

Work ability of people with sickle cell disease: scoping review protocol

Capacidade para o trabalho de pessoas com doença falciforme: protocolo de revisão de escopo

Sânzia Bezerra Ribeiro¹
ORCID: 0000-0001-8068-2715

Eliana do Sacramento de Almeida¹
ORCID: 0000-0002-0305-2469

Flávia Karine Leal Lacerda¹
ORCID: 0000-0003-0222-3825

Anderson Reis de Sousa¹
ORCID: 0000-0001-8534-1960

Evanilda Souza de Santana Carvalho²
ORCID: 0000-0003-4564-0768

Sílvia Lúcia Ferreira¹
ORCID: 0000-0003-1260-1623

¹Universidade Federal da Bahia,
Salvador, BA, Brasil

²Universidade Estadual de Feira de
Santana, Feira de Santana, BA, Brasil

Editors:

Ana Carla Dantas Cavalcanti
ORCID: 0000-0003-3531-4694

Paula Vanessa Peclat Flores
ORCID: 0000-0002-9726-5229

Alessandra Conceição Leite
Funchal Camacho
ORCID: 0000-0001-6600-6630

Corresponding author:

Sânzia Bezerra Ribeiro
E-mail: sanziazar@gmail.com

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ABSTRACT

Objective: To map the evidence on the work capacity of people with sickle cell disease according to the Joanna Briggs Institute (JBI) manual guidelines. **Method:** The search sources will be: Physiotherapy Evidence Database (Pedro), Scientific Electronic Library Online (SciELO), Latin American and Caribbean Health Sciences Literature (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed, Cochrane, Cumulative Index to Nursing and Allied Health Literature (CINAHL), SCOPUS, Web of Science, Embase, BVS-Psi, Theses and Dissertations Catalog of the Coordination for the Improvement of Higher Education Personnel (CAPES), and Google Scholar as gray literature. Published studies that meet the inclusion criteria will be considered without language and time restrictions. Two independent reviewers will select publications, and, if necessary, a third reviewer will participate in case of disagreements. Data will be extracted using an instrument developed by the reviewers, and the results will be presented and described through tables, flowcharts, graphs, and narrative and interpretative synthesis.

Descriptors: Anemia, Sickle Cell; Work Capacity Evolution; Work Performance; Work-Life Balance.

RESUMO

Objetivo: Apresentar um protocolo de revisão de escopo para mapear e descrever os estudos disponíveis na literatura científica acerca da presença e participação do pai no cuidado ao filho com doença grave. **Método:** O protocolo seguirá o método proposto pelo *Joanna Briggs Institute* (JBI) e as diretrizes do *Preferred Reporting Items for Systematic reviews and Meta-Analyses – Extension for Scoping Reviews* (PRISMA-ScR) para relato de protocolos de revisão. Nossa pergunta norteadora foi “Como ocorre a participação do pai no cuidado ao filho com doença grave?”. Será utilizada uma estratégia de busca detalhada empregando a estratégia PCC (população, conceito e contexto) nas bases de dados CINAHL, Embase, Scopus, *Web of Science*, SciELO, PubMed e Biblioteca Virtual em Saúde (BVS). Para busca de literatura cinzenta, serão utilizados o *Google Acadêmico* e Catálogo de Teses e Dissertações da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES). Dois revisores independentes selecionarão os resultados da busca por meio da informação do título e resumo. Em seguida, realizarão a leitura dos estudos na íntegra, considerando os critérios de elegibilidade, e extrairão, por meio de um formulário padronizado, as informações pertinentes à revisão a qual esse protocolo se propõe. Os resultados serão demonstrados na forma de quadro, fluxograma, figuras, resumo narrativo e descritivo.

Descritores: Pai; Relações Pai-Filho; Comportamento Paterno; Cuidado da Criança; Doença Catastrófica.

INTRODUCTION

Work ability (WA) can be understood as the physical and mental capacity demonstrated by a worker to perform tasks, considering the demands of the work and its social, cultural, organizational, and environmental aspects⁽¹⁾. Studies suggest that the risk of loss of WA may be more pre-

valent in women, influenced by their involvement in occupations with greater work precariousness⁽²⁻³⁾. WA becomes an important indicator of the quality of life for workers, as low levels of WA impact their health, which may lead to the need for actions that promote changes in workers' lifestyles and organizational changes that promote well-being and a healthy stay at work⁽³⁾.

