



Systematic Literature Review on Access to Domain Based Quality of Life (QoL) for Children with Cerebral Palsy

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ABSTRACT:

Introduction: Cerebral Palsy (CP) is a complex neurodevelopmental disorder impacting children's movement and overall livelihood. This systematic literature review explores factors influencing access to quality of life (QoL) for children with cerebral palsy. The review aims to provide evidence-based insights into barriers and facilitators affecting various QoL domains for this population.

Objectives: The objective of this study is to identify and analyse factors that influence access to inclusive QoL for children with cerebral palsy. By exploring existing research, the study seeks to shed light on the significance of interventions and support systems that empower these children living with disabilities to lead fulfilling lives.

Method: A comprehensive search strategy was employed across academic databases using predefined search terms. The review identified 21 relevant studies, which were critically analysed and synthesized to extract evidence-based insights into the factors influencing QoL domains.

Result: The review revealed significant factors influencing QoL for children with cerebral palsy, including social well-being, acceptance, functioning, participation, physical health, self-esteem, access to services, and pain/impact of disability. These domains contribute to the overall QoL of children living with cerebral palsy.

Conclusion: While the existing literature provides valuable insights into factors impacting QoL for children with cerebral palsy, there are gaps that call for further research. These include the need for studies that incorporate children's subjective perspectives, address underrepresented populations, focus on longitudinal analysis, consider access to services, and conduct comparative studies. By addressing these gaps, researchers and rehabilitation professionals can develop targeted interventions to enhance the QoL of children with cerebral palsy and contribute to their overall well-being and meaningful participation in society. This systematic review provides valuable guidance for future research and interventions in this crucial area.

Keywords: Cerebral Palsy, Quality of Life, Children etc.

1. Introduction:

The impact of Cerebral Palsy extends sometimes beyond physical limitations, encompassing psychological, social, and educational aspects that can significantly influence a child's quality of life (QoL). In recent era, there has been increasing recognition of the importance of providing inclusive opportunities and support systems to enhance the QoL of children with physical disabilities, however the neuro developmental disorders are sometimes overlooked. Inclusivity access assessment on Quality of life is a complex construct, which includes well-being, fulfillment, and satisfaction, those are difficult to detect among populations living with CP specially children, without involvement of their primary caregivers. This systematic literature review needed to explore the concept of "Quality of Life" domains for children with cerebral palsy, investigating the factors that contribute to or hinder their access to a meaningful life. By understanding these factors, this review seeks to shed light on the significance of practices and interventions that can empower children with cerebral palsy to lead deserving lives and participate in communities to improve their well-being and overall development.

Different analytical QoL emphasizes the provision of equal opportunities, support, and resources to ensure that children with CP can participate in and enjoy a fulfilling and meaningful life alongside general society (Gilson et al., 2014). The systematic review ensures the factors and domains that influence the well-being and life satisfaction of children living with cerebral palsy, aiming to identify barriers and facilitators to their access to an enriched life. The review emphasizes the significance of studies that are conducted to identify interventions that can optimize and analyse the overall development and social integration of children with cerebral palsy. The issues that justify the investigation of this literature review to be considered, as the limited understanding of factors that are closely related to analyse quality of life defining social, emotional, functional, behavioural aspects for children with cerebral palsy (Park et al., 2016), despite of having diverse studies till date at different part of the world.

Research Question: The research question for this systematic literature review is formulated as follows: "What factors and domains influence to determine greater access to quality of life for children living with cerebral palsy?"

The research question justifies as it was not very common in society to understand the various aspects that impact the social, emotional well-being and participation of children with cerebral palsy. Investigating these factors can inform the development of targeted interventions and support systems for rehabilitation health professionals like physiotherapist, occupational therapist, orthotist etc to enhance overall quality of life and ensure relevant intervention planning for their holistic development.

2. Aim of the Literature Search:

This systematic literature review aims to explore the factors influencing access to inclusive quality of life for children with cerebral palsy. A comprehensive search was conducted across academic databases using predefined search terms. The review identified 21 numbers of near to relevant studies that were critically analysed and synthesized to provide evidence-based insights into the barriers and facilitators affecting the different domains of QoL of this population. The findings highlight the importance of addressing especially social and healthcare aspects to determine factors of access as well as hinderance to inclusive quality of life for children living with cerebral palsy. The implications of the study underscore the significance of targeted interventions and comprehensive support systems to promote positive outcomes and maximize the potential of children with cerebral palsy in achieving a fulfilling life.

