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Well-being focused interventions for caregivers of children with developmental disabilities: a scoping review protocol

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ABSTRACT

Introduction Children with developmental disability (DD) may depend on their family caregivers to fulfil their complex health needs. Family caregivers are generally described as persons providing unpaid for services for the child with DD at home who need to be supported in a manner that supports and promotes his/her well-being. This review aims to identify and map the range of interventions available for caregivers of children between the ages of 5–16 with DD.

Methods and analysis The methodological framework for conducting scoping review as published by Arksey and O'Malley and the Joanna Briggs Institute's guidelines will used in this study. Primary research articles will be obtained through a systematic search of CINAHL, Psych INFO, PubMed, ERIC and COCHRANE Library. Further grey literature will be obtained from Google Scholar search. Study selection process will be done by two independent researchers based on a predetermined inclusion criteria. Review findings comprising interventions, intervention components and outcomes will be presented using tables and narrative text.

Discussion The proposed scoping review will give an extensive review of interventions aimed at improving the well-being of caregivers of children with DD. This scoping review would provide recommendations on interventions that have significantly improved the well-being caregivers of children with DD. Additionally, the review would guide future work on intervention development and primary research in this field.

Registration This scoping review protocol has been registered with the Open Science Framework (https://osf.io/tkbrh).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This scoping review uses a robust methodological approach following the Joanna Briggs Institutes guidelines.
⇒ The review includes studies across the globe and will present findings that can be translated into appropriate health system response in different settings.
⇒ Selection of studies and extraction of data will be done by two independent reviewers to ensure accuracy and inter-rater reliability.
⇒ The study selection is limited to those published in English language.
⇒ Evidence presented relates to only developmental disability and not every disability in general.

INTRODUCTION

Globally, about a 100 million children under the age of 15 years are reported to have developmental disability (DD).[1] DDs are lifelong conditions due to an impairment in physical, learning, language or behaviour areas. Children with DD may require diverse assistance to address behavioural and other challenges that may arise as result of the impairments.[2] Conditions under the umbrella term DD include attention-deficit/hyperactivity disorder, autism spectrum disorder (ASD), blindness, cerebral palsy, moderate to profound hearing loss, learning disability, intellectual disability (ID), seizures, stuttering or stammering or any other developmental delay.[3] A global analysis of disease burden as of 2016 suggests that blindness was the most prevalent DD, followed by hearing loss, ID and ASD. However, ID was the largest contributor to longer number of years lived with disability in all the 195 countries examined. The estimated number of children aged 0–5 years with DD had risen from 598.5 million in 1990 to 632.0 million in 2016. Low-income and middle-income countries accounted for the majority (50.2 million) with the remaining representing high-income countries.[4] Boyles *et al* conducted a study on the trends in the prevalence of DD in children from 3 to 17 years in the USA between 1997 and 2008 using a parent report diagnosis.[5] The conclusions were that over the past 12 years there was an increase in DD from 12.84% to 15.4%. They concluded that DD were quite common in the USA as approximately one in six had DD between years 2006 and 2008. In a more recent study conducted between 2014 and 2016, the prevalence of DD in children between 3 and 17 had increased from 5.76%

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to 6.99%.[6] This recent study was not based on patient report but rather on clinical diagnosis. Comparing the findings, the reported prevalence was lower in the latter study which the authors attributed to a more restricted definition of the concept of DD which they used.[5 6]