Entering and remaining in the job market are also challenges for people with special health conditions, such as sickle cell disease (SCD). Due to the chronicity of the disease and the intense and progressive pain, people with SCD experience restrictions in the physical, psychological, and independence domains, in addition to suffering from the possibility of limitations and loss of WA⁽⁴⁻⁵⁾.

The term "sickle cell diseases" refers to hemoglobinopathies that contain hemoglobin S in their constitution, with sickle cell anemia (gene "S") being the most severe form. It is estimated that, worldwide, 250,000 children are born each year with sickle cell anemia, with a ratio of 1/1,000 live births, corresponding to approximately 5% of the world population⁽⁶⁾. Sub-Saharan Africa has the highest prevalence of SCD, followed by India and the Mediterranean area, but it is also present in Europe and the Americas⁽⁶⁻⁷⁾. In Brazil, the prevalence is higher among people of African descent, with the highest rates in the Northeast, where the prevalence of the gene is 3%⁽⁸⁻⁹⁾. Bahia has the highest prevalence, with a ratio of 1/650 live births, corresponding to a 5.5% prevalence of the gene^(8,10). Data from the Ministry of Health indicate that these frequencies can vary from 6% to 10% in the Black population⁽¹⁰⁾. This prevalence in the Recôncavo Baiano region is even higher, with the municipality of Cachoeira presenting a ratio of 1:314 live births⁽¹⁰⁾. SCD is a disease that contributes to lower functional capacity scores in these individuals⁽¹¹⁾.

Regarding the relationship between people with SCD and work, studies in several countries, including Brazil, demonstrate that the functional losses caused by the chronicity of SCD, combined with the consequences of low education and qualifications, contribute to difficulties in entering the labor market⁽¹²⁻¹⁴⁾. This is reflected in high rates of unemployment or engagement in underemployment and/or informal work relationships for these individuals⁽¹²⁾. Research also reveals that individuals with less severe forms of the disease who live in rural areas, have a high level of education, are married, practice regular physical activity, have a job, and have access to and adhere to treatment have higher quali-

ty of life scores⁽⁴⁾. A study with English workers with SCD found that the greater frequency and severity of vaso-occlusive and painful crises contribute to lower productivity at work and worse quality of life scores for these individuals⁽¹⁵⁾. Furthermore, vaso-occlusive crises make it difficult to fully perform the role of a worker in the present and generate poor prospects for the future despite the significant importance attributed to work^(1,5). Despite being an important indicator due to its influence on the health, well-being, and employability of workers, WA still needs greater attention in Brazil⁽¹⁾.

Although the existing literature shows that advances in health have made it possible to increase the life expectancy of people with SCD and, consequently, the possibility of fulfilling the role of a worker, no review studies have been found to date that systematize the WA aspects of people with SCD as a resource to understand the impact of the chronicity of the disease on their functionality, thus enabling adequate access to and retention in the job market.

This review, therefore, will contribute to the understanding of the concept of WA, systematizing the findings for better comprehension by health professionals, managers, and employers regarding the possibilities and limitations of workers with SCD in workspaces. This will allow for more inclusive actions aimed at promoting and protecting the health of workers with SCD; it will serve as theoretical support in the formulation of public policies that enable people with SCD to enter and remain in the job market; and, finally, it may contribute to expanding access and retention at work, improving working conditions, and enhancing the quality of life for workers with SCD.

In view of the above and based on a preliminary search carried out in Prospective Register of Systematic Reviews (PROSPERO), Medical Literature Analysis and Retrieval System Online (MEDLINE), the Cochrane Database of Systematic Reviews, and JBI Evidence Synthesis on this topic, no existing systematic reviews or protocols were found, completed, or in progress during searches conducted in September and December 2022, February 2023, December 2023, and March 2024. Therefore, this scoping review is justified in summarizing the available evidence on WA in the context of SCD.

Search question

What evidence is available on the work ability of people with sickle cell disease?

Secondary questions

1. How does the literature conceptualize work ability?
2. What facilitators and barriers impact the WA of people with SCD when entering and remaining in the job market?

Inclusion criteria

Participants

All studies conducted with people with sickle cell disease (sickle cell anemia, SC hemoglobinopathies, DS hemoglobinopathy, S/beta-thalassemia), aged over 18 years and with different levels of education, which consider the implications of sickle cell disease on work-related outcomes, regardless of the production sector, employment relationship (formal and informal), and geographic context, will be included. Studies with individuals who only present the sickle cell trait, as well as studies that address functional capacity in children, adolescents, and the elderly, will be excluded.