The aim of this literature search is to identify and gather relevant studies that investigate access to inclusive quality of life for children with cerebral palsy, may or may not be impaired with functional limitations as per GMFCS scale. By systematically reviewing existing research, then to gain insights into the factors that impact the well-being and life satisfaction of targeted population i.e., children with cerebral palsy. The goal is to inform and contribute to the understanding of the barriers and facilitators affecting their access to an enriched and inclusive life, leading to the development of targeted interventions and support systems to enhance their overall quality of life.

3. Search Strategy:

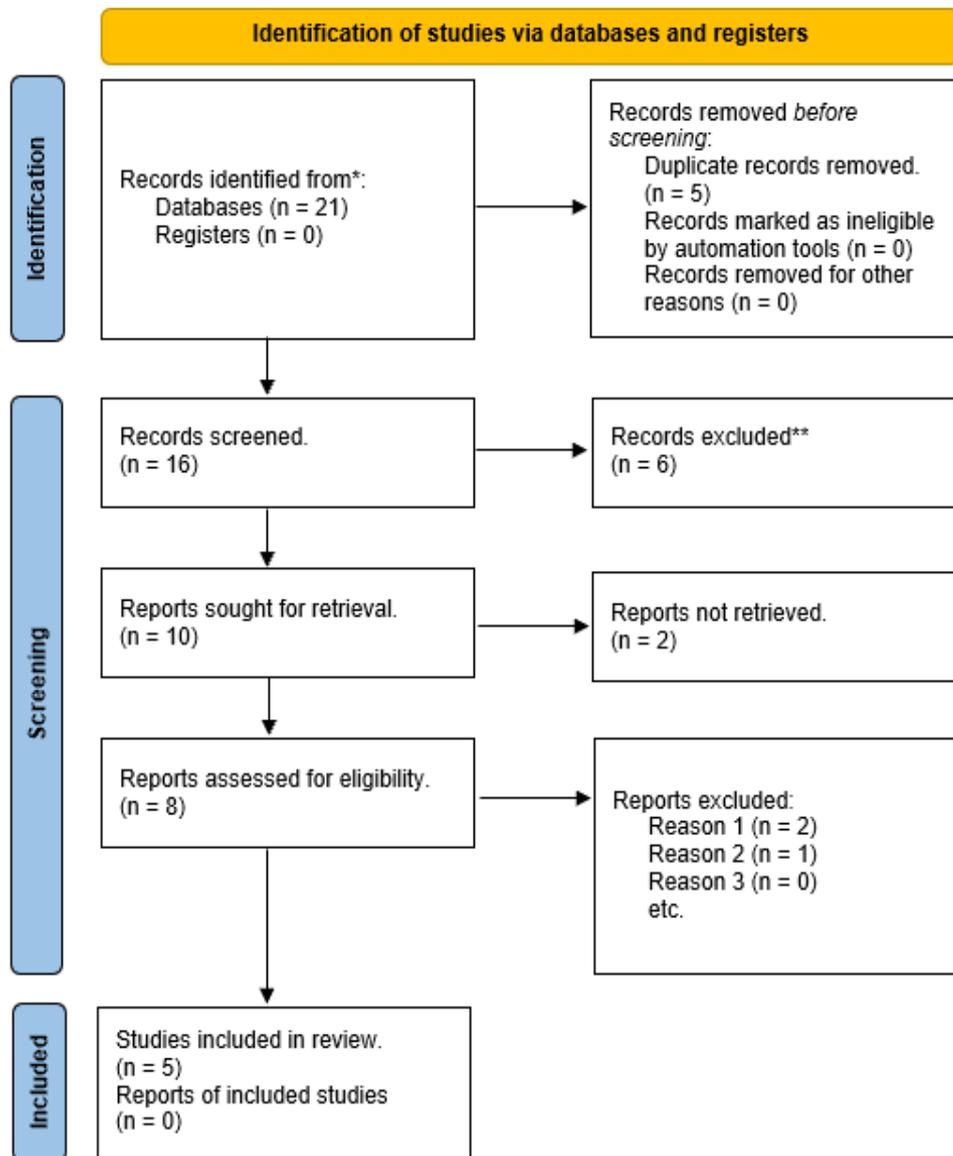
The search strategy for this systematic literature review involved a comprehensive and methodical approach to identify relevant open-sourced studies on the factors influencing access to quality of life for children with cerebral palsy. The relevant academic databases search engines, such as CINAHL, Medline, NHS were used through online library access to conduct the search and develop a search string using a combination of Medical Subject Headings (MeSH) terms and keywords, such as "Cerebral Palsy," "children," "quality of life," "access," "barriers," "facilitators," "interventions," etc used in a form of Boolean operator and Truncation.

