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Quality of life of individuals born preterm: scoping review

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ABSTRACT

Objectives: to map the knowledge produced on the assessment of the quality of life of individuals born preterm. **Methods:** a scoping review was developed according to the JBI manual and structured based on the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) recommendations. Information on language, country, population characterization, main results, as well as the instruments and domains used to assess the quality of life of live preterm births was extracted. **Results:** of the 509 works initially identified, 22 articles were included. These pointed to the impairments in quality of life caused by preterm birth, which may be greater in populations of preterm births with some disability. Sixteen types of instruments, answered by children, adolescents, and adults born prematurely, and by their parents and caregivers, were used to measure quality of life. Instruments applied to parents or caregivers showed lower scores than those reported by individuals themselves. **Conclusion:** the lower the gestational age, the greater the potential impairment in the quality of life of individuals born prematurely, especially in terms of physical, psychological, emotional, and social domains.

Descriptors: Infant, Premature; Child; Adolescent; Adult; Quality of Life.

INTRODUCTION

Quality of life (QoL) has become a fundamental aspect of health since the 1990s. It is currently used in healthcare services, consultations and research, and as one of the criteria for patient assessment[1].

The World Health Organization (WHO) defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"[2]. The concept of health-related QoL (HRQoL) has a more restricted meaning and refers to situations that associate QoL with an individual's experiences with health, illness, and medical interventions[1,2].

Technological advances in the field of neonatology have led to an increase in the survival rate of newborns with increasingly lower gestational ages. Consequently, concern regarding their prognoses and QoL has grown, since birth before term and the need for complex and continuous medications, devices or care to ensure survival can lead to physical, psychological, and emotional impairments into adulthood[3-5]. Living with conditions that require special care can compromise the daily lives and QoL of individuals born preterm, not only after birth but also in other phases of the life cycle.

The unsatisfactory QoL of individuals born preterm is related to prolonged health problems, developmental delays, cognitive impairments, attention deficit/hyperactivity disorder, and poor perception by parents or caregivers of the QoL of

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the individual born preterm. Controlling these factors can lead to this population enjoying better QoL, similar to those born at term[6-8].

In assessing the QoL of individuals born preterm, studies indicate that parents and/or direct caregivers are largely responsible for information related to QoL[1,9]. Despite the importance of parental reports, they can be influenced by personal feelings and expectations. Children can self-report their QoL using specific instruments[1,9], and those under seven years of age are able to answer questions about their physical and mental health, provided the questions are formulated according to their level of understanding[9]. Although most of the instruments used to assess QoL are aimed at children over eight years old, there are instruments used to assess younger children, from the age of four[1].

Given the above, the following questions arise: How do individuals born preterm assess their QoL? When assessed by parents or caregivers, are there similarities or discrepancies in the reports? What are the main QoL assessment instruments used in individuals born preterm? Are there greater impacts on the QoL of preterm individuals depending on gestational age?

Answering these questions could enhance the practices of health professionals by offering comprehensive and longitudinal care to this population, and help identify existing gaps for future research[1,10-12].

Therefore, this study aimed to map the knowledge produced on the assessment of QoL in individuals born preterm.

METHODS

Scoping review developed according to the JBI manual[13] to conduct a broad literature search on evidence related to the QoL of individuals born preterm and the factors that influence it throughout life.

The review was developed in nine stages[13]. In the first stage, the objective and research question were defined and aligned using the mnemonic PCC: P (Population) children, adolescents, and adults born preterm; C (Concept) Quality of Life (QoL); and C (Context) worldwide. From this, the following research question was formulated: What knowledge is available in the literature regarding the assessment of QoL in individuals born preterm?

In the second stage, primary studies on the QoL of individuals classified as preterm at birth (gestational age between 23 weeks and 37 weeks and six days), regardless of birth weight, from the perspective of the individuals themselves or their primary caregiver (parents or legal guardians), without language restrictions, published between February 2015 and April 2022, were included. This inicial period was delimited due to the production of a systematic review[10] on the subject, including studies up to January 2015. Studies that did not answer the research question, duplicates across databases, review articles, commentaries, editorials, dissertations, and theses were excluded.

