H. (2012) 'Contested voices? Methodological tensions in creative visual research with children', *International Journal of Social Research Methodology*, 15(2), pp. 105–117.
- Lynch, K. (2007) 'Love Labour as a Distinct and Non-Commodifiable Form of Care Labour', *The Sociological Review*, 55(3), pp. 550–570.
- Madan, A., Srinivasan, R. and Pandya, K. (2017) 'Parent-child relations: changing contours and emerging trends', in T.S. Saraswathi, S. Menon, and A. Madan (eds) *Childhoods in India Traditions, Trends and Transformations*. Oxon and New York: Routledge India, pp. 135–154.
- Majumdar, P. and Sarkar, A.K. (2025) 'Family centered approach to child protection services in India: Future scope for non- governmental organizations to prevent child maltreatment', *Child Protection and Practice*, 5, p. 100157.
- Malhotra, S. and Kaur, R.P. (1997) 'Temperament Study on Children of Mentally Ill Parents', *Hong Kong Journal of Psychiatry*, 7(1), pp. 39–45.
- Malhotra, S. and Shah, R. (2015) 'Women and mental health in India: An overview', *Indian Journal of Psychiatry*, 57(Suppl 2), pp. S205–S211.
- Malvankar, A. (2018) 'Elementary School Education and the Right to Education Act, 2009', *Article Sociological Bulletin*, 67(2), pp. 220–235.
- Mandal, S. (2016) 'Emerging Trends of Inter-State Migrant Workers in India: A Study of Legal Framework', *Indian Journal of Law and Justice*, 7(1), p. 106.
- Manigandan, C. et al. (2000) 'Psychological wellbeing among carers of people with spinal cord injury: a preliminary investigation from South India', *Spinal Cord*, 38(9), pp. 559–562.
- Markowska-Manista, U. (2018) 'The ethical dilemmas of research with children from the countries of the Global South. Whose participation?', *Polish Journal of Educational Studies*, 71(1), pp. 51–65.
- Masiran, R. et al. (2023) 'The positive and negative aspects of parentification: An integrated review', *Children and Youth Services Review*, 144, p. 106709.
- McCarthy, A. (2023) *Children and NGOs in India: Development As Storytelling and Performance*. Oxford, United Kingdom: Taylor & Francis Group.

- McManus, A. and Dhar, L. (2008) 'Study of knowledge, perception and attitude of adolescent girls towards STIs/HIV, safer sex and sex education: (A cross sectional survey of urban adolescent school girls in South Delhi, India)', *BMC Women's Health*, 8, p. 12.
- M.D., P. and S.K., S. (2019) 'Child Welfare – Measures to Combat Violation, Exploitation, & Abuse', *International Journal of Management, Technology, and Social Sciences*, pp. 52–67.
- MDU (2025) *Gillick competence*. Available at: <https://www.themdu.com/guidance-and-advice/guides/gillick-competence> (Accessed: 4 April 2025).
- Mehendale, A. (2022) 'Social work on child rights: My journey, challenges, and vision', in M. Desai and N. Mehta (eds) *Child-Centred Social Work in India: Journeys and the Way Forward*. Oxford, United Kingdom: Taylor & Francis Group, pp. 251–302.
- Mehta, A.K. and Gupta, S. (2005) 'The Impact of HIV AIDS on Women Care Givers in Situations of Poverty: Policy Issues'. Rochester, NY: Social Science Research Network.
- Metzing, S. et al. (2020) 'The prevalence of young carers – a standardised survey amongst school students (KiFam-study)', *Scandinavian Journal of Caring Sciences*, 34(2), pp. 501–513.
- ME-WE (2021) *Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe*, CORDIS. Available at: <https://cordis.europa.eu/article/id/435365-supporting-europe-s-youngest-caregivers> (Accessed: 29 July 2025).
- Ministry of Women and Child Development (MWCD) (2022 a) *Mission Vatsalya: Implementation guidelines*, Government of India. Available at: <https://missionvatsalya.wcd.gov.in/public/pdf/children-related-law/vatsalyaguideline.pdf> (Accessed: 19 November 2024).
