Research Article

Grandparenting Children With Special Needs and Disabilities: A Narrative Review

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The primary goal of this narrative review is to gather research contributions regarding the experiences of grandparents who are involved in raising children with special needs and disabilities. A survey design was used to collect titles of articles from both online and offline databases of national and international journals, chapters, or full-length books from the fields of family science, gerontology, and disability impairments. The compiled list, consisting of 149 entries up to December 2023, was analyzed using PRISMA-Narrative guidelines, including a flow diagram and harvest plot to illustrate the results. The findings reveal various types, roles, duties, and functions of grandparenting. A few new forms of emergent long-distance care, respite care, custodial care, and surrogate grandparenting are observed. The review emphasizes specific findings related to grandparenting special children across different timelines and cultures. It calls for a reassessment, revision, and updating of past or present theories, paradigms, and models of grandparenting, tools, and measurement, as well as interventions to enhance their skills in light of the changing landscape of dealing with children with special needs and disabilities in the upcoming age of virtual relationships and the digital world of the future.

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Abbreviations:

- ADL Activities of Daily Living
- ADD Attention Deficit Disorder
- ADHD Attention Deficit Hyperactivity Disorder

- ASD Autism Spectrum Disorder
- CG Custodial Grandparent
- CWSN Children with Special Needs
- CWD Children with Disabilities
- CWSN-D Children with Special Needs & Disabilities
- DD Developmental Delays
- GPEP: Grandparent Empowerment Program
- GPTI Grandparent Therapeutic Intervention
- GP Grandparent (-ing)
- GF Grandfather
- GC Grandchild
- ID Intellectual Disabilities
- QOL Quality of Life

The distinction between children with special needs (CWSN) and children with disabilities (CWDs) is important. CWSNs require support due to learning variations, medical conditions, behavioral challenges, or environmental factors. CWDs have distinct limitations affecting their physical, cognitive, or sensory abilities. Examples of CWSN include those who have experienced sexual abuse, domestic violence, or natural disasters, while individuals with cerebral palsy, visual impairment, or hearing impairment are considered CWDs. Gupta (2017) discusses this distinction and the overlap between the two categories.

What or Who Is a Grandparent?

An operational definition of a grandparent (GP) could be: "an individual who has at least one child who has become a parent, making them the parent of the child's parent." This definition focuses on the observable and measurable criteria for identifying a grandparent, which is having a child who has become a parent. The first generation is the child, the second generation is the parent, and the third generation is the GP. They are individually known as either grandfather (GF) or grandmother (GM) from the paternal or maternal side. Most Indian languages have separate labels for addressing a GP depending upon whether they are from the father's or mother's side. Across nations and cultures, grandparenting is a fundamental personal and social role. The customary duties, functions, and

responsibilities expected of GPs involve providing help, care, and support to younger generations, guided by the norms of non-interference and obligation. They are expected to provide emotional support, share wisdom and knowledge, offer childcare, pass down cultural traditions, provide guidance and mentorship, and contribute to the family's well-being and stability (Timonen, 2020).

Most GPs report satisfying ratings for the role they play in their respective families. The **stages of grandparenthood** are dynamic. They change as the GC grows. They serve as guides for infant and toddler care and become playmates for the GC aged 4-8. The GP-GC relationship wanes when the child between 8 and 12 years gets closer to same-age peers. By adolescence in the GC, the GP role becomes primarily supportive (Thiele & Whelan, 2006; Thomas, 1990).

For children aged 3-5, the joint tasks between the GP-GC dyad may involve activities like dusting, setting the table, emptying waste baskets, putting away toys, sweeping, or mopping. As the child grows to 5-7 years old, they may help with making beds, sorting or folding clothes, watering plants, and caring for pets. Between the ages of 7 and 10, GCs may join their GPs in making lunches, washing dishes, preparing desserts or salads, loading the washing machine, and vacuuming. From the age of 10 and onwards, they may become involved in washing windows, helping prepare dinner, and cleaning the bathroom (Pieper, 1976).

The **grandparent-grandchild connection** is a unique inter-generational bond that often involves unconditional love, care, guidance, sharing of wisdom, life experiences, and support (Sandler, Warren, & Raver, 1995). The relationship provides a sense of security, stability, and continuity by passing down family history, traditions, and values. It offers opportunities for learning different perspectives or understanding intergenerational differences (Kivett, 1991; Scheman et al. 1988). While generally positive, potential challenges include conflicting parenting styles, generational gaps, and geographical distance impacting interaction (Matson, May, & Clarke, 2007). Further, some GPs provide minimal or no help in caring, do not understand the child, blame the parents for the child's problems, or are overprotective of their GC. If there is geographical distance that limits the frequency of interaction, these consequences are aggravated. To delve deeper, this relationship is characterized by love, companionship, bonding, wisdom sharing, and mutual support. They have implications for their mental and physical health outcomes such as increased stress, emotional draining, and strain for both generations. All this may necessitate additional support, understanding, and resources to maintain the well-being of all individuals involved (Kivett, 1991; Scheman et al. 1988; Matson, May, & Clarke, 2007).

Some inherent rewards are experienced by GPs. The relationship may lend meaning to their own life, and help them relive their own childhood or personal past. Kivnick (1982) identified five kinds of rewards or meanings inherent to GP experiences. **Spoil or Indulgence** includes the attitude of lenience toward GC. **Centrality** is the assumption that being a GP gives them meaning for their life. **Valued elder** believes their role is to inculcate the values and norms of their generation in the younger generations. **Reinvolvement with Personal Past** is when the GP relives one's own earlier lives through their GC. **Immortality through a Clan** is a patriarchichal or matriarchical responsibility having the sense of seeing the lineage and living through generations.

Role, Types and Styles

GPs can take on various roles, types, and styles, depending on the family dynamics and individual preferences. Here are some common ones:

Traditional GP involves offering love, support, and guidance to their GC while respecting the parents' authority. Typical aspects include nurturing and caregiving, cultural transmission, educational or emotional support, guidance and advice, family bonding, financial assistance, and protection from negative circumstances. GPs provide a safe and understanding environment, share traditions and values, offer mentorship based on life experiences, assist with education, strengthen family bonds, help with expenses, and shield children from adverse situations. They are involved with their families through sharing family stories, passing on cultural traditions, teaching practical skills, encouraging outdoor explorations, instilling moral values, nurturing emotional intelligence, promoting lifelong learning, teaching financial responsibility, encouraging respect for the family, and emphasizing the importance of the family. Their involvement is crucial in providing a stable and supportive environment for grandchildren's growth and well-being (Hurme, Westerback, & Quadrello, 2010).

Long-distance GPs live far away from their GC following a geographic relocation. This predicament can present challenges in maintaining a close relationship. They need to use technology or make occasional visits to stay connected and involved in the lives of their GC. They have to rely on virtual interactions and thoughtful gestures during remote/video conferencing. All the duties, functions, and responsibilities of traditional GP have to be shared through digital means like online tutoring or mentoring. Special occasions, events, and celebrations are observed despite the distance. They need to maximize the meaningful use of every short duration or occasion for contact or celebration. If there are cultural, language, and religious barriers in addition to technological, the diminished face-to-face

contact may be hardly effective. However, with careful planning, one can touch the GC and get involved in their lives (Bangerter & Waldron, 2014; Nedelcu & Wyss, 2020; Rice, 2019; Schuler, Schuler, & Dias, 2022; Sigad & Eisikovits, 2013; Fuller-Thomson, 2005; Westheimer & Kaplan, 1999).

Active vs. Passive GP or Engaged vs. Disengaged GP refers to the extensity and intensity of bonding or involvement between the GP and the GC through providing childcare, attending school events, and participating in various activities. They may frequently spend time with their GC, offer to babysit, and actively engage in their upbringing. Passive GPs, on the other hand, take a more hands-off approach, and are less involved in day-to-day caregiving and activities, preferring to offer support and guidance from a distance and respecting the parents' authority in raising the GC. Both these grandparenting styles can be valuable to grandchildren in different ways. Active GPs can provide immediate support and create lasting memories, while passive GPs may offer a sense of stability and wisdom from a more reserved position. An ideal mixture of both styles is needed for any given instance to help the child's development (Bates, Taylor, & Stanfield, 2018). This Cherlin & Furstenberg (1985a; 1985b) typology of active-passive GPs has been contested by later researchers. Whose GC reported as active GP was not necessarily perceived to be so by the grandchild and vice versa (Harwood, 2001).

Respite GP refers to a volunteer or a paid caregiver who provides short-term care for children, often in situations where the child's primary caregivers need a break or some time off. This arrangement allows the primary caregivers to have some respite from their caregiving responsibilities while ensuring that the children are well cared for. Such GPs can offer support, companionship, and supervision to the children during the time they spend together. Many of these GPs may suffer stress, and often, the challenge of their own failing health due to increasing age. In addition, they may face housing complications and financial burdens. In the West, Grandparents Respite Programs are available to provide temporary relief to GPs from their ongoing responsibilities of caring for their GC (Strand et al. 1999).