Concept

The included articles will consider work ability according to the theoretical stress-strain model of Rutenfranz and Colquhoun, developed at the Finnish Institute of Occupational Health (FIOH) in the 1980s. This model defines WA as the physical and mental capacity of the worker to perform the tasks required by the job, considering social, cultural, organizational, and environmental aspects^(1,2).

Context

The review will include studies on formal and informal work/occupation in different productive sectors and geographic contexts, allowing for various inferences about WA. Due to the scarcity of studies on the topic, the context will not be specified regarding the production sector, location, or work environment. All available studies that meet the inclusion and exclusion criteria will be included.

Types of sources

This scoping review will consider qualitative and quantitative research studies without excluding specific study designs due to the scarcity of studies on the topic and the need to capture as much of the existing literature as possible to respond to the proposed objectives. Therefore, quantitative experimental, quasi-experimental, and analytical and descriptive observational studies will be included, as well as qualitative studies, including articles based on phenomenology, grounded theory, oral history, qualitative description, ac-

tion research, and studies that address feminist theories, intersectionality, and work as a social determinant of health. Systematic reviews, opinion articles, texts that meet the inclusion criteria, and additional sources from gray literature, dissertations, and theses will also be included.

METHOD

This scoping review will be conducted using the criteria proposed in the Joanna Briggs Institute (JBI) methodology manual for scoping reviews, available at [Scoping.pdf \(reben.com.br\)](https://www.reben.com.br). The research was developed using the PCC mnemonic, where P represents Population – women and men with sickle cell disease, C represents Concept – Work Ability, and C represents Context – Global, covering formal and informal work/occupation in different productive sectors. Based on this structure, the research question, study objective, and descriptors were formulated.

Search strategy

The search strategy will be essential to locate original published studies that meet the inclusion criteria. Initially, a preliminary search was conducted in the PubMed, Scientific Electronic Library Online (SciELO), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Google Scholar databases to identify articles related to the topic. Some of these articles were used in the introduction of this protocol. Additionally, systematic and scoping review databases, such as Cochrane, Open Science Framework (OSF) HOME, and JBI Evidence, were consulted to check for completed and ongoing reviews on the topic, but no relevant records were found. This scoping review protocol was registered with OSF HOME in April 2023 and is available at the following website: <https://osf.io/ndzk9/>.

Considering the need to expand the search, a second review stage will include additional sources of information and databases. The MEDLINE/LILACS (*Literatura Latino-Americana e do Caribe em Ciências da Saúde*), CINAHL, PEDro (physiotherapy database), BVS-Psi, Cochrane, Excerpta Medica Database (Embase), Scopus, and Web of Science databases will be used. The following descriptors will be utilized in Portuguese: “capacidade de trabalho,” “capacidade laborativa,” “capacidade de emprego,” “doença falciforme,” “anemia falciforme”; and in English: “work ability” OR “work capacity” AND “sickle cell disease,” “labor capacity” AND “sickle cell disease,” as described by *Descritores em Ciências da Saúde* (DeCS)/Medical Subject Headings (MeSH). Boolean operators AND, OR, and NOT will refine the

search and identify additional terms/keywords that can contribute to developing a more robust search strategy. The search will also include identifying other sources of information and databases that can contribute to new studies, including gray literature such as Google Scholar and the Brazilian Digital Library of Theses and Dissertations (BDTD). The assistance of a librarian will be crucial in optimizing the search for these studies. The search strategy (Figure 1) will include all identified keywords and indexing terms, and it will be adapted for each database and/or source

of information. A table will be prepared containing this information (source of information/database, keywords/indexing terms, search strategy, date, and number of studies found) and will be included as an appendix in the final article of this review. The reference list of all included sources of evidence and the authors' contact details will be examined to clarify doubts and identify additional studies. Given the already identified scarcity of studies on this topic, studies published without time limitations will be included in this review, preferably in English, Spanish, and Portuguese.

