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RESEARCH TRENDS ON PARENTAL READINESS IN RAISING CHILDREN WITH DOWN SYNDROME: A BIBLIOMETRIC ANALYSIS

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Abstract:

This study examines the intellectual structure and research trends of social science publications on Down syndrome parents. Scopus data on English-language sociology journal articles was used for a bibliometric analysis. Descriptive indicators and visualization were used to identify publication trends, prolific authors, leading countries, influential journals, and dominant research themes. Research output on Down syndrome parental issues has gradually increased, indicating academic interest. Developing nations contributed little to most publications. Keyword analysis revealed parental support, family adaptation, caregiving challenges, and social inclusion as research themes. The findings show gaps in cultural context and parental readiness research in non-Western societies, despite growing literature. This comprehensive review of existing research provides valuable insights for future Down syndrome family studies and policy development.

***Keywords**: Down syndrome; parents; parental support; caregiving; bibliometric analysis*

Abstrak

Penelitian ini mengkaji struktur intelektual dan tren penelitian dalam publikasi ilmu sosial yang membahas orang tua anak dengan Down syndrome. Data diambil dari artikel jurnal bidang sosiologi berbahasa Inggris yang terindeks dalam Scopus dan dianalisis menggunakan pendekatan bibliometrik. Indikator deskriptif dan teknik visualisasi digunakan untuk mengidentifikasi tren publikasi, penulis yang produktif, negara terkemuka, jurnal berpengaruh, serta tema penelitian dominan. Hasil analisis menunjukkan bahwa jumlah penelitian mengenai isu orang tua anak dengan Down syndrome mengalami peningkatan secara bertahap, yang mencerminkan meningkatnya perhatian akademik. Namun, kontribusi negara berkembang masih relatif terbatas. Analisis kata kunci mengungkapkan tema utama berupa dukungan orang tua, adaptasi keluarga, tantangan pengasuhan, dan inklusi sosial. Meskipun literatur terus berkembang, penelitian terkait konteks budaya dan kesiapan orang tua di masyarakat non-Barat masih belum banyak dikaji. Tinjauan

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komprehensif ini memberikan wawasan penting bagi penelitian selanjutnya serta pengembangan kebijakan yang berorientasi pada keluarga anak dengan Down syndrome.

Kata kunci: Down syndrome; orang tua; dukungan keluarga; pengasuhan; analisis bibliometrik

INTRODUCTION

Down syndrome is a common genetic disorder that makes it hard for people to think, socialize, and adapt. It lasts a lifetime and affects not only the person with the disorder but also their family. Parents of children with Down syndrome are essential for their care, advocacy, and decision-making as they mature. Previous studies have demonstrated that parents often face multifaceted challenges, including emotional turmoil, societal stigma, financial constraints, and limited access to appropriate educational and social support services (Hodapp, 2017; Van Riper, 2020). Thus, parental preparedness and capacity to address these demands are critical determinants influencing family welfare and the developmental trajectories of children with Down syndrome. In recent decades, an increased global emphasis on inclusive education, disability rights, and family-centered practices has resulted in a growing body of research regarding parents of children with Down syndrome. Earlier studies have examined a range of subjects, such as parental stress, coping strategies, social support networks, and family adaptation processes (Cuskelly & Gunn, 2019). Nevertheless, these studies are scattered across various disciplines, journals, and geographical contexts, complicating efforts to achieve a holistic understanding of the evolution of research in this domain over time. Researchers and policymakers cannot find the most important themes, new trends, and areas that haven't been studied enough because there isn't a single overview of the literature.

Empirical evidence indicates that research regarding parents of children with Down syndrome is primarily undertaken in developed nations, whereas viewpoints from developing regions are insufficiently represented (Alnahdi & Schwab, 2021). This imbalance is problematic because cultural values, family structures, and social welfare systems differ significantly across contexts, potentially influencing parental experiences and preparedness in various ways. Without sufficient representation of varied socio-cultural contexts, existing knowledge may be contextually limited and less relevant to global policy and practice. While these methods provide in-depth qualitative insights, they are limited in their ability to quantitatively map large volumes of publications and reveal structural patterns within a research field. In contrast, bibliometric analysis offers a systematic and objective approach to examining publication trends, influential authors and journals, collaboration networks, and dominant research themes through quantitative indicators (Donthu et al., 2021). This approach is particularly suitable for identifying the intellectual structure and research trajectory of a rapidly expanding field.

