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Caregiving experiences among parents of children with physical and intellectual disabilities: a qualitative systematic review

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ABSTRACT

Introduction: Research indicates that parents of children with disabilities undergo more significant stress and experience poorer mental and physical health outcomes in comparison to parents of children who do not have disabilities. This study aimed to identify caregiver experiences encountered by parents of children with physical and intellectual disabilities.

Methods: The study used a systematic review method with the guidelines of Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) and PRISMA 2020. The review focused on parents caring for children with physical and intellectual disabilities. The literature was searched for relevant studies from five electronic databases including PubMed, CINAHL, Web of Science (core collection), Cochrane, and Scopus. This systematic review examined 14 articles out of a total of 63,400 articles found. The study used a thematic analysis method to analyze the study.

Results: Providing care for children with physical and intellectual disabilities requires addressing a variety of challenges. It is critical to have a comprehensive understanding of these intricacies to ensure that families receive the necessary support and interventions. Our synthesis identified seven themes: (1) gendered and emotional experiences, (2) compromising quality of life: physical and psychological impact, (3) lack of knowledge about disabilities, (4) lack of social support, (5) stigma, (6) uncertain future of the recipient, and (7) unavoidable caregiving responsibility.

Conclusions: The results of this study provide recommendations that health professionals and researchers further explore these challenges and strive to build a supportive and inclusive environment that recognizes the unwavering dedication of parents and prioritizes the optimal care and development of children with disabilities.

Keywords: children, disability, parent, qualitative systematic review

Introduction

Raising children with disabilities can be a challenging experience for parents, often leading to higher levels of stress. Compared to parents who do not have disabled children, those who are raising children with disabilities tend to have poorer mental and physical health outcomes (Bray et al., 2017; Fritz, 2020; Iacob et al., 2020; Panczykowski et al., 2022). Raising a child with a disability can present unique challenges for parents; it requires significant emotional, physical, and financial resources (Yuen Shan Leung and Wai Ping Li-Tsang, 2003; Neely-Barnes and Dia, 2008; Isa et al., 2016; Aktan, Orakcı and Durnalı, 2020). Research indicates that parents who care for children with disabilities,

whether physical or intellectual, may experience heightened levels of chronic stress and poor health outcomes (Song and Singer, 2006; Cramm and Nieboer, 2011; George, Shacter and Johnson, 2011; Peer and Hillman, 2014; Patton et al., 2018).

An estimated 1.3 billion people, representing 16% of the world's population, are affected by disability (WHO, 2023). The prevalence of physical disabilities such as cerebral palsy ranges from 2.6 to 3.2 per 1,000 children, while estimates of the prevalence of intellectual disabilities vary, with recent data suggesting 11.1 to 12.2 per 1,000 children (Maenner et al., 2016; McGuire et al., 2019). The Convention on the Rights of Persons with Disabilities defines "living with a disability" as the condition of having a long-term physical, mental, intellectual, or sensory impairment that, when combined with the environment, restricts an individual's ability to participate in society on an equal footing with others. Children and adolescents with disabilities represent a diverse group, with each individual having unique life experiences. They reside in all communities and may be born with or develop distinct impairments that, when considered within their environment, can result in difficulties with functions such as vision, mobility, communication, self-care, and socialization (UNICEF, 2023). This systematic review specifically concentrated on intellectual and physical disabilities due to their distinct health requirements, intricate health profiles, experiences with healthcare disparities, and the consequent policy implications associated with these disabilities (Liao et al., 2021; Hassett et al., 2024).

Parents with children who have disabilities face unique challenges when it comes to providing care for their offspring (Panczykowski et al., 2022). To fully appreciate the extent of these challenges, it is essential to understand the specific obstacles each parent encounters. Qualitative studies have revealed that parents bear the emotional burden of caring for their children and must prioritize their own well-being (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021; Vatne et al., 2023). Implementing effective nursing strategies to enhance parents' experience can significantly contribute to improving the care of children with disabilities (Murdoch and Chang, 2022).

The existing literature highlights the need for a comprehensive systematic review on the experiences of parents of children with physical and intellectual disabilities. While some reviews have focused on specific aspects, such as general practice experiences (Thomas et al., 2023) and fathers' perspectives (Marsh, Brown and McCann, 2020), a holistic review is still lacking.

Current research emphasizes the increased stress levels and health risks faced by these parents (Peer and Hillman, 2014), as well as the challenges in navigating healthcare systems and societal stigma (Codd, Andrews and Roberts, 2023; Thomas et al., 2023). However, there remains a need for more diverse perspectives and a focus on mothers and fathers across different life stages, justifying the need for a comprehensive systematic review.

The primary aim of this study was to conduct a comprehensive review of the themes that arose from the experiences encountered by parents of children with physical and intellectual disabilities. Physical disabilities refer to conditions that affect an individual's mobility, physical functional capacity, agility, strength, and stamina, such as cerebral palsy and multiple sclerosis (Hodge, 2019). Meanwhile, intellectual disability involves significant limitations in intellectual functioning and adaptive behavior, originating during the developmental period. It affects reasoning, problem-solving, planning, learning, communication, social participation, and independent living (Gopalan, 2016; Tassé, Luckasson and Schalock, 2016). By exploring these challenges, the study aims to understand parents' experiences in such situations comprehensively. The insights gained from this study could prove invaluable as a reference for future research endeavors that aim to delve deeper into the difficulties experienced by parents caring for disabled children. Notably, the authors of this systematic review have formulated the following research question for the study: "What themes emerged from the experiences of parents with physical and intellectual disabilities?"

Materials and Methods

Review design

The qualitative systematic review adhered to the guidelines for systematic reviews outlined by Bettany-Saltikov and McSherry (2016), which involves a seven-step process. First, the review question was formulated to ensure clarity and focus. Second, objectives, inclusion, and exclusion criteria were specified. Third, a comprehensive and systematic search of relevant literature was conducted. Fourth, appropriate studies were selected for inclusion in the review. Fifth, the methodological quality of the research papers included was evaluated. Sixth, relevant data were extracted. Last, the findings were synthesized, summarized, and presented (Bettany-Saltikov and McSherry, 2016). This review also adhered to the Enhancing Transparency in

Table 1. Critical appraisal of studies.