- Ministry of Women and Child Development (MWCD) (2022 b) *Operational guidelines regarding implementation of 'Saksham Anganwadi and Poshan 2.0'*. New Delhi: Government of India. Available at: <https://cdnbbsr.s3waas.gov.in/s34c144c47ecba6f8318128703ca9e2601/uploads/2024/12/202412111663461918.pdf> (Accessed: 19 November 2024).
- Miller, S.P. (2024) 'Thematic analysis.', *Salem Press Encyclopedia*. Salem Press.
- Morgan, C.D. and Murray, H.A. (1935) 'A method for investigating fantasies: the thematic apperception test', *Archives of Neurology & Psychiatry*, 34, pp. 289–306.
- Muris, P. and Meesters, C. (2004) 'Children's Somatization Symptoms: Correlations with Trait Anxiety, Anxiety Sensitivity, and Learning Experiences', *Psychological Reports*, 94(3_suppl), pp. 1269–1275.
- Myers, M.D. and Newman, M. (2007) 'The qualitative interview in IS research: Examining the craft', *Information and Organization*, 17(1), pp. 2–26.

- Nagrajan, R. (2021) 'School enrolment data indicates 45% OBCs, 19% Dalits in India', *Times of India*, 30 July. Available at: <https://timesofindia.indiatimes.com/india/school-enrolment-data-indicates-45-obcs-19-dalits-in-india/articleshow/84877162.cms> (Accessed: 27 April 2022).
- Nap, H.H. et al. (2020) 'The awareness, visibility and support for young carers across Europe: A Delphi study', *BMC Health Services Research*, 20(1), pp. 1–16.
- Ndungu, F.W., Bergen, L.V. and Mineo, R. (2025) 'Young carers in sub-Saharan Africa: a scoping review of current research and future directions', *International Journal of Care and Caring*, 1(aop), pp. 1–23.
- Newbold, Paul., Carlson, W.L. and Thorne, Betty. (2023) *Statistics for business and economics*. Harlow : Pearson Education Limited,.
- Nieuwenhuys, O. (2020) 'Women and children in social reproduction and the global womb: Comment on Newberry and Rosen', *Focaal*, 2020(86).
- Nigudkar, M. (2022) 'Integrating child-centred social work education and practice', in M. Desai and N. Mehta (eds) *Child-Centred Social Work in India: Journeys and the Way Forward*. Oxford, United Kingdom: Taylor & Francis Group, pp. 195–214.
- Norozi, A. and Moen, T. (2016) 'Research with Children', *print) Mediterranean Journal of Social Sciences MCSER Publishing*, 7(3), pp. 2039–2117.
- Notermans, C. and Swelsen, L. (2022) 'Decolonizing the Gender and Land Rights Debate in India: Considering Religion and More-than-Human Sociality in Women's Lived Land Relatedness', *Religions*, 13(3), p. 254.
- Nunnally, J.C. (1978) *Psychometric Theory*. New York: McGraw-Hill.
- Olang'o, C.O., Nyamongo, I.K. and Nyambedha, E.O. (2012) 'Children as caregivers of older relatives living with HIV and AIDS in Nyang'oma division of western Kenya', *African Journal of AIDS Research*, 11(2), pp. 135–142.
- Olshansky, E. et al. (2012) 'Enhancing the Construct and Content Validity of Rating Scales for Clinical Research: Using Qualitative Methods to Develop a Rating Scale to Assess Parental Perceptions of Their Role in Promoting Infant Exercise', *The International journal of educational and psychological assessment*, 10(1), pp. 36–50.
- Onwuegbuzie, A. and Leech, N. (2005) 'On Becoming a Pragmatic Researcher: The Importance of Combining Quantitative and Qualitative Research Methodologies', *International Journal of Social Research Methodology*, 8(5), pp. 375–387.
- Pal, G.C. (2018) 'Disability, Social Policy and Inclusiveness: The Missing Links', *Journal of Social Inclusion Studies*, 4(2), pp. 301–324.