Therefore, this study aims to map global research trends on parents of children with Down syndrome within the field of sociology through a comprehensive bibliometric and thematic analysis of publications indexed in Scopus from 2006 to 2026. By examining publication trends, leading contributors, and thematic patterns, the study provides a systematic overview of existing scholarship and identifies research gaps that warrant further investigation. The findings are expected to guide future research directions and support the development of more inclusive, evidence-based policies and interventions aimed at strengthening parental readiness and family support systems for children with Down syndrome.

Specifically, the objectives of this study are to:

1. examine patterns of international research collaboration in studies focusing on parents of children with Down syndrome.
2. identify the leading countries, authors, journals, and institutions contributing to this research area; and
3. explore the main thematic clusters and research foci related to parental roles, challenges, support, and readiness through keyword co-occurrence analysis.

The findings of this study provide insights into influential research streams, collaboration networks, and dominant themes, while offering directions for future research and informing evidence-based, family-centered policies to strengthen parental support for children with Down syndrome.

RESEARCH METHODS

This study adopts a bibliometric analysis approach to examine research trends and thematic developments in studies focusing on parents of children with Down syndrome. Bibliometric analysis enables the quantitative mapping of scholarly literature to identify publication patterns, influential contributors, and dominant research themes within a specific field (Donthu et al., 2021). Data were retrieved from the Scopus database, which was selected due to its extensive multidisciplinary coverage and robust citation indexing system. Compared to other academic databases, Scopus offers reliable and comprehensive bibliometric data, making it particularly suitable for large-scale analyses of research output and intellectual structures (Baas et al., 2020).

Research Strategy

This study employed a quantitative bibliometric research design to examine scholarly publications focusing on parents of children with Down syndrome. The research was conducted using secondary data retrieved from the Scopus database, which served as the primary data source. Data collection was carried out from 2006 to January 2026 to obtain the most recent and complete bibliographic records available at the time of analysis.

The research target comprised journal articles discussing parents of children with Down syndrome within the social sciences domain. The population of this study included all publications indexed in Scopus related to this topic. The research sample consisted of articles selected through a systematic screening process based on predefined inclusion criteria.

Data Source And Selection Criteria

Data were collected using the Scopus advanced search feature by applying the following search string to the TITLE-ABS-KEY fields:

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TITLE-ABS-KEY ( Down syndrome parents )
AND ( LIMIT-TO ( SUBJAREA , "SOCI" ) )
AND ( LIMIT-TO ( DOCTYPE , "ar" ) )
AND ( LIMIT-TO ( LANGUAGE , "English" ) )
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Only peer-reviewed journal articles written in English and indexed under the Social Sciences (SOCI) subject area were included. Other document types such as reviews, books, book chapters, and conference proceedings were excluded to ensure data consistency and scholarly rigor.

Data Collection Procedure

Bibliographic data, including publication year, authorship, institutional affiliation, journal source, citation counts, and keywords, were exported from Scopus in formats compatible with bibliometric analysis. The dataset was then screened to remove duplicates and irrelevant records prior to analysis.

Data Analysis Techniques

The analysis employed bibliometric performance indicators to examine publication trends and research productivity. Keyword co-occurrence analysis was conducted to identify dominant research themes and thematic relationships within the literature. Visualization techniques were used to illustrate collaboration patterns and thematic structures in studies related to parents of children with Down syndrome.

RESULTS AND DISCUSSION

The results of this bibliometric analysis provide a comprehensive overview of publication trends, collaboration patterns, and thematic structures in research focusing on parents of children with Down syndrome. Using bibliographic data retrieved from the Scopus database, this study identifies key contributors, influential journals, as well as leading countries and institutions that shape the development of this research area. The findings also show patterns in publication output, international co-authorship networks, citation impact, and keyword co-occurrence. This helps us understand how research on the roles, support, and challenges of parents of children with Down syndrome has evolved over time. The next sections will go into more detail about these results and explain why they are important for future research, making policies, and building support systems for families with children with Down syndrome.

International Research Collaboration Patterns

Figure 1 shows that the number of articles about parents of children with Down syndrome has been increasing slowly over the course of the study. In the early years of publication, especially from 2006 to 2012, not much research was published, and most of it was only done in one country. There wasn't much international cooperation during this time, which shows that most of the early research was done in one country and in one context (Brown & Rillotta, 2020).

