# PSYCHOLOGICAL WELL-BEING IN CAREGIVERS OF CHILDREN WITH DISABILITIES: BIBLIOMETRIC ANALYSIS OF THE LITERATURE

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Abstract - The primary aim of this study is to find scientific literature on psychological well-being and to show how the publications in this field are designed. Bibliometric methodology, combined with the scientific mapping technique, were used in this investigation. Different procedures related to the qualification, scrutiny, assessment, and estimation of scientific documents were carried out. 148 valid articles were retrieved from Scopus Database between 1990 to 2023 related to psychological well-being in caregivers of children with disabilities. The researchers initiated 148 distinct articles. Medicine was the furthermost studied area followed by psychology which contributed to 54.73% and 52.03% total number of publications respectively. The findings also discovered that there was a clear interest among developed countries in studying problems related to psychological well-being. The findings revealed that the evolution in the study of psychological well-being is constant and continuous, with articles in English being the most used medium for researchers to present their findings. This study focuses specifically on a single database that functions as the primary source for the papers. While Scopus is widely recognised as a comprehensive database that indexes scholarly papers, it does not provide complete coverage of all available resources. This study's findings could contribute to the existing knowledge on providing a thorough analysis of trends in studies pertaining to psychological well-being.

Keywords: Bibliometric Analysis, Psychological Well-being, Scientific Mapping, Scopus Database

# INTRODUCTION

Caregivers of children with disabilities especially autism spectrum disorders (ASD) tend to experience lower levels of psychological well-being (PW) compared to caregivers of children with other developmental disorders and caregivers of typically developing children (Cappe et al., 2011; Mount & Dillon, 2014; Sullivan, 2017; De Hayes & Watson, 2013; Amireh, 2019; Basri & Nik Hashim, 2019; Porter & Loveland, 2019; Siu et al., 2019; Lee et al., 2017). The limited availability of information pertaining to disabilities has resulted in the dependency of individuals within society on traditional and lay beliefs for the reason of explaining the root cause of these kinds of disorders. Malaysia, as a multiethnic nation, exhibits a diversity of perspectives on disabilities, particularly in relation to children with ASD. According to Ilias et al. (2017), the Malay culture has the belief that there may exist mystical or spiritual forces that disrupt the well-being of children. In contrast, individuals who are not Muslims held the belief that their current afflictions were a result of misdeeds committed in a past life, leading them to seek out witchdoctors as a means of remedy (Ilias et al., 2017). In the context of Muslim families, it is seen that those with children with disabilities encounter challenges in effectively managing their children's needs.

These difficulties encompass a dearth of emotional and financial resources, often leading to the necessity of quitting employment. However, it is noteworthy that these families maintain a belief that their children's condition is a divine trial bestowed upon them by Allah S.W.T. Nevertheless, caregivers may encounter persistent difficulties and recurring challenges, which can potentially result in depression and diminished psychological well-being. This is primarily due to their concerns for the future of the children under their care and the difficult endeavour of acquiring sufficient resources, particularly a high income, to ensure a desirable quality of life for the children (Alenazi et al., 2020; Vasilopoulou & Nisbet, 2016).

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Bibliometric is a sphere of research which analyses bibliographic subject matter quantitatively through the study of a subject area and the detection of its leading trends. Bibliometric surveys have systematic and rational approaches to discover the flows and trends of information in a field structure (HernándezTorrano et al., 2020). This study aims to extend the understanding of psychological well-being (PW) presenting a bird's eye view of the research conducted in this field in recent decades using a bibliometric approach.

Bibliometric synopses provide an objective and systematic approach to examining the transmission of knowledge and the structural patterns within a particular field (Van Raan, 2014). They allow for the identification of the field's scientific origins, the detection of emerging thematic areas, and the identification of gaps in the existing literature (Skute et al., 2019). Ultimately, these synopses contribute to the advancement of the field.

This article is structured as follows. In the following section, the researchers highlight the review of literature on psychological well-being among caregivers of children with disabilities. Section 3 of the paper focuses on the comprehensive bibliometric research. This section provides an overview of the methodologies employed and the specifics of data collection. Subsequently, the research results and findings are thoroughly investigated and analysed in section 4. Finally, the conclusion is presented in section 5 and the list of references provided at the end of this article.