In the third stage, a search for publications was conducted in the following databases: Medical Literature Analysis and Retrieval System (MEDLINE/PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL), *Excerpta Medica dataBASE* (EMBASE), Cochrane Library, APA Psychology Information (PsycINFO), and Latin American and Caribbean Health Sciences Literature (LILACS). Secondary searches were performed in Google Scholar and in the reference lists of the studies included in this review. These databases were selected to encompass national and international studies. Search strategies were constructed in each database, using controlled and uncontrolled descriptors (keywords), which were synthesized according to the PCC strategy and its combinations. To illustrate this process, the search strategy used in the MEDLINE database is presented in Table 1.

The search took place between February and April 2022. This stage was carried out independently by two duly trained researchers. To prepare for the reviews, one reviewer received training from the JBI Brazil and subsequently shared the learned guidelines with the other reviewers before the study commenced.

Table 1 - Strategy used in the *Medical Literature Analysis and Retrieval System Online* - MEDLINE database (via PubMed), 2022

Strategy used in the *Medical Literature Analysis and Retrieval System Online* - MEDLINE database
(Child [Mesh Terms] OR Children [All fields] OR Adolescent [Mesh Terms] Adolescents [All fields] OR Adolescence [All fields] OR Teens [All fields] OR Teen [All fields] OR Teenagers [All fields] OR Teenager [All fields] OR Youth [All fields] OR Youths [All fields] OR Adult [Mesh Terms] OR Adults [All fields]) AND ("Premature Birth" [Mesh Terms] OR "Birth, Premature" [All fields] OR "Births, Premature" [All fields] OR "Premature Births" [All fields] OR "Preterm Birth" [All fields] OR "Birth, Preterm" [All fields] OR "Births, Preterm" [All fields] OR "Preterm Births" [All fields] OR "Infant, Premature" [Mesh Terms] OR "Infants, Premature" [All fields] OR "Premature Infant" [All fields] OR "Preterm Infants" [All fields] OR "Infant, Preterm" [All fields] OR "Infants, Preterm" [All fields] OR "Preterm Infant" [All fields] OR "Premature Infants" [All fields] OR "Neonatal Prematurity" [All fields] OR "Prematurity, Neonatal" [All fields]) AND ("Quality of life" [Mesh Terms] OR "Life Quality" [All fields] OR "Health-Related Quality of Life" [All fields] OR "Health Related Quality Of Life" [All fields] OR HRQOL [All fields] OR "Personal Satisfaction" [Mesh Terms] OR "Satisfaction, Personal" [All fields] OR Satisfaction [All fields])

In the fourth stage, the *Rayyan*® bibliographic manager (online version, Qatar Computing Research Institute, Qatar) was used to import the retrieved articles and exclude duplicate studies. Then, the titles and abstracts were analyzed according to the inclusion and exclusion criteria mentioned in the second stage, in conjunction with the PCC strategy of this study. Subsequently, the articles that underwent a new analysis in the fifth stage were selected.

During the development of the fifth stage, the studies were read in full. After the final selection of the texts, an analysis of the respective references was carried out using secondary searches. Throughout all stages, the differences between the two reviewers were discussed and reviewed with the support of a third reviewer.

The search and selection process was recorded based on the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)[14].

In the sixth stage, the main information was extracted and described from the selected articles, such as language, country, population characterization, main results, criteria used for QoL assessment, instruments used, and the QoL domains evaluated. The reviewers extracted the information from the selected studies jointly, with support from the third reviewer.

After collecting the information, a meeting was scheduled between the three reviewers to reach a consensus regarding the information obtained. In the seventh stage, the results were analyzed.

In the eighth stage, the data collection protocol developed in Microsoft Word® (2024, Microsoft Corporation, United States) enabled the synthesis and interpretation of data and the numerical analysis of the distribution of studies, which were represented by a narrative summary of the results and related to the objective and research question of the review.

In the ninth stage, a summary of the evidence containing conclusions, observations, and existing gaps was presented.