Between 2013 and 2018, the number of publications went up a little bit, and the first partnerships between countries started to form. Although collaborative activities remained relatively sparse, this period marked the beginning of international engagement, as researchers from different countries began to co-author studies addressing parental roles and challenges associated with Down syndrome. These early collaborative links suggest growing scholarly interest and the gradual expansion of research networks beyond national boundaries (Cuskelly & Gunn, 2020; van Riper et al., 2021).

A more notable shift occurred from 2019 onwards, when publication output increased substantially. This period was characterized by a clearer presence of international co-authorship, reflecting a transition toward more interconnected research practices. The rise in collaborative publications during these years indicates that the research field has reached a more mature stage, where cross-national perspectives are increasingly valued to address complex social and family-related issues (Marchal et al., 2021; Donthu et al., 2021).

In the most recent years, particularly between 2021 and 2024, international collaboration became more visible and structured, with multiple countries participating in joint research efforts. This development highlights the growing recognition of the importance of comparative and cross-cultural approaches in understanding parental experiences and support systems for children with Down syndrome (Alnahdi & Schwab, 2021; Lim et al., 2023). The apparent decline in 2026 is likely due to incomplete indexing at the time of data collection rather than a reduction in collaborative activity.

Overall, the year-by-year analysis demonstrates a clear progression from limited and localized research toward more internationalized collaboration. This trend underscores the increasing integration of global research efforts and emphasizes the need for sustained and inclusive international partnerships to further advance knowledge in this field, particularly in underrepresented regions (Rahman & Abdullah, 2025).

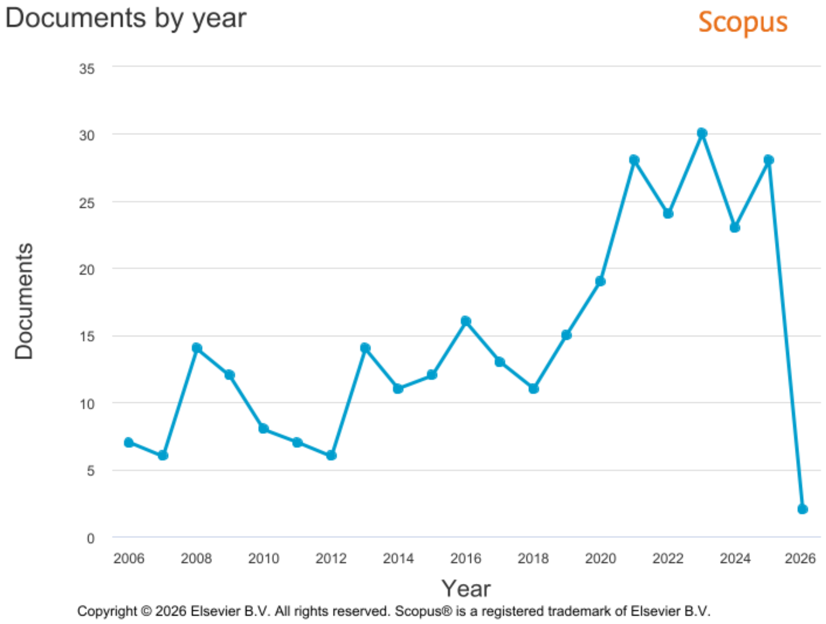

Figure 1. Publication Trends by Year

Leading Countries, Authors, Journals, and Institutions

Figure 2 illustrates the international research collaboration network by country in studies focusing on parents of children with Down syndrome. The visualization reveals a highly centralized collaboration structure, where a small number of countries occupy dominant positions within the global research network. Such centralized patterns are commonly observed in established research fields, where countries with strong research infrastructures tend to dominate knowledge production and collaboration activities (Donthu et al., 2021; van Riper et al., 2021). Node size indicates publication volume, while the strength of connecting lines reflects the intensity of collaborative relationships between countries.

The United Kingdom emerges as the most prominent and influential contributor, positioned at the centre of the collaboration network with the largest node size. This indicates not only a high volume of publications but also extensive international collaboration with multiple countries. The central role of the United Kingdom suggests that it functions as a research hub in this field, facilitating knowledge exchange and cross-national research partnerships related to parental roles, caregiving experiences, and social support systems for children with Down syndrome (Brown & Rillotta, 2020; Cuskelly & Gunn, 2020).