# LITERATURE REVIEW

### 1. Psychological Well-Being

The concept of psychological well-being originated from the understanding that being healthy encompasses more than just being free of bodily illnesses (Ryff, 1989; Ryff & Keyes, 1995). Psychological well-being is a primary objective for individuals, as it pertains to their need for improved psychological state. This is closely related to an individual's perception of personal emotional expression and engagement in everyday routines (Duan et al., 2016; Thomson et al., 2018).

The concept of psychological well-being development, as proposed by Ryff (1989) and further elaborated by Ryff and Keyes (1995) and Ryff (2014), pertains to a key aspect of positive psychology that focuses on the individual. This construct encompasses various dimensions, including positive relationships with others, autonomy, self-acceptance, purpose in life, environmental mastery, and personal growth.

A study conducted by Ilias et al. (2019) revealed that caregivers of children with disabilities have challenges in maintaining satisfactory psychological well-being. These challenges are caused by various factors, including an insufficient support system characterised by limited awareness about disabilities, inadequate government policies, logistics barriers that restrict access to necessary services, difficulties in finding suitable educational institutions, childcare facilities, therapies, and healthcare services, a shortage of qualified healthcare professionals, and the financial burden associated with caregiving responsibilities.

Moreover, a significant portion of the rural population suffers from a lack of adequate infrastructure, resulting in disabled children being forced to spend their days in welfare centres to fulfil their physical demands (Amin & Sar, 2016). Akram (2019) claims that caregivers of children with disabilities experience suicidal ideation as a result of inadequate social support. In the context of Singapore, it has been reported that a Japanese mother tragically took the life of her autistic son through strangulation, afterwards proceeding to a forested area where she stabbed herself to death as well.

The mother of a child experienced a substantial depressive condition, resulting in an eight-kilogram weight loss and prolonged insomnia (Berita, 2020). In addition, caregivers of children with disabilities have claimed that they face formidable and frequently isolating issues. This is due to the fact that their children may experience meltdowns, outbursts, and exhibit strong needs. Nevertheless, they continue to say that their children have important and meaningful roles in their lives.

Previous studies have found that caregivers of children with disabilities experience challenges in family functioning and increased levels of stress (De Hayes & Watson, 2013). These caregivers

frequently report difficulties in managing their child's behavioural and emotional issues (Firth &Dryer, 2013; McStay, Dissanayake, Scheeren, Koot, &Begeer, 2014). In addition, Ilias et al. (2017) observed that mothers reported elevated levels of depression and anxiety compared to fathers. Similarly, Etournaud (2017) also highlighted that caregivers of children with disabilities reported more stress and were almost three times as exposed to psychological poor health and distress.

While most of the earlier research has concentrated on the variables that contribute to psychological well-being among students, employees, older ages and immigrants, and its consequences, this study focuses on identifying the trend of research on psychological well-being among caregivers of children with disabilities. In this current study, the researchers adopt a bibliometric analysis in conjunction with the scientific mapping technique. This technique enables us to take a broader view on the phenomena of psychological well-being.

### **METHODOLOGY**

#### 1. Method

Pritchard (1969) has defined bibliometrics as "the application of statistical and mathematical methods to books and other media of communication". This phrase implies that bibliometrics analysis assesses the attributes of books (or, in the case of this study, a collection of literature) based on the bibliographic data included in the books themselves (Zakaria et al., 2021). Bibliometric analysis is a widely utilised and rigorous approach for assessing and analysing large quantities of scientific data (Donthuet al., 2021) and it has gained immense popularity in business research in recent years (Donthu et al., 2020; Donthu, 2021; Khan et al., 2021).

More importantly, the popularity of bibliometric analysis in business research is not a trend rather a reflection of its effectiveness for (i) managing large volumes of scientific data, and (ii) generating high research impact (Donthu et al., 2021). It provides a mechanism for determining the study's trend and pattern (Ahmi & Mohamad, 2019). The patterns of the studies can be observed through the classification of publication either by type, source, language, subject area, year, and country. Related matrices such as citations, citations per year, h index, and g index can be used to measure the publication's impact and performance.