Specification was made regarding inclusion criteria of full texted articles (e.g., studies focusing on children with cerebral palsy and their quality of life, with or without mild to moderate involvement of intellectual or physical disabilities) and exclusion criteria's (e.g., studies not directly related to QoL living with cerebral palsy with severe intellectual or physical disabilities, Mix studies of children and adults with cerebral palsy). To ensure that the review included the most relevant and up-to-date literature, a publication date range was set between year of January 2010 to December 2020. The retrieved articles were exported to documents library for further organization and screening. The titles and abstracts of the retrieved articles were screened to identify potentially relevant studies. Irrelevant articles were excluded based on the inclusion and exclusion criteria. The full texts of the selected articles were obtained for further evaluation and data extraction. By following this systematic search strategy, at the end it minimized bias and ensured that the findings were evidence-based and informative for addressing the research question.

4. Methodology:

The selection process steps involved are shown in the below figure no. 01 (PRISMA diagram):

- i. In this phase of the systematic literature review, to avoid reviewing duplication, five articles that appear more than once in results are omitted, by exporting the entire list of articles from each database to citation manager EndNote for generating reference and citation in Harvard style and then a process was followed to identify and evaluate relevant studies that are kept aside derived from the gross search of articles.
- ii. The remaining 16 articles were subjected to undergo initial screening through abstract review.
- iii. A reference of author, keywords, publication type, accuracy, objectivity, report of result and validity of outcomes were evaluated to align accordingly to address the research question and record excluded another six unmatched articles.
- iv. Further two more articles were excluded for unavailability of full text report that satisfy the research question.
- v. Based on the final step three more articles were excluded out of eight based on reason specified in the diagram legends.
- vi. Five filtered articles that are relatively close to the research question are now ready for full review.



R1: Irrelevant population covered.
R2: required interventions are missing.
R3: very complex outcomes.

Figure No. 01: PRISMA DISGRAM

4.1 Grading Quality Assessment:

GRADE is a widely used system for grading the quality of evidence and strength of recommendations in healthcare research. It assesses the quality of evidence based on study design, risk of potential bias, consistency of results, precision, and miscellaneous factors. This approach classifies evidence as high, moderate, low, or relatively very low quality. The methodological quality of the included studies was evaluated using systematic reviews and meta-analyses checklist to get graded the final articles through SIGN guidance. The below diagram shows the quality grade assessment of the articles used for this literature search using 4 point scale.



SL No	Quality	Symbol	Score	No. of Articles
1	High Quality	⊕⊕⊕⊕		1
2	Moderate Quality	⊕⊕⊕		4
3	Low Quality	⊕⊕		0
4	Very Low Quality	⊕		0

Figure No. 02: The Quality of articles on a 4-point scale

4.2 Full Text Evaluation & Data Extraction:

Full texts of the selected articles were obtained from search engines that are mentioned in search strategy and downloaded in separate folder. Each study was thoroughly read, keeping focus on finding of the domains of quality-of-life children with cerebral palsy.

Relevant data were extracted from those final five studies, including study design, sample size, participant characteristics, place of study, interventions, statistical tools used, key findings and funding information and factors influencing access to quality of life. This information was organized in a systematic manner for analysis and synthesis to below mentioned data extraction table format.

