

Economic burdens on parents of children with autism: a literature review

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Review

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Abstract

This review aims to summarize evidence from published articles regarding the economic burdens on parents of children diagnosed with autism to elaborate on current research status, discern key findings and provide suggestions for future studies. A total of 1024 records were identified through our systematic literature research, and 33 studies were included in the review. The 33 included studies reported findings from 10 different countries around the world. These articles (published from 2003 to 2017) used a variety of research methods, including quantitative ($n = 26$), qualitative ($n = 4$), and mixed ($n = 3$) study designs. In summary, parents of autistic children were susceptible to adverse employment impacts and increased financial burdens, especially mothers. More attention should be given to the development of appropriate medical resource allocation and the alleviation of economic burdens on parents of children with autism.

Introduction

Autism is a neurological developmental disorder characterized by deficits in social reciprocity, delays in communication skills and the presence of repetitive behaviors that violate social norms (DSM-5, American Psychiatric Association¹). It affects approximately 16.8/1000 (ie, 1/59), predominantly males (ie, a prevalence ratio of 4:1). Autism is a disability that adversely affects not only the child but also the entire family, especially parents who have to devote time and energy to wrestle with the dual responsibilities of managing their autistic children and maintaining paid employment.

Parents may confront varying degrees of economic burden to address the financial demands of their autistic children when their financial resources are exhausted. The factors purported to contribute to the economic burdens on parents with children diagnosed with autism include but are not limited to additional medical expenditures, reduced employment opportunities and increased time consumption.

Objectives

This review aimed to appraise the economic burdens on parents of children with autism from an individual rather than a societal perspective to elaborate current research status, discern key findings and provide suggestions for future studies. The present review represents the first systematic synthesis of research findings relating specifically to economic burdens on parents of children with autism. In addition, this review may lay a foundation for researchers and improve policymakers' and program planners' understanding of the economic burdens on parents. Given that decisions on autism treatment are based on negotiations within the family and that autism-related costs fall on the household budget, it is reasonable to appraise economic burdens from the individual perspective of parents. Here, we propose to summarize existing evidence on economic burdens on parents of autistic children by stratifying them into direct costs, such as drugs, transportation and hospitalization, and indirect costs, such as unemployment and time spent caring for disabled children. We directly reported the estimated costs provided in original articles rather than converting them into a consistent form of currency.

Methods

Search strategy

An electronic literature search in compliance with the preferred reporting items for systematic review and meta-analysis (PRISMA) statement² was performed to retrieve published English articles concerning the economic burdens on parents of children with autism. Three computerized databases, including PubMed, Embase, and Web of Science, were searched for relevant publications using the keywords (autism OR ASD OR Autism Spectrum Disorder) AND (parent OR mother OR father OR families OR caregiver) AND (economic OR cost OR financial OR employment).