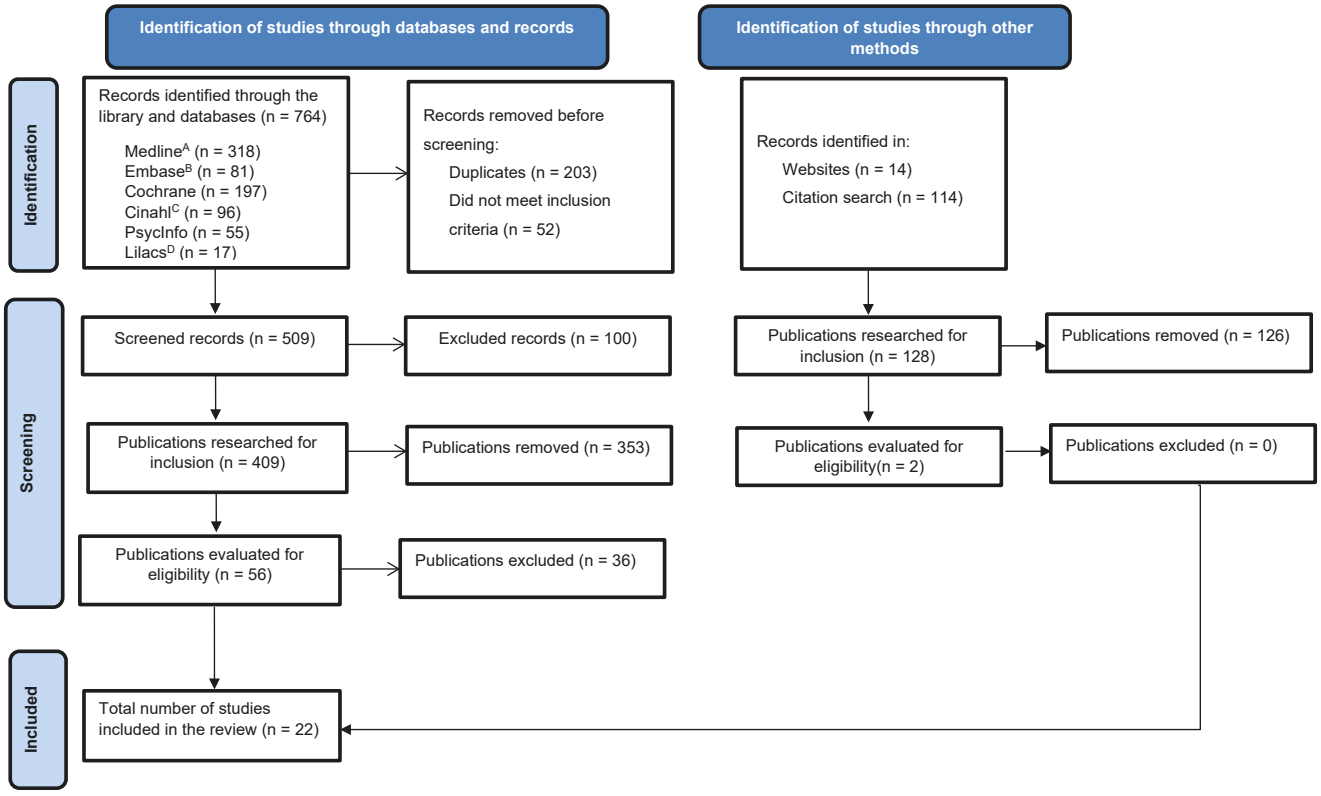
The reliability of the data presented in the selected publications was ensured through adequate referencing, rigorous data treatment, and clear presentation. Given the nature of this scoping review and the methodology adopted, a formal assessment of the methodological quality of the included studies was not required.

RESULTS

Initially, 509 references were identified from the primary search in the databases, and 121 were found in other sources; seven in Google Scholar and 114 from the references, totaling 630 studies. In the first analysis, 100 works were removed as they were duplicates, totaling 530 articles for title and abstract reading. After this procedure, 474 works were excluded, totaling 56 articles for full-text reading. Based on the established inclusion criteria, 22 articles[1,6-9,11,12,15-29] were included to compose the corpus of analysis. Figure 1, prepared according to PRISMA-ScR[14], illustrates the number of articles retrieved from the respective databases, the reasons for exclusion, and the final composition of the sample of included studies.