- Pallant, J. (2016) *SPSS Survival Manual*. Open University Press.
- Panda, S. (2015) 'Political Connections and Elite Capture in a Poverty Alleviation Programme in India', *The Journal of Development Studies*, 51(1), pp. 50–65.

- Pande, M. (2014) *The impact of poverty on the lives and education of young carers in India*. University of Cambridge.
- Pande, M. (2022) 'Impact Of Poverty on the Lives and Education of Young Carers in India', in Y. Baiza (ed.) *Education in Troubled Times: A Global Pluralist Response*. Cambridge: Cambridge Scholars Publishing, pp. 236–249.
- Pandey, A., Mishra, R. and Singh, R. (2022) 'Social networks as providers of social protection to urban migrants in Delhi', *Asian and Pacific Migration Journal*, 31(4), pp. 426–453.
- Parsekar, S. *et al.* (2023) 'Perceptions and Experiences of Informal Caregivers of Breast Cancer Patients in South India: A Qualitative Study', *Asian Pacific Journal of Cancer Prevention*, 24(5), pp. 1651–1658.
- Parsekar, S.S. *et al.* (2023) 'Perceptions and Experiences of Informal Caregivers of Breast Cancer Patients in South India: A Qualitative Study', *Asian Pacific Journal of Cancer Prevention*, 24(5), pp. 1651–1658.
- Patterson, S.E. and Margolis, R. (2019) 'The Demography of Multigenerational Caregiving: A Critical Aspect of the Gendered Life Course', *Socius*, 5, p. 2378023119862737.
- Pelle, J. (2021) 'Young Carers from Black Asian Minority Ethnic (BAME) Communities', *Child and Adolescent Mental Health*. 3rd edn. CRC Press.
- Pett, Marjorie A, Lackey, N.R. and Sullivan, J.J. (2003) 'Evaluating and Refining the Factors', *Making Sense of Factor Analysis*. SAGE Publications, Inc., pp. 167–206.
- Pett, Marjorie A., Lackey, N.R. and Sullivan, J.J. (2003) 'Rotating the Factors', *Making Sense of Factor Analysis*. SAGE Publications, Inc., pp. 131–166.
- Piedmont, R.L. and Hyland, M.E. (1993) 'Inter-item correlation frequency distribution analysis: A method for evaluating scale dimensionality', *Educational and Psychological Measurement*, 53(2), pp. 369–378.
- Pot, M., Kadi, S. and Staflinger, H. (2024) 'Gaps in public support for young carers: policies and young people's experiences in Austria', *International Journal of Care and Caring*, pp. 1–16. A
- Punch, S. (2002) 'Research with Children: The Same or Different from Research with Adults?', *Childhood*, 9(3), pp. 321–341.
- Putnick, D.L. and Bornstein, M.H. (2016) 'GIRLS' AND BOYS' LABOR AND HOUSEHOLD CHORES IN LOW- AND MIDDLE-INCOME COUNTRIES', *Monographs of the Society for Research in Child Development*, 81(1), pp. 104–122.
- Radheshyam, A., Ramani, V.K. and Naik, R. (2025) 'Achieving universal health coverage in India: a scoping review on the requisite public health actions', *Frontiers in Public Health*, 12.

- Rai, A. and Majumder, S. (2019) 'Withdrawing the No-detention Policy: Punishing Children for the System's Failure', *Social Change*, 49(2), pp. 353–360.
- Rajivan, A. et al. (2020) *State of the Young Child in India*. Oxon: Mobile Creches. Available at: <https://lccn.loc.gov/2019056992> (Accessed: 6 March 2022).
- Ramu, G.N. (2006) *Brothers and Sisters in India : A Study of Urban Adult Siblings*. University of Toronto Press.
- Rees, G. (2017) 'Children's activities and time use: Variations between and within 16 countries', *Children and Youth Services Review*, 80, pp. 78–87.
- Reja, U. et al. (2003) 'Open-ended vs. Close-ended Questions in Web Questionnaires', *Developments in Applied Statistics*, 19, pp. 159–177.