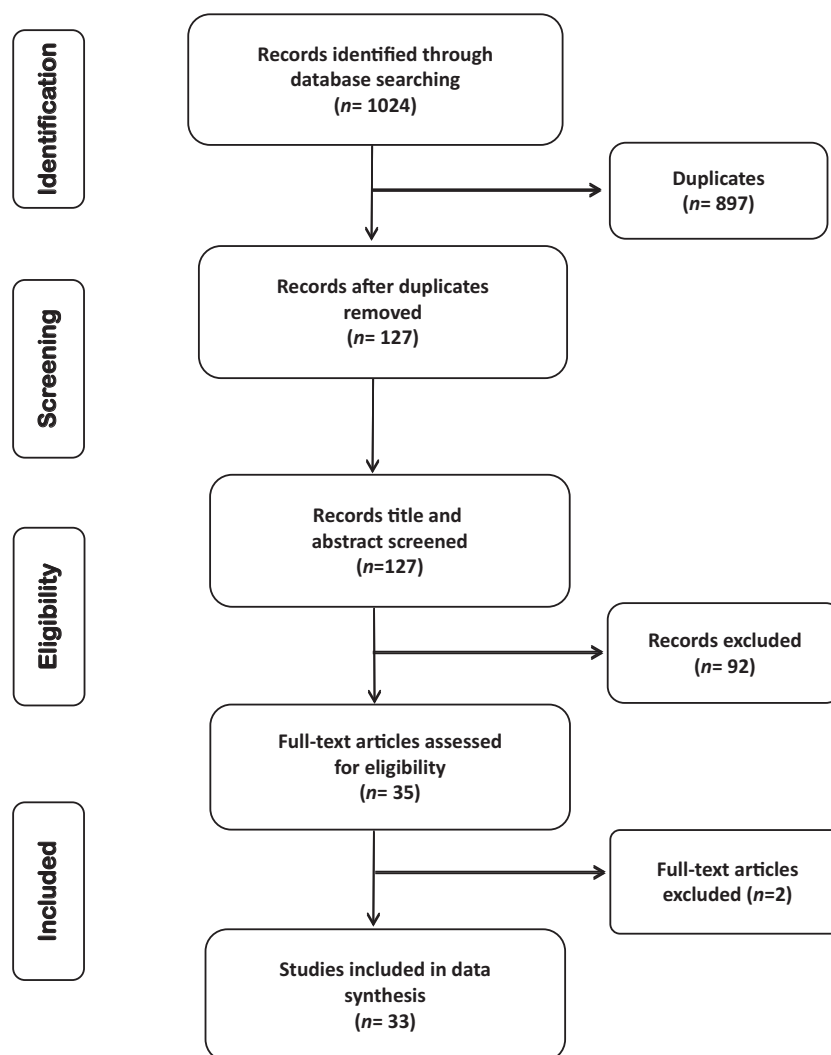


Figure 1. Flow diagram of reviewed studies.

Selection criteria

For the records, the following criteria were required for articles to be eligible: published in peer reviewed journals; reported empirical findings rather than theoretical outcomes; involved data on parents raising at least one child with autism under 18 years old; and reported information related to economic burdens on parents. Eligible publications also need to avoid the following exclusion criteria: doctoral dissertations or master's thesis; and reviews, editorials or commentaries.

Before the electronic search was commenced, all authors achieved a consensus on retrieval strategies by consulting a senior adviser. References cited by all eligible citations were manually reviewed for additional relevant studies that might have been omitted. We did not report the methodological qualities of these included studies.

Results

Description of studies

A total of 1024 citations were retrieved through our search. After 897 duplicates were removed, a list of 127 records was screened.

The titles and abstracts of the remaining 127 records were reviewed separately by two authors. As a result, 92 were excluded for not matching the selection criteria. The remaining 35 potentially relevant articles were scrutinized independently by two authors. Discrepancies between two authors were resolved through discussion. After 2 theoretical articles were eliminated, a total of 33 relevant articles were identified as eligible for this review, as shown in Figure 1.

Given the inconsistency of study methodologies, including data sources, analytic methods, and estimation contents, meta-analysis was not conducted to quantitatively estimate the economic burdens on parents of autistic children. We used systematic review to report study outcomes and descriptive statistics to present study characteristics.

These articles (published from 2003 to 2017) used a variety of research methods, including quantitative ($n = 26$), qualitative ($n = 4$) and mixed ($n = 3$) study designs. A cross-sectional method was adopted in all studies except one longitudinal study with a 12-year follow-up.³ These included studies reported findings from 10 different countries around the world, including the United States ($n = 16$), China ($n = 4$), Australia ($n = 3$), Columbia ($n = 3$), the UK ($n = 2$), Canada, Brunei, Oman, Ireland, and Sweden ($n = 1$ each). Some

studies employed quantitative methods to collect data from relatively large groups, such as administrative-level sources, while other studies adopted qualitative methods to draw information from small sample interviews. More than half ($n = 22$, 66.7%) of the included studies were conducted on relatively small sample sizes ($n \leq 500$), and 27.3% ($n = 9$) of the included studies involved over 1000 participants. Almost all studies included parents of both genders, except for 3 studies that focused exclusively on mothers; key information of included studies is shown in [Table 1](#).

Direct costs for parents of children with autism

Empirical evidence proved that the existence of an autistic child imposed immense economic costs on parents. Sixteen studies reported autism-related direct costs borne by parents.

