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Review



Quality of life among Indonesian school-aged children with attention-deficit hyperactivity disorder: A concept analysis

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Abstract

This concept analysis aimed to clarify the conceptual significance of quality of life (QoL) among school-aged children diagnosed with attention-deficit hyperactivity disorder (ADHD). The concept analysis framework developed by Walker and Avant was utilized to examine the notion of QoL in Indonesian school-aged children with ADHD by searching three databases (Google Scholar, PubMed, and PsycINFO). A comprehensive analysis of 14 selected relevant studies was conducted. The model case was provided to define the concept of QoL in school-aged children with ADHD, followed by additional cases such as borderline, related, and contrary cases. The key characteristics of the concept of QoL about children with ADHD include (1) the subjective perception of both children and their parents regarding the children's life experiences with ADHD; (2) the ability of children and their parents to identify and assess the satisfaction levels in various aspects of the children's lives, including physical, emotional, social, and academic domains; and (3) the existence of measures that can be used to evaluate the perception of QoL in children with ADHD by children and their parents. Perceptions of both parents and children are essential to understanding the concept of QoL among school-aged children with ADHD. Therefore, the existing instrument can be used, but the nursing interventions of QoL for Indonesian children may need to be developed by targeting parents and children. **Keywords:** ADHD; children; parents; quality of life.

A ttention-deficit hyperactivity disorder (ADHD) is one of the most reported behavioral problems that may influence both children and their parents. The World Health Organization (WHO) defines ADHD as a hyperkinetic disorder that requires the definite presence of pervasive and persistent abnormal inattention and restlessness levels that can be observed directly and not related to some other mental disorder, such as autism or affective disorders.^[1] These difficulties raise awareness in the world since the number of ADHD is increasing over the years.

The National Center for Health Statistics mentioned that 11.3% of American children aged 5–17 years were diagnosed with ADHD during 2020–2022.^[2] In Asia, Chinese children and adolescents who had ADHD were 6.5%, 6.4%, and 4.2% in Mainland China, Hong Kong, and Taiwan, respectively.^[3] In Indonesia, the prevalence of mental-emotional problems increased from 6% in 2013 to 8.8% in 2018, and ADHD was one of the most frequent mental health problems affecting Indonesian children and adolescents compared to other Asian countries.^[4]

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American Psychiatric Association defined ADHD as a neurodevelopmental condition characterized by deficits in attention, organization, and impulse control. Specifically, youngsters exhibiting inattention and disorganization will display the following behaviors: an inability to sustain focus on a task, appearing inattentive, and misplacing items. In addition, children with hyperactivity-impulsivity will display excessive physical activity, restlessness, difficulty remaining seated, interfering with others' activities, and impatience. Both situations occur consistently and excessively compared to their age and developmental level.^[5] ADHD may persist into adulthood and impair social, academic, and occupational functions and some aspects of quality of life (QoL) among children and adolescents.^[6]

QoL refers to an individual's subjective assessment of their living situation, considering cultural and value systems and their personal objectives, expectations, standards, and worries. QoL has a multifaceted impact on individuals, encompassing their physical well-being, mental condition, personal convictions, social connections, and their interaction with significant aspects of the environment.^[6] However, as children's and adolescents' perceptions differ from adults' perceptions, the perception of QoL in children may relate to their ages and developmental functions, including aspects related to physical, emotional, social, and academic performance, as a questionnaire of Pediatric QoL Inventory (PedsQLTM) commonly utilized among the pediatric population. ^[7] Later, many studies were conducted to evaluate the perception of the QoL among healthy and unhealthy individuals in the age group of children and adolescents.

Wallander and Koot (2015) examined three primary methods for comprehending the QoL in children: health-related QoL, social indicators, and subjective well-being. Children's perspective of their experience of health, disease, disability, impairment, and the impact of medical treatment is referred to as health-related QoL. Social indicators encompass various factors that can provide insight into various aspects of children's lives. These factors include but are not limited to poverty, family structure, residential stability, infant mortality, vaccination rates, adherence to pediatric routine care, classroom size, high school graduation rates, suicide rates, mental health diagnoses, tobacco use, and juvenile incarceration rates. Subjective well-being is positive experiences in children's lives, such as happiness, satisfaction, and meaning that children perceive.^[8] School-aged children in South Korea perceived a sound QoL as having a positive relationship, effective parental communication, and high levels of satisfaction with the school experience.^[9] Moreover, other studies specifically investigate QoL in children with physical problems and mental health problems, including ADHD.