- Ritchie, J. et al. (2013) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. 2nd edn, Sage. 2nd edn. London: SAGE Publications Ltd.
- Robson, E. (2000) 'Invisible carers: young people in Zimbabwe's home-based healthcare', *Area*, 32(1), pp. 59–69.
- Robson, E. (2004) 'Hidden Child Workers: Young Carers in Zimbabwe', *Antipode*, 36(2), pp. 227–248.
- Robson, E. et al. (2006) 'Young Caregivers in the Context of the HIV/AIDS Pandemic in Sub-Saharan Africa', *Population, Space and Place*, 12(2), pp. 93–111.
- Rogoff, B. (2003) *The Cultural Nature of Human Development*. Oxford, New York: Oxford University Press.
- Rosen, R. (2023a) 'Childhood in and Through Social Reproduction Theory', in S. Balagopalan, J. Wall, and K. Wells (eds) *The Bloomsbury Handbook of Theories in Childhood Studies*. London: Bloomsbury, pp. 418–438.
- Rosen, R. (2023b) 'Emergent solidarities and children on the move: what's "crisis" got to do with it?', in R. Rosen et al. (eds) *Crisis for Whom?: Critical global perspectives on childhood, care, and migration*. London: UCL Press, pp. 20–35.
- Rosen, R. and Newberry, J. (2018) 'Love, labour and temporality', *Feminism and the Politics of Childhood : Friends or Foes?* University College London, pp. 117–133.
- Rotabi, K.S. et al. (2019) 'Building an Effective Child Protection System in India: Integrating a Rights-Based Perspective in Social Work Education Within a Strategy of Developing Professional Association', *Journal of Human Rights and Social Work*, 4(2), pp. 128–139.
- Roy, P. (2015) *Situation of Children and Child Rights in India*. New Delhi: Butterflies.
- Sagayam, M.S., Sengupta, A. and Mazundar, S. (2025) 'Healthcare Referral, Market Imperfection and Health Policies in India: A Populist Argument', *Journal of Health Management*, p. 09720634251326492.

- Saha, U.C. and Saha, K.B. (2010) 'A trend in women's health in India – What has been achieved and what can be done', *Rural and Remote Health*, 10(2), pp. 296–306.
- Sahoo, R. and Suar, D. (2009) 'Do young carers deserve justice? Young caring in the context of illness', *Psychology and Developing Societies*, 21(1), pp. 133–150.
- Sahoo, R. and Suar, D. (2010) 'Influence of Social Environment on Young Carers, Assistance and Consequences of Caregiving', *Psychological Studies*, 55(4), pp. 323–329.
- SAKSHI (2025) 'Role of NGOs in India', 26 May. Available at: <https://sakshingo.org/role-of-ngos-in-india/> (Accessed: 29 March 2026).
- Sangar, S., Dutt, V. and Thakur, R. (2019) 'Burden of out-of-pocket health expenditure and its impoverishment impact in India: evidence from National Sample Survey'.
- Sanjaya, K. (2022) 'Rights Of Inter State Migrant Workers In India: An Unfair Tale', *Lexigentia*, 8, pp. 176–195.
- Santini, S. et al. (2020) 'Positive and Negative Impacts of Caring among Adolescents Caring for Grandparents. Results from an Online Survey in Six European Countries and Implications for Future Research, Policy and Practice', *International Journal of Environmental Research and Public Health*, 17(18).
- Saragosa, M. et al. (2022) 'The Young Carers' Journey: A Systematic Review and Meta Ethnography', *International Journal of Environmental Research and Public Health*, 19(10), p. 5826.
- Saraswathi, T.S., Menon, S. and Madan, A. (2017) *Childhoods in India Traditions, Trends and Transformations*. Oxon and New York: Routledge India.
- Sarin, M.N. (2020) 'The Right of Children to Free and Compulsory Education Act (RTE): A Case Study of its Functioning in Delhi, Uttar Pradesh and Punjab', *Educational Quest-An International Journal of Education and Applied Social Sciences*, 11(3).