#### 2. Data Collection

Scopus is widely regarded as the most comprehensive and extensive database globally, offering a highly efficient and complex search platform for accessing research articles, manuscripts, research papers, short surveys, and literature surveys (Falagas et al., 2008; Zhu & Liu, 2020). Various search terms can be utilised to identify scholarly articles that are related to specific organisations, time periods, and other relevant factors. These search terms can include primary keywords as well as secondary keywords, which serve to refine the search based on the selected primary and secondary search criteria. For the purposes of this study, we focused on all documents with the title "psychological well-being".

As proposed by Zakaria et al. (2021) the following query has been run against the Scopus database as illustrated by the Figure 1 below. A total of 148 documents were obtained from the search query, conducted on July 17, 2023, and next utilised for further analysis. The search strategy has been illustrated and presented in Figure 1.



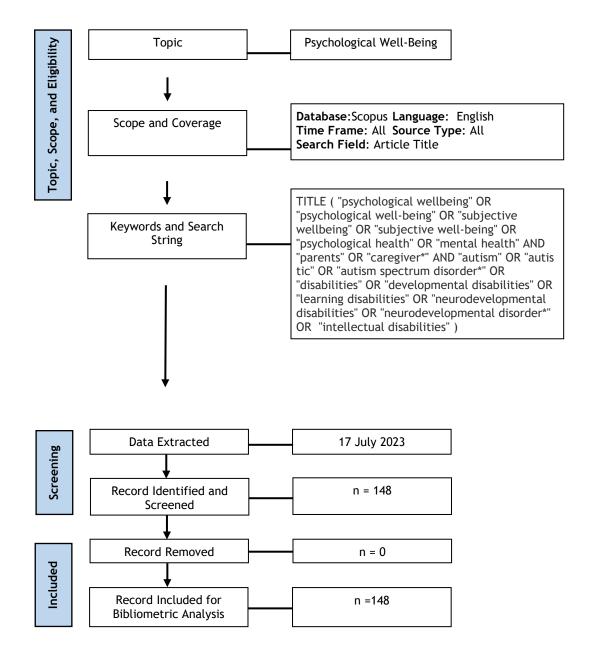


Figure 1: Flow diagram of the search strategy

All the documents were subjected to the bibliometric analysis. We routinised (i) Microsoft Excel 2019 to calculate the frequencies and percentage of the published materials, and to create the relevant charts and graphs (Ahmi et al., 2020); (ii) VOS viewer 1.6.17 version to generate and visualise the bibliometric networks, and (iii) Harzing's Publish and Perish software to calculate the related citations metrics.

### **RESULTS AND FINDINGS**

# 1. Documents Profiles

Bibliometric studies provide valuable information regarding scientific discoveries at both national and international levels. In addition, this study makes extensive use of Scopus as its primary source. From this analysis, seven (7) document types were found. Table 1 shows that journal articles were the most common source, representing 134 (90.41%) of the total followed by review papers (n=8; 5.48%) and erratum (n=2; 1.37%). In contrast, editorial, conference paper, book chapter and book were quite low, each accounting for 0.68% of the total.

Table 1: Document Type				
Document Type	Total Publications (TP)	Percentage (%)		
Article	134	90.41		
Review	8	5.48		
Erratum	2	1.37		
Editorial	1	0.68		
Conference Paper	1	0.68		
Book Chapter	1	0.68		
Book	1	0.68		
Total	148	100.00		

Table 2 presents a comprehensive enumeration of two (2) distinct types of data sources. The most common type of publication is journals, accounting for 98.63% (n=146) of the total. Books, on the other hand, make up just 1.37% of the publications, equating to a total of 2.

Table 2: Source Type				
Source Type	Total Publications (TP)	Percentage (%)		
Journal	146	98.63		
Book	2	1.37		
Total	148	100.00		

According to the data displayed in Table 3, the majority of the papers obtained were published in English language, accounting for 96.40% of the total publications, with a total number of 144 publications. Then, there are three (3) publications in Spanish, and the least common languages utilised within these studies were Chinese and Persian.