Seven studies adopted a comprehensive perspective to estimate the direct costs for parents of children diagnosed with autism. The study by Roddy et al.⁴ revealed that the mean attributable cost for each autistic child was computed to be €28,464.89 a year; this cost was determined by the severity of the children's autism. Horlin et al.⁵ found that the median annual cost of autism was \$34,900 Australian dollars, with approximately \$1400 Australian dollars spent on each additional symptom of the autistic children. Young et al.⁶ noted that parents faced an average out-of-pocket expense of \$705.39 for each autistic child, 85.7% of whom endured an expense under \$500 and the remaining 14.3% of whom suffered a cost of over \$1000. With a focus on modeling the relationship between national Medicaid expenses and the economic costs among families who have children diagnosed with autism, Parish et al.⁷ confirmed a prominent association between state Medicaid subsidies and the financial burdens experienced by these families. Families receiving more Medicaid subsidies were less likely to experience economic difficulties. In an attempt to examine health expenditures incurred by parents who have children affected with autism, Wang et al.⁸ noted that parents in urban and rural areas endured an annual per capita additional cost of 60.8% and 74.7%, respectively, in contrast to the provincial statistics for 2007. Behavioral therapies made up 54.3% of the total costs, accounting for the largest cost driver. Cidav et al.⁹ appraised the impacts of age-related variations in health service expenses among families of children with autism. The results showed that aging was associated with significantly higher costs for institution-based care and lower costs for community-based therapeutic services. The study by Sharpe et al.¹⁰ identified factors contributing to economic outcomes in parents living with autistic children. The results revealed that factors such as receiving medical treatments, sustaining non-reimbursed expenses and living with low income may aggravate economic concerns for parents, while the use of speech and language therapy functioned conversely.

Four studies provided narrative information about the direct economic implications on the parents of children suffering from autism. Phelps et al.¹¹ qualitatively characterized the potential ramifications of raising autistic children on parents and found that economic challenges were one of the seven thematic content areas derived from informational interviews. The study conducted by Tait et al.¹² shed light on life experiences among parents living with autistic children. The results demonstrated that most parents faced significant financial blows due to the appearance of their disabled children. The study by Zablotsky et al.¹³ used nationwide claims data to explain the economic impacts of autistic children on parents. The results showed that parents raising children with autism in combination with other disabilities confronted the

greatest financial pressures. According to Saunders et al.,¹⁴ children diagnosed with autism that was comorbid with mental retardation caused greater negative economic impacts on parents, involving both cash expenditures and job disruptions.

Health insurance plays a role in modifying the economic burdens on parents of children with autism. Three studies examined the regulating effects of insurance on the direct costs for parents who have children with autism via insurance claims data from private insurers, state Medicaid agencies, or both sources. Parish et al.¹⁵ noted that the average health care costs related to an autistic child amounted to \$9.70 per \$1000 of income. The out-of-pocket spending of families covered by private insurance was more than 5 times the spending of families insured by public insurance. The most common components of out-of-pocket costs were drug prescriptions, outpatient visits, and dental care. Thomas et al.¹⁶ found the following: children who enjoyed private insurance coupled with Medicaid insurance assumed the highest total excess costs, which accumulated to \$11,596; children only insured by Medicaid insurance ranked in the middle, with costs of \$7238; and children covered by private insurance alone fell in the bottom tier, with costs of \$4486. The research by Chatterji et al.¹⁷ confirmed that families of children with autism fared worse than families of children with other intellectual disabilities. Most parents living with autistic children endured varying degrees of financial burden, and approximately 47% of the respondents declared that insurance coverage failed to meet the exorbitant costs.

Two studies provide insights into the direct costs for parents of children with autism by comparing them with non-matched control groups. In an attempt to compare the differences in financial pressures between the families of autistic children and those of children with other disabilities, Xiong et al.¹⁸ calculated the financial expenditures for children with autism relative to children with other disabilities. The result noted that the annual economic costs for an autistic child were 19,582.4 yuan, while those of a physically disabled child and a mentally retarded child were 16,410.1 yuan and 6391.0 yuan, respectively. The study by Ou yang et al.¹⁹ focused on comparing the economic strains borne by the parents of children suffering from autism relative to those borne by the parents of children with mental retardation. The findings proved a moderate degree of economic burden on parents of autistic children. Specifically, 39% of parents of children with autism perceived financial hardships, while the comparable percentages for parents of children with fragile X syndrome and intellectual disability were 60% and 29%, respectively.