Of the 22 articles included in the review, 19 were published in English[6-8,11,12,15-19,21-29], one in German[20], and two in Portuguese[1,9]. The studies were conducted in Finland[12,16], Canada[11,24], Norway[15,23,27], Germany[20,26], Sri Lanka[6], United States[17], Switzer-

Figure 1 - Flowchart of the process of identifying and selecting the articles included in the review, 2023



Source: Prepared according to criteria of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR), 2020[14]
Note: [A]Medline - Medical Literature Analysis and Retrieval System Online; [B]Embase - Excerpta Medica DataBASE; [C]Cinahl - Cumulative Index to Nursing and Allied Health Literature; [D]Lilacs – Latin American and Caribbean Health Sciences Literature.

land[8], Brazil[1,9,21,28,29], France[18,19], Austria[22], Holland, and Germany[7] and United Kingdom and Ireland[25].

Assessment instruments used

Figure 2 illustrates the instruments used to assess the QoL of individuals born preterm. In seven of the 22 studies analyzed, more than one QoL assessment instrument was used[1,7,15,17-19,23].

Some instruments were answered by participants themselves[7,11,12,16,23,24,27], while others were answered according to the perspective of parents or caregivers[6,17,20-22,28], since the children investigated were unable to answer. Furthermore, some instruments were answered by both the participants and their parents or caregivers[1,8,9,15,18,19,25,26,29].

Study population

When analyzing the population of the selected studies, most participants (*f* = 14) were children with an average age of zero to 12 years[1,6,8,9,12,15,17-22,25,28], followed by adults (*f* = 7) aged 18 to 36 years[7,11,15,16,23-25-27], and a smaller participation of adolescents (*f* = 6) aged 13 to 17 years[11,20,23,26,27,29]. Many parents and caregivers also participated in the studies, as participants were children whose age was incompatible with answering the QoL instrument[6,17,20,21,22,28].

Gestational age at birth

Figure 3 highlights that the study populations were distributed across various gestational ages: eight studies included a population with less than 37 weeks of gestation[1,6,9,12,20,21,28,29], one with less than 33 weeks[27], three studies with less than 32 weeks[7,17,26], three studies with less than 30 weeks[8,22,24], four with less than 28 weeks[11,15,19,23], two with less than 26 weeks[18,25], and one study did not mention the population's gestational age[16]. In 11 studies[6,11,12,15,16,22-27], individuals born preterm were compared with a control population born at term. In the remaining studies, there was no reference/comparison population.

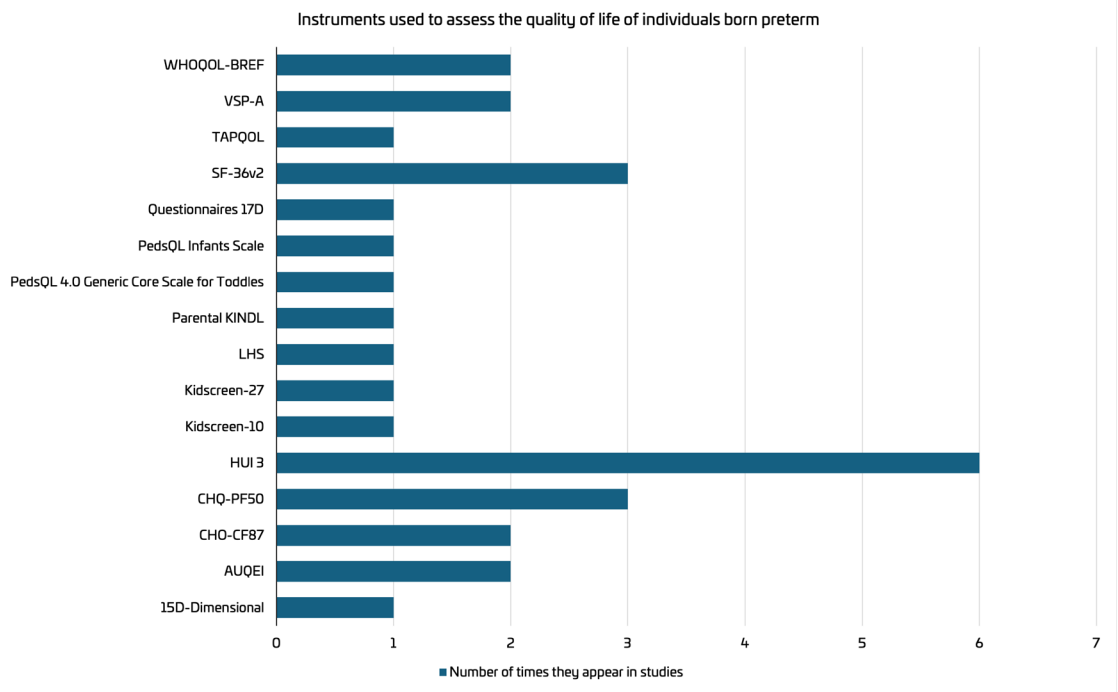
Quality of life of individuals born preterm