Children with DD have long-term multiple impairments and activity limitation as well as complex healthcare needs. They have problems with feeding, sleep and exhibit challenging behaviours such as aggression, hyperactivity, impulsivity, self-injurious behaviours and destructive behaviours.[7] These and other problems of children with DD make caring for them stressful,[8] increase care burden,[9 10] negatively affecting the functioning and stability of families.[11 12] Family caregivers (persons providing informal unpaid services for children at home) may view provision of continuous care to the child with DD as a moral responsibility and will do it in both chronic and acute situations.[13] Family caregivers in most cultures are mainly mothers who assume the caring responsibility for the child's life.[14] It has been asserted that most of these mothers are overburdened with caring duties and may experience episodes of depression, anxiety, grief and social isolation. In worse-case scenarios, mothers or caregivers in general do lose their employments or give up their businesses to be able to support their disabled child.[14 15] Subsequently, the care demands negatively affect caregivers physically,[16] psychologically and socially.[17 18] For example, it has been documented that chronic stress negatively affects caregivers' cardiovascular, immune and gastrointestinal systems[19 20] and this is linked to disturbances in the cortisol patterns.[21] Somatic symptoms like headaches, backaches, gastrointestinal problems, and respiratory infection have been reported[22 23] in caregivers of children with disabilities. The bigger impact is that poor health status of the caregiver is linked to frequent hospitalisations of the child with DD,[24] emotional and behavioural problems,[25] lower health related quality of life of the child,[26] negative parenting behaviour due to caregivers irritability and hostility towards the child.[27 28] Several studies abound in the literature highlighting the experiences of caregivers of children with specific disability and the need for a support service that improves the well-being of caregivers.[11 29–33] Despite the fact that most of these current studies are based on specific disabilities especially in ASD,[11 29 30 32] the need for support services for caregivers of children with DD is still necessary. Though currently there exist some systematic reviews in the field,[28–31] nevertheless, these reviews are either focused on the child with the disability and not the caregiver[28 29] or the focus is on just autism[31] or only on the level of caregiver burden.[30] Therefore, to the best of our knowledge, it is imperative to synthesise the evidence on existing support services or intervention that seeks to promote the well-being of family caregivers.

Review aims

The review aims to:

1. Identify the types of support systems or interventions available for caregivers of children with DD.
2. Summarise key intervention strategies and outcomes for caregivers of children with DD.
3. Identify research gaps in the literature through evidence mapping.

METHODS AND ANALYSIS

This scoping review process is guided by the methodological framework of Arksey and O'Malley[33] and the Joanna Briggs Institutes (JBI) guidelines.[34] Based on these guidelines, the scoping review process comprise six stages namely: (1) identifying the research question; (2) identifying relevant studies; (3) study selection process; (4) charting the data; (5) collecting, summarising and reporting the results and (6) a consultation exercise. The review is intended to start from December 2022 and end by March 2023. PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) checklist is provided as online supplemental file 1.

Stage 1: identifying the research question

1. What types of interventions or support programmes have been implemented and evaluated for caregivers of children with DD?
2. What are the strategies and characteristics of interventions for caregivers of children with DD?
3. What are the caregiver outcomes assessed using the current caregiver interventions?

Stage 2: identifying relevant studies

Searching for studies in a scoping review usually adapts a broad approach irrespective of it being qualitative or quantitative.[34] Nevertheless, the search is supposed to be comprehensive enough to identify even grey literature. The JBI provides a three-step strategy and this will be used in the scoping review.[34] The first step will begin with limited search of at least two databases which are relevant to the study. The aim of this initial search is to analyse text words that are found in the retrieved papers with the focus on the title and the abstract. The key words or index terms will also be analysed. The second step will involve conducting another search using all the index terms that will be identified in step one. In this case, the search will not be limited to only two databases but rather it will be done across all databases that is to be used in the scoping review. The final step will involve searching the reference list of all identified studies for additional studies. Databases vary in how subject headings are indexed. Therefore, keywords may be modified according to each database index terms. Table 1 presents basic keywords constructing the search strategy.

Initial search

Two databases (CINAHL Complete and Psych Info) will be used for the initial search. The search terms will be caregiver, carer, child, children, developmental disability, intellectual disability, developmental delay, intervention, programme,

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Table 1 Search strategy

Key word	Alternative words
Caregiver	Father, mother, parent, family, carer
Children	Juvenile, young adult, teenager, adolescent
Developmental disability	Developmental delay, cognitive disabilities, developmental disorders, intellectual disabilit, learning disabilities, neurodevelopmental disabilities, intellectual and developmental disabilities, cognitive impairment, intellectual disability
Intervention	Supports, services, education, training, programme, therapy
Supports	Maternal health, self-care, peer-support, parent groups
Well-being	Wellness, health

training, well-being, well-being, well-being. Boolean operators like 'OR' and 'AND' will be used to link the words for the search. The search will not be limited to any time period and but to journal articles in English language.

Search across five databases

Five databases will be searched namely, PubMed, PSYCHINFO, Cochrane Library, ERIC and CINAHL complete. The following key words will be used: caregiver, well-being, interventions, child and developmental disabilities. In a scoping review, it is always important to construct a comprehensive search with the aim of not missing out on any study or article. For the databases search, the indexing terms or medical subject headings (MeSH) specific to the particular database will be used. Apart from the MeSH or indexing term for a particular keyword, alternative keywords will be used. For example, a phrase like developmental disabilities, alternative key words such as developmental delay, cognitive disability or neurodevelopmental disability or intellectual disability will be used. Additionally, to broaden the search, the root word will be used and truncation symbol will be put at the end. For example, famil* will yield results of family and families. Quotation marks will be used for phrase searching to ensure that the results retrieved from the search engine are accurate. A phrase like developmental disabilities will bring back results that have those words in them. For example, in PubMed a search returned 32 208 results while 'developmental disabilities' returned 28 735.

The search in the databases will be done using modified search strategy specific to each database. Boolean operators like 'OR' and 'AND' will be used to link the words for the search. The final search strategy will be developed by NN and a librarian at the University of Witwatersrand, Faculty of Health and Medical Sciences library.

As an illustration, we will input the following key words to search articles in the CINAHL database: (MH "Caregivers" OR father* OR mother* OR parent* OR famil* OR caregiver* OR caregiver* OR carer*) AND (MH "Wellness" OR "well-being" OR health) AND (MH "Psychosocial Intervention" OR educat* OR train* OR program* OR therap* OR intervention* OR treatment* OR skill*) AND (MH "Child" OR child* OR juvenile OR "young adult*" OR teenage* OR adolescen*) AND (MH "Developmental Disabilities" OR "developmental delay*" OR "cognitive disabilit*" OR "developmental disorder*" OR "intellectual disabilit*" OR "learning disabilit*" OR "neurodevelopmental disabilit*" OR "intellectual and developmental disabilit*" OR "cognitive impairment*" OR "mental* retard*"). The search strategy for the various databases are presented as online supplemental file 2.

Searching the reference of identified studies/other sources

The reference list of identified studies will be searched to identify additional studies. This is important because the researchers will like to exhaust all possible means and to avoid as much as possible any chance of excluding some studies.

Stage 3: study screening and selection

Screening and selection of the studies will be guided by the predetermined inclusion and exclusion criteria. The results from each of the database will be imported to a reference manager, Mendeley to remove duplicates. After removal of the duplicates, the articles will be exported to Covidence, a review management system for screening of the articles. The screening of the titles and the abstract will be done independently by two reviewers (DAA and JNS) for eligibility. Differences which will arise among the reviewers will be resolved by NN. The screening of titles and abstracts are followed by the full text review done independently by two reviewers (DAA and JNS). In the event of a disagreement, a third reviewer (NN) the final decision.