Additionally, one study examined economic consequences by combining direct medical costs with direct nonmedical costs. Lavelle et al.²⁰ sought to understand the associations among autism diagnoses, service uses and cost outcomes. The result indicated that autism was related to \$3020 in health care expenditures and \$14,061 in nonhealth care expenses, which were mainly ascribed to educational expenditures (\$8610).

Indirect costs for parents of children with autism

In addition to the direct expenditures for parents of children with autism, it is also meaningful to depict the broader economic snapshot pertaining to job interruptions or income losses on these parents. The present review yielded 15 studies regarding indirect costs for parents of children with autism.

Parents may be absent from work to take their autistic children to appointments with psychiatrists or health professionals. Evidence continues to accumulate concerning adverse impacts of

Table 1. The key information of included studies.

First author	Publish year	Country	Method	Study groups	Costs included
Phelps ¹¹	2009	US	Qualitative	80 caregivers	Narrative information: economic challenges
Roddy ⁴	2018	Ireland	Quantitative	195 parents	Average annual cost
Tait ¹²	2012	Brunei	Mixed	30 parents	Narrative information: financial situation
Xiong ¹⁸	2011	China	Quantitative	227parents	Economic burden per year
Thomas ¹⁶	2016	US	Quantitative	346 parents	(1) Total expenditures (2) Pay by insurance
Young ⁶	2009	US	Quantitative	107 parents	Out-of-pocket expenditures
Chatterji ¹⁷	2015	US	Quantitative	Unclear	Out-of-pocket costs
Sharpe ¹⁰	2007	US	Mixed	423 parents	Narrative information: financial problem
Ouyang ¹⁹	2015	US	Quantitative	185 parents	39% reported financial burden 25% quitting employment
Saunders ¹⁴	2015	US	Quantitative	2406 parents	Narrative information: (1) Financial difficulty (2) Stop work
Jarbrink ³³	2003	UK	Quantitative	17 parents	(1) The total costs (2) Income lost
Wang ⁸	2012	China	Quantitative	290 parents	(1) Health care costs
Lavelle ²⁰	2014	US	Quantitative	201 caregivers	(1) Health care costs (2) Non-health care costs
Zablotsky ¹³	2014	US	Quantitative	3005 parents	Narrative information: financial situation
Montes ²⁵	2008	US	Quantitative	131 parents	Loss of income
Montes ²¹	2008	US	Quantitative	82 parents	39% reported effected employment decisions
Hartley ²²	2014	US	Quantitative	73 couples	(1) Time spent in child care (2) Time spent in paid employment
Hill ²³	2015	UK	Qualitative	10 parents	Obstacles in continued employment
Mccabe ²⁸	2010	China	Qualitative	70 mothers	Employment experiences
Leslie ³⁴	2017	US	Quantitative	2647 parents	Workforce participation
Mcauliffe ²⁹	2017	Australia	Quantitative	207 mothers	Work participation
Mcevilly ³¹	2015	Sweden	Quantitative	149,567 parents	Sick leave Work participation
Hodgetts ³⁰	2014	Canada	Mixed	139 mothers	Employment Leisure participation
Callander ³	2017	Australian	Quantitative	10,000 families	Labor force participation
Cidav ⁹	2013	Columbia	Quantitative	45,948 children with ASD	Health care expenditures
Baker ²⁷	2010	US	Quantitative	563 parents	66% employment effects on mothers
Horlin ⁵	2014	Australia	Quantitative	317 parents	(1) Median family cost per annum (2) Loss of income
Ou ²⁶	2015	China	Quantitative	459families	Average loss of annual income
Parish ⁷	2012	Columbia	Quantitative	2123 parents	Narrative information: financial Burden
Houser ²⁴	2014	US	Qualitative	37 parents	Narrative information: (1) Parents' Employment Experiences (2) Employment-Related Challenges (3) Increased work stoppages (4) Work-hour reductions
Al-Farsi ³²	2013	Oman	Quantitative	150 Caregivers	Financial expenses per year
Parish ⁷	2012	Columbia	Quantitative	2123 parents	Financial Burden per year