The quality of life was assessed based on physical, psychological, emotional, and social domains. To a lesser extent, some studies evaluated the relationship between QoL and morbidities resulting from prematurity. Table 2 presents the grouping of the domains addressed.

Regarding the main results of the studies, the lowest QoL scores were obtained through comparisons with individuals born at term[6,18,25]. In studies that included only individuals born preterm[7,18,20-22,27], an even lower score was observed compared to healthy individuals born preterm, and in groups of individuals born preterm with some disability or morbidity[12,16,25,28].

In the perception of parents and/or caregivers, some preterm infants aged between 18 and 36 months were assessed as having a lower QoL than expected[17]. However, in some studies, children born preterm aged five to eight years and seven to ten years self-assessed more negatively than their caregivers[1,19]. Discrepancies were also found when comparing the reports of caregivers with those of children born preterm aged between 10 and 19 years and between

Figure 2 - Instruments used to assess the quality of life of individuals born preterm, 2023



Note: 15D-*Dimensional* – 15-*Dimensional health-related quality of life measure*; AUQEI – *Autoquestionnaire Qualité de Vie Enfant Imagé*; *Child Health Questionnaire-Child Form* 87 (CHQ-CF87); CHQ-PF50 – *Child Health Questionnaire - Parent Form* 50; *Health Utilities Index Mark* 3 (HUI3); LHS – *Life Health Scale*; *Parental* KINDL; PedsQL 4.0 *Pediatric Quality of Life Inventory* 4.0; TAPQOL: *Preschool Children Quality of Life Questionnaire*; VSP-A – *Vecu et Sante Percue de l'Adolescent*; WHOQOL-BREF – *World Health Organization Quality of Life assessment – Brief*.

Figure 3 - Gestational age of individuals born preterm participating in the studies included, 2023