What is presently known on this subject?

• The meaning of quality of life is usually based on self-perception; however, among Indonesian school-aged children with ADHD, it is rarely clarified and discussed.

What does this article add to the existing knowledge?

- This study contributes to the importance of understanding the concept of QoL among school-aged children with ADHD based on the perspectives of both parents and children.
- There are four mainly discussed aspects of QoL among school-aged children with ADHD, including physical, emotional, social, and academic domains.

What are the implications for practice?

• The existing instrument can be used in the Indonesian context; however, as parent's and children's perspectives are essential, targeting both is necessary to develop nursing interventions in Indonesia.

Many studies evaluated QoL in children with severe conditions, including Asthma, Cancer, Congenital Heart Disease, Type 1 Diabetes Mellitus, and even Stroke.^[10–14] Some studies applied generic scales, and others applied disease-specific scales of QoL. The other research specifically examined the QoL in children and adolescents who have mental health issues.^[15,16] QoL in children with ADHD was also frequently studied in many pieces of literature. Some studies investigated the concept alone, and other studies compared it to parents' or family's perception of other problems such as Asthma, Diabetes Mellitus, and Psychopathological profiles; the other study focused on the perception of QoL in caregivers.^[17–21]

In Indonesia, studies have yet to be conducted on QoL in school-aged children. Some studies focus on healthy children, and other studies mainly focus on children with physical problems such as Cancer, Major Thalassemia, and Type 1 Diabetes Mellitus.^[22-25] Moreover, only one study evaluated the QoL among school-aged children with ADHD in the school for children with special needs in West Java by adopting the generic scale of pediatric QoL (PedsQL).^[26] However, little is known about QoL among school-aged children with ADHD in Indonesia. To have a deeper understanding of the notion of QoL among Indonesian school-aged children with ADHD, it is imperative to carry out a concept analysis.

Walker and Avant (2019) explained that concept analysis is the process of examining the structure and function of a concept so we will have a better understanding of the concept in terms of knowing how to measure the concept, how to differentiate overlapping concepts, how to develop a new nursing diagnosis or intervention based on the concept, and how to understand the meaning of the concept by logically thinking. Concept analysis is essential because a concept will be affected by culture, context, and social factors, which are the dynamic factors that will make the concept tentative and may change slowly or quickly based on the changes of related factors. In the end, the result of concept analysis is parallel with the nursing process, especially nursing diagnosis, intervention, and

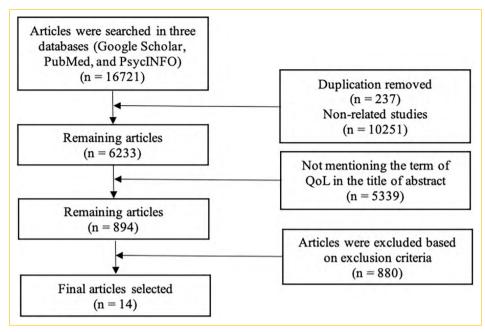


Figure 1. The process of article selection.

outcomes, and they include antecedents (etiology), defining characteristics (defining signs and symptoms), and definition (health problem).^[27]

To support the concept analysis process, the authors searched and reviewed related articles regarding the concept of QoL in school-aged children with ADHD. The literature evaluation was performed using electronic searches in the appropriate journals. The analysis includes several popular search engines, such as Google Scholar, PubMed, and PsycINFO, which have the following keywords: "ADHD," "School-Aged Children," and "QoL" and should mention the terms of "QoL" in the title or abstract. The search was limited to complete articles specifically focusing on one or more aspects of QoL, including physical, emotional, social, and academic capabilities. However, articles on ADHD children with both physical and other mental health problems and comorbidity were excluded, as presented in Figure 1. Overall, 14 articles were reviewed, as seen in Table 1.