The United States represents another key contributor, showing strong collaborative ties with the United Kingdom and other countries. Its substantial node size reflects significant research productivity, while its collaborative links indicate active participation in international co-authorship. Together, the United Kingdom and the United States form the core of the global research network, shaping dominant research agendas and methodological approaches in studies on parents of children with Down syndrome (Marchal et al., 2021; Peer & Hillman, 2022).

In contrast, countries such as Malaysia, Taiwan, and Ireland appear as smaller and more peripheral nodes within the network. Their limited node size and fewer collaboration links suggest lower publication output and restricted involvement in international research partnerships. Although these countries contribute valuable perspectives to the literature, their peripheral position indicates that research from developing and smaller research systems remains underrepresented in the global discourse (Alnahdi & Schwab, 2021; Lim et al., 2023). This imbalance highlights structural disparities in research capacity, access to funding, and international networking opportunities.

At the institutional and author levels, a similar concentration pattern can be inferred from the country-level collaboration structure. Leading authors and institutions are predominantly affiliated with universities and research centers located in the United Kingdom and the United States. These institutions often benefit from established research infrastructures, interdisciplinary expertise, and long-standing international collaborations, enabling sustained scholarly productivity (Donthu et al., 2021). Consequently, a limited cohort of authors and institutions wields an outsized impact on the generation and distribution of knowledge within this research domain.

The concentration of articles in a small number of international journals is similar to the dominance of leading countries in terms of where they are published. These journals are the main places where research on parents of children with Down syndrome is published. This shows how important they are in shaping academic debates and research priorities (Van Riper et al., 2021). This focus on a few areas of study helps to strengthen and make the field more visible, but it may also limit the range of theoretical and contextual insights that are available in the literature.

Overall, the results show that research on parents of children with Down syndrome is not equally represented around the world. Leadership is concentrated in a small number of countries, authors, journals, and institutions. International collaboration has grown over time, but it is still mostly focused on well-known research centers. To encourage research that is more inclusive, culturally sensitive, and globally representative, it is essential to expand collaborative networks to include regions and institutions that are not well represented (Rahman & Abdullah, 2025). This research should better reflect the diverse experiences of parents from different social and cultural backgrounds.

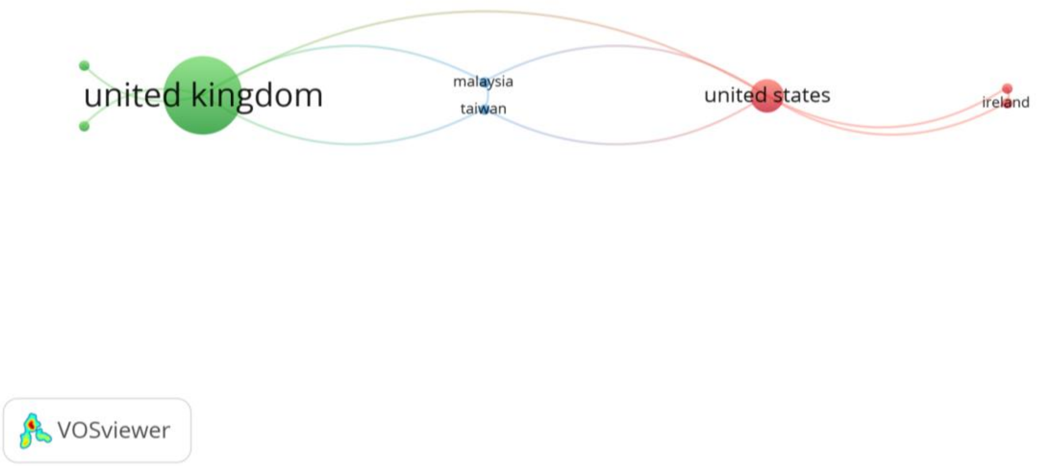

Figure 2. International Research Collaboration Network by Country in Studies on Parents of Children with Down Syndrome

Thematic Clusters and Research Foci

The keyword co-occurrence analysis shows that there are a number of related thematic clusters that define research on parents of children with Down syndrome. Figure 3 shows that the most important cluster is "Down syndrome," which is closely related to keywords like parents, families, and children. This means that the focus of this research field is on parental perspectives and family contexts (Brown & Rillotta, 2020; Van Riper et al., 2021).