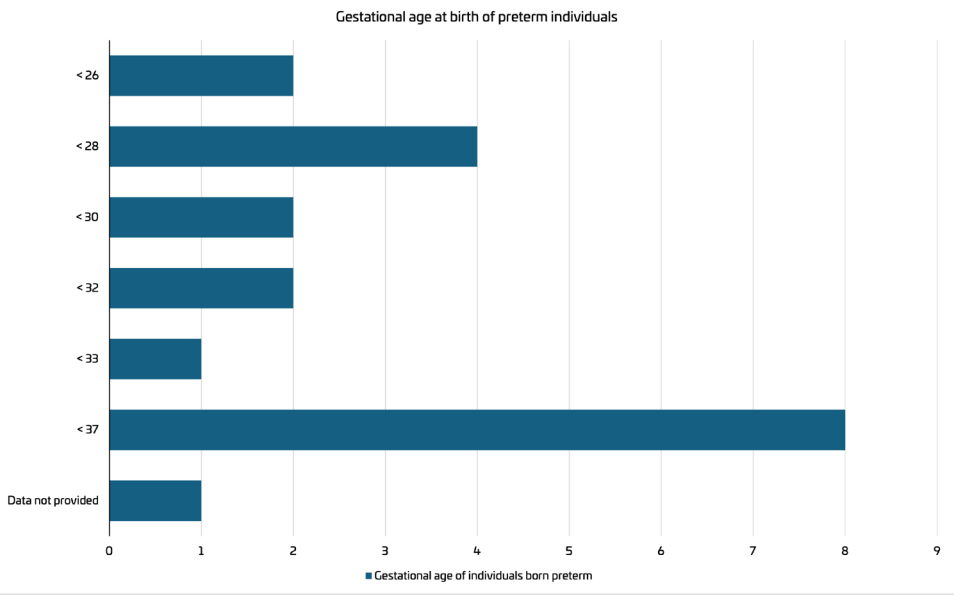


Table 2 - Assessment of Quality of life based on the grouping of physical, psychological, emotional, and social domains, 2023

Physical aspects: mobility, sight, feeding, sexual activity, vitality, speech, excretion, ambulation, dexterity, pain, body pain, hearing, breathing, physical functioning, autonomy, communication, appearance, and body image[1,6,8,9,11,12,16-19,21,23-28]
Psychological and emotional aspects: mental function/health, psychological well-being, mental flexibility, depression, cognition, learning, memory, concentration, psychosocial functioning, attention, anxiety, working memory, lower competence, emotion and emotional role, self-esteem and withdrawal[1,7,8,11,12,15-19,22-28]
Social aspects: social functioning, social role, social limitation, overall health, general perception of health, overall behavior, schoolwork, absence of a partner, family, friends, time of parental impact, and leisure[1,8,9,12,15,16,19,21,22,24,29]
Morbidities related to prematurity and also associated with lower QoL* scores were: developmental delay, birth complications, presence of prolonged illnesses[6]; surgical closure of patent ductus arteriosus, attention deficit/hyperactivity disorder, severe neurodevelopmental impairment[8]; leukomalacia[29], and language delay[18].

three and seven years. The self-assessment of the individuals was more positive than the assessment of their caregivers[9,29].

From the point of view of individuals born preterm and their caregivers, QoL can change over the years. In a study, the QoL has improved in the perception of parents and caregivers, with increased scores in those with children aged between 10 and 18 years[15], while other studies showed little change in relation to the improvement of QoL until adulthood[11,26].

Research suggests conducting longitudinal and long-term follow-up studies to understand the differences across life stages, as trajectory analysis can help predict the future needs of this population[11,12,16]. Observational studies can reveal changes in the perceptions of parents and individuals born preterm themselves over time and what factors may be related to this process[9,18]. Prospective cohort studies can show if there have been improvements in neonatal treatments and the development of less invasive therapies that aid cognitive development[7]. Cohort studies focusing on extremely premature infants and children with limitations in objective functions[8] and research on preventive interventions can be conducted to determine if it is possible to mitigate the long-term effects of extremely premature birth[18].

DISCUSSION

This scoping review mapped available evidence on the QoL of individuals born preterm throughout their life cycle, i.e., the QoL of this population in childhood, adolescence, and adulthood was revealed.

Quality of life related to prematurity has been predominantly studied in children aged 0 to 12 years, which influences how assessment instruments are applied. As the studies involve children, most QoL instruments were answered by the participants and their parents or caregivers[1,8,9,15,18,19,25,26,29], contributing to a broader view of QoL from different perspectives. The participation of parents and caregivers is fundamental in the assessment of children's QoL, as it broadens the analysis beyond the traditionally considered domains, incorporating information on emotions, behaviors, and social interactions[30].

When QoL was assessed in adolescence, the instruments were answered by subjects with a history of preterm birth and also by their parents/caregivers[15,23,25,26,29], allowing for a broader view of the construct. In this age group, the perception of QoL of the target population of the study, in general, showed divergence in relation to the perception of QoL reported by parents/caregivers.