Materials and Method

This research adhered to the conceptual analysis approach developed by Walker and Avant. The process of concept analysis consists of eight steps: Concept selection, determination of analysis objectives, identification of the concept's uses, determination of defining attributes, identification of a model case, identification of additional cases, identification of antecedents and consequences, and identification of empirical referents.^[27] Below, we provided a comprehensive explanation of the intricate procedures involved in Walker and Avant's concept analysis:

1. Selecting a concept: The topic was chosen based on the prevalence of ADHD cases in Indonesia, the importance of

QoL in children with ADHD, and the extent of research on this concept among school-aged children in Indonesia.

- 2. Determining the aims of the analysis: A concept analysis was conducted to enhance the authors' comprehension of QoL in school-aged children with ADHD by comparing published articles on the concept.
- 3. Identifying the uses of the concept: The selected concept was investigated by conducting a literature review of published articles on the concept of QoL in school-aged children with ADHD.
- 4. Determining the defining attributes: The characteristics of QoL in school-aged children with ADHD were described based on the literature review based on research conducted in Indonesia or worldwide and published in Indonesian or English.
- 5. Identifying model case (s): The model case was presented to describe the actual characteristics of QoL in school-aged children with ADHD.
- 6. Identifying additional cases: Three additional cases, such as borderline, related, and contrary cases, were presented. The additional cases are essential to differentiate the characteristics of QoL in school-aged children with ADHD, whether the concept is clearly explained by comparing it with characteristics from borderline, related, or contrary cases.
- 7. Identifying antecedents and consequences: The precursors of the QoL among school-aged children with ADHD and its impacts or outcomes were identified.
- Identifying empirical referents: Using the instrument(s) to evaluate the concept of QoL among school-aged children with ADHD by measuring the defining characteristics of the concept.

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/ Schwörst af al ADHD madication	13.	Hakkaart-van Roijen et al. (2007) ¹⁴⁶	Societal cost			>	>	Better social relationship Mental health and self-esteem problem	CHQ/parents
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Concept Analysis of QoL of School-aged Children with ADHD

Selecting a Concept

The concept of QoL among school-aged children with ADHD was selected because of the increased tendency of the prevalence number of ADHD worldwide and in Indonesia and the severe impacts of ADHD on QoL among school-aged children. Furthermore, the number of studies conducted regarding QoL in Indonesia's school-aged children is still limited compared to healthy children or children with physical problems.

Determining the Aims of the Analysis

This concept analysis aimed to elucidate the definition of the QoL concept in school-aged children with ADHD and provide a deeper comprehension of the concept to guide future research, policy, and practice.

Identifying Uses of the Concept

Some online dictionaries were explored to find the meaning of QoL. The Oxford Learner's Dictionaries (2023) mentioned that QoL is "The level of health, comfort, and happiness that a particular person or group has." This definition is compared to the concept of "standard of living" defined as "The amount of money and level of comfort that a particular person or group has." Interestingly, QoL does not depend on money to create convenience and happiness, which is different from the meaning of the standard of living.^[28,29] This definition is supported by the Macmillan Dictionary (2023), which states that QoL is "the enjoyment of life at a basic level, which includes being happy and healthy, rather than having lots of money."^[30]

Meanwhile, the Merriam-Webster Dictionary (2023) mentioned that there are two perspectives of QoL such as general well-being as "overall enjoyment of life" and specific QoL as "The degree to which a person or group is healthy, comfortable, and able to enjoy the activities of daily living."^[31] Furthermore, the Lexico Dictionary (2023) revealed a similar definition of QoL: "The standard of health, comfort, and happiness experienced by an individual or group."^[32] According to the definitions, health is crucial in enhancing an individual or group's impression of a high standard of living. The sense of QoL will be contingent upon individuals' comprehension, which is influenced by their developmental stages.

Widely known as a social concept, there were two approaches to QoL: Subjective and objective.^[33] The subjective approach consists of the affective and cognitive components reflecting the QoL as happiness and satisfaction. Meanwhile, the objective approaