

Grandparenting Children With Special Needs and Disabilities: A Narrative Review

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Abstract

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 a PRISMA 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 guide for infant and toddler care, and become playmates for the GC aged 4-8. The GP-GC relationship wanes when the child between 8-12 years gets closer to same age peers. By adolescence in the GC, the GPs role becomes primarily supportive (Thiele & Whelan, 2006; Thomas, 1990).

For children aged 3-5, the joint tasks between 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 7-10, GC 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 (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 in 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 patriarchical 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 take 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 grandfamilies (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 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.

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 2024, was subjected to bibliometric analysis by using a PRISMA flow diagram and harvest plot to depict the results (Table 1; Figure 1). The 20-item PRISMA2020 Checklist was adhered to. (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).

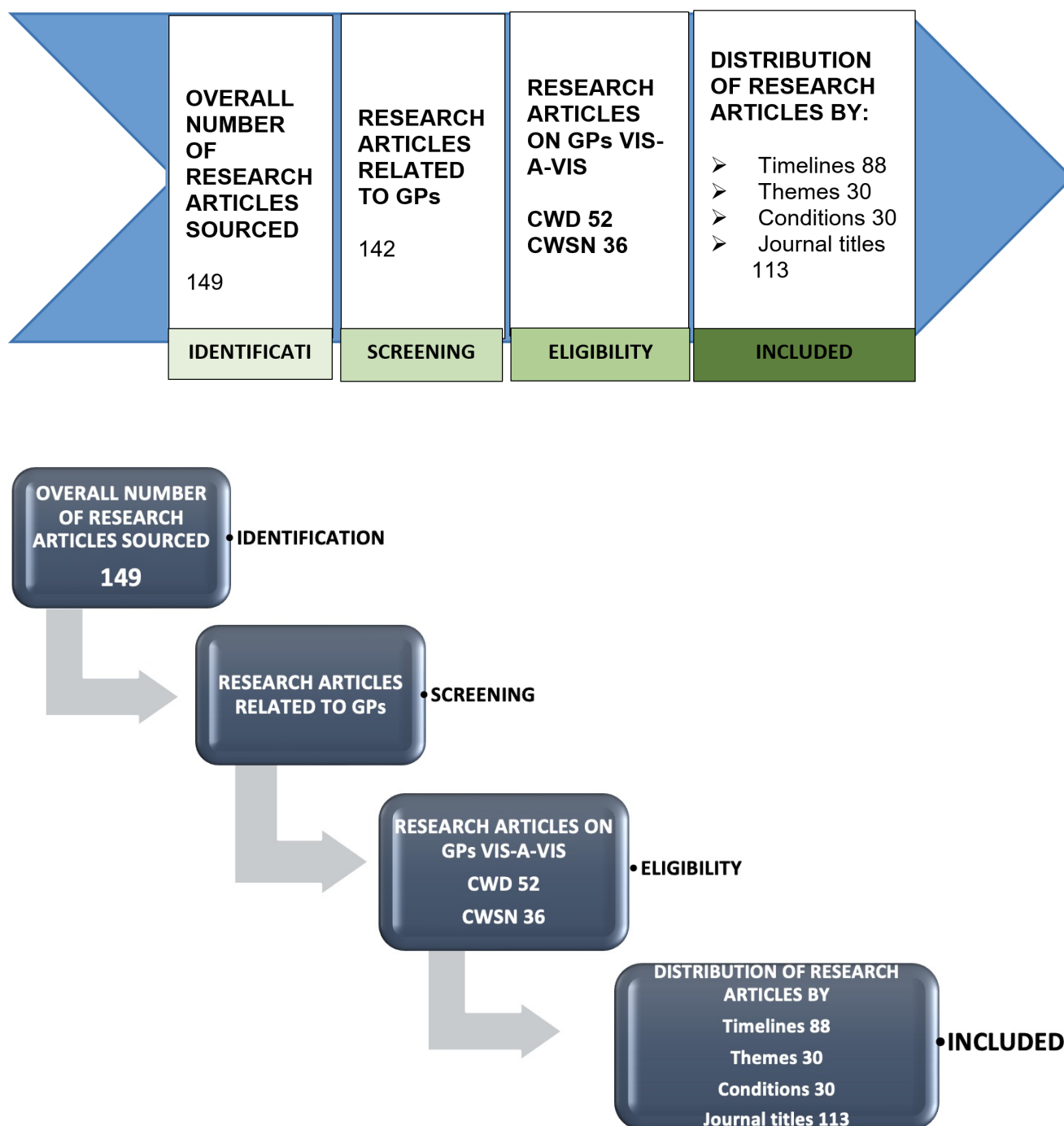


Figure 1. Prisma Flow Diagram depicting the procedure for review

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

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

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.

1. **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).

2. **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%). The topics 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 ambivalence 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. 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 GCs 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. It's 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).

3. **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 participation diversity 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).

4. 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).

5. Culture and Grandparenting

The study of links between 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. 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. 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. 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

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)...

Summary & Recommendations

In summary, this research emphasizes the importance of GPs as a crucial everyday support system for CWSN-Ds. This area of study seems to still have many unanswered questions about the short-term and long-term effects of GP involvement on their GC, as well as the reciprocal impact. The intergenerational dynamics of this support system within families, unique experiences from diverse cultural backgrounds, core skills in their involvement, advocacy, legal and financial implications, and potential for enhancement all remain unexplored. During these challenging times of weakening intergenerational connections, it is crucial to revive problem-focused interdisciplinary field research, create comprehensive theories and models of grandparenting, and develop measurement tools, training programs, and community-based interventions. These efforts are essential to support future generations effectively in the evolving landscape.

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