	Aims clearly reported	Adequate reporting of sample	Adequate reporting of data collection methods	Adequate reporting of data analysis methods	Appropriate Research design	Appropriate recruitment strategy	Appropriate Data collection method	Appropriate data analysis method	Researcher–participant relationship considered	Ethical issues considered
Hu et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Hamedanchi et al. (2016)	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Cannot tell	Yes
Douglas, Redley and Ottmann. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pancsofar et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Willis et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Cameron and Cooper. (2020)	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Dunn, Jahoda and Kinnear. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Rafferty, Tidman and Ekas. (2020)	Yes	Yes	Cannot tell	Yes	Yes	Yes	Cannot tell	Yes	Cannot tell	No
Tekola et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Kyle Jackson and Andipatin. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	No
Uribe-Morales, Cantero-Garlito and Cipriano-Crespo. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
L. Murdoch and Chang. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Vatne et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes
Tekola et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes

Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines (Tong et al., 2012).

Search strategy

A thorough and systematic search was conducted to identify relevant studies from five electronic databases including PubMed, CINAHL, Web of Science (Core Collection), Cochrane, and Scopus. The search process was comprised of three steps. First, appropriate keywords were identified in Medical Subject Headings (MeSH). The four primary concepts searched were '(parents OR caregivers OR mother OR father OR parent) AND (disability OR disabilities OR disabled OR impairment OR impaired OR special OR special needs) AND (children OR adolescents OR youth OR child or teenager) AND (experiences OR perceptions or attitudes OR views OR feelings OR qualitative or perspective).' Second, a comprehensive search was devised to conduct a thorough search plan that incorporated index terms, keywords, and Boolean operators to merge the search terms within and across all four concepts. Truncation symbols were utilized to render the search plan more efficient and effective. Third, to ensure a thorough search for any relevant literature, we manually examined the reference lists of all eligible studies (Cooper et al., 2018).

Eligibility criteria

The eligibility criteria for the study were established based on its research design, context, participants, and the phenomenon of interest. In order to be deemed eligible, the study was required to meet the following specific criteria: i) it must have a qualitative research design; ii) it should focus on exploring the experiences of parents of children with intellectual and physical disabilities; iii) the study must concentrate on parents of children with disabilities aged 18 years or younger; iv)

Identification of studies via databases and registers

Identification

Records identified from*:
   Databases (n = 63,400)
   CINAHL: 7,022
   Pubmed: 39,286
   Web of Science: 13,006
   Cochrane Library: 111
   Scopus: 3,975

→

Records removed *before screening*:
   Duplicate records removed (n =5,372)

Screening

Records screened
(n =52,656)

→

Records excluded**
(n = 52,334)

Reports sought for retrieval
(n = 322)

→

Reports not retrieved
(n = 236)

Reports assessed for eligibility
(n = 86)

→

Reports excluded:
   - Irrelevant article type and methodology (n = 32)
   - Wrong population (n = 16)
   - Unabale to extract qualitative data (n = 11)
   - other reasons (n = 13)

Included

Studies included in review
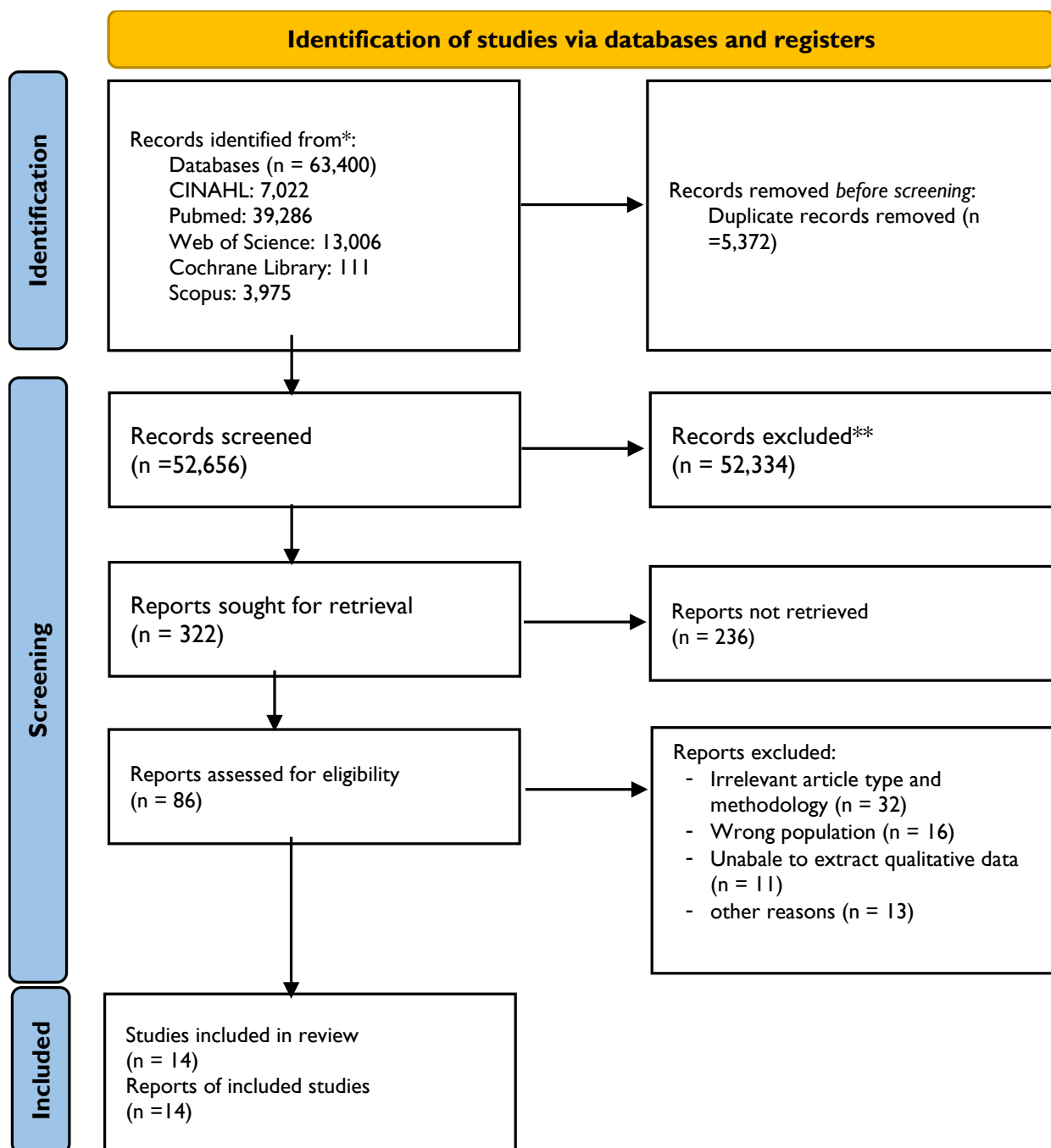(n = 14)
Reports of included studies
(n =14)

Figure. 1. PRISMA flow chart

the study must include parents (either father or mother) of children with disabilities; v) it must be written in English.

We have employed the following criteria to exclude studies: i) studies published in a language other than English; ii) studies that include treatment or intervention studies and clinical trials; iii) non-research articles, editorials, opinion pieces, conference abstracts, or proceedings; iv) cohort studies; v) studies pertaining to health services offered by non-registered health professionals; vi) studies involving animal research.

Study selection

During the study selection process, we followed several steps. First, we conducted a thorough search for relevant articles, both published and unpublished, dating back to the earliest available records up until January 2024. We then saved all the results in EndNote 20. The second step involved sorting the collected articles. Two independent reviewers, M and IC, participated in this process without knowing each other's findings. They carefully examined the remaining research works based on titles and abstracts and

selected relevant articles that met the eligibility criteria for full-text screening. There were no conflicts during this review process.

The initial search found 63,400 articles. Using EndNote software, 5,372 studies were removed due to duplication. We screened 52,656 publications during title and abstract screening, with 52,334 deemed ineligible. We sought retrieval of 322 article reports, but 236 were not retrieved (the full-text was unavailable). Eighty-six reports were assessed for eligibility, 32 were excluded due to irrelevant article types and methodologies, 16 due to the wrong population, 11 were unfit to extract qualitative data, and 13 for other reasons. Ultimately, 14 sources were included in our final analysis. The process used to select the sources is presented in Figure 1 through the PRISMA flow chart.

Quality appraisal

The authors, in pairs, independently performed the quality assessment of the included papers using the Critical Appraisal Skills Programme (CASP) - Qualitative Research Checklist (Critical Appraisal Skills Programme, 2019). This checklist comprises ten items that evaluate the suitability and clarity of each primary study. There were no conflicts during this review process. The result of the quality appraisal is presented in Table 1. None of the papers were excluded based on the quality appraisal results.

Data extraction

The data collected comprised a comprehensive study breakdown, including the author(s), year of publication, country of origin, study aim(s), design, sampling, data collection method, analysis, sample characteristics, constructs, and findings. The extraction form was subjected to a pilot test in three studies, and no further modifications were deemed necessary. Two reviewers collected the data independently to minimize the possibility of errors. To resolve conflicts during the extraction process, we conducted several meetings to facilitate discussions and reach a consensus on data coding.

Data synthesis

Data were extracted and recorded using a table consisting of author name, year, method, and theme findings from each study. Based on the coding, an initial thematic map was developed to distill overarching themes. The authors collectively examined the significance and interconnectedness of different themes across the data set. The themes were carefully scrutinized, reviewed, and defined until agreement was

reached. Using thematic analysis, we then grouped them into themes based on similarities (Braun and Clarke, 2006). The thematic analysis process consists of six critical phases. First, the researcher must gain a deep understanding of the obtained data. Next, the researcher is responsible for generating initial codes. Subsequently, pertinent themes in the data are identified. Following this, a comprehensive review of the identified themes is conducted. The researcher then proceeds to define and name the themes. Finally, a comprehensive report is crafted based on these analyses (Braun and Clarke, 2006).

Results

The results are presented in three sections: characteristics of included studies, research method, and research findings (main themes).

Characteristics of included studies

Participants

Fourteen studies were conducted involving parents, with one study extending to include other family members such as grandparents and uncles (Hu et al., 2015). Among these, eight studies focused exclusively on fathers (Cameron and Cooper, 2020; Dunn et al., 2021; Jackson and Andipatin, 2021; Pancsofar et al., 2019; Rafferty et al., 2020; Uribe-Morales et al., 2021; Vatne et al., 2022), one on mothers (Murdoch and Chang, 2022), and four included both parents (Hamedanchi et al., 2016; Willis et al., 2019; Tekola et al., 2020; 2022). One source, however, referred to parents without specifying further details (Douglas et al., 2017).

The research involved parents aged between 25 and 72 years and children aged from 1 to 21 years. The studies included 89 girls and 47 boys, with eight studies not providing data on the children's gender. Among the parents, there were 148 mothers and 168 fathers. Only one study specified the gender of five grandparents and one uncle, which included four females and three males.(Hu et al., 2015). One study did not provide information about the gender of the parents involved (Douglas, Redley and Ottmann, 2017).

Diagnosis

Seven studies focused on intellectual disabilities (Hamedanchi et al., 2016; Yang, Byrne and Chiu, 2016; Douglas, Redley and Ottmann, 2017; Willis et al., 2019; Dunn, Jahoda and Kinnear, 2020; Tekola et al., 2023; Vatne et al., 2023). Others had complex diagnostic disabilities such as autism, deafblind (Pancsofar et al.,

2019), dyspraxia (Jackson and Andipatin, 2021), Down syndrome, Mowat Wilson syndrome, and ADHD accompanied (Uribe-Morales et al., 2021).

Countries

The majority of articles (*n*=8) come from the European continent such as Norway, Spain, Ireland and the UK (Willis et al., 2019; Cameron and Cooper, 2020; Dunn et al., 2021; Uribe-Morales et al., 2021; Murdoch and Chang, 2022; Vatne et al., 2022;). Two articles were from Asia, such as China and Iran (Hu et al., 2015; Hamedanchi et al., 2016; Yang, Byrne and Chiu, 2016). Two were from the South Africa (Jackson and Andipatin, 2021; Tekola et al., 2022), two articles were from the United States (Pancsofar et al., 2019; Rafferty et al., 2020) and one article was from Australia (Douglas et al., 2017).

Settings

The studies were conducted in different settings such in the children's school (Hu et al., 2015; Pancsofar et al., 2019; Uribe-Morales et al., 2021; Tekola et al., 2022), the participant's home (Cameron and Cooper, 2020) and both (Willis et al., 2019; Vatne et al., 2022). Two researches were conducted online (Rafferty et al., 2020; Murdoch and Chang, 2022), while others did not mention the place of research. This series of studies primarily aimed to understand the experiences and challenges faced by parents, particularly fathers, of children with physical and intellectual disabilities. They investigated aspects including the parenting experiences, of children with disabilities, and the role and impact of parenting. The sample sizes varied significantly with 136 participants in total, ranging from as few as four to as many as 42 participants. The studies recruited participants based on their stated objectives, with some focusing solely on children, parents, or both, and none relied solely on parents to access children's experiences.

Data collection

The predominant research methodology for gathering data from parents involved using semi-structured individual, as seen in approximately seven articles (Douglas et al., 2017; Pancsofar et al., 2019; Willis et al., 2019; Cameron and Cooper, 2020; Rafferty et al., 2020; Dunn et al., 2021; Uribe-Morales et al., 2021; Murdoch and Chang, 2022) and focus group interviews (Rafferty et al., 2020). Additionally, six studies utilized unstructured deep interviews (Hu et al., 2015; Hamedanchi et al., 2016; Jackson and Andipatin, 2021; Tekola et al., 2020; 2022; Vatne et al., 2022).

Data analysis

The analysis results indicate that thematic analysis was widely adopted as the most commonly employed method for qualitative data interpretation in the studies under review. Four studies used grounded theory (Hamedanchi et al., 2016; Cameron and Cooper, 2020; Rafferty, Tidman and Ekas, 2020; Lauren Murdoch and Chang, 2022), two used content analysis (Pancsofar et al., 2019; Vatne et al., 2022), phenomenological (Murdoch and Chang, 2022), transcript analysis (Hu et al., 2015), discourse analysis (Uribe-Morales et al., 2021), and thematic analysis (Douglas et al., 2017; Jackson and Andipatin, 2021; Tekola et al., 2022).

Main themes

This section presents a synthesis of the themes identified across the studies, organized under differences in caregiving experiences faced by parents with physical disabilities and those with intellectual disabilities.

Gendered and emotional experiences

Gender roles may influence expectations regarding physical caregiving tasks. Fathers with physical disabilities might grapple with societal perceptions of masculinity when faced with caregiving responsibilities compared to mothers. However, in some communities, mothers with intellectual disabilities, often primary caregivers, may face heightened scrutiny and support for their caregiving abilities compared to fathers.

Parents of children with intellectual disabilities sometimes have mixed emotions and doubts about their ability to provide care for their children (Yang, Byrne and Chiu, 2016). However, fathers' experiences were unique (Dunn et al., 2021). Five of 17 studies said fathers tend to have mixed feelings about caregiving tasks when considering their careers, while mothers don't (Hamedanchi et al., 2016; Yang, Byrne and Chiu, 2016; Douglas et al., 2017; Dunn et al., 2021; Jackson and Andipatin, 2021). Fathers, in particular, may need to reassess their priorities and redefine their parenting role. This could mean adjusting their work schedules, reducing their working hours, or leaving their jobs altogether to care for their children. As a result, they may need more time for leisure activities, spending time with their partners, or taking care of themselves (Hamedanchi et al., 2016; Douglas, Redley and Ottmann, 2017k). On the other hand, fathers may question their identities as men and fathers in light of societal expectations that view caregiving roles as non-masculine. These challenges are complex and require careful consideration. *"I had to give up working and not*

working err...it is...and for a man deciding not to work to care, to care for the children, and understand our biology and how we are shaped you know and understand social pressure on males being a provider and things like that and so it's, for me as a person..." (Cameron and Cooper, 2020).

Two studies found that single mothers of children with intellectual disabilities often face a variety of difficulties, including financial instability, social stigma, and inadequate support systems (Willis et al., 2019; Tekola et al., 2022). Parents of children with a physical disability frequently compare their children's behavior and communication with healthy individuals of the same age. Consequently, some parents experience helplessness, upset, entrapment, judgment, and isolation due to their own and others' negative perceptions of their child's behavior and communication. The discourses of shame and blame serve as constraints for them. "*So, it does make me feel really, really guilty... the fact that giving up work meant that she's had to, you know .... When other people are going out and decorating the house we've had to make do with what we've had"* (Dunn, Jahoda and Kinnear, 2020).

Compromising quality of life: physical and psychological impact

Two studies found that parents who have various health issues, including diabetes, high blood pressure, heart disease, and insomnia, face significant challenges in managing their healthcare needs. These challenges include difficulties finding time for regular medical checkups and treatment (Hu et al., 2015). "As she got older, I refused to consider myself getting older and it took me a long while to start using the hoist and things that were provided. But I realized, after a few problems with health wise, that meant I better start using the hoist" (Dunn, Jahoda and Kinnear, 2020). The fathers have conveyed the considerable burden their caregiving duties exerted on their emotional and physical wellness over an extended period

Ten studies have shown that caregivers who have children with intellectual disabilities often suffer from chronic depression and poor health, which can significantly impact their overall quality of life. These caregivers frequently experience negative emotions like feeling low, hopeless, helpless, and a sense of meaninglessness (Yang, Byrne and Chiu, 2016). Although they face difficulties, they continue to recognize the importance of their duty as guardians (Pancsofar et al., 2019). Providing care for children with intellectual disabilities can present a significant emotional burden to their parents. These parents may face numerous challenges in supporting and caring for their children. "Well, it was a blow, a difficult period, I am still in psychological treatment for it, and well, it is something difficult to fit in, it is something that is going to be for life and that does not have a solution as such" (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021).

Lack of knowledge about disabilities

Five studies found that parents with intellectual disabilities understand less about the disabilities their children have than physical disabilities (Jackson and Andipatin, 2021; Tekola et al., 2022). Many families struggle with the lack of awareness about their child's disorder, including its implications and available therapeutic options. This affects the family's financial stability and puts pressure on the father to assume a more traditional provider role, adding to the stress of explaining the disorder and its impact on others, such as schools (Pancsofar et al., 2019). Parents should empower themselves by gaining knowledge, skills, and resources to facilitate their children's physical activity (Hu et al., 2015; Willis et al., 2019). Health professionals should provide parents with condition-specific information to help them better understand their infant's condition. Unfortunately, only a minority of parents report receiving such information. "*...still to this day, there is nothing that is specific to children with Down syndrome from health professionals. It's like you're the first person ever who has had a child with Down syndrome"*(Douglas, Redley and Ottmann, 2017).

Lack of social support

All 17 studies found that both parents of children with intellectual disabilities and physical disabilities experienced lack of community support such as family, government and financial support. Parents of children with intellectual disabilities often require more specialized and comprehensive support services tailored to cognitive functioning (Hamedanchi et al., 2016; Dunn et al., 2021;), whereas parents with children having physical disabilities may focus on adaptive strategies and accessible environments (Willis et al., 2019; Pancsofar et al., 2019; Jackson and Andipatin, 2021; Uribe-Morales et al., 2021).

Caregivers feel they receive little support from society and believe that the government needs to pay more attention to this vulnerable group. They also face difficulty in accessing future public services and welfare provisions. Effective coordination and communication among various agencies are crucial in facilitating the search for information and resources. Families have

expressed concerns regarding limited support from services and are apprehensive about the availability of future care options (Pancsofar et al., 2019). The vast majority of parents hold the view that the society is not adequately equipped with the necessary facilities and resources to enable optimal participation of individuals with intellectual disabilities in various aspects of life. *"I go to the place where they primarily accept the child, and if I go somewhere and they reject him, I would certainly terminate my relationship"* (Hamedanchi et al., 2016). The participants expressed a desire for social acceptance and a sense of belonging for both themselves and their children. Most of the mothers mentioned that they wanted to feel accepted by people and participate in social activities with all members of their family (Hu et al., 2015).

Ten research studies have demonstrated that caregivers of children affected by intellectual disabilities or physical disorders often limit their exposure to public spaces. They tend to prefer staying at home while providing care to their children with intellectual disabilities, as opposed to venturing out to public places where they might face discrimination. As a result, some caregivers may have to reduce their social interactions with friends (Willis et al., 2019; Tekola et al., 2020). *"There is a huge pressure. There is exclusion starting from my family and there are very difficult situations, but I don't have a choice but to accept that. There is a problem when we go on the road and when people see us and even in our family. You will be excluded eh ...especially from my family, nobody accepted me including my mother. Because of this, I am not living in the community. I am living only with my child..."* (Tekola et al., 2020). Moreover, parents of children with disabilities often struggle to include them in schools and communities (Pancsofar et al., 2019; Willis et al., 2019). This can lead to uncomfortable and even humiliating experiences when the child is in public (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021).

The research conducted on the topic of parents with children having intellectual disabilities has consistently underscored the importance of social support. However, the study participants expressed dissatisfaction with the lack of significant public or government support. They highlighted their need for financial assistance and professional guidance to care for their child with intellectual disabilities effectively (Hu et al., 2015; Yang, Byrne and Chiu, 2016; Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021). *"Most families like us* [who have a child with intellectual disability] *are not rich, because our savings have mostly been spent on medical treatments for the child's disability. The hospitals providing rehabilitation services are far away, in the developed cities. So we had to pay for traveling fee and spend lots of time"* (Yang, Byrne and Chiu, 2016),

Stigma

All 14 studies found that both parents of children with intellectual disabilities and physical disabilities experienced stigma. Parents with children having intellectual disabilities encounter significant stigma and legal challenges related to their parenting capabilities (Hamedanchi et al., 2016; Dunn et al., 2021), whereas parents with children having physical disabilities may face more practical barriers related to accessibility and economic stability (Pancsofar et al., 2019; Willis et al., 2019; Jackson and Andipatin, 2021;Uribe-Morales et al., 2021).

Many uncertainties arise due to negative attitudes toward individuals with intellectual disabilities and developmental disorders (Yang, Byrne and Chiu, 2016; Tekola et al., 2020). Several parents also mentioned how they would isolate themselves and their children from social life due to the stigma they faced (known as affiliate stigma). However, many participants felt isolated and unsupported and had to take care of their child's needs independently, which left them feeling like they had to "fend for themselves" (Vatne et al., 2023).

Children with developmental disorders face various types of stigma, including courtesy stigma, public stigma, and affiliate stigma. Consequently, they often find it challenging to be included in other children's activities and games. Some parents report being stared at and pitied by the public when they are with their children. *"The attitude of other people, because x [my child] can listen but can't talk, they say, why doesn't your child talk. My neighbors used to say my child is Duda* [tongue-tied]. *They were saying, did you give birth to a Duda? They were teasing me. They were making fun of me saying her oldest child is like this. They were saying I must have done something* [to cause the child's condition]. *They were saying all of this in my presence, but I used to pretend that I was not listening but cry when I got home"* (Tekola et al., 2020).

Uncertain future of the recipient

Four studies have revealed that parents of children with intellectual disabilities often harbor concerns about the future and the well-being of their offspring (Douglas et al., 2017; Cameron and Cooper, 2020; Rafferty et al., 2020; Tekola et al., 2022;). Parents of children with physical disabilities often focus on health management and maintaining independence (Jackson and Andipatin,

2021) while those with children having intellectual disabilities face uncertainty regarding legal rights, ongoing support needs, and societal acceptance (Hamedanchi et al., 2016).

Parents of women with intellectual disabilities were typically more cautious on marriage issues rather than physical disabilities. In particular, they are troubled by the financial, emotional, and daily care requirements that their children may require after the parents' demise. Fathers, in particular, are anxious about the future as their health declines. The marriage paradox, which individuals often face with intellectual disabilities, is another concern that weighs on parents' minds. However, despite their worries, parents find strength in the benefits they have received and the challenges they have surmounted while tending to their children and family (Yang, Byrne and Chiu, 2016; Rafferty, Tidman and Ekas, 2020; Tekola et al., 2020). "*I cannot help sighing whenever I think about my child's future. It is always a big rock in my mind. I have no idea about what he can do independently once he enters the society. No one will want to employ him because of his incompetence*" (Yang, Byrne and Chiu, 2016).

The news of a child's disability can be devastating, making it difficult for parents to cope. It's a time filled with fears, worries about the future, and uncertainty as fathers begin to plan for their children's future and accept that there will come a time when they can no longer look after them. This brings several concerns, such as anxiety about the quality of care that their child will receive. Feeling that they cannot rely on the system to care appropriately for their child is the leading cause of stress for parents when they try to envision their child's future (Douglas, Redley and Ottmann, 2017; Cameron and Cooper, 2020). "*What he is going to be like when he grows up? Like I say he is probably going to be stuck to us for the majority of his life anyway*..." (Cameron and Cooper, 2020).

Unavoidable caregiving responsibility

Two studies found that caring for a child with an intellectual disability is seen as an inevitable duty, seamlessly woven into the fabric of daily life (Willis et al., 2019; Douglas et al., 2017). Numerous caregivers have expressed their unwavering commitment to assisting their children with intellectual disabilities in making progress as part of their caregiving responsibilities. Focusing on the obligation to improve or rehabilitate has helped these caregivers remain dedicated to their caregiving duties and make informed decisions regarding their child's care (Yang, Byrne and Chiu, 2016; Willis et al., 2019). "*Needless to say, it is my duty to care*

for my daughter's daily life, such as cooking for her, dressing her, washing her clothes, and preventing her from hurt. I am her mother. These are what I should do. No one can do it better than me. Every parent would do the same thing for their child" (Yang, Byrne and Chiu, 2016). Caring for children with disabilities is a shared responsibility, particularly when their children require constant care to manage daily struggles (Douglas, Redley and Ottmann, 2017).