Figure 1 - Search Strategies. Cachoeira, BA, Brazil, 2023-2024

DATABASES/INFORMATION SOURCES	SEARCH STRATEGY	AMOUNT
Embase Human Resources Abstracts	("work skills" OR "work ability" OR "work capacity") AND "chronic diseases" AND ("sickle cell anemia" OR "Sickle cell diseases" OR "sickle cell illness")	146
Scopus	TITLE-ABS-KEY-AUTH ("work skills" OR "work ability" OR "work capacity") AND TITLE-ABS-KEY-AUTH ("sickle cell anemia" OR "Sickle cell diseases" OR "sickle cell illness")	10
Socindex	("work skills" OR "work ability" OR "work capacity") AND ("sickle cell anemia" OR "Sickle cell diseases" OR "sickle cell illness")	0
SocINDEX with Full Text (EBSCOhost)	("work skills" OR "work ability" OR "work capacity") AND ("chronic disease" OR "chronic illness" OR "long term conditions" OR "chronic conditions") NOT ("elderly" OR "geriatrics" OR "aging" OR "older")	7
MEDLINE/PubMed (via National Library of Medicine)	("work skills" OR "work ability" OR "work capacity") AND ("sickle cell anemia" OR "Sickle cell diseases" OR "sickle cell illness") NOT "children"	6
Embase	('chronic disease' OR 'chronic illness' OR 'long term conditions' OR 'chronic conditions') AND ('sickle cell anemia'/exp OR 'sickle cell anemia' OR 'sickle cell diseases' OR 'sickle cell illness') AND 'adults' NOT 'children' NOT ('elderly' OR 'geriatrics' OR 'aging' OR 'older') AND [embase]/lim NOT ([embase]/lim AND [medline]/lim)	53
Embase	((('work skills evaluation' OR 'work ability') AND evaluation OR 'work capacity evaluation') AND 'chronic disease' OR 'chronic illness' OR 'long term conditions' OR 'chronic conditions') AND ('black person' OR 'african american') AND ('sickle cell anemia'/exp OR 'sickle cell anemia' OR 'sickle cell diseases' OR 'sickle cell illness') AND [embase]/lim NOT ([embase]/lim AND [medline]/lim)	17
Psyinfo	(Any Field: "sickle cell anemia" OR Any Field: "Sickle cell diseases" OR Any Field: "sickle cell illness") AND Any Field: "work capacity" OR Any Field: "work skills" OR Any Field: "work ability") AND Index Term: Job Performance	106
Google Scholar	("anemia falciforme" OR "doença falciforme" OR "sickle cell diseases" OR "sickle cell illness") AND ("capacidade de trabalho" OR "work capacity") AND (mulher* OR mujer* OR women)	173
SciELO Citation Index (Web of Science)	(((((TS=("work skills") OR TS=("work capacity")) OR TS=(work ability)) AND TS=(Sickle cell disease)) OR TS=(sickle cell anemia)) OR TS=(sickle cell illness)) AND TS=(chronic diseases)	9
Physiotherapy Evidence Database (Pedro)	Sickle cell disease AND work capacity sickle cell disease AND work ability sickle cell disease AND work skills	1 1 0
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	("work skills" OR "work ability" OR "work capacity") AND "chronic diseases" AND ("sickle cell anemia" OR "Sickle cell diseases" OR "sickle cell illness")	0
Web of Science (WOS)	(((((ALL=("work skills") OR ALL=("work ability")) OR ALL=("work capacity")) AND ALL=("chronic diseases")) AND ALL=("sickle cell anemia")) OR ALL=("Sickle cell diseases")) OR ALL=("sickle cell illness"))	175
Brazilian Digital Library of Theses and Dissertations (BDTD)	"work skills" OR "work ability" AND "chronic diseases" OR "sickle cell anemia" OR "Sickle cell diseases"	138
TOTAL		842

Study selection

The preliminary selection will be conducted by reading the titles and abstracts of the articles containing the selected descriptors. Two independent researchers will carry out this process. Bibliographic management software, Zotero 6.0⁽¹⁶⁾, will be used to manage citations and remove duplicates from the articles found. The selection process of included studies and data extraction will be conducted using the Rayyan platform⁽¹⁷⁾. The reviewers will independently analyze each included article according to the inclusion criteria. The exclusion of an article will be based on its non-compliance with the inclusion criteria and will be duly recorded and reported in the scoping review.

In case of disagreement between the reviewers regarding the inclusion of a study, the team will discuss whether to withdraw or include the study. If necessary, a new reviewer will be involved, or the study authors may be contacted to clarify any doubts. The results of the research, including the process of identification, selection, eligibility, and inclusion of studies, will be presented in the final scoping review, following the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses for Scoping Reviews (PRISMA-ScR) flowchart, available at: JBI Manual for Evidence Synthesis - JBI Global Wiki (refined.site)⁽¹⁸⁾.