- Sebastian, D. and Sekher, T. (2012) 'Intergenerational care and support for the elderly: evidence from Kerala State, India'. *European Population Conference*, Sweden.
- Sen, S., Banerjee, A. and Chakma, N. (2025) 'Regional differences in child marriage among women in India: substantiation from large-scale survey', *Vulnerable Children and Youth Studies*, 20(1), pp. 57–77.
- Shah, G. et al. (2006) *Untouchability in rural India*. Sage Publications.
- Shah, S. and Debnath, N. (2021) 'Determinants of Multidimensional Poverty in Rural Tripura, India', *Journal of Quantitative Economics*, 20(1), pp. 69–95.
- Sharma, A. (2023) 'An Overview of Roles and Functions of NGOs in India.', *Medium*, 18 July. Available at: <https://medium.com/@anushkasharmamain/an-overview-of-roles-and-functions-of-ngos-in-india-1a7bc414a42c> (Accessed: 29 March 2026).

- Sharma, D.S. (1998) 'Hindu Values', *Asian Values: Encounter with Diversity*, pp. 106–117.
- Shaw, R.M. *et al.* (2020) 'Ethics and positionality in qualitative research with vulnerable and marginal groups', *Qualitative Research*, 20(3), pp. 277–293.
- Singh, G. and Dubey, A. (2016) 'Mental Health and Well-Being of Caregivers: A Review of the Literature', *International Journal of Indian Psychology*, 3(4), pp. 98–105.
- Singh, N.N., McKay, J.D. and Singh, A.N. (1998) 'Culture and Mental Health: Nonverbal Communication', *Journal of Child and Family Studies*, 7(4), pp. 403–409.
- Singh, S. and Jayaram, R. (2020) 'Attainment of the sustainable development goal of poverty eradication: A review, critique, and research agenda', *Journal of Public Affairs*, 22(1), pp. 1–10.
- Sk, M.I.K. *et al.* (2021) 'Disparities in three critical maternal health indicators amongst Muslims: Vis-a-vis the results reflected on National Health Mission', *BMC Public Health*, 22(1).
- Skovdal, M. and Ogutu, V.O. (2009) "I washed and fed my mother before going to school": understanding the psychosocial well-being of children providing chronic care for adults affected by HIV/AIDS in Western Kenya', *Globalization and Health*, 5, p. 8.
- Smith, P., Cowie, H. and Blades, M. (2015) 'Helping Others and Moral Development', *Understanding Children's Development*. 6th edn. Sussex: Wiley, pp. 297–338.
- Smyth, C., Blaxland, M. and Cass, B. (2010) "So that's how I found out I was a young carer and that I actually had been a carer most of my life". Identifying and supporting hidden young carers', *Journal of Youth Studies*, 14(2), pp. 145–160.
- Sonobe, T. *et al.* (2025) 'Elderly Caregiving: A Gendered Analysis on Caregivers' Labor, Time-use, and Well-being', *Asian Economic Papers*, 24(1), pp. 159–177.
- Sreenivas, D. (2010) 'Forging new communities: Gendered childhood through the lens of caste', *Feminist Theory*, 11(3), pp. 267–281.
- Sriram, R. (1993) 'Family Studies in India: Appraisal and New Directions', in T.S. Saraswathi and B. Kaur (eds) *Human Development and Family Studies in India: An Agenda for Research and Policy*. New Delhi: Sage India Pvt Ltd, pp. 122–135.
- Srivastava, A. (2020) 'Time Use and Household Division of Labor in India—Within-Gender Dynamics', *Population and Development Review*, 46(2), pp. 249–285.
- Srivastava, R. (2011) *Internal migration in India*. New Delhi: Human Development in India. Available at: <https://ruralindiaonline.org/media/documents/16wkshpReportInternalMigrationHumanDevelopmentIndia2EN20111231.pdf#page=7>.

- Srivastava, S.K. and Agnihotri, K. (2022) 'A study on modern teaching pedagogy with special reference to outcome-based education system', *International Journal of Business Excellence*, 26(1), p. 95.