Table 3: Languages				
Language	Total Publications (TP)	Percentage (%)		
English	144	96.40		
Spanish	3	2.01		
Chinese	1	0.67		
Persian	1	0.67		

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Total	148	100.00

Different subject areas took part in handling research across the years. As the Scopus database search keywords are into interdisciplinary and multi-dimensional subject areas, the aforementioned table demonstrates the major contribution is made from medicine and psychology (54.73% and 52.03%) respectively. Whereas, social sciences signified 30 publications (20.27%),art and humanities and neuroscience contributed to 11 publications (7.43%) respectively. The other subject areas in psychological well-being in caregivers of children with disabilities researchare tabulated in Table 4.

Table 4: Subject Area				
Subject Area Total Publications (TP) Percent				
Medicine	81	54.73		
Psychology	77	52.03		
Social Sciences	30	20.27		
Arts and Humanities	11	7.43		
Neuroscience	11	7.43		
Health Professions	9	6.08		
Nursing	5	3.38		
Environmental Science	5	3.38		
Biochemistry, Genetics and Molecular Biology	2	1.35		
Multidisciplinary	1	0.68		
Agricultural and Biological Sciences	1	0.68		

# 2. Research Growth and Trends

Scopus Database generates analysis for various parameters among which the documents are generated from years 1990 to 2023. There were slow increases in the number of publications on psychological well-being in caregivers of children with disabilities starting from 1990 until 2007, but since 2008 the number of publications per year has gradually increased although experiencing some fluctuations. The highest productivity was recorded in 2023, with a total of 32 publications produced, representing 21.62 percent of all publications produced during the study period, and it is expected to improve in the coming years. The details indicator about the research published on psychological well-being in caregivers of children with disabilities is shown in Table 5.

	Table 5: Year of Publication							
Year	ТР	% TP	NCP	тс	C/P	C/CP	h	g
1990	1	0.68	8	0.24	0.24	0.03	1	1
2002	1	0.68	13	0.62	0.62	0.05	1	1
2004	1	0.68	73	3.84	3.83	0.05	1	1
2006	3	2.03	244	14.35	4.78	0.06	3	3
2007	1	0.68	45	2.81	2.81	0.06	1	1

2008	2	1.35	41	2.73	1.37	0.07	2	2
2009	1	0.68	8	0.57	0.57	0.07	1	1
2010	3	2.03	41	3.15	1.05	0.08	3	3
2011	1	0.68	71	5.92	5.92	0.08	1	1
2012	3	2.03	104	9.45	3.15	0.09	2	3
2013	5	3.38	196	19.6	3.92	0.10	4	5
2014	5	3.38	223	24.78	4.96	0.11	4	5
2015	6	4.05	224	28	4.67	0.13	6	6
2016	5	3.38	71	10.14	2.03	0.14	5	5
2017	5	3.38	152	25.33	5.07	0.17	5	5
2018	10	6.76	235	47	4.70	0.20	7	10
2019	9	6.08	150	37.5	4.17	0.25	6	9
2020	10	6.76	81	27	2.70	0.33	6	9
2021	26	17.57	383	191.5	7.37	0.50	11	19
2022	18	12.16	88	88	4.89	1.00	5	9
2023	32	21.62	40	40	1.25	1.00	3	5

Notes: TP=total number of publications; NCP=number of cited publications; TC=total citations; C/P=average citations per publication; C/CP=average citations per cited publication; h=h-index; and g=g-index

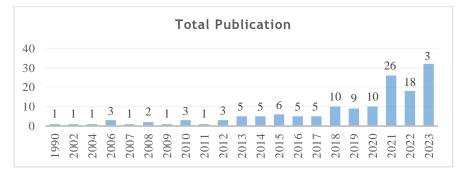


Figure 2. Total Publications by Year

Figure 2 exemplifies total publicationsby year ranging from 1990 until 2023. The analysis reveals that, in general, the growth of research on psychological well-being in caregivers of children with disabilities gained global attention after 2007. Furthermore, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) was ratified in 2006 and became legally binding in 2008 (Kanter, 2008). This signifies the ending of several decades of endeavours aimed at enhancing the safeguarding of the human rights of individuals with disabilities, enabling them to fully participate in their human rights on an equitable support with others.