Data Extraction

Data extraction will be conducted using an instrument (Figure 2) developed by the researchers following the methodological guidance for JBI scoping reviews. Two independent reviewers will carry out the extraction process. In case of disagreements, a third reviewer may be involved, or the studies' authors may be contacted to clarify any doubts.

The extracted data will include study characterization aspects such as reference, author, title, year, country, type of study, and the study's objective. Additionally, detailed aspects of the studies will be included, such as population, concept, context, instruments, procedures, strategies, domains, dimensions, variables, and the main outcomes related to work ability.

If necessary, the data extraction instrument may be modified and revised during the extraction process. Any changes made will be duly reported in the review article.

Figure 2 – Data extraction instrument. Cachoeira, BA, Brazil, 2024

GENERAL INFORMATION								
Investigator who extracted the data: xxxxxxxxx Extraction date: xxxxxxxxx								
SCOPING REVIEW DETAILS:								
Review title: WORK ABILITY OF PEOPLE WITH SICKLE CELL DISEASE: A SCOPING REVIEW General objective of the review: Map the evidence on the work ability of people with sickle cell disease globally.								
Review questions:								
-What evidence is available on the work ability of people with sickle cell disease?								
-How does the literature present the concept of work ability?								
-What are the facilitators and barriers that impact the work ability of people with sickle cell disease when entering and remaining in the job market?								
Inclusion/exclusion criteria:								
Population: Women and men with sickle cell disease, aged over 18 years, diagnosed with SCD.								
Concept: Work ability								
Context: Global, formal, and informal occupations across different productive sectors and geographic locations.								
EXTRACTION OF STUDY CHARACTERIZATION:								
Source of Information/Database:								
N	Reference	Author	Title	Year	Country	Type of study/ methodological approach	Research Question	Objective of the Study
DETAILS OF THE STUDY								
Inclusion Criteria								
Main results								
Concept								
Components of work ability (attributes, characteristics...)								
Facilitating factors for work ability								
Hindering factors (barriers) to work ability								
Conclusions								

Source: JBI Manual for Evidence Synthesis adapted from Aromataris and Munn, 2021.

Data analysis and presentation

Rayyan software will support data analysis for organizing and managing the data extracted from selected articles. The choice of presentation format will be guided by the content of the included sources and the review questions and objectives. The software can select the appropriate graphs, tables, and charts representing the extracted and analyzed data. Explanations of the categories presented will be based on the theoretical framework and described in a narrative synthesis. For qualitative data extraction, the textual corpus related to strategies, procedures, domains, dimensions, and variables of work ability will be analyzed using IRAMUTEQ (R Interface for Multidimensional Analysis of Texts and Questionnaires), a software that categorizes information based on textual analysis⁽¹⁹⁾. Based on the categories provided by IRAMUTEQ, more in-depth analyses can be conducted using Thematic Analysis as proposed by Braun and Clarke⁽²⁰⁾. The final report of this scoping review will adhere to the recommendations outlined in the JBI guidelines, available on the JBI Evidence Synthesis website (Chapter 11: Scoping Reviews - JBI Manual for Evidence Synthesis - JBI Global Wiki - refined.site)⁽¹⁸⁾.

*Paper extracted from the dissertation "Functionality, work ability, adaptation and health care of women and men with sickle cell disease: case study", presented to the Universidade Federal da Bahia, Salvador, BA, Brazil.

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CONFLICT OF INTERESTS

The authors have declared that there is no conflict of interests.

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AUTHORSHIP CONTRIBUTIONS

Project design: Ribeiro SB, Sousa AR de, Carvalho ES de S, Ferreira SL

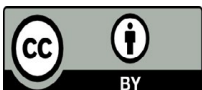
Data collection: Ribeiro SB, Almeida E do S de, Lacerda FKL, Sousa AR de, Carvalho ES de S, Ferreira SL

Data analysis and interpretation: Ribeiro SB, Almeida E do S de, Lacerda FKL, Sousa AR de, Carvalho ES de S, Ferreira SL

Writing and/or critical review of the intellectual content: Ribeiro SB, Almeida E do S de, Lacerda FKL, Sousa AR de, Carvalho ES de S, Ferreira SL

Final approval of the version to be published: Ribeiro SB, Almeida E do S de, Lacerda FKL, Sousa AR de, Carvalho ES de S, Ferreira SL

Responsibility for the text in ensuring the accuracy and completeness of any part of the paper: Ribeiro SB, Almeida E do S de, Lacerda FKL, Sousa AR de, Carvalho ES de S, Ferreira SL



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