Custodial GPS takes on the primary caregiving role for their GC when the parents are unable to care for them. Parenthesis is when GPs fully take over the role of parents This is becoming more common. CGs have legal responsibility for the child. Despite their age or health, they take their roles seriously, often sacrificing sleep and using more sleep medication. Maternal GPs tend to offer the highest levels of support. In Indian families, GPs play various roles, including mentor, historian, companion, and child-care provider, and they are honored for their unconditional love and guidance. They are grandparent-headed families or grand families (Emick & Hayslip, 1999; Hayslip et al 1998). CGs of

children with ASD face unique challenges, including 24/7 care demands, insufficient services, financial burdens, and social isolation (Hillman & Anderson, 2019). GC raised by CG may experience adverse mental/behavioral health and educational outcomes compared to those raised by biological parents (Xu et al. 2022). CGs, especially those with higher education, poor health, and other responsibilities, report higher levels of burden and obligation (Grünwald, Damman, & Henkens, 2022).

Surrogate GP involves a non-family member taking on a GP-like role in a child's life, providing support and guidance, often resembling second-time-around parenting. This can occur when natural parents are unable to fulfill their roles due to factors such as alcoholism, drug abuse, teenage pregnancy, divorce, incarceration, or AIDS. Surrogate grandparenting can take various forms, including volunteer programs, formal childcare arrangements, and informal mentorship or role modeling within the community (Burton & Devries, 2019; Burton, Dilworth-Anderson, & Merriwether-De Vries, 2014; Erbert & Alemán, 2008; Fitzgerald, 2001; Sands & Goldberg-Glen, 2000; Minkler & Szinovacz et al.1999; Roe, 1996).

Theories, Paradigms, and Models

Understanding these theories, models, and paradigms is vital to gaining valuable insights into the complexities of practices in GPs, informing policies, and interventions aimed at supporting positive GP-GC relationships and enhancing the well-being of both generations. Some key areas that they address include role strain theory (Merton, 1957), intergenerational solidarity, transmission, or developmental theory (Bernhold & Giles, 2017), life course perspective, cultural and cross-cultural paradigms, and family systems theory (Allen, Henderson, & Murray, 2019). Other theoretical models, although less emphasized, are the evolutionary-genetic perspective, cognitive-developmental perspective (Schultz, 1980), the resilience, transactional, and ecological models, psychoanalytic approaches, psycho-social developmental perspectives (Silverstein, Giarrusso, & Bengtson, 2003), and the theories of aging (Schultz, 1980). A few more specific or focused explanations include the continuing bonds theory, feminist theory, theory of GP development (Strom & Strom, 1997), and uncertainty theory (Pandialagappan & Ibrahim, 2018).

Tools and Measurements

Researchers and professionals employ various methods to assess GP relationships, including contact frequency, activities, emotional closeness, support, and overall impact. They also consider the impact on GPs' lives and GC's development. Common methods include surveys, interviews, observations, and standardized assessments. The techniques used can be home visits, phone calls, letters, or activities and engagements with GC, such as playing games, reading, providing childcare, and attending special events. Signs of emotional closeness and support, expression of affection, trust, and mutual understanding between the GP-GC dyad, impact on one another's lives, changes in physical and mental health, social well-being, and overall life satisfaction are taken into account. (Hank et al. 2018).

The tools commonly used for grandparenting arranged in chronological order include: The **Parent-Grandparent as Educator Questionnaire** (PGEQ; Yusuf, 2016) is a multi-dimensional tool for measuring parents' and GPs' religious thoughts, culture, morality, socialization, education, and other skills that they pass on to children and grandchildren; **The Posttraumatic Growth Inventory** (PTGI; Orit & Shirley, 2016) is used to assess growth following the transition to grandparenthood after the birth of the first GC, promoting strengths-based interventions for this population; **The Vineland Adaptive Behavior Scales** (VABS; Sparrow, Balla, & Cicchetti, 2005) assist GPs in evaluating personal-social skills in children with intellectual and developmental disabilities from birth to adulthood; **Drew & Smith's Questionnaire** (1999) assesses cross-generational family dysfunction by measuring the impact of parental separation/divorce on grandparent-grandchild relationships, covering contextual information and measures of health and coping strategies using parameters like proximity, contact frequency, and emotional involvement after parental divorce. **The Child Health Assessment Questionnaire** (CHAQ; Singh et al. 1994) is used to monitor the functional abilities and limitations of children with juvenile idiopathic arthritis and other rheumatic diseases. **The Pediatric Evaluation of Disability Inventory** (PEDI; Haley et al, 1992) helps GPs assess the functional capabilities and performance of CWDs in terms of activities of daily living (ADL), mobility, and social functions within their natural environments. **The Family Empowerment Scale** (FES; Koren et al. 1992) - enables grandparents to evaluate the impact of a child's disability on the family's empowerment, resources, and well-being, as well as the family's capacity to manage the difficulties associated with caring for a child with a disability.

Research Questions and Scope for Study

The area of research on grandparenting appears to be wide open, with few available reviews on the topic. There are many unanswered questions about the topics and themes related to GPs and their impact on both the GPs and the GC, the challenges faced by GPs, available support systems, and intergenerational dynamics within the family. Studies have also explored the unique experiences of GPs from different cultural and ethnic backgrounds.

One area of academic interest is the research on GPs about CWSN or CWDs. Questions about the short-term and long-term impacts of GP involvement in caring for them, the specific health and well-being challenges faced by GPs, and the legal and financial implications or challenges they face need to be explored. Additionally, the review aims to identify any GP skills or practices exclusive to special needs or disability conditions, and how these can be enhanced for the benefit of both parties. Cultural and ethnic factors influencing the experiences of GPs raising such children are also to be considered. A comprehensive review of existing literature is likely to shed light on these unanswered questions and may lead to further investigation, deepening our understanding of grandparenting complexities in these situations.

Objectives

Based on the aforementioned need, rationale, and justification for the study, the main aim of this narrative review was to compile research contributions on or about the experiences of grandparents participating in or raising CWSN-Ds.

Method

A survey method was used to gather titles of articles from national and international journals in the fields of family science, gerontology, and disability impairments, as well as chapters or full-length books and publications related to understanding the specific diagnosis or needs of children about their GPs. It also covered their reactions, legal and financial aspects of child care, advocacy, emotional support, safe and inclusive environment, and understanding of GP styles. Various online and offline databases and search engines such as Google Scholar, PsycINFO, ERIC, Research Gate, Web of Science, and PubMed were utilized for the database searches.

The search strategy for data extraction involved identifying various sources like books, journal articles, and websites, along with information on authors, publication dates, titles, volume, issue, page numbers, and URLs. The extracted data was formatted in 2021-APA-7 style. Accuracy was double-checked to prevent errors in the reference list. Extracted data was organized logically in an Excel spreadsheet for the study's reference list. Data synthesis included reviewing, understanding, and extracting relevant information highlighting the main ideas, arguments, or results from various sources. Key points and themes were identified, summarized, and compared across sources. The information was organized cohesively in the study, with proper citations in the required style.

Procedure

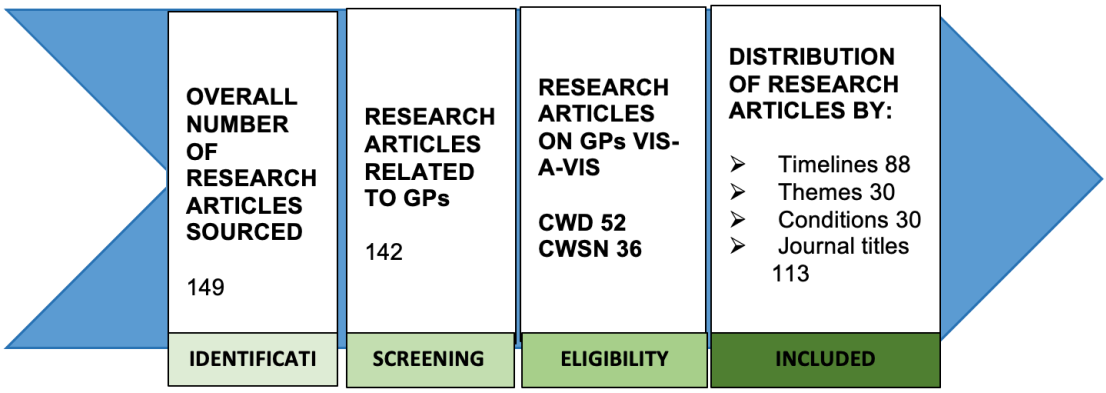
After entering the raw data on reference listing in an Excel spreadsheet, the codification, categorization, and classification of the themes reflected by the titles included in the study were generated and subjected to inter-observer reliability checks by involving two mutually blinded independent coders for at least a quarter of entries in the overall sample of research articles to minimize the risk of bias which yielded a robust correlation coefficient (r: 0.93). A descriptive and interpretative statistical analysis was carried out by applying measures of non-parametric statistics using IBM SPSS Statistics (Version 27). Effect sizes were analyzed using Cohen’s guidelines as 0.91 (Cohen, 2013), which is interpreted as an 'almost perfect agreement' (Landis & Koch, 1977). Face validity is found to be high for the classification of the thematic categories covered by the research papers.

The compiled list of 149 entries till the search period ending December 2023, was subjected to bibliometric analysis by using PRISMA-Narrative guidelines for preparing the flow diagram and harvest plot to depict the results (Table 1; Figure 1).

Specifically, the guidelines involve clearly stating the objectives and rationale in the introduction, detailing the search strategy, data extraction process, and data synthesis in the methods section, presenting study characteristics, summarizing and analyzing individual study findings in the results section, followed by interpretation, discussion of implications, and suggestions for future research directions, culminating in a conclusion based on the evidence presented. The 20-item PRISMA2020 Checklist was perused (Page et al. 2021).