Discussions

This qualitative systematic review aims to identify and synthesize evidence about the experiences of parents with children who have physical and intellectual disabilities. Our analysis revealed seven themes: (1) gendered and emotional experiences, (2) compromising quality of life: physical and psychological impact; (3) lack of knowledge about disabilities; (4) lack of social support; (5) stigma; (6) uncertain future of the recipient; and (7) unavoidable caregiving responsibility

Gendered and emotional experiences

The discussion about caregiving roles for fathers and mothers, especially in the context of their careers, highlights significant gender-based disparities and societal expectations. Fathers often feel conflicted about caregiving tasks due to traditional role expectations tied to their identities as providers. While fathers struggle with the potential impact of caregiving on their careers, mothers do not face the same level of conflict. This difference may be rooted in long-standing societal norms that primarily assign caregiving responsibilities to females (Yang, Byrne and Chiu, 2016). Single mothers encounter a distinct set of challenges, including financial instability, social stigma, and inadequate support systems. These difficulties can exacerbate the stress of balancing work and caregiving, making it even more critical to address societal structures that fail to adequately support single parents (Willis et al., 2019).

When fathers take on caregiving roles, they encounter distinct identity challenges. Societal expectations often categorize caregiving as a non-masculine activity, causing fathers to question their roles as men and parents. Cameron and Cooper (2020) exemplify this struggle from a father's perspective who had to reconcile his decision to prioritize caregiving over working. The quote mirrors the internal conflict experienced by many fathers: the pressure to conform to the traditional male provider role versus the personal desire or necessity to engage in caregiving. The

complexity of these issues requires a multifaceted approach. Addressing financial and structural support for single mothers is essential, as is challenging the rigid gender norms that dictate caregiving roles. Encouraging a societal shift toward viewing caregiving as a shared responsibility can help alleviate the pressure on fathers to conform to traditional roles and enable more equitable participation in caregiving tasks.

The challenges faced by parents of children with intellectual disabilities are multifaceted and often fraught with emotional and practical difficulties. Parents frequently experience a mix of emotions and may harbor doubts about their abilities to provide care. Fathers, in particular, may encounter significant adjustments as they need to reassess their priorities and redefine their roles within the family (Yang, Byrne and Chiu, 2016). This may entail modifying their work schedules, reducing their hours, or even departing from their jobs entirely to meet the needs of their children. These adaptations can have far-reaching implications for their personal and family lives.

Caregivers often experience challenges in comparing their children's behavior and communication with typically developing peers, leading to feelings of helplessness, frustration, entrapment, judgment, and isolation. Negative perceptions from others can exacerbate these emotions, as societal expectations and stereotypes about intellectual disabilities impose additional burdens on caregivers. The story of a parent feeling guilty about making financial sacrifices to provide care is emblematic of the pressures and discourses of shame and blame many caregivers face (Dunn, Jahoda and Kinnear, 2020). The emotional toll on caregivers is significant and multifaceted, with guilt being a common experience among parents who must make substantial sacrifices, such as giving up work, which can lead to financial constraints (Dunn, Jahoda and Kinnear, 2020).

Compromising quality of life: physical and psychological impact

Providing care for children with physical and intellectual disabilities is a complex task that demands a great deal of attention and dedication from parents. The journey of caregiving is marked by various complexities that encompass not only the practical aspects of meeting the child's needs but also the emotional, social, and financial dimensions (Hamedanchi et al., 2016). One of the primary challenges in caregiving involves the day-to-day tasks associated with meeting the child's physical and medical needs. This includes tasks such as assisting with mobility, managing medications, and attending to specialized healthcare requirements. The demands of

daily care can be physically exhausting, and parents often find themselves navigating a healthcare system that may lack adequate support and resources (Smith, 2020).

Caring for a child with disabilities can present significant emotional challenges for parents. Research indicates that parents of such children often grapple with elevated levels of stress, anxiety, and feelings of social isolation (Brown, Harry and Mahoney, 2018). These emotional impacts are not solely attributable to the child's condition but rather stem from the ongoing uncertainty and difficulties that accompany long-term caregiving.

Lack of knowledge about disabilities

The studies reveal the challenges faced by caregivers of children with intellectual disabilities who have intellectual or physical disorders themselves. Often, these caregivers limit their exposure in public spaces and social circles to avoid discrimination (Chien et al., 2015; Willis et al., 2019; Tekola et al., 2023). This struggle for inclusion extends to schools and communities, adding another layer of complexity to their experiences (Pancsofar et al., 2019; Willis et al., 2019). Sadly, the presence of their children in society often leads to uncomfortable and even humiliating encounters (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021). These findings emphasize the urgent need for greater societal awareness, empathy, and targeted interventions to create a more inclusive and understanding environment for caregivers and their children with intellectual disabilities.

Lack of social support

This review illustrates that individuals tasked with caring for those with intellectual disabilities face a dual challenge of societal neglect and insufficient governmental support. These caregivers express concerns about the inadequacy of available resources and attention for their difficult and often emotionally draining work. The lack of available public services and support programs worsens the challenges experienced by families in need (Yang, Byrne and Chiu, 2016). In addition, ineffective communication and coordination among different agencies make it more difficult for caregivers to obtain essential information and resources. Pancsofar et al. (2019) point out that families perceive a dearth of support services and foresee limited future care options. According to studies conducted by Hamedanchi et al. (2016), the majority of parents feel that society does not have sufficient resources and facilities to allow individuals with

intellectual disabilities to be included and participate meaningfully. This multifaceted challenge calls for urgent attention and collaborative efforts from both policymakers and societal stakeholders to address the existing gaps and enhance the overall well-being of this vulnerable population.

Although social support is essential, studies consistently show that participants perceive a need for more substantial public and government support. The participants unanimously agree that they need practical assistance, particularly in the form of financial aid and professional guidance, to help them navigate the challenges of caring for a child with intellectual disabilities. This collective call for tangible support (Hu et al., 2015; Yang, Byrne and Chiu, 2016; Douglas, Redley and Ottmann, 2017; Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021) underscores the urgent necessity for targeted interventions that address the identified gaps in support services. The findings underscore the significance of acknowledging the critical function of social support and actively implementing measures that address the particular needs articulated by caregivers in their pursuit to provide optimum care for their children.