Another important group of themes has to do with the roles of parents and their experiences as caregivers. This is shown by words like "parental experiences," "diagnosis," and "intervention." These terms indicate a significant focus on parents' emotional reactions, adaptation mechanisms, and participation subsequent to a child's diagnosis, along with their involvement in early intervention and support initiatives (Cuskelly & Gunn, 2020). This group of themes shows how important parents are in helping their children navigate healthcare, school, and social services.

A further cluster is associated with psychosocial outcomes and well-being, represented by keywords such as quality of life and acceptance. This indicates that research has increasingly focused on how parents cope with caregiving challenges and how formal and informal support mechanisms influence family well-being (Marchal et al., 2021). Moreover, the presence of the keyword inclusion indicates an increasing scholarly focus on inclusive practices and social participation, implying a broadening of research interests beyond clinical perspectives to encompass wider social and educational contexts (Alnahdi & Schwab, 2021).

While these themes predominate in the literature, topics concerning parental readiness and preparedness are still relatively underexamined. Recent evidence from Asian contexts indicates that cultural values, family structures, and access to community-based support significantly influence parental readiness and coping strategies (Rahman & Abdullah, 2025). These results indicate significant avenues for future research, especially in investigating context-specific readiness and empowerment strategies for parents of children with Down syndrome in various socio-cultural environments.

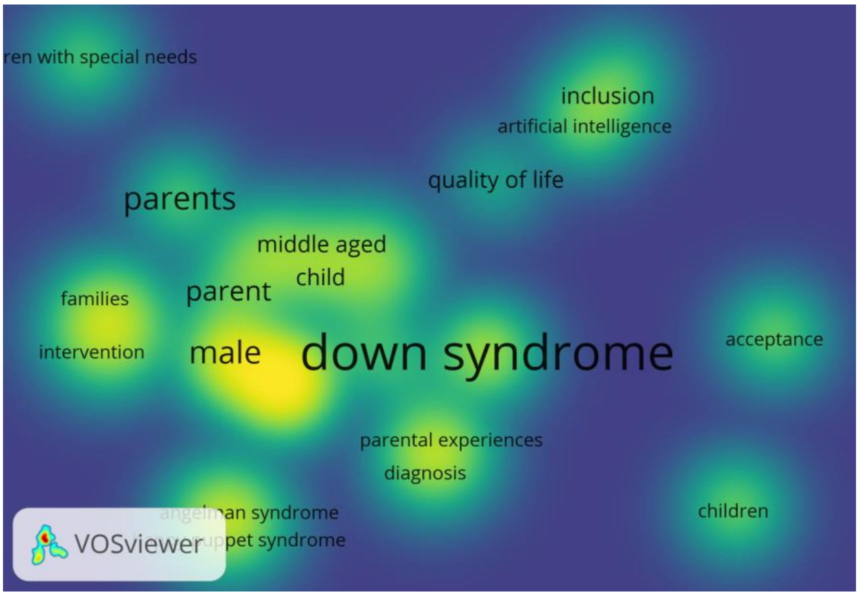

Figure 3. Keyword Co-occurrence Network of Research on Parents of Children with Down Syndrome

CONCLUSION

This study offers a comprehensive bibliometric analysis of research concerning parents of children with Down syndrome in the field of social sciences. The results show that the number of publications has been steadily rising over time. This shows that more researchers are interested in parental roles, challenges, and support systems. The analysis also shows that international research collaboration is not equal. The analysis also shows that international research collaboration is not equal, with a limited number of countries conducting the majority of research and forming cross-national partnerships, while contributions from developing regions remain constrained.

The thematic analysis based on keyword co-occurrence shows that most of the current research is focused on parental experiences, caregiving responsibilities, family involvement, and mental and emotional health. The themes related to parental readiness, preparedness, and context-specific support strategies appear to be inadequately developed, revealing substantial gaps in the current literature. These gaps underscore the imperative for subsequent research that incorporates diverse socio-cultural contexts and examines parental readiness across various stages of the family life course.

This study enhances the understanding of the intellectual framework and research pathways in this field, providing substantial direction for future inquiries. The findings clarify major themes, key contributors, and patterns of collaboration, offering insights that could inform the creation of more inclusive, evidence-based policies and family-centered interventions aimed at improving support systems for parents of children with Down syndrome.

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