The study included original research articles and reviews from national and international journals, as well as book titles and chapters in English with ISSN/ISBN details. It used keywords like grandparent,

CWSN, CWD, intergenerational relationships, or equivalent terms. Excluded were descriptive essays, newsletters, magazines, periodicals, unpublished dissertations, seminar proceedings, webinars, conferences, audiovisual materials, and incomplete or misleading cross-references from available sources. The ethical issues in caring for CWD GPs include respecting diverse ethnic groups, parental autonomy, and privacy. GP should provide support, collaborate with parents and professionals, respect informed consent, and be mindful of power dynamics. Maintaining integrity and accurately representing GPs' perspectives in research are essential (Venkatesan, 2009).



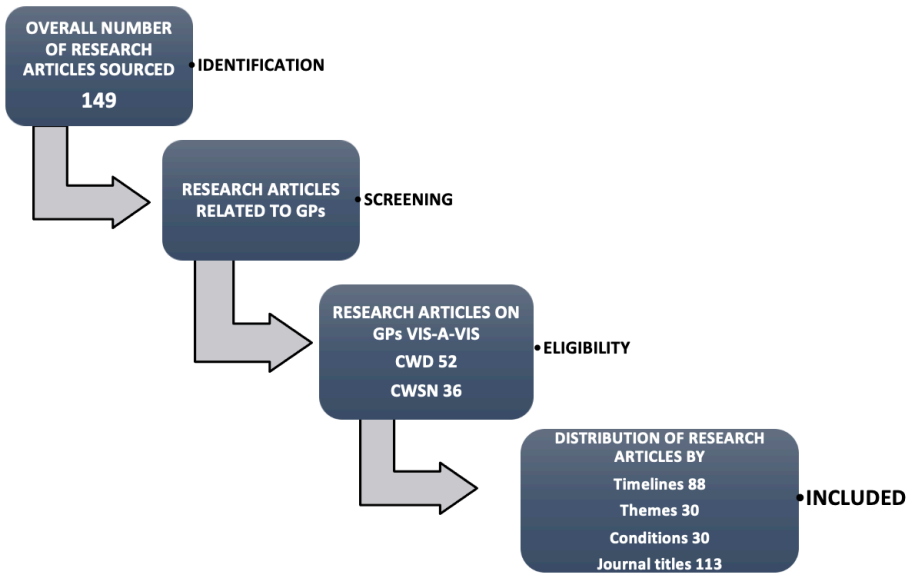


Figure 1. Prisma Flow Diagram depicting the procedure for review

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Variable	N	%
A. Format		
ORA	106	71.14
Books	28	18.79
Chapters	8	5.37
Reviews	7	4.70
B. Journals		
The International Journal of Ageing & Human Development	8	5.37
Journal of Intergenerational Relationships	5	3.35
Educational Gerontology	4	2.69
Journal of Autism and Developmental Disorders	4	2.69
Families in Society	4	2.69
Others	124	83.21
C. Timelines		
1957-1980	7	4.70
1981-1985	5	3.35
1986-1990	7	4.70
1991-1995	10	6.71
1996-2000	16	10.74
2001-2005	14	9.40
2006-2010	19	12.75
2011-2015	21	14.09
2016-2020	40	26.85
2021>	10	6.71
D. Topics/Themes		
GEN	60	40.27

Variable	N	%
CWDs	53	35.57
CWSN	36	24.16
E. Condition-Specific;		
Autism	11	7.38
IDs	5	3.36
ADHD	3	2.01
LD	3	2.01
DDs	2	1.34
HoH/Deaf	1	0.67
Psychopath	1	0.67
Adjustment	1	0.67
Epilepsy	1	0.67
Physical Illmesss	1	0.67
PH	1	0.67
No Condition Specified	90	60.40
Others	34	22.82
F. Theme-Specific		
Reaction-Experiences	27	18.12
Culture	16	10.74
Support	9	6.04
Reactions/Impacts	9	6.04
Measures	8	5.36
Theory	7	4.69
Training	7	4.69
Role	5	3.36

Variable	N	%
Problem Behavior	4	2.68
Diagnosis	3	2.01
Needs	2	1.34
Policy	1	0.67
No Theme SpecifiedS	51	34.23

Table 1. Harvest plot showing the frequency distribution of compiled literature on GP in CWSN/Ds (N: 124)

Results

The results of this compilation of 150 references on GP vis-a-vis CWSN-Ds (Table 1; Figure 1) are presented under headings on format, timelines, journal titles, topics, or themes.

A. **Format:** A majority of the publications in this review consist of original research articles (N: 106 out of 149; 71.14%), followed by books (N: 28 out of 149; 18.79%), chapters in books (N: 8 out of 149; 5.37%), and a few review articles (N: 7 out of 149; 4.70%).

B. **Timelines:** Based on the **timeline**, there has been a 3-4 times increase in the number of publications about GP and CWSN/Ds since 1957-80 (N: 7; 4.70%). The earliest research paper in this collection (LaBarre, Jessner, & Ussery, 1960) examined the influence of GMs versus mothers on the development of psychopathology in children during their early years. In the 1960s, there was a growing interest in the changing roles and interaction styles of middle-class American GPs, particularly the comparison between traditional and more playful types (Neugarten & Weinstein, 1964).

C. **Title of journals:** Search engines index various journals focused on GP issues, encompassing intergenerational, aging, and family matters. "The International Journal of Ageing and Human Development" featured the highest number of articles (7 out of 153; 5.65%) on GP in CWSN-Ds, followed by "Educational Gerontology" (5 out of 153; 4.03%), among others. However, no journal is titled as exclusively addressing GPs. These journals claiming focus on GPs include:

- Journal of Intergenerational Relationships
- International Journal of Ageing and Human Development

- Grand Families: The Contemporary Journal of Research, Practice and Policy
- Educational Gerontology
- Gerontologist
- Journal of Gerontology
- Aging and Society
- European Journal of Ageing
- Journal of Family Issues
- Family Relations
- Families, Systems & Health: The Journal of Collaborative Family Healthcare
- Family and Community Health
- Journal of Family & Adoption Law

There is a **National Research Center on Grandparents Raising Grandchildren**. **Grandparents** Day has been celebrated every year since 1961. it is observed on the first Sunday of September every year in India. The day is observed with activities like youngsters spending time with their GPs, going out for a walk or dinner, giving them a call or sending them a card, expressing love for them or sharing memories with them, seeking advice, or just being there with them.

D. **Topic-specific:** This section provides detailed information about the specific research topics that have been explored in the area of GP vis-a-vis CWSN/Ds.

a. **Needs:** Research has shown that the needs of GPs of CWSN/Ds vary based on their situations and available resources. GPs have expressed a need for emotional support, information about their child's disability, reassurance, assistance with caregiving, respite care, financial support, guidance on navigating healthcare and educational systems, as well as social connections and peer support (Wakefield et al. 2014).

The NIMH-Family Assessment Needs Schedule (NIMH-FAMNS; Peshawaria et al. 1995) outlines 20 specific needs in GPs of CWSN/Ds. The needs include the desire for information about the child's condition, hostel placement services, government benefits, and family guidance. GPs also sought assistance with future planning for family members, communication skills training, spending quality time with their wards, marriage and sexual issues, and obtaining financial assistance. Overall, the areas of demand covered a wide range of information needs, child management, services, hostel placement, marriage, sexuality, financial support, vocational guidance, future planning, and physical, social, and emotional

support.

Themes extracted in this study cover the role of GPs in children's personality formation, their health and well-being, their role as surrogate parents, their image as portrayed in contemporary children's literature, their role and impacts in the lives of their GC, kinds of supports provided by them, their intensity and extensity of caregiving. Other themes of study found in the available literature are topics like inter-generational communication and conflict, role or extent of emotional support, legal-financial responsibilities, availability of community services-resources, advocacy, education, and inclusion. A few studies address GPs and children or adolescents with gender identity problems the seniors are found to be on a back-foot themselves needing education to be open, supportive, and accepting about such issues rather than practice silence or secrecy in such matters (Stelle et al. 2010).

b. **Perceptions-Reactions-Coping-Adjustment-Experiences:** Call it by whatever name, these have been a topic of concern since the first full-fledged research write-up on GPs and CWSN/Ds (Berns, 1980). It was noted that negative emotions like resentment, discomfort, and embarrassment toward the handicapped grandchild needed to be resolved to offer emotional support to the parents. Over time, research shifted towards exploring different types, roles, and support systems for GPs raising CWDs, including cultural variations and condition-specific inquiries. However, areas such as measurements, grandparenting theories, rights, and ethical issues have received less attention in research.

   How do GPs perceive and react to disability in their families? GPs' perceptions and reactions to disability in their families have been the most prioritized area of research in this compilation (27 out of 149; 19.12%). This compilation has only THREE references on GP perceptions of disabilities in their GC (Erbert & Alemán, 2008; Katz & Kessel, 2002; Sands, & Goldberg-Glen, 2000). And, they are related to surrogate parenting. The topics on reaction revolve around four key themes: managing their own emotions, prioritizing family needs over their own, acting as intermediaries to maintain family relationships, and expressing concerns about the family's future QOL. While some GPs respond with unconditional love and support, others may worry about the future or choose not to interfere. Many report close relationships with their children, accepting their disability, and actively participating in their ADL (Findler & Taubman–Ben-Ari, 2016; Miller, Buys, & Woodbridge, 2012; Woodbridge, Buys, & Miller, 2009).

   Developmental and mental health issues in children can change over time. For example, a

speech delay at ages 0-3 might become an academic delay at 4-6, then lead to behavior problems at 7-9, and eventually develop into adjustment, conduct, or emotional disorders. This progression could contribute to juvenile delinquency or emotional behavior disorders (Venkatesan, 2017a; 2017b; Venkatesan & Purusotham, 2006). In such fluid situations, GPs can be caught between ambivalency of denial and acceptance. GPs are not primary caregivers. Their reactions include a two-pronged worry about both the parent and the affected grandchild. After the initial mourning process, most GPs typically reconcile to the situation and provide crucial instrumental emotional support for the parent as well as the CWSN/D (Heller & Swigonski, 2014; 2015; Hughes et al. 2017; Lederer & Pugliese, 2005).

Abdul-Malak and Meyer (2019) found that GPs of CWSN/Ds provide intensive care, including feeding, bathing, and medical support. This care work either improved their fitness or had adverse effects due to physical strain. Some GPs sustained their fitness, while others experienced negative impacts on their health due to the physical demands of caregiving like chasing, bending, and lifting for their aging bodies.

GPs' reactions to a grandchild with special needs can be categorized as **immediate, short-term, and long-term** responses. The sudden onset of a disability in the family can lead to shock, tears, disbelief, and a quest for information as **immediate reactions**. This is often followed by feelings of grief, depression, and sadness as they come to terms with the situation. In the **short term**, GPs adjust to the new situation and provide emotional support to their grandchild and parents. They may have doubts about the child's future and go through various emotional stages beginning with their initial shock, numbness, denial, bargaining, rejection, hysteria, anger, and guilt to eventual acceptance. Seeking information about the child's condition becomes important at this time. Research suggests that grandparents who adjust, support, and involve themselves in their GC disability experience fewer negative feelings and more positive ones (Vadasy et al. 1986; Schilmoeller & Baranowski, 1998)

In the **long term**, GPs typically focus on accepting and adapting to the situation, advocating for their GC's needs, and coping with the diagnosis. Proximity to the affected child and parents, access to accurate information, effective communication channels, and their general health significantly impact this process. GPs start providing emotional and financial support for the family, aiming to prevent social isolation for the child and help the family adjust and grow (Scherman et al. 1995). When a child with a disability is in the family,

grandparents react by offering practical assistance in caring for the child in feeding, dressing, and bathing by providing parents with much-needed respite (Novak-Pavlic et al. 2022; Seligman, 1991). Some GPs may initially not react or struggle to understand and respond to their GC's special needs due to a lack of awareness, understanding, or emotional preparedness. In extreme cases, pathological reactions such as depression, denial, blaming parents, disengagement, or hostility towards the situation can occur (Brunello & Rocco, 2019; Lee & Gardner, 2010).

The **reverse impact** of disability in GPs on healthy GC is often overlooked in the literature. The question is: When there is a disability in the GP, how does the GC react to it? It is important to highlight how unaffected children can develop empathy, resilience, and inclusivity through role modeling from their GPs. Shared experiences and mutual support can strengthen their bond, leading to a greater understanding of disabilities and acceptance of individual differences. In some cases, GC may take on caregiving responsibilities, impacting their emotional and social development while fostering a sense of responsibility and empathy (Ihara, Horio, & Tompkins, 2012).

In brief, the concerns of GPs revolve around the child's condition, handling emotional reactions, feeling ignored, and worrying about the future. Coping factors include belief in a higher power, inner resilience, positive life perspective, support from family, friends, and community, access to government benefits, and increased religious devotion. Hindering factors encompass financial difficulties, health issues, family challenges, social stigma, and misinformation. GPs provide financial support, emotional assistance, household help, support for siblings, guidance for the child, mediation in family conflicts, and recreation (Scherman et al.1995; Vadasy, 1987).

c. **Supports:** GPs support mothers of CWSN/D through emotional support, sharing knowledge and experience in child care, and providing practical help such as babysitting, transportation, household chores, and respite (Gardner et al. 2004; Cate et al, 2007; Sandler, Warren, & Raver, 1995). The mothers who received such support have also rated the GPs highly admitting positive impacts on their mental health and improvements in their QOL (Crettenden, Lam, & Denson, 2018; Kresak, Gallagher, & Kelley, 2014; Seligman et al. 1997; Gardner et al. 1994). When GPs have limited financial resources, they may offer emotional support, share skills, and knowledge, and provide childcare. Cross-cultural studies show that factors like gender, age, health, length of caregiving, and the number of GC are

significant adaptive qualities for raising a GC with a disability (Wang et al, 2019). Dada, Bastable, and Halder (2020) compared the social support of grandparents of children with intellectual and developmental disabilities in India and South Africa. They found that social support was linked to children's extensity of participation in India and intensity in South Africa, cautioning against generalizing results across different countries. There can be sometimes, a negative or adverse impact on the health of GPs (Hughes et al. 2007).

GP support for GC takes various forms including spending time together, sharing meals, and engaging in activities like watching TV, going for walks, reading stories, and showing affection. They also guide family issues like separation, remarriage, custody, discipline, and emotional challenges while imparting values and safety skills. Some GPs go further by engaging in advocacy and support groups to connect with others facing similar challenges and access resources for their GC's well-being through legal and financial planning. (Silverstein & Giarrusso, 2019; Hayslip & Smith, 2013; Blustein & Phillips, 2019; Thompson, 2021)

Contemporary forms of grandparenting include "Gramping," where GPs travel with their GC, "Tech-savvy" GPs who use technology to stay connected, "Grandparenting as a Lifestyle" involving living closer or cohabitating, "Eco-conscious" GPs promoting sustainable practices, and "Active Aging" where GPs prioritize health and wellness by engaging in physical activities to keep up with their GC (Harrington-Meyer & Abdul-Malak, 2020a; 2020b; Adesman & Adamec, 2020).

d. **Grandfathers vs Grandmothers**

Researchers have been interested in the differences in roles for GFs and GMs of CWSN/D. It is generally agreed that maternal GMs have a more positive relationship with their daughters and paternal GMs with their sons, impacting their empathic view of their CWSN (Harris, Handleman, & Palmer, 1985). Parents have reported difficulty in dealing with GPs' emotional responses despite their supportive role, seeking physical support from them in addition to emotional and financial support (Hastings, 1997; Hornby & Ainsworth, 1994).

GMs, more than GFs, take on an all-consuming caregiving role for GC with developmental delays or disabilities, despite feeling uncertainty and constant worry about the future (Pittman, Nodvin, & Howett, 2016; Mccallion & Janicki, 2014; Janicki et al. 2000; McCallion et al. 2000). In some cultures, GMs may experience shame, suffering, and stigma, leading to social rejection due to their GCs condition (Huang et al. 2020; Yang et al. 2018; Venkatesan,

2004).

The differences in GPs for CWDs may involve emotional support, nurturing care, and communication styles. GMs tend to use open-sympathetic communication and hands-on caregiving, while grandfathers focus on problem-solving communication and physical activities/outdoor pursuits. These differences reflect unique contributions from both GMs and GFs in the care of GC with disabilities. Studies show a link between maternal GM care and eating disorder psychopathology in granddaughters (Schwartz, 2013; Caetti et al. 2008).

e. **Culture and Grandparenting**

The study of links be culture and GPs emerges as the second most prioritised theme for research among CWSN/Ds as shown by the results of this review (N: 16 out of 149; 10.74%). GPs vary across cultures due to societal norms, family structures, ethnic practices, and economic conditions. In some cultures, grandparents provide central childcare and emotional support by living with their families. In Western societies, changing dynamics and geographical distance may result in less direct involvement in GC's lives. In traditional Indian society, GPs are revered and hold significant roles in extended joint families. They are expected to provide guidance, share wisdom, and pass down cultural values. In contemporary Indian families, their roles are evolving, with many taking on active childcare responsibilities and serving as mentors, adapting to modern lifestyles while preserving traditional values and bridging generational gaps. South Asian grandparents are addressed and treated with respect, and elderly GPs rely on their family members to satisfy their needs (Babu et al, 2017; Singh, 2013).

Condition-Specific Grandparenting

Patterns of grandparenting can indeed vary based on specific disease or disability conditions. GPs may adjust their roles and involvement to accommodate the unique needs and challenges associated with a particular condition. For example, they may provide more hands-on care for a GC with a physical disability, while focusing on emotional support and advocacy for another child with a developmental disorder. Regardless of the child's condition, GPs advocate for their needs, provide emotional support for both the parents and the child, and offer understanding and empathy. They often educate themselves about their GC's condition, offer respite care, and may contribute financially to therapy, interventions, or specialized education.

a. **Autism**

GPs vis-a-vis autism is the most frequently addressed special needs group by the researchers in this compilation (N: 11 out of 149; 7.38%). GPs expressed negative emotions such as feeling "bad," "heartbroken," "shocked," or "hurt" upon learning of their GC's autism diagnosis (De et al. 2016). Many maternal GPs made personal sacrifices, such as using retirement funds, delaying retirement, or moving in together to support their GC. Despite role confusion, burden, and conflicts, most reported coping fairly or very well with their GC's condition, though they expressed significant worry for their adult child's well-being (Hillman, Wentzel, & Anderson, 2017; Hillman, Marvin, & Anderson, 2016; D'Astous et al. 2013; Santomauro, 2009; Hillman, 2007; Margetts, Le Couteur, & Croom, 2006). Zakirova-Engstrand et al. (2020) studied the perceived needs of GPs of preschool-aged children with autism in Sweden. They used the Grandparents' Needs Survey and the SDQ Impact supplement for data collection. GPs expressed the most needs in areas of information and childcare for planning and providing quality family-centered early intervention services. GPs are also recognized as crucial in playing a calming role when these children have significant behavioral difficulties (Prendeville & Kinsella, 2019).

b. **ADD/ADHD**

Non-parental caregiving, particularly from GPs, has been found to decrease ADD/ADHD symptoms and improve self-control in young children. Non-parenting caregivers are individuals who take care of children but are not the biological parents of those children. They can include GPs, aunts, uncles, other relatives, or even non-relative individuals who provide care and support for children in the absence of their parents. For instance, GPs attending meditation lessons and practicing at home have led to positive behavior changes in children (Tong & Kawachi, 2021; Pandya, 2020; Leder et al. 2003). When caring for children with ADD/ADHD, GPs should educate themselves about the condition, focus on behavioral regulation, avoid judgment, be positive role models, establish routines, spend quality time with the child, and educate other family members about the condition. GPS needs to refrain from offering outdated child-rearing advice to parents of such children (Kirzner, 2012).

c. **Problem Behaviors**

One-third of children raised by GPs show clinically elevated behavior problem scores compared to those raised by parents. Children tend to show more problem behaviors when they are raised by grandparents because of the likely greater generation gap, age, health issues, their felt role strain, and financial strain. GPs endure high stress while handling these children and face the

social stereotype of being the "cause" of these problems in various cultures (Edwards, 2018; 2009; 2006). Blaming GPs without considering other contributing factors for children's behavior problems should be avoided. Overlooking GPs' positive impacts and ignoring broader family dynamics and environmental influences is risky.

When addressing **sibling rivalry** (a problem behavior), GPs need to act as mediators and facilitate conflict resolution. They can foster positive communication, model fairness, and address competition for attention and resources among the siblings. GPs have the advantage of using different caregiving styles than parents, allowing them to minimize favoritism and prevent serious conflicts. Stepping into the parental role to defuse sibling disputes during grandparenting requires timing and tact (Ravindran & Rempel, 2011).

d. **Developmental Delays/Intellectual Disabilities**

It is shown that GPs' involvement and satisfaction with their role were a function of their attitudes towards DD in children in general and the relationship they had with fathers, i.e., their adult children as well as their own life experiences (Katz & Kessel, 2002). Findler (2014) constructed a Multidimensional Experience of the Grandparenthood Model comprising four dimensions: the cognitive, emotional, behavioral, and symbolic dimensions. These dimensions are linked to the thought, feeling, and action/behavioral aspects of how GPs view their role and responsibilities or functions and relationships with their GC. This model helped develop the following scales: Multidimensional Experience of Grandparenthood; Multidimensional Scale for Perceived Social Support, Level of Differentiation of Self Scale, Family Adaptability and Cohesion Evaluation Scale, Perceived Stress Scale, and Posttraumatic Growth Inventory.

e. **Other Conditions**

Nybo, Scherman, and Freeman (1998) found the role of GPs "important" and "indispensable" in family systems with a **deaf child**. Shaw (2005) observed that maternal GPs were more involved than paternal grandparents in communication programs for **deaf-blind children**. GPs aided parents and children with epilepsy through respite care, emotional support, financial assistance, and transportation (Romeis, 1981). Priboi et al (2022) conducted a systematic review of GPs with severe physical illness in GC, finding intense fear due to a lack of knowledge and professional help.

Children With Special Needs

In contrast to primary caregivers for CWDs, GPs caring for CWSN may require medical and educational support. The CWSN may have experienced trauma such as **domestic violence, abuse, parental separations, or family disruptions,** and are needing stability, security, and support. GPs play a crucial role in providing love, comfort, and a nurturing environment for CWSN, including those in conflict with the law, victims of substance abuse, delinquents, and those with emotional-behavioral disorders. They need to show healthy relationships and effective communication. Some GPs advocate for the children's well-being and ensure they have access to the necessary support and resources to recover from trauma. Their presence in the household acts as a protective factor and social support for the abused child. Guest et al. (2019) identified five themes related to GPs' experiences, including emotional impact, social experiences, involvement, information needs, and support needs for children with **Cleft LIP/Palate**. Results showed that GPs experienced difficult emotions around the time of diagnosis and were concerned about the child's treatment and future experiences. They supported the whole family but lamented that they received little information or support themselves. In the case of **HIV-infected** adolescent kin, GPs appeared to be over-concerned about behavior problems, emotional difficulties, and sexual abuse of their wards (Linsk & Mason, 2004).

In brief, the historical interest in research themes related to GPs dates back to the 1930s, with writings primarily by clinicians or psychiatrists. Initially, negative views prevailed, considering GPs as a "disturbing factor" or "negative influence" on child development, often seen as "too strict or lenient." By the 1960s, perceptions shifted to view GPs as "fun-loving entertainers" or as repositories of traditional knowledge and wisdom. Currently, global practices of GPs, for both children with and without special needs, reflect increased women's empowerment, employment, and migration (Arber & Timonen, 2012).

Grandparent Therapeutic Interventions

Grandparent therapeutic interventions involve utilizing the unique bond between the dyad to promote emotional well-being and support. These interventions may focus on enhancing communication, building resilience, and fostering positive relationships within the family unit. GPs can provide a sense of stability, wisdom, and comfort to their GC, which can have a therapeutic effect on both generations.

By involving GPs in therapy sessions or activities, their presence and guidance can contribute significantly to the overall healing and growth process for the entire family.

Each GP caring for a grandchild with special needs or disabilities ideally requires personalized assistance. Support groups like Grandparents Raising Grandchildren, The National Grandparents Network, and others provide emotional and informational support, skill-building, training, and recreational activities. Exclusive GPTI programs have been studied for their success in children with Down syndrome (Baranowski & Schilmoeller, 1999). There are reading materials, reference guides, training kits, and manuals available for upskilling GPs of CWSN/Ds (Sánchez Gómez et al. 2021; Geere, 2003; Glover, 2001; George, 1988; Sonnek, 1986). The workshops for GPs of CWSN/DS focus on addressing challenges such as involvement in their GC's lives, bridging generational gaps, managing health issues, spending quality time, dealing with geographical distance, and balancing between spoiling children and respecting parents' rules (Toledo & Brown, 2013; Meyer & Vadasy, 1986)...

Limitations & Recommendations

Research on GP roles in families with CWDs faces several significant limitations. One key challenge is the **scarcity of comprehensive data** that adequately captures the diversity and complexity of these roles. Existing research designs often overlook crucial factors like cultural differences, socio-economic status, and family structures, leading to an incomplete understanding of the GP experience. **Methodological hurdles** pose another barrier to progress in this field. Obtaining a representative sample of GPs for research purposes proves challenging, potentially skewing insights into typical experiences and needs within this demographic. The variability in GP involvement further complicates efforts to categorize and measure their contributions effectively.

Understanding **the psychological and emotional impacts of caring** for CWDs on GPs remains limited. Exploring a wide range of experiences, from stress and coping mechanisms to emotional rewards, requires more in-depth investigation. The intricate dynamics among GPs, their children (the parents of CWDs), and the children themselves significantly influence the challenges faced by GPs. Moreover, **the role of policy and support services** presents a constraint on research avenues. Existing support services often overlook the unique needs of grandparents, focusing predominantly on nuclear families. Future research must evaluate current resources critically and identify areas for improvement to better assist this group.

Lastly, **ethical considerations and privacy concerns** impede thorough investigations into families of CWDs. Families may be hesitant to share information that could potentially stigmatize or harm their privacy. This hinders a comprehensive understanding of their experiences. In sum, **future research** needs to navigate a complex web of data limitations, methodological challenges, psychological and emotional factors, policy and support service inadequacies, and ethical concerns to gain a comprehensive understanding of this vital familial role.

Summary & Recommendations

In summary, this study highlights the crucial role of GPs as essential support for CWSN. There are many unanswered questions about how GP involvement affects both the children and the GPs themselves. Exploring topics like intergenerational dynamics, cultural backgrounds, necessary skills, and potential enhancements offers new avenues for research. It is vital to conduct interdisciplinary studies, develop theories, create measurement tools and programs, and prioritize longitudinal research to understand the impact of GP caregiving and improve their well-being. Investigating cultural and family influences on GP coping and exploring ways to support CWSN alongside GPs are important areas for further study in today's changing society.

References

- Abdul-Malak, Y., & Meyer, M. H. (2019). Grandparenting children with disabilities and its impact on grandparent health. *Innovation in Aging*, *3*(Suppl 1), S628. https://doi.org/10.1093/geroni/igz038.2341
- Adesman, A., & Adamec, C. (2020). *The grand family guidebook: Wisdom and support for grandparents raising grandchildren with special needs.* Center City, MN: Hezelden Publishing.
- Allen, K. R., Henderson, A C., & Murray, M. M. (2019). Theoretical approaches to grandparenting. Chapter 1. In: Hayslip Jr., B., & Fruhauf, C.A. (Eds.). Grandparenting influences the dynamics of family relationships. New York: Springer. Pp. 3-16.
- Arber, S., & Timonen, V. (2012). Twelve: Grandparenting in the 21st century: new directions. In Contemporary Grandparenting. (pp. 247-264). Bristol, UK: Policy Press. https://doi.org/10.51952/9781847429698.ch012
- Babu, N., Hossain, Z., Morales, J. E., & Vij, S. (2017). Grandparents in Bangladesh, India, and Pakistan: A way forward with traditions and changes in South Asia. In Grandparents in cultural

context (pp. 159-186). Routledge.