- Stapf, I. et al. (2023) 'Respecting children`s rights in research ethics and research methods', *Journal of Children and Media*, 17(3), pp. 393–399.
- Stephen, C. (2012) *India, The Idea Of Nation And The Subaltern Indian Woman* | Savari, Dalit Web. Available at: <http://www.dalitweb.org/?p=184> (Accessed: 19 April 2022).
- Suar, D. (1994) 'Discrimination against the girl child in India', *Social Action*, 44(3), pp. 14–26.
- Subramanian, V. (2020) 'Parallel partnerships: Teach for India and new institutional regimes in municipal schools in New Delhi', *International Studies in Sociology of Education*, 29(4), pp. 409–428.
- Sürücü, L., Maşlakçı, A. and Yıkılmaz, İ. (2024) 'Exploratory Factor Analysis (EFA) in Quantitative Researches and Practical Considerations', *Gümüşhane Üniversitesi Sağlık Bilimleri Dergisi*, 13(2), pp. 947–965.
- Tabachnick, B.G. and Fidell, L. (2013) *Using Multivariate Statistics*. 6th edn. United Kingdom: Harlow : Pearson Education.
- Thapa, P. et al. (2024) 'Unlocking the potential of informal healthcare providers in tuberculosis care: insights from India', *BMJ Global Health*, 9(2), p. e015212.
- Thompson, S., Rohwerder, B. and Arockiasamy, C. (2021) *Freedom of Religious Belief and People with Disabilities: A Case Study of People with Disabilities from Religious Minorities in Chennai, India*. Brighton: The Institute of Development Studies and Partner Organisations.
- Thrush, A. and Hyder, A. (2014) 'The neglected burden of caregiving in low- and middle-income countries', *Disability and Health Journal*, 7(3), pp. 262–272.
- Thunberg, S. (2022) 'Safeguarding personal integrity while collecting sensitive data using narrative interviews – a research note', *International Journal of Social Research Methodology*, 25(5), pp. 711–715.
- Thurstone, L.L. (1931) 'Multiple Factor Analysis', *Psychological review*, 38(5), pp. 406–427.
- Tisdall, E.K.M. and Punch, S. (2012) 'Not so “new”? Looking critically at childhood studies', *Children's Geographies*, 10(3), pp. 249–264.
- Tiwari, C. et al. (2022) 'Internal Migration and Rural Inequalities in India', *Population Research and Policy Review*, 41(4), pp. 1673–1698.
- Tongco, M. (2007) 'Purposive Sampling as a Tool for Informant Selection', *Ethnobotany Research and Applications*, 5, pp. 147–158.

- Tremmel, J. et al. (eds) (2023) *Issue topic: Young Carers (Part II), Intergenerational Justice Review*. Intergenerational Justice Review.
- Ugargol, A.P. and Bailey, A. (2021) 'Reciprocity between older adults and their caregivers in emigrant households of Kerala, India', *Ageing & Society*, 41(8), pp. 1699–1725.
- UNICEF (2020) *UNDERSTANDING CHILD MIGRATION IN INDIA*. Available at: <https://www.unicef.org/india/media/3416/file/child-migration-india2020-policy-brief.pdf>.
- UNICEF (no date a) 'Children in India'. Available at: <https://www.unicef.org/india/children-in-india> (Accessed: 7 October 2021).
- UNICEF (no date b) *Results for children in India*. Available at: <https://www.unicef.org/india/research-reports/results-children-india> (Accessed: 7 October 2021).
- United Nations Childrne's Fund (UNICEF) (2007) *The State of the World's Children 2007: Women and Children : the Double Dividend of Gender Equality*. New York: UNICEF. Available at: <https://www.unicef.org/montenegro/media/8196/file/MNE-media-MNEpublication408.pdf>.
- United Nations Development Programme (UNDP) and Oxford Poverty and Human Development Initiative (OPHI) (2020) *Charting pathways out of multidimensional poverty: Achieving the SDGs*. Available at: <https://ophi.org.uk/Publications/GMPI11-2020>.