Identifier	Article (Author and Year)	Research design	Location of study	Sample size	Sample Characteristics, Inclusion/Exclusion criteria	Intervention	Statistical Tools and outcome measure	Key finding	Limitation	Funding of research
ISSN: 1748-3107	Assistive technology for promoting adaptive skills of children with cerebral palsy: ten cases evaluation Stasolla, F. et al. (2019)	single-subject experimental design	University of Bari, Italy & study conducted at individual places of participants.	10 participants and 60 external raters for social validation	Including criteria concerned diagnosis of cerebral palsy with at least fourth level of the Gross Motor Function Classification System (GMFCS), and incapacities of independent access to preferred items. Excluding criteria were any other associated developmental disorders.	A multiple probe design was implemented for Studies I and II. Study I involved five participants exposed to a combined program aimed at enhancing choice process of preferred items and locomotion fluency. Study II involved five further children for a combined intervention finalized at ensuring them with literacy access and ambulation responses.	Kolmogorov-Smirnov test was performed to assess a significant difference between the first baseline and the first intervention	Implications for Rehabilitation is basic form of assistive technology-based program may be helpful for supporting adaptive skills of children with cerebral palsy and different levels of functioning. The program may improve the children indices of positive participation and constructive engagement with positive effects on their quality of life.	Limited sample size and study was based on a single-subject experimental design, preventing the generalization of the outlined results without any caution.	Self funded by Department of Neurosciences, University of Bari, Corso Italia
ISSN: 1817-1745	Quality of Life in Indian Children with Cerebral Palsy Using Cerebral Palsy-quality of Life Questionnaire Das, S. et al. (2017)	Quantitative experimental study based on Questionnaire	Guru Teg Bahadur Hospital, India	Caregiver of 50 children	Age group between 4-12 years were taken, including 32 male & 18 females, those are pre-enrolled in child development centre of the hospital.	The various domains assessed using this questionnaire were – social and emotional well-being, acceptance, functioning, participation, physical health, self-esteem, access to services onset of disability. Scoring of the items involved two steps as per the CP-QOL child questionnaire.	The data were analysed using the a standard statistical Package i.e. Cronbach's α was used to determine the interval consistency and reliability of the subscales.	Overall QOL was assessed with respect to GMF score, however findings did not vary much with GMF score due to limited sample size and the different understanding of disability and subsequent care provided by the caregivers. Thus, age had a significant impact on the QOL, could be as a reason of decreased mobility and access to services of	different perception of caregiver regarding the disability may not be overruled as bias. The QOL is negatively affected by the presence or absence of epilepsy, due to the limited sample size in the study.	No specific grants or financial support was taken from any external sources.

								older children and average QOL in children with CP was compromised.		
ISSN: 0305-1862	Exploring quality of life of children with cerebral palsy and intellectual disability: What are the important domains of life? Davis, E. et al. (2017)	Qualitative research using a grounded theory approach.	Victoria, Australia	The 18 children and their caregivers.	9 males & 9 females with median age of 12 (range 7–17) years and nearly two thirds of children were classified as Gross Motor Function Classification System Level IV or V.	Eleven numbers of QoL domains were identified namely, physical health, body comfort, behaviour and emotion, communication, predictability and routine, movement and physical activity, nature and outdoors, variety of activity, independence, and autonomy, social connectedness, and access to services. The participants caregiver has undergone the questionnaire survey with concepts described in the International Classification of Functioning, Disability and Health model of disability, Fitness, Function, Family, Friends, and Fun to document the finding for further analysis.	Coded by NM using NVivo analysis software	The 11 QOL domains emerged from the study qualitative data could be considered as essential factors necessary for health professionals, while counselling and supporting children with CP and their families.	The study necessarily not addressed all the unique aspects of QOL for children with CP and ID, and an important task is to translate these findings into a measure that can quantify QOL for this group.	Early Career Fellowship, Grant/Award Number: 1072442; Senior Research Fellowship from the National Health and Medical Research Council, Grant/Award Number: 1117105 and 1077966; National Health and Medical Research Council, Grant/Award Number: 1103745; Victorian Government's Operational Infrastructure Support Program; Victorian Department of Health and Human Services
ISSN: 0883-0738	Quality of Life in Children With Cerebral	Qualitative literature review.	Melbourne, Victoria, Australia	Not specified	Children aging 4-12 years living with cerebral palsy	The Cerebral Palsy Quality of Life–Child Questionnaire, that was developed by clinicians and researchers, was based on qualitative interviews with children with	Not specified	The article presents an overview for clinicians and researchers intending to use quality of life measures on children	The study was limited without focusing on sensitivity to change of	National Health Medical Research Grant (NHMRC 284514), Murdoch Children's