- Bangerter, L. R., & Waldron, V. R. (2014). Turning points in long-distance grandparent–grandchild relationships. *Journal of Aging Studies*, 29: 88-97.
- Baranowski, M. D., & Schilmoeller, G. L. (1999). Grandparents in the lives of grandchildren with disabilities: Mothers' perceptions. *Education and Treatment of Children*, 22(4): 427-446.
- Bates, J. S., Taylor, A. C., & Stanfield, M. H. (2018). Variations in grandfathering: characteristics of involved, passive, and disengaged grandfathers. *Contemporary Social Science*, *13*(2), 187-202.
- Bernhold, Q., & Giles, H. (2017). Grandparent-grandchild communication: A review of theoretically informed research. *Journal of Intergenerational Relationships*, *15*(4), 368-388.
- Berns, J. H. (1980). Grandparents of handicapped children. *Social Work*, *25*(3): 238-39.
- Blustein, J., & Phillips, L. R. (2019). Grandparents of children with disabilities: a review of the literature and implications for practice. *Journal of Intergenerational Relationships*, 17(3): 297-314.
- Bridges, L. & Roe, A. (2007). Children's perspectives on their relationships with grandparents following parental separation: a longitudinal study, *Social Development,* 16: 539-554.
- Brunello, G., & Rocco, L. (2019). Grandparents in the Blues. The effect of childcare on grandparents' depression. *Review of Economics of the Household*, *17*, 587-613.
- Bullock, K. (2006). Get thee behind me: African-American grandparents raising grandchildren who experienced domestic violence. In: Hampton R. & Gullotta T. (eds.). *Interpersonal Violence in the African-American Community: Evidence-based prevention and treatment practices*, New York: Springer 149-163.
- Burton, L. M., Dilworth-Anderson, P., & Merriwether-deVries, C. (2014). Context and surrogate parenting among contemporary grandparents. In Single Parent Families (pp. 349-366). Routledge.
- Burton, L., & Devries, C. (2019). Challenges and rewards: African American grandparents as surrogate parents. In Families and Aging (pp. 101-108). Routledge.
- Canetti, L., Kanyas, K., Lerer, B., Latzer, Y., & Bachar, E. (2008). Anorexia nervosa and parental bonding: the contribution of parent–grandparent relationships to eating disorder psychopathology. *Journal of Clinical Psychology,* 64(6): 703-716.
- Cate, I. M. P. T., Hastings, R. P., Johnson, H., & Titus, S. (2007). Grandparent support for mothers of children with and without physical disabilities. *Families in Society*, *88*(1), 141-146.
- Cherlin, A. J., & Furstenberg, F., Jr. (1985a). *The new American Grandparent: A place in the family; a life apart*. Cambridge, MA: Harvard University Press

- Cherlin, A., & Furstenberg, F. F., Jr. (1985b). Styles and strategies of grandparenting. In V. L. Bengtson & J. F. Robertson (Eds.), Grandparenthood (pp. 97–116). Sage Publications, Inc.
- Cohen, J. (2013). *Statistical power analysis for the behavioral sciences*. Academic press.
- Crettenden, A., Lam, J., & Denson, L. (2018). Grandparent support of mothers caring for a child with a disability: Impacts for maternal mental health. *Research in Developmental Disabilities*, 76: 35-45.
- Dada, S., Bastable, K., & Halder, S. (2020). The role of social support in participation perspectives of caregivers of children with intellectual disabilities in India and South Africa. *International Journal of Environmental Research and Public Health.* 17(18): 6644. https://doi.org/10.3390/ijerph17186644
- D'Astous, V., Wright, S. D., Wright, C. A., & Diener, M. L. (2013). Grandparents of grandchildren with autism spectrum disorders: Influences on engagement. *Journal of Intergenerational Relationships,* 11(2), 134-147. DOI: 10.1080/15350770.2013.782744
- De, M., Huda, N., Kumar, V., Chakrabarty, R., Chakraborty, C., & Basu, I. (2016). Impact of the grandchild's autism diagnosis on the grandparent: a case study. *The Beats of Natural Sciences*, 3-4 (3): 1-10. DOI:10.1037/0022-3514.44.5.1056
- Drew, L. A., & Smith, P. K. (1999). The impact of parental separation/divorce on grandparent-grandchild relationships. *The International Journal of Aging and Human Development*, 48(3): 191-216.
- Edwards, O. W. (2006). Teachers' perceptions of the emotional and behavioral functioning of children raised by grandparents. *Psychology in the Schools,* 43(5): 565-572.
- Edwards, O. W. (2009). Empirical investigation of the psychosocial functioning of children raised by grandparents. *Journal of Applied School Psychology,* 25(2): 128-145.
- Edwards, O. W. (2018). School perceptions of children raised by grandparents. *Journal of Applied School Psychology*, 34(1): 86-100.
- Emick, M. A., & Hayslip Jr, B. (1999). Custodial grandparenting: Stresses, coping skills, and relationships with grandchildren. *The International Journal of Aging and Human Development*, 48(1): 35-61.
- Erbert, L. A., & Alemán, M. W. (2008). Taking the grand out of grandparent: Dialectical tensions in grandparent perceptions of surrogate parenting. Journal of Social and Personal Relationships, 25(4): 671-695.
- Findler, L. (2014). The experience of stress and personal growth among grandparents of children with and without intellectual disability. *Mental Retardation*, 52(1): 32-48. https://doi.org/10.1352/1934-9556-52.1.32

- Findler, L., & Taubman–Ben-Ari, O. (2016). Grandparents of children with disabilities: Theoretical perspectives of intergenerational relationships. New York: Springer.
- Fitzgerald, M. L. (2001). Grandparent parents: Intergenerational surrogate parenting. Journal of Holistic Nursing, 19(3): 297-307.
- Fuller-Thomson, E. (2005). Canadian First Nations grandparents raising grandchildren: A portrait in resilience. *The International Journal of Aging and Human Development*, *60*(4): 331-342.
- Gardner, J. E., Scherman, A., Efthimiadis, M. S., & Shultz, S. K. (2004). Panamanian grandmothers' family relationships and adjustment to having a grandchild with a disability. *The International Journal of Aging and Human Development*, *59*(4), 305-320.
- Gardner, J. E., Scherman, A., Mobley, D., Brown, P., & Schutter, M. (1994). Grandparents' beliefs regarding their role and relationship with special needs grandchildren. *Education and Treatment of Children*, 17 (2): 185-196.
- Geere, S. (2003). *The grandparent's and other relative caregiver's guide to raising children with disabilities*. Oklahoma City: Oklahoma Human Services.
- George, J. D. (1988). Therapeutic intervention for grandparents and extended family of children with developmental delays. Mental Retardation, 26(6): 369.
- Gladstone, J.W. (1989). Grandmother–grandchild contact: the mediating influence of the middle generation following marriage breakdown and remarriage, *Canadian Journal on Aging*, 8: 355-365.
- Glover, B. B. (2001). *Grandparents caring for young children with disabilities: a labored love.* United States: SKI-HI Institute.
- Grünwald, O., Damman, M., & Henkens, K. (2022). The experiences of grandparents looking after their grandchildren: examining feelings of burden and obligation among non-custodial grandparents. Ageing & Society, 1-18. DOI: 10.1017/S0144686X22001027
- Guest, E., Costa, B., McCarthy, G., Cunniffe, C., & Stock, N. M. (2019). The experiences and support needs of grandparents of children born with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, *56*(9): 1181-1186.
- Gupta, N. (2017). Major issues and challenges in special education in India. Traverse City, MI: Horizon Books.
- Haley, S. M., Coster, W. J., Ludlow, L. H., et al. (1992). *Pediatric Evaluation of Disability Inventory (PEDI). Development, Standardization, and Administration Manual*. Boston, MA: New England Medical Center Hospital.

- Hank, K., Cavrini, G., Di Gessa, G., & Tomassini, C. (2018). What do we know about grandparents? Insights from current quantitative data and identification of future data needs. *European Journal of Ageing*, 15(3): 225-235.
- Harrington-Meyer, H. M., & Abdul-Malak, Y. (2020b). *Grandparenting children with disabilities* (pp. 1-26). New York: Springer.
- Harrington-Meyer, M., & Abdul-Malak, Y. (2020a). Policy challenges for grandparents of children with disabilities. *Journal of Elder Policy*, 1(1): 97-120.
- Harris, S.L., Handleman, J.S., & Palmer, C. (1985). How parents and grandparents view the autistic child. *Journal of Autism and Developmental Disorders*, 15: 127-137.
- Harwood, J. (2001). Comparing grandchildren's and grandparents' stake in their relationship. *The International Journal of Aging and Human Development*, *53*(3), 195-210.
- Hastings, R.P. (1997). Grandparents of children with disabilities: a review, *International Journal of Disability, Development and Education,* 44:4, 329-340. DOI: 10.1080/0156655970440404
- Hayslip, B., & Smith, G. C. (2013). *Resilient grandparent caregivers: a strengths-based perspective on rearing grandchildren with disabilities.* New York: Springer.
- Hayslip, B., Jr, Shore, R. J., Henderson, C. E., & Lambert, P. L. (1998). Custodial grandparenting and the impact of grandchildren with problems on role satisfaction and role meaning. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 53(3): S164–S173. https://doi.org/10.1093/geronb/53b.3.s164
- Heller, H. M., & Swigonski, S.J. (2014). Grandparents of children with disabilities: A review of the literature. *Families in Society*, 95(1): 3-11.
- Hillman, J. (2007) Grandparents of children with autism: a review with recommendations for education, practice, and policy, *Educational Gerontology,* 33(6): 513-527. DOI: 10.1080/03601270701328425
- Hillman, J. L., & Anderson, C. M. (2019). It's a battle and a blessing: the experience and needs of custodial grandparents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders,* 49(1): 260–269.
- Hillman, J. L., Wentzel, M. C., & Anderson, C. M. (2017). Grandparents' experience of autism spectrum disorder: identifying primary themes and needs. *Journal of Autism and Developmental Disorders*, 47(10): 2957–2968.
- Hillman, J., Marvin, A. R., & Anderson, C. M. (2016). The experience, contributions, and resilience of grandparents of children with autism spectrum disorder. *Journal of Intergenerational Relationships*,

14(2), 76-92. DOI: 10.1080/15350770.2016.1160727

- Hornby, G., & Ainsworth, T. (1994). Grandparent support for families who have children with disabilities: a survey of parents. *Journal of Child and Family Studies,* 3: 403-412.
- Huang Y-P, Wang S-Y, Kellett U, Chen C-H. (2020). Shame, suffering, and believing in the family: The experiences of grandmothers of a grandchild with a developmental delay or disability in the context of Chinese culture. Journal of Family Nursing. 26(1): 52-64. DOI:10.1177/1074840719895264
- Hughes, G.A., Smith, RR., Ellers, V.L.. & Johnson, K.A. (2017). The experiences of grandparents raising grandchildren with disabilities. *Journal of Intergenerational Relationships*, 17(4): 505-520.
- Hughes, M. E., Waite, L. J., LaPierre, T. A., & Luo, Y. (2007). All in the family: The impact of caring for grandchildren on grandparents' health. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62(2): S108-S119.
- Hurme, H., Westerback, S., & Quadrello, T. (2010). Traditional and new forms of contact between grandparents and grandchildren, *Journal of Intergenerational Relationships,* 8(3): 264-380. DOI: 10.1080/15350770.2010.498739
- Ihara, E. S., Horio, B. M., & Tompkins, C. J. (2012). Grandchildren caring for grandparents: Modeling the complexity of family caregiving. *Journal of Social Service Research*, *38*(5), 619-636.
- Janicki, M. P., McCallion, P., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent caregivers I: Characteristics of the grandparents and the children with disabilities for whom they care. Journal of Gerontological Social Work, 33(3): 35-55.
- Katz, S., & Kessel, L. (2002). Grandparents of children with developmental disabilities: Perceptions, beliefs, and involvement in their care. *Issues in Comprehensive Pediatric Nursing*, 25(2): 113-128.
- Kelley, S. J., Whitley, D. M., & Campos, P. E. (2011). Behavior problems in children raised by grandmothers: The role of caregiver distress, family resources, and the home environment. *Children and Youth Services Review,* 33(11): 2138-2145.
- Kirzner, J. M. (2012). *Help! My grandchild has ADHD. What these children and their parents wish you knew*. Scotts Valley, California: Create Space Independent Publishing Platform.
- Kivett, V. R. (1991). The grandparent-grandchild connection. Marriage & Family Review, 16(3-4): 267-290.
- Kivnick, H. Q. (1983). Dimensions of grandparenthood meaning: Deductive conceptualization and empirical derivation. *Journal of Personality and Social Psychology*, 44(5): 1056-1068.

- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37(4): 305-321.
- Kresak, K. E., Gallagher, P. A., & Kelley, S. J. (2014). Grandmothers raising grandchildren with disabilities: sources of support and family quality of life. *Journal of SEarly Intervention*, *36*(1), 3-17. https://doi.org/10.1177/1053815114542506
- LaBarre, M. B., Jessner, L., & Ussery, L. (1960). The significance of grandmothers in the psychopathology of children. *American Journal of Orthopsychiatry*, 30(1): 175.
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement
- Leder, S., Grinstead, L. N., Jensen, S., & Bond, L. (2003). Psychotherapeutic treatment outcomes in grandparent-raised children. *Journal of Child and Adolescent Psychiatric Nursing*, 16(1): 5-14.
- Lederer, M. A., & Pugliese, J.L. (2005). Grandparents Raising grandchildren with disabilities: A review of the literature and suggestions for practice. *Journal: Educational Gerontology*, 31(9): 657-674.
- Lee, M., & Gardner, J. E. (2010). Grandparents' involvement and support in families with children with disabilities. *Educational Gerontology,* 36(6): 467-499. DOI: 10.1080/03601270903212419
- Linsk, N. L., & Mason, S. (2004). Stresses on grandparents and other relatives caring for children affected by HIV/AIDS. *Health & Social Work*, *29*(2): 127-136.
- Margetts, J. K., Le Couteur, A., & Croom, S. (2006). Families in a state of flux: The experience of grandparents in autism spectrum disorder. *Child: Care, Health and Development,* 32(5): 565-574.
- Mason, J., May, V., & Clarke, L. (2007). Ambivalence and the paradoxes of grandparenting. The Sociological Review, 55(4): 687-706.
- May, V., Mason J. & Clarke, L. (2012). Being there, yet not interfering: the paradoxes of grandparenting. In: Arber, S. & Timonen, V. (ed.): *Contemporary grandparenting: changing family relationships in global contexts.* Bristol: Policy, 139-158.
- McCallion, P., Janicki, M. P., Grant-Griffin, L., & Kolomer, S.R. (2000). Grandparent caregivers II: Characteristics of the grandparents and the children with disabilities for whom they care. Journal of Gerontological Social Work, 33: 57–83.
- Mccallion, P., & Janicki, M. (2014). Grandparents as carers of children with disabilities: Facing the challenges. Routledge.
- Merton, R. K. (1957). *Social Theory and Social Structure.* New York: Free Press.

- Meyer, D. J., & Vadasy, P. F. (1986). *Grandparents workshops: How to organize workshops for grandparents of children with handicaps.* Seattle: University of Washington Press.
- Miller, E., Buys, L., & Woodbridge, S. (2012). Impact of disability on families: grandparents' perspectives. Journal of Intellectual Disability Research, 56(1): 102-110.
- Minkler, M., & Roe, K. M. (1996). Grandparents as surrogate parents. Generations: Journal of the American Society on Aging, 20(1): 34-38.
- Nedelcu, M., & Wyss, M. (2020). Transnational grandparenting: An introduction. *Global Networks*, 20(2): 292-307.
- Neugarten, B. L., & Weinstein, K. K. (1964). The changing American grandparent. *Journal of Marriage and the Family*, 26(2): 199-204.
- Novak-Pavlic, M., Abdel Malek, S., Rosenbaum, P., Macedo, L. G., & Di Rezze, B. (2022). A scoping review of the literature on grandparents of children with disabilities. *Disability and Rehabilitation,* 44(13): 3326-3348.
- Nybo, W. L., Scherrnan, A., & Freeman, P. L. (1998). Grandparents' role in family systems with a deaf child. *American Annals of the Deaf*, 143: 260-267.
- Orit, T., & Shirley, B. S. (2016). Measuring personal growth of new grandparents: a practical tool for social workers. *Research on Social Work Practice,* 26(6): 704-711. https://doi.org/10.1177/1049731514564165
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D.,... & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *International Journal of Surgery*, *88*, 105906. doi: 10.1136/bmj.n71
- Pandialagappan, T., & Ibrahim, R. (2018). Theories of grandparental stress. *Journal of Business and Social Review in Emerging Economies*, *4*(1), 101-106.
- Pandya, S. P. (2020). Meditation improves self-control in ADHD-diagnosed children and empowers their primary caregiver grandparents. *Child and Adolescent Social Work Journal,* 37: 369-384.
- Peshawaria, R., Menon, D. K., Ganguly, R., Roy, S., Pillay, RPRS., & Gupta, A. (1995). Grandparents: Support, Impact, and need. In: Understanding Indian families having persons with mental retardation. Chapter 4. (Pp. 155-178). Secunderabad: National Institute for the Mentally Handicapped.
- Pieper, E. (1976). Grandparents can help. Exceptional Parent, 6(2): 7-10.
- Pittman, L., Nodvin, J., & Howett, M. (2016). Grandparents as caregivers for grandchildren with intellectual and developmental disabilities. In: Rubin, I.L., Merrick, J., Greydanus, D.E., Patel, D.R.