autistic children on parental employment. The study by Montes et al.²¹ shed light on the impacts of autistic children on parental employment. The results revealed that parents of children with

autism endorsed more negative effects on employment decisions and work attendance than did parents of children with other health conditions. Hartley et al.²² surveyed 73 couples to examine the

parental division of labor in caring for their autistic children. The result supported a model of partial role specialization in which mothers take on more care tasks and fathers were engaged in more paid work. The study conducted by Hill et al.²³ offered a qualitative overview of the occupational dilemma faced by parents of autistic children. The results showed that parents faced multiple obstacles in employment, including misunderstandings with colleagues, a lack of opportunities and rigid support policies. Callander et al.³ conducted a longitudinal survey to evaluate the influences of ASD on parental employment. The results showed that parents who had autistic children aged between 2 and 11 years had a higher number of absentee days and poorer job performance.

Childcare access failed to mitigate work disruption among mothers. According to the study by Houser et al.²⁴, parents of children with autism reported decreasing work hours and increasing work stoppages. Parents made changes in employment following the autism diagnosis to reduce nonparental care time and manage therapy schedules.

Raising children with autism consumes extra time that could otherwise be spent in paid work or leisure activities. The time that parents must spend outside of work to care for their autistic children represents a relevant economic burden. Indirect cost calculations have indicated that income losses with regard to autistic children can be of great economic significance to parents. Montes et al.²⁵ used a nationally representative sample to appraise families' economic losses attributed to their autistic children. The result confirmed a negative correlation between household incomes and the presence of autistic children. The average annual income losses associated with an autistic child amounted to \$6200, accounting for 14% of household incomes. Ou et al.²⁶ sought to evaluate the economic effects on parents who have autistic children in preschool compared with those who have children with other forms of mental retardation. The results showed that 58% of parents living with autistic children reported adverse employment impacts, which was three times that of parents who had children with other mental disorders. The average annual income losses of parents of autistic children amounted to 44,077 yuan (\$7226), compared with 20,788 yuan (\$3408) for children with other mental disorders. The study by Horlin et al.⁵ estimated the income lost by parents due to competing caregiving demands. The result showed that the income losses associated with an autistic child accumulated to \$29,200, which accounted for 90% of the total costs.

Studies have consistently found that adverse occupational impacts concentrated on the female parents of autistic children due to their major involvement in caring for children. Baker et al.²⁷ noted that 66% of participants reported that the care responsibilities of autistic children mainly caused occupational restrictions on mothers. Furthermore, workplace challenges rather than socioeconomic variables predicted limited employment opportunities for mothers. McCabe²⁸ conducted a qualitative study to elaborate employment experiences among mothers living with autistic children. The result revealed that although mothers acknowledge the attractiveness of work, they can only make sacrifices to assume the role of a mother. According to Mcauliffe et al.,²⁹ single mothers who have children suffering from autism confronted obvious financial disadvantages as a consequence of inadequate employment opportunities and job security policies. Hodgetts et al.³⁰ evaluated potential outcomes of professional support services for mothers of autistic children. The findings confirmed that discontinuous services significantly predicted job interruptions and disrupted the leisure activities of mothers. The study of Cidav et al.⁹ examined the comparative vocational impacts on female versus

male parents who have children with autism. The result noted that bringing up autistic children may deprive mothers of 7 hours at work each week, while fathers did not differ significantly in their labor participation. Mcevilly et al.³¹ elaborated on the association between raising autistic children and participating in the labor force. The results revealed that parents of children with autism sustained more work absences than did parents of normal children, disproportionately affecting mothers more than fathers. According to the study by Al-Farsi et al.³², the additional costs of raising autistic children account for 15% of families' monthly incomes; these costs are mainly ascribed to lost job opportunities or to mothers' decisions to stop working, with 48.4% and 41.2% for low- and middle-high-income families, respectively.

The total cost for parents of children with autism

One study examined the full economic impact by combining direct costs with indirect costs. Jarbrink et al.³³ found the costs incurred by an autistic child to be €89,104. Parents spent 60 hours supporting the autistic child each week, including a reduction of 17 hours in leisure activities, which translated into an additional average weekly cost of £231.