	<p>Palsy: Implications for Practice</p> <p>Gilson, K.- M. et al. (2014)</p>				<p>cerebral palsy and their caregivers. These interviews focused on what the child needed to be happy and have a good quality of life and provided content for the development of items. The domain included for the questionnaire are Social well-being and acceptance, functioning, participating and physical health, access to services, family health, emotional wellbeing, pain and feelings about disability are compared using another three developed questionnaires i.e. the Caregiver Priorities and Child Health Index of Life with Disabilitie, the Pediatric Quality of life Inventory CP Module and the DISABKIDS CP Module.</p>		<p>with cerebral palsy and provides recommendations for future research that will better inform practice in the field.</p>	<p>quality of life instruments and how they are used to evaluate the effectiveness of rehabilitation interventions. This have further opened a scope of research.</p>	<p>Research Institute, and Victorian Health Promotion Foundation</p>
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ISSN: 0012-1622	Health-related quality of life and upper-limb impairment in children with cerebral palsy: developing a mapping algorithm. Tonmukaya kul, U. et al. (2020)	Minimising Impairment Trial based on	Melbourne, Victoria, Australia	76 participants, caregivers.	Children aging between 6 to 15 years (40 females & 36 males) with mild upper limb deformity, using orthotic aids.	Caregivers have participated for CPQoL-Child proxy questionnaire with seven domains to derive CHU9D score, which save nine domains. A negative correlation between the four classifications and HRQoL were expected as of higher levels of classification indicate lower levels of functioning and a positive correlation between the CPQoL-Child and CHU9D were expected as well.	Australian adolescent population-specific scoring algorithm	Weak negative correlations between functioning levels and HRQoL measures were found in children with CP and mild upper-limb impairment. Also the study has produced a mapping algorithm to generate CHU9D index scores from the CPQoL-Child responses.	The model performance of the study was validated using the internal data set only, no external validation was conducted. Also, the proxy report HRQoL has been identified that many participants had limited ability to self-report the CPQoL-Child and CHU9D.	Centre of Research Excellence in Cerebral Palsy (NHMRC no. APP1057997). Australian Catholic University (no. 2013000413), Princess Margaret Hospital Foundation, the Centre of Research Excellence in Cerebral Palsy (no. APP1057997).
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5. Analysis of Findings & Discussions:

The analysis of findings in a systematic literature review involves critically examining and interpreting the data extracted from the included studies. This step aims to identify patterns, trends, and implications across the literature to answer the research question and address the review's objectives.

The extracted data, that are based on common topics of QoL domains related to the research question are further grouped together as similar aspects of different questionnaire-based studies are used to categorically avoid potential bias and focus on the outcome measures against the aim of those studies (Böling et al., 2015). While contrasting the findings from studies, discrepancies or contradictions in the results are tried to get identified, however same tools are not repeatedly used for more than one study. Some studies mentioned participants improved their performance, nevertheless differences among children occurred. Indices of positive participation increased as well during the study (Stasolla et al., 2018). Another study that has significantly used questionnaire based on different domain of social and emotional well-being, acceptance, functioning, participation, physical health, self-esteem, access to services onset of disability to analyse score of QoL (Aggarwal et al., 2017). Other research shows using TNO-AZL questionnaires, children reported lower HRQoL compared with children in the general population but reported a higher HRQoL than their care giving parents (Janssen et al., 2010). Similar Questionnaire based studies are reviewed where, factors identifying livelihood qualities are slightly i.e., physical health, body comfort, behaviour and emotion, communication, predictability and routine, movement and physical activity, nature and outdoors, variety of activity, independence, and autonomy, social connectedness, and access to services and applied to derive family health based QoL (Davis et al., 2017). On average most of the articles present an overview for researchers intending to use domains of QoL measures on children with cerebral palsy for providing recommendations for future research that also satisfy the research question. Sub-group analyses based on factors such as study design, participant characteristics, or interventions to explore potential variations in the findings are not relevant, since every study was unique with their findings according to their variables. The sample size has varied from 10 to 76, that was a minor limitation for the review, however age group involved had a similar pattern (Gilson et al., 2014). To develop a mapping algorithm, one of the reviewed studies have included impact of upper limb impairment with mild to moderate GMFCS, and produced health related mapping algorithm to generate Child Health Utility 9D scores out of CPQoL-Child responses (Tonmukayakul et al., 2020). Cumulatively the limitations of those studies found as lesser sample size, proxy findings based on caregiver understanding and those could not be completely overruled, since they might affect the overall interpretation of the findings.