As a result, over the last decade, there has been an explosion of debates and studies on psychological well-being in caregivers of children with disabilities, which has expanded this research field. Previous studies have developed models of normative coping in the context of families of children with disabilities, focusing less on the negative attributes associated with these

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families. These models have placed more importance on the reasons of stress that families encounter, and the coping techniques they use (Urey & Viar, 1990).

Over the past five (5) years, there has been a significant increase in the number of published articles, surpassing 10 per year. In 2018, there was a significant rise in citation distributions, with a peak of 383 citations. Conversely, the lowest number of citations was observed for publications in 2021. This is due to the relatively short period that has elapsed after the publication era.

# 3. Citation Analysis

Table 6 reports the citation metric of the papers obtained from the Scopus database. There were 2491 citations reported from 1990 until 2023 for 148 articles, with an average of 582.53 citations per year.

Table 6: Citations Metrics			
Metrics	Data		
Total Papers	148		
Total Citations	2491		
Number of Years	21		
Citations per Year	582.53		
Citation per Paper	603.04		
Citations per Author	822.42		
Papers per Author	49.69		
Authors per Paper	70.99		
h-index	78		
g-index	104		

Table 7 summarises 12article documents on psychological well-being in caregivers of children with disabilities most often cited, based on the number of times each was cited. The three (3) documents most often cited were the on parental mental health (Tonge, et al., 2006), family quality of life and psychological well-being by Pozo et al. (2014), as well as another document on subjective well-being (Werner, &Shulan, 3013). Other documents most often cited were literature reviews or those that addressed the psychological well-being in caregivers of children with disabilities with related issues of (a) coping and well-being, (b) community mental health services, (c) family function and behavioural problems, and (d) mental health.

### Table 7: Most Highly Cited Articles: Those with a Minimum 50 Citations per Document

No.	Authors	Title	Year	Cites	Cites per Year
1	M.M. Seltzer, J.S. Greenberg, F.J. Floyed, J. Hong	Accommodative Coping and Well-Being of Midlife Parents of Children with Mental Health Problems or Developmental Disabilities	2004	73	3.84

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2	B.Tonge, A. Breteton, M. Kiomall, A. Mackinnon, N. King, N. Rinehart	Effects on Parental Mental Health of an Education and Skills Training Program for Parents for Young Children with Autism: A Randomised Controlled Trial	2006	196	11.53
3	J.M. Cramm, A.P. Nieboer	Psychological Well-Being of Caregivers of Children with Intellectual Disabilities: Using Parental Stress as a Mediating Factor	2011	71	5.92
4	L. Brookman-Frazee, M. Baker-Ericzen, N. Stadnick, R. Taylor	Parent Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders	2012	78	7.09
5	S. Werner, C. Shulan	Subjective Well-Being among Family Caregivers of Individuals with Developmental Disabilities: The Role of Affiliate Stigma and Psychosocial Moderating Variables	2013	109	10.90
6	P. Pozo, E. Sarria, A. Brioso	Family Quality of Life and Psychological Well- Being in Parents of Children with Autism Spectrum Disorders: A Double ABCX Model	2014	146	16.22
7	R. Jellett, C.E. Wood, R. Giallo, M. Seymour	Family Functioning and Behaviour Problems in Children with Autism Spectrum Disorders: The Mediating Role of Parent Mental Health	2015	57	7.13
8	A. Li, J. Shaffer,J. Bagger	The Psychological Well-Being of Disability Caregivers: Examining the Roles of Family Strain, Family-to-Work Conflict, and Perceived Supervisor Support	2015	60	6.67
9	N.S. Da Paz, J.L. Wallander	Interventions that Target Improvements in Mental Health for Parents of Children with Autism Spectrum Disorders: A Narrative Review	2017	90	15.00
10	D. Catalano, L. Holloway, E. Mpofu	Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review	2018	85	17.00
11	C. Papadopoulus, A. Lodder, G. Constantinou, G. Randhawa	Systematic Review of the Relationship between Autism Stigma and Informal Caregiver Mental Health	2019	55	13.75
12	J. Lugo-Marin, L. Gisbert-Gustemps, I. Setien-Ramos, G. Espanol-Martin, P. Ibanez-Jimenez et al.	COVID-19 Pandemic Effect in People with Autism Spectrum Disorder and Their Caregivers: Evaluation of Social Distancing and Lockdown Impact on Mental Health and General Status	2021	58	29.00