Discussion

The special needs of caring for autistic children are often costly and stressful, incurring illness-related financial burdens on parents. The results summarized in the present review consistently indicated that parents who have children suffering from autism experienced adverse employment impacts and sustained financial burdens; these findings were especially true for mothers.

Based on a systematic search strategy, the electronic search yielded 33 studies pertaining to the assessment of economic burdens on parents of children with autism. Both quantitative data on financial expenditures or cost calculations and narrative information about economic costs were collected in this review. These 33 eligible citations covered a variety of research methods. Some studies employed quantitative methods to collect data from relatively large samples, such as administrative sources or insurance claim data, whereas others adopted qualitative methods to collect information from small sample interviews. In addition, three studies used mixed methods with quantitative approaches to calculate the economic impacts on parents attributable to their autistic children. More than half ($n = 22$, 66.7%) of these studies were based on relatively small sample sizes ($n = 500$ or less), and 27.3% ($n = 9$) of these studies involved over 1000 participants. Almost all studies included parents of both genders, except for three studies that focused exclusively on mothers. Mothers made up the majority of the sample sizes, whereas only a minority of the study participants were fathers. The 33 included studies reported findings from 10 different countries, which mainly originated in the USA ($n = 16$), followed by China ($n = 4$), Australia and Colombia ($n = 3$ each). Most studies were carried out in countries with substantial autism resources. Therefore, it is imperative to support studies in resource-poor settings, despite advancements in the past decades.

Inconsistencies in data sources, cost components, analytic methods, study periods and country settings made it impractical to make direct comparisons between studies. Some studies estimated economic burdens based on subjective reports without setting up control groups or considering potential influencing

factors, which inevitably leads to biases. Most studies recruited participants from special institutions; therefore, low-income or disadvantaged minorities who cannot afford the cost were less likely to be recruited. Most studies only appraised the short-term financial impacts on parents of autistic children, and dynamic processes of economic burdens that evolve over time were not estimated. No recent study reported the extent to which economic burdens on parents related to autism contribute to disparities in outcomes for autistic children. Although not the focus of this review, the current literature lacks data on unquantifiable costs, such as the psychosocial costs experienced by parents, which refer to the costs associated with the psychological symptoms, such as stigma, grief, and exclusion, arising from their experience with their autistic children.

There is a marked need for greater consistency in methodology to allow for a comparable analysis of the economic burdens suffered by parents of autistic children across different conditions. A fertile area for further research is to use valid methods to measure long-term economic impacts on parents of autistic children. Parents from low-income families who have children diagnosed with autism should be recruited to obtain widely representative samples. Future studies could benefit from cross-disciplinary collaborations involving experts from economic and medical fields. Future studies should also include information on psychological outcomes that can be linked to economic indicators.

Limitations

It should be noted that the present review has several unavoidable limitations. The included studies investigated economic costs by adopting retrospective questionnaires and may be affected by recall errors and selection bias; however, for studies using prospective designs, the use of diaries to record information over a specific time period may run the risk of low compliance. In addition, because the present review focused exclusively on articles published in English, relevant findings published in other languages were not included.

Conclusions

Children diagnosed with autism require various forms of support across multiple domains, such as medical care, special education and community assistance; these substantial economic burdens are a considerable concern for the entire family, especially for parents. This review summarized evidence that provided useful information for estimating the economic burdens on parents of children with autism. While it is difficult to compare economic burdens among studies, as different definitions and methods were used to measure and quantify costs, this review directly reported the cost values provided in the original articles rather than converting the values into a consistent form of currency. The findings summarized in this review demonstrated that parents of autistic children were susceptible to adverse employment impacts and increased financial burdens, especially for mothers. It is advisable to develop appropriate medical resource allocation and alleviate the economic burdens on parents of autistic children.

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approval and agrees to be accountable for all aspects of work ensuring integrity and accuracy. Yamin Li contributed to conception, acquisition, analysis, critically revised the manuscript. Gave final approval, agrees to be accountable for all aspects of work ensuring integrity and accuracy.

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