Most of the domain factors that was used to while considering developed or traditional questionnaire i.e., Cerebral Palsy Quality of Life–Child (CP QoL-Child); the Caregiver Priorities Child Health Index of Life with Disabilities and the Paediatric Quality of life Inventory CP Module and the DISABKIDS CP Module had concept that described in the International Classification of Functioning, Disability and Health model of disability, thus a consensus uniformity was found to determine the Health QoL related factors, such as, (i) social well-being and acceptance, (ii) Functioning, (iii) Participation and physical health, (iv) Emotional well-being and self esteem, (v) Access to services, (vi) Pain and impact of disability and (vii) Family health (Tonmukayakul et al., 2020)., irrespective of mild to moderate level of functional or intellectual limitations, whereas, sex of the participants were not a vital factor to get significant changes (Aggarwal et al., 2017). Conflict of outcome evidence and potential reasons for discrepancies are not found in reviewed studies.

6. Gap of literature and Recommendations:

The gap in the literature refers to areas within the existing research where there is a scarcity of comprehensive studies or insufficient attention given to certain aspects of this topic, however the findings are only used here for a period of ten years.

Limited focus on subjective perspectives: Many of the studies might have primarily relied on caregiver or clinician assessments of the QoL of children with cerebral palsy since the children was nonverbal or experiencing functional/intellectual limitations to participate. There may be a need for more research that incorporates the direct perspectives and voices of the separate group of children as per specified inclusion criteria, considering their experiences, preferences, and opinions.

Underrepresented populations: The literature may also be skewed towards certain age groups and limited participants, GMFCS levels of cerebral palsy or background, leaving gaps in our understanding of how QoL varies among different subgroups of children with cerebral palsy in low- and middle-income countries.

Longitudinal studies: There might be a shortage of longitudinal studies that track changes in QoL over time for same group of children with cerebral palsy. Such studies are vital for identifying factors that influence QoL trajectories and the effectiveness of interventions.

Access to services and support: Studies may not have fully explored the factors affecting access to necessary rehabilitation services like therapy sessions, orthotic assistive devices and other positional support systems that can significantly influence the QoL of children with cerebral palsy.

Comparative studies: Need for more comparative studies that examine the multi-dimensional factors considering QoL of children with cerebral palsy in relation to their peers those with other chronic conditions.

Cultural considerations: Lack of research that investigates how cultural factors and societal attitudes influence the access to and perception of QoL for children with cerebral palsy in different regions and communities of world.

Addressing loopholes would require conducting new research studies that specifically target the above mentioned identified areas. When conducting this systematic literature search, careful analysis was also done to identify these gaps and design research that fills them. Such a way, researchers comprising of multi-disciplinary team can contribute valuable insights to the field, to help broaden the the understanding of factors influencing the essential QoL of children with cerebral palsy.

7. Conclusion:

Despite the existing body of research in this area, very limited numbers of studies are identified, however certain aspects have not received adequate attention, hindering a comprehensive understanding of the factors and domains influencing QoL for these children. Filling these gaps will lead to better support and interventions for children with cerebral palsy by rehabilitation health professionals, ultimately improving overall well-being and meaning of life of them, including their caregivers.

Abbreviations:

CHU9D: Child Health Utility 9D scores.

CINAHL: Cumulated Index to Nursing and Allied Health Literature.

CPQoL-Child: Cerebral Palsy Quality of Life – Child.

GMFCS: Gross Motor Function Classification System.

GRADE: Grading of Recommendations Assessment, Development and Evaluation.

HRQoL: Health Related Quality of Life.

QoL: Quality of Life.

SIGN: Scottish Intercollegiate Guidelines Network.

TNO-AZL: Netherlands Organisation for Applied Scientific Research Academic Medical Centre.

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