Review inclusion criteria/Eligibility criteria

The following criterion, will be applied in selecting the studies:

Population

The review will consider primary studies whose participants are adults above age 18 years old and caring for a child with DD between the ages of 5–16 years old. Thus, the study considers adult family caregivers providing daily care for the child with DD. Family caregivers operationally defined as parents, relatives or other non-kin members providing unpaid for services for the child at home. Any caregiver not involved in the daily care process of the child will be excluded. This is because caregivers who may not be intensely involved in the care of the child with DD but only provide a supporting role once a while could have different health needs and experiences. Adults with DD may have different needs as compared with children. Also, the diagnosis of most DDs in children is mostly confirmed after 5 years.[35 36]

Concept

We will include interventions that are aimed at improving the well-being of caregivers of children with DD. Interventions that are not focused on the health of the caregiver and on the child with DD will not be included. Interventions focused on the child with DD may not necessarily have an impact on the

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primary caregiver. Again, not all interventions are tailored towards the well-being of the caregiver.

Context

The context of the current review will not be restricted to any particular geographical location. That is, the review will include studies from both resource constraint developing countries and developed settings. This will provide a more comprehensive and broader understanding of the categories of interventions for caregivers across contexts.

Types of studies

Studies to be included in the scoping review are: Randomized Control Trial, Quasi-experimental (Cohort) Trial, Single Group Trial, Single Subject Experimental Design. However, studies such as opinions pieces as: conference presentations, dissertations, discussion papers, case study, book, editorials or commentaries and systematic review will be excluded. The interventions are aimed at assessing its impact on certain outcome variables, therefore it will be impossible to achieve this with opinion papers and others. Systematic reviews and meta-analysis provide evidence-based and are pool of interventions put together and such evidence may not be relevant for the scoping review.

Research papers in languages other than English will be excluded as the researchers might have need to translate those studies before they could be used. Search for studies will not be limited to any time period.

Types of outcome measures

All types of interventions will be considered, including those that will focus on one particular outcome or multiple outcomes. Thus, the interventions could address any or all of the following outcome areas: stress, burden, social support, physical health, mental ill health.

Stage 4: data extraction

Charting the results is also referred to as extraction of results. Joanna Briggs Institute, 2015 Charting results provides a descriptive and logical summary of the results. It is an iterative process as the charting table is updated continually. The information that will be charted include author(s), year of publication, origin/country of origin, purpose of study, study population and sample size, methodology, intervention type and key findings. Table 2 is the proposed data extraction template.

Stage 5: collecting, summarising and reporting the results

The results will be summarised using multiple methods as follows: numeric, narrative and thematic approaches. The studies will be summarised under these headings: distribution by geographical location, journals, year of publication and number of participants. Others will include number of assessments, inclusion and exclusion criteria, interventions, quality assessment and analysis of themes.

Quality assessment of data

Unlike systematic reviews, scoping reviews do not require quality assessment of the data.[37] Nevertheless, non-assessment of quality in scoping reviews may limit the usefulness of the review findings.[34] Therefore, some authors suggest that this could be done at the discretion of reviewers depending on the purpose of the review. To obtain an idea of the quality of the studies and the resultant caregiver outcomes, the JBI Critical Appraisal Checklists[38] will be used for assessing methodological quality of included studies in this review.

Patient and public involvement

None.

Expected results

Data synthesis from this review will unearth current caregiver interventions in use or developed that will serve as basis to develop or adapt interventions for various contexts where they are non-existent. The intervention types, support systems, services, strategies or mode of delivery and the resultant caregiver health outcomes will be captured to facilitate identification of support needs gaps in the literature. Thus, data from this review would facilitate evidence mapping to engender new areas that will require research.

CONCLUSION

The scoping review of interventions for caregivers of children with DD will provide a detailed summary of the available evidence for the effectiveness of interventions in improving the well-being of caregivers.

Ethics and dissemination

No ethics approval is required since the study involve synthesis of only already published information from primary studies. After completing this scoping review, the results will be disseminated through publication in a peer-reviewed journal.

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Contributors DAA and NN initiated and designed the study. DAA and JNS will do the screening of abstract and full text with disagreement to be resolved by NN. All authors read and approved the final manuscript.

Table 2 Sample data extraction sheet

Author /year	Country of origin	Purpose of study	Study population	Sample size	Methodology	Intervention details	Key findings
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