# 4. Geographical Distribution of Publications

The publication of retrieved documents was made possible by researchers from 41 different countries. Table 8 shows the top five (5)countries that contributed to the publication on psychological well-being in caregivers of children with disabilities. The United States ranked first with a total of 51 (34.46%) documents followed by the United Kingdom (n=20; 13.51%) and Australia (n=17; 11.49%).

### Table 8: Top 5 Countries contributed to the publications (which produce more than 5 papers)

Country	Total Publications (TP)	Percentage (%)
United States	51	34.46
United Kingdom	20	13.51
Australia	17	11.49
Canada	11	7.43
China	9	6.08

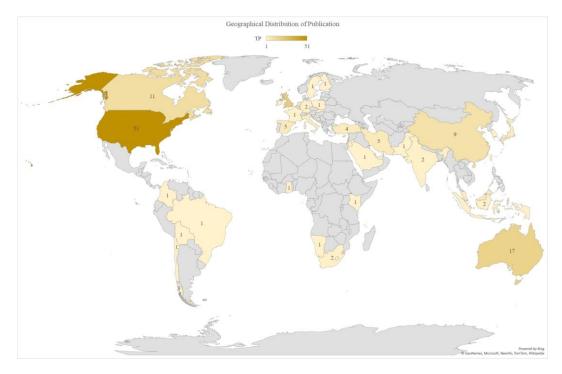


Figure 3. Geographical Distribution of Publication

# CONCLUSION AND FUTURE RESEARCH INCLINATION

This paper presents a bibliometric review to gain more clearer insight into the trends, historical assessment, forecasts, and contributions of the psychological well-being in caregivers of children with disabilities literature. The research on this topic made a debut and mushroomed in 2002 and increased year by year since then. Medicine was the second most studied field, followed by psychology, and the main countries in this field were theUnited States and United Kingdom, which were responsible for the majority of the publications on the subject of psychological well-being in caregivers of children with disabilities research.

The study also indicated that developed countries have a keen interest in researching psychological well-being issues among caregivers of children with disabilities. Psychological well-beingresearch is constantly evolving, with English articles being the most common form of communication for academics to share their findings.

The results show that, starting in 2008 and continuing through 2023, the trend of publications annually grew, with 2023 recording the highest output. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), which was adopted by the UN General Assembly in December 2006, may have contributed to the upward trend in this field of study. Subsequently, the

UK joined the pact in 2009, and the UN Committee on the Rights of Persons with Disabilities, acting as an autonomous expert body, has been overseeing the state parties' adherence to the pact.

This endeavour has raised awareness among the state's parties. In accordance with the UN Convention on the Rights of the Person with Disabilities, the United Kingdom agrees to protect and promote disabled people's human rights, including the elimination of disability discrimination, allowing disabled people to live independently in the community, ensuring an inclusive education system, and protecting disabled people from all forms of exploitation, violence, and abuse.

The scope of this study is limited to the Scopus Database, which serves as the primary source of the papers. Despite the fact that Scopus is one of the most well-known databases that indexes all scholarly papers (Rusly et al., 2019), it does not comprehensively cover all of the resources available. Other available databases, such as Web of Science, Google Scholar, and Dimensions, are likely to be added in future studies which will contribute to the production of more intriguing and useful outcomes. However, despite this restriction, this study may make a significant contribution to the body of knowledge by providing a complete trend analysis of the studies connected to psychological well-being in caregivers of children with disabilities.

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