Studies assessing QoL in adolescents show their ability to report their own perceptions of their QoL and the need to consider

their statements. Despite the importance of the reports from parents/caregivers, the adolescent's statement should not be underestimated[1,29]. The parents' report remains relevant, since they often have a great influence on their children's education and the identification of possible health problems[10]. The information presented by the parents should be considered, even if their children's perception is different, because the aspects evaluated in the instruments relate to subjective issues[31].

A study evaluated QoL and its relationship with prematurity in adult individuals. At this stage of life, repercussions on QoL were also identified, such as alterations throughout human development, demonstrating the importance of its assessment throughout the life cycle[31]. With advancing age, the challenges related to prematurity are added to those related to age transitions, such as studying, working, leaving the parental home, finding a partner, and living a social and independent life[27].

Individuals with a history of preterm birth suffer greater impairment in domains related to physical aspects and the ability to perform daily tasks, such as sight, communication, hearing, dexterity, and pain, which are often affected by their birth conditions.

Meta-analysis studies[32,33] show that individuals born preterm are at a higher risk of physical and neurological developmental problems compared to individuals born full term. Cerebral palsy and motor and cognitive impairments stand out among these problems, as they are conditions with a significant impact on the performance of daily activities.

Individuals with a history of prematurity also frequently reported impairments in psychological and emotional aspects. These are related to the mental health of the preterm individual who, in most cases, has difficulty coping with negative feelings and emotions due to the influence of an unfavorable emotional environment or the lack of adequate parental stimulation for the development of socio-emotional balance[34].

Social aspects relate to leisure and relationships with friends and family. In this review, we identified the difficulties of some individuals born preterm with these issues, showing the importance of addressing this aspect with this population from their childhood. Studies demonstrate lower levels of social skills in individuals born preterm compared to their peers born at term. The effects of this deficit in sociability can be perceived in the different developmental phases of these individuals[35], which would justify reports of impairments in this aspect of QoL in this population.

Finally, morbidities related to prematurity, i.e., acute or chronic health problems related to birth at low gestational age, also emerged as factors associated with QoL impairments. In general, when comparing healthy preterm individuals to preterm individuals with some morbidity, the average QoL scores tend to be lower for the latter group, suggesting a direct relationship between prematurity and its complications and the lower QoL of this population.

The crucial role of healthcare professionals in the context of prematurity stands out, as they are essential for identifying factors that negatively impact the QoL of these individuals and for seeking appropriate therapeutic strategies. They must be trained to understand the long-term complications caused by premature birth, and thus, promote early activities and interventions to promote health. Outpatient follow-up for this population in the first years of life should occur continuously[36].

Furthermore, considering the reports of preterm-born individuals who were never questioned by healthcare professionals about their birth condition, given the results of this study, it is recommended to investigate gestational age at birth in healthcare settings. This allows for a more accurate assessment of the current health status of individuals at different ages.

The QoL of individuals born preterm has been studied using a wide variety of instruments. Despite this heterogeneity, all studies used recognized, validated measures with good psychometric properties. In some studies, generic QoL assessment instruments were used. By satisfactorily providing objective measures of this construct, these instruments are reliable and valid; however, they are not considered sensitive to measuring specific aspects of QoL linked to specific morbidities[37], such as those related to preterm birth. This aspect should be considered in future studies.

As this is a scoping review, some limitations of this study should be considered, such as the non-inclusion of theses and dissertations, which may have led to less available evidence on the subject. However, the results already indicate significant evidence on the QoL of individuals born preterm, and may be useful to guide the actions of health professionals. Furthermore, this study can serve as motivation for future investigations with the adoption of other methodological approaches and the combination of different instruments for data collection.

CONCLUSION

There is evidence that preterm birth causes impairments in quality of life (QoL) that manifest at different stages of the life cycle. In populations of preterm-born individuals with disabilities, the impairments may be even greater.

Instruments to measure QoL can be completed by children, adolescents, and adults born prematurely, and by their parents and caregivers. However, instruments applied to parents or caregivers show lower scores than those achieved with self-report instruments completed by individuals.

There is also evidence that the lower the gestational age at birth, the greater the risks of morbidity and the greater the potential impairments in QoL for this population, especially in relation to the physical, psychological, emotional, and social domains.

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Conflict of interest

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