Parents who care for children with disabilities play a critical role in enriching not only their families but society as a whole. Acknowledging and appreciating the significant challenges they face in this endeavor is essential (Hu et al., 2015). The potential for personal distress among parents poses a genuine concern, and its ripple effect can impact the child's overall well-being and the entire family unit (Uribe-Morales, Cantero-Garlito and Cipriano-Crespo, 2021). Understanding and addressing these challenges is imperative to fostering a supportive environment that recognizes the resilience of these families while ensuring the optimal care and development of children with disabilities. By identifying the unique hurdles these parents face, we can work toward implementing targeted interventions and support systems that enhance these families' overall quality of life and contribute to a more inclusive and compassionate society (Yang, Byrne and Chiu, 2016).

Raising children with disabilities can be financially challenging. Families often face additional costs related to medical treatments, therapies, adaptive equipment, and specialized education, which can strain their finances (Jones et al., 2017). Unfortunately, financial assistance and support services are limited, compounding the financial difficulties. The impact of these economic challenges goes beyond the immediate parent-child relationship and affects siblings'

interactions. Siblings of children with disabilities may face unique experiences, such as changes in family routines, feelings of neglect, and the need to adapt to their brother or sister's specific needs (Meadan, Halle and Ebata, 2010). While some siblings may develop remarkable empathy and resilience, others may face emotional challenges, highlighting the delicate balance within sibling relationships.

Stigma

One significant concern is the stigma experienced by these families, which frequently results in social isolation. Many parents report refraining from social interactions to avoid the adverse judgment and pity directed toward their children. This phenomenon, known as affiliate stigma, impacts children and their families, who seek social acceptance and a sense of belonging (Hu et al., 2015). Mothers, in particular, express a strong desire to be embraced by society and to engage in social activities with their families. However, the pervasive stigma often excludes them and lacks support (Vatne et al., 2023).

The stigma and lack of social support experienced by parents of children with intellectual disabilities and developmental disorders create significant challenges. Addressing these issues requires a comprehensive approach that includes social support networks, public education, inclusive policies, community activities, and professional training. By fostering a more understanding and supportive environment, we can help alleviate these families' burdens and promote their well-being and social inclusion.

Uncertain future of the recipient

Research indicates that parents/caregivers of individuals with intellectual disabilities are primarily concerned about their children's futures. Future caregiving provision and marriage are critical issues (Wong et al., 2004). The impact of future uncertainties related to intellectual disabilities has been observed to cause chronic anxiety and depression among parents (Haley and Perkins, 2004). In some extreme cases, parents have made unconventional decisions, such as arranging marriages for their children with intellectual disabilities to strangers, in order to secure future caregiving. The complex interplay between future uncertainties, parental well-being, and unconventional decisions underscores the need for a nuanced understanding of the multifaceted challenges faced by families navigating the intricacies of intellectual disabilities (Yang, Byrne and Chiu, 2016).

Unavoidable caregiving responsibility

Caring for a child with disabilities can significantly affect the relationship between a parent and their child. The considerable demands of caregiving can increase the parent's attention and involvement, often altering the typical roles of parent and child. The parent may assume the roles of nurturer, caregiver, therapist, and advocate for their child's needs (Lloyd et al., 2019). The demands of caring for a child with disabilities can be emotionally and physically taxing for parents, which can either strengthen their familial bonds through shared challenges or introduce strains. In addition, parents may experience social isolation due to the unique needs and demands of caregiving. They may struggle to participate in social activities due to the necessity for specialized care and attention, leading to feelings of loneliness and exclusion (Turner et al., 2019).

The policy implication based on findings

The qualitative systematic review underscores the intricate challenges experienced by parents caring for children with physical and intellectual disabilities. The findings suggest several policy implications aimed at improving the quality of life for these families and fostering inclusivity in society. The proposed measures include tailored support programs for male and female caregivers, expanded access to comprehensive care services, mental health support, educational workshops, and financial assistance. Furthermore, policies to facilitate long-term planning for the caregiving needs of individuals with disabilities are needed.

One limitation of this systematic review is that it only included publications written in English. This could have impacted the search results and study findings, potentially introducing selection bias. Additionally, as this review was qualitative in nature and the reviewers were not the principal investigators of the included studies, there is a possibility that specific nuances and subtleties may not have been fully captured, potentially enriching and deepening the findings.

Conclusion

Understanding and providing care for children with physical and intellectual disabilities necessitates addressing a multifaceted array of challenges. It is imperative to possess a comprehensive understanding of these intricacies to ensure that families receive the requisite support and interventions. Healthcare professionals and researchers are actively exploring these challenges and endeavoring to establish a supportive and inclusive environment that acknowledges the unwavering dedication of parents and prioritizes the optimal care and development of children with disabilities.

Conflict of Interest

No potential conflicts of interest.

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Tabel 2. Articles included in the review.

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
Hu et al. (2015)	China	N=26 parents Mother (13) Father (7) Grandparents (5) Uncle (1) Gender Male (9) Female (17)	N=26 Children Type Autism (5) Intellectual Disability (7) Cerebral Palsy (4) Fragile X syndrome (5) Down Syndrome (5)	Developmental disabilities	To describe the perceptions that Chinese families of children with developmental disabilities have pertaining to their needs	Focus group discussions and in-depth interviews with transcript analysis	• Survival needs • Sufficiency needs Enhancement needs
Hamedanchi et al. (2016)	Iran	N=10 elderly parents Gender Female (5) Male (5) aged (60–72 years)	N=10 children	Intellectual disabilities	To describe the unpleasant and bitter experiences of the elderly parents of children with intellectual disability.	Unstructured in-depth interviews with phenomenological analysis	• Inappropriate behavior toward the child in the society, the society's failure to support the child with intellectual disability, • Sorrows experienced by parents, the child's problems. • barriers in the care of children with intellectual disability. • Limitations due to aging.
Douglas et al. (2017)	Australia	N=11 parents	N=11 Children Down Syndrome (7) Cerebral Palsy (3) Unspecified (1) Gender Male (8) Female (3) Age (1 – 6)	Intellectual disability (Down Syndrome, Cerebral Palsy)	To explore the information needs of parents of infants with an intellectual disability in the first year of life.	Semi-structured interviews c with descriptive thematic analysis	• The infant's condition. • The infant's specific needs • Available supports and services
Pancsofar et al. (2019)	United States	N=15 fathers	N=15 children Deafblind (11) Autism (4) Age (3-21)	Complex Disabilities: Deafblind and Autism	To investigate fathers' construction of their involvement in their children's education	Semi-structured interviews with content analysis	• It's different than with your other kids: Constructing fathering of children with complex disabilities. • How do you balance that? Fathers' work experiences and school involvement, and • Tag team: Co-parenting relationships and fathers' school involvement. • Identified that explored the intersections between fathers'

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
							work experiences and co-parenting relationships in their school involvement experiences.
Willis et al. (2019)	Norway	Forty-four parents (26 mothers, 18 fathers)	31 children with a range of disabilities Type Cerebral Palsy (12), GMFCS, Acquired brain Injury (2), Intellectual Disability (17 Gender Male (18) Female (13) Age (6-17)	Cerebral Palsy, GMFCS, Acquired brain Injury, Intellectual Disability	To explore how an ecological intervention encourages parents of children with disabilities to develop as facilitators, to enable ongoing physical activity participation in a child's local environment	Semi-structured interviews with grounded theory	• Active ingredients of the intervention that enabled learning and empowerment to transpire. • Parent learning and empowerment as a process, • Related outcomes
Cameron and Cooper (2020)	British	N=4 fathers Age (30-59)	N=5 children Gender Boy (4) Girl (1) Age (5-14)	Learning disabilities	To get as close as possible to understanding the experience of these fathers in their role as carers	Semi-structured interview with interpretative phenomenological analysis	• Fatherhood: not doing enough, not doing it right". • Crossing worlds: relearning how to communicate and reclaiming fatherhood. • "Uncertain futures."
Dunn, Jahoda and Kinnear. (2020)	UK	N=7 older fathers Age (61-68)	N=7 children Gender Female (4) Male (3) Age (28-37)	Intellectual disability	To gain a more in depth understanding of older father carers' experiences of parenting.	Semi-structured interviews with constructivist grounded theory analysis	• Wearing different hats: how fathers' sense of identity had altered over the years. • Family comes first": importance placed on the family unit. • "Getting on in years": the challenges faced by ageing fa theirs parenting their son/daughter
Rafferty et al. (2020)	USA	N=28 fathers	N=28 Children Autism spectrum disorder (ASD) (12) ASD/ID (n = 16)	Children with autism spectrum disorder with or without intellectual disability	To examine perceptions of parenting roles and father–child rela tionship quality in fathers of children with asd and asd/id.	Interview with phenomenological analysis	• Pre-birthexpectations • Adjustments • Experiences • Co-parenting • Quality of father–child relationships
Tekola et al. (2020)	Ethiopia	N=14 mothers and 4 fathers Age 25-50	N=14 Intellectual Disability	Development disorder	To explore perceptions and experiences of stigma among parents of children with dd in ethiopia and examine the	in-depth interviews with using thematic analysis	• Dimensions of parents' perceived stigma experiences • Public stigma

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
			6 = Autism primary diagnosis while the other four autistic children exhibited delays in one or more areas of development, such as language, motor skills, or cognitive abilities. Gender: Female 5 Male 13		contributing and protective factors for internalised stigma based on the perspectives of the parents themselves		• Courtesy stigma • Affiliate stigma • Perceived consequence of stigma • Parents' positive social experiences/or lack of stigma • Factors influencing affiliate stigma. • perceived family support and acceptance • increased awareness about dd
Jackson and Andipatin (2021)	South Africa	N=14 fathers mean age of 41	N=14 children Gender Female (1) Male (13)	Dyspraxia *(physical disability)*	To explore the subjective challenges that fathers experience in parenting a child that presents with dyspraxia in the cape metropole area	Semi-structured individual interviews with thematic analysis	• Health literacy • Helplessness • Circumscribed interactions • Schools' acquiescence • Lack of support
Uribe-Morales et al. (2021)	Spanish	N=7 young fathers Age (36-49)	N=9 children with various diagnoses. Gender Male (7) Female (2) Age (1 -14)	Children with various diagnoses (hearing impairment, 1P36 deletion syndrome, Down syndrome, Mowat Wilson syndrome, ADHD accompanied by high abilities and oppositional defiant disorder, and ASD)	To explore the perception and experience of fathers of children with disabilities in caring for their children; to know their role and how these tasks impact their daily life, health and physical, mental and/or emotional well-being.	Semi-structured interviews with discourse analysis	• Shared responsibilities • Somewhat difficult to fit in • Either you join or you split.
Murdoch and Chang (2022)	England	N=6 mothers Age (35 – 60)	N=6 Children Age (3-18)	Children with learning disabilities (LD)	To explore how parents experienced caring for their child with LD and procedural anxiety in hospital.	Semi-structured interviews with interpretative phenomenological analysis	• Emotional toll: parents characterized their experiences as highly emotional; reporting feeling stressed, anxious, and worried. • Restraint and holding parents spoke of their experiences of restraint which were largely viewed as negative and sometimes inappropriate. • Advocacy: parent articulated their responsibility as advocates for their children.

Author and Years	Country	Parents	Children	Type of Disability	Aim of Study	Qualitative methods and analysis	Theme
							• Going it alone: parents were extremely proactive in managing their child's anxieties, but some also felt highly pressurized and isolated. • Inconsistency and uncertainty: parents experience consistency and uncertainty in their children's care from health care professionals which led to anxiety and frustration.
Vatne et al. (2022)	Norway	N=7 fathers	N=7 children	Intellectual disability diagnosis; three with co-morbid conduct disorders. Two children had a diagnosis of progressive nature, one with physical manifestations, the other with both intellectual and physical manifestations.	To explore men's experience of being a father in families with childhood disability.	Semi-structured interviews with conventional content analysis	• Children's needs in the father child relationship, • Fathering behavior perceived to meet children's needs, • Factors perceived to influence father behaviors, and • psychological wellbeing among fathers
Tekola et al. (2023)	Ethiopia	N=14 mothers and 4 fathers Age 25-50	N=14 Intellectual Disability 6 = Autism primary diagnosis while the other four autistic children exhibited delays in one or more areas of development, such as language, motor skills, or cognitive abilities. Gender: Female 5 Male 13	Autism, cerebral palsy, Intellectual Disabilities, ADHD	To explores the experiences of parents) raising children with developmental disabilities in urban and rural Ethiopia	Interviews with thematic analysis	• Socio-cultural beliefs influenced recognition of and responses to delays/differences. • Nuanced and diverse family relationships and social life. • Multiple and intersecting struggles • 'My child is my jewel': parents' faith, positive outlook, and hope.