(eds). (2016). *Health care for people with intellectual and developmental disabilities across the lifespan*. Springer, Cham. https://doi.org/10.1007/978-3-319-18096-0_6

- Prendeville, P., & Kinsella, W. (2019). The role of grandparents in supporting families of children with autism spectrum disorders: A family systems approach. *Journal of Autism and Developmental Disorders,* 49(2): 738-749.
- Priboi, C., Gantner, B., Holmer, P., da Silva, L. N., Tinner, E. M., Roser, K., & Michel, G. (2022). Psychological outcomes and support in grandparents whose grandchildren suffer from a severe physical illness: A systematic review. Heliyon. E9365.
- Ravindran, V. P., & Rempel, G. R. (2011). Grandparents and siblings of children with congenital heart disease. *Journal of Advanced Nursing*, *67*(1), 169-175.
- Rice, W. (2019). Long-Distance Grandparenting (Grandparenting Matters): Nurturing the Faith of Your Grandchildren When You Can't Be There in Person. Ada, Michigan: Baker Books.
- Romeis, J. C. (1981). The role of grandparents in adjustment to epilepsy. *Social Work in Health Care*, 6(1): 37-43. DOI: 10.1300/j010v06n01_04
- Sánchez Gómez, M. C., Martín-Sevillano, R., Martín-Cilleros, M. V., Marcos, J. M., & García-Peñalvo, F. J. (2021). Nurturing grandchildren with Down syndrome: a qualitative study on grandparents' needs using digital tools. *Frontiers in Psychology,* 12: 661205.
- Sandler, A. G., Warren, S. H., & Raver, S. A. (1995). Grandparents as a source of support for parents of children with disabilities: A brief report. *Mental Retardation*, 33: 248-250.
- Sands, R. G., & Goldberg-Glen, R. S. (2000). Grandparent caregivers' perception of the stress of surrogate parenting. Journal of Social Service Research, 26(3): 77-95.
- Santomauro, J. (2009). *Your special grandchild: a book for grandparents of children diagnosed with Asperger's Syndrome.* Philadelphia: Jessica Kingsley Publishers.
- Scherman, A., Gardner, J. E., Brown, P., & Schutter, M. (1995). GPs' adjustment to grandchildren with disabilities. *Educational Gerontology*, 21(3): 261-273.
- Scherman, A., Goodrich, C., Kelly, C., Russell, T., & Javidi, A. (1988). Grandparents as a support system for children. *Elementary School Guidance & Counseling,* 23(1):16-22.
- Schilmoeller, G. L., & Baranowski, M. D. (1998). Intergenerational support in families with disabilities: Grandparents' perspectives. *Families in Society*, 79(5): 465-476.
- Schuler, E., Schuler, F. D. M. G., & Dias, C. M. D. S. B. (2022). Transnational grandparenthood: A qualitative study on the relationship of grandparents and grandchildren in the migration context. *Interpersonal: An International Journal on Personal Relationships*, 16(2): 200-220.

- Schultz, N.W. (1980). A cognitive-development study of the grandchild-grandparent bond. Child Study Journal, l0: 7-26.
- Schwartz, S. (2013). (Ed.). *A love like no other grandmother shares experience with grandchildren who have special needs.* Parker Road, Colorado: Outskirts Press.
- Seligman, M. (1991). Grandparents of disabled grandchildren: Hopes, fears, and adaptation. *Families in Society*, 72(3): 147-152.
- Seligman, M., Goodwin, G., Paschal, K., Applegate, A., & Lehman, L. (1997). Grandparents of children with disabilities: Perceived levels of support. *Education and Training in Mental Retardation and Developmental Disabilities*, 32(4): 293-303.
- Shaw, S.L. (2005). Grandparent involvement in the communication development of children who are deafblind, *Educational Gerontology*, 31(1): 51-71. DOI: 10.1080/03601270590522198
- Sigad, L. I., & Eisikovits, R. A. (2013). Grandparenting across borders: American grandparents and their Israeli grandchildren in a transnational reality. *Journal of Aging Studies*, 27(4): 308-316.
- Silverstein, M., Giarrusso, R., & Bengtson, V. L. (2003). Grandparents and grandchildren in family systems: A social-developmental perspective. Chap. 4. In: V. L. Bengtson, & A. Lowenstein. (Eds.) *Global aging and challenges to families*, Pp. 75-102.
- Silverstein, N. M., & Giarrusso, R. (2019). Grandparenting children with special needs: implications for the health and well-being of grandparents. *Journal of Family Issues*, 40(12): 1707-1731.
- Singh, A. (2013). Indian diaspora: voices of grandparents and grandparenting. Rotterdam/Boston: Sense Publishers.
- Singh, G., Athreya, B. H., Fries, J. F., & Goldsmith, D.P. (1994). Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis and Rheumatism*. 37(12): 1761-1769. doi:10.1002/art.1780371209
- Sonneck, I.M. (1986). Grandparents and the extended family of handicapped children. In R.R. Fewell & P.F. Vadasy (Eds.), Families of handicapped children, (pp 99-120). Austin, TX: Pro-Ed
- Sparrow, S.S., Balla, D. A., & Cicchetti, D. V. (2005). *Vineland Adaptive Behavior Scales: Second Edition (Vineland-II)*. Circle Pines, MN: American Guidance Service.
- Stelle, C., Fruhauf, C. A., Orel, N., & Landry-Meyer, L. (2010). Grandparenting in the 21st century: Issues of diversity in grandparent–grandchild relationships. *Journal of gerontological social work*, *53*(8), 682-701.
- Strang, V. R., Haughey, M., Gerdner, L. A., & Teel, C. S. (1999). Respite—a coping strategy for family caregivers. Western Journal of Nursing Research, 21: 450-457.

- Strom, R., & Strom, S. (1997). Building a theory of grandparent development. *The International Journal of Aging and Human Development*, 45(4): 255-286.
- Szinovacz, M. E., DeViney, S., & Atkinson, M. P. (1999). Effects of surrogate parenting on grandparents' well-being. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 54(6): S376-S388.
- Thiele, D. M., & Whelan, T. A. (2006). The nature and dimensions of the grandparent role. *Marriage & Family Review*, 40(1): 93-108.
- Thomas, J. L. (1990). The grandparent role: A double bind. The International Journal of Aging and Human Development, 31(3): 169-177.
- Thompson, C. E. (2021). *Grandparenting children with special needs: A guide for success.* Philadelphia: Jessica Kingsley.
- Timonen, V. (Eds.). (2020). Grandparenting practices around the world. Bristol, UK: Policy Press.
- Toledo, S., & Brown, D. E. (2013). *Grandparents as parents: a survival guide for raising a second family.* New York and London: The Guilford Press.
- Tong, L., & Kawachi, I. (2021). Factors moderating the link between early childhood non-parental care and ADHD symptoms. *Heliyon*, 7(12).
- Vadasy, P.F. (1987). Grandparents of children with special needs: Supports especially for grandparents. *Children's Health Care, l*6(2): 1-23.
- Vadasy, P.F., Fewell, R.R., & Meyer, D.J. (1986). Grandparents of children with special needs: Insights into their experiences and concerns. Journal of the Division for Early Childhood, lo: 36-44.
- Venkatesan, S. (2004). Children with developmental disabilities: A training guide for parents, teachers, and caregivers. California: Sage.
- Venkatesan, S. (2009). *Ethical Guidelines for Bio-Behavioral Research.* Mysore: All India Institute of Speech and Hearing.
- Venkatesan, S. (2017a). Diagnostic decision tree for a specific learning disability. *International Journal of Education and Psychological Research*, 6(2): 121–127.
- Venkatesan, S. (2017b). Opinion: Case vignette on life span approach to diagnosis of specific learning disability in India. *Journal of Psychology and Clinical Psychiatry*, 3(5): 469-470. DOI: 10.15406/jcpy.2017.08.00469.
- Venkatesan, S., & Purusotham, P. (2006). Historical analysis of the course and clinical presentations of children with learning disabilities in India. *Disabilities and Impairments,* 21(2): 99–107.

- Wakefield, C. E., Drew, D., Ellis, S. J., Doolan, E. L., McLoone, J. K., & Cohn, R. J. (2014). 'What they're not telling you': A new scale to measure grandparents' information needs when their grandchild has cancer. Patient Education and Counseling, 94(3): 351-355.
- Wang, C.D., Hayslip, B., Sun, Q., & Zhu, W. (2019). Grandparents as the Primary Care Providers for Their Grandchildren: A Cross-Cultural Comparison of Chinese and U.S. Samples. *The International Journal of Aging and Human Development*. 89(4):331-355. doi:10.1177/0091415018824722
- Westheimer, R., & Kaplan, S. (1999). Long-distance grandparenting. NCJW *Journal*, 22(2): 30.
- Woodbridge, S., Buys, L., & Miller, E. (2009). Grandparenting a child with a disability: An emotional roller coaster. Australasian Journal on Ageing, 28(1): 37-40.
- Xu, Y., & Harrison, T. M. (2023). Socioemotional and behavioral problems of grandchildren raised by grandparents: the role of grandparent–grandchild relational closeness and conflict. *Children*. 10(10):1623. https://doi.org/10.3390/children10101623
- Xu, Y., Wang, Y., McCarthy, L. P., Harrison, T., & Doherty, H. (2022). Mental/behavioral health and educational outcomes of grandchildren raised by custodial grandparents: A mixed methods systematic review. *Health & Social Care in the Community*, *30*(6), 2096–2127. https://doi.org/10.1111/hsc.13876
- Yang, X., Artman-Meeker, K., & Roberts, C. A. (2018). Grandparents of children with intellectual and developmental disabilities: Navigating roles and relationships. Intellectual and Developmental Disabilities, 56(5): 354-373.
- Yusuf, M. (2016). The measurement analysis of Parent-grandparents as Educator Questionnaire (Parent Version). *International Review of Management and Marketing*, 6(4): 1-5.
- Zakirova-Engstrand, R., Roll-Pettersson, L., Westling Allodi, M., & Hirvikoski, T. (2020). Needs of grandparents of preschool-aged children with ASD in Sweden. *Journal of Autism and Developmental Disorders*, 50(6): 1941–1957.

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