- Vasanta, D. (2004) 'Childhood, Work and Schooling: Some Reflections', *Contemporary Education Dialogue*, 2(1), pp. 5–29.
- de Vaus, D. (2013) *Surveys In Social Research*. 6th edn. London: Routledge.
- Verma, G. (2023) 'Internal Migration in India and Its Impact on Children's Education and Well-Being', in B. Potnuru, N. Thakur, and P. Kumar (eds) *Development Outlook of Education and Migration: An Indian Perspective*. Cham: Springer Nature Switzerland, pp. 143–162.
- Vikram, K., Ganguly, D. and Goli, S. (2024) 'Time use patterns and household adversities: A lens to understand the construction of gender privilege among children and adolescents in India', *Social Science Research*, 118, p. 102970.
- Visvanathan and Rani, E. (2015a) 'Children Affected by HIV/AIDS are at Vulnerable Due to Caregiving Activities to their HIV-Infected Family Members-Findings from Cross-Sectional Study in Tamil nadu, India', *International Journal of Multidisciplinary Research and Development*, 2(11), pp. 343–346.
- Visvanathan and Rani, E. (2015b) 'Quality of life (QOL) and caregiving responsibilities of children affected by HIV and AIDS (CAA) in', *International Journal of Multidisciplinary Research and Development Online* www.allsubjectjournal.com, 2, pp. 488–493.

- Vyas, S., Hathi, P. and Gupta, A. (2022) 'Social disadvantage, economic inequality, and life expectancy in nine Indian states', *PNAS*, 119(10), pp. 1–7.
- Walker, O., Mason, J. and Moulding, R. (2024) 'The psychosocial outcomes of young carers in Australia: a scoping review', *Journal of Youth Studies*, pp. 1–22.
- Warhurst, A., Bayless, S. and Maynard, E. (2022) 'Teachers' Perceptions of Supporting Young Carers in Schools: Identifying Support Needs and the Importance of Home–School Relationships', *International Journal of Environmental Research and Public Health*, 19(17), p. 10755.
- Warren, J. (2007) 'Young Carers: Conventional or Exaggerated Levels of Involvement in Domestic and Caring Tasks?', *Children & Society*, 21(2), pp. 136–146.
- Webbink, E., Smits, J. and de Jong, E. (2012) 'Hidden Child Labor: Determinants of Housework and Family Business Work of Children in 16 Developing Countries', *World Development*, 40(3), pp. 631–642.
- WHO (no date) *Data for India, World*. Available at: <https://data.worldbank.org/?locations=IN-1W> (Accessed: 21 April 2022).
- Wilson, K., Loh, J.U. and Purewal, N. (2018) 'Gender, Violence and the Neoliberal State in India', *Feminist Review*, 119(1), pp. 1–16.
- Women and Child Development Department (WCD) (2013) *Revised Bal Sangopan Yojana Implementation*. Government of Maharashtra. Available at: <https://www.wcdcommune.com/resources/pdf/scheme/C2%20Bal%20Sangopan%20Scheme.pdf> (Accessed: 27 February 2025).
- World Health Organisation (2019) *Countries are spending more on health, but people are still paying too much out of their own pockets*. Available at: <https://www.who.int/news/item/20-02-2019-countries-are-spending-more-on-health-but-people-are-still-paying-too-much-out-of-their-own-pockets> (Accessed: 5 July 2025).
- Xu, H. (2021) 'What should adult children do for their parents?', *Nursing Ethics*, 28(3), pp. 346–357.
- Yates, S. et al. (2024) 'Epistemic injustice in experiences of young people with parents with mental health challenges', *Sociology of Health & Illness*, 46(4), pp. 702–721.
- Ytterhus, B. et al. (2024) 'Children as next of kin's experiences, practices, and voice in everyday life: a systematic review of studies with Norwegian data (2010–2022)', *Scandinavian Journal of Public Health*, 53(3), pp. 311–329.
- Yu, Y. et al. (2013) 'Domestic chores workload and depressive symptoms among children affected by HIV/AIDS in China', *AIDS Care*, 25(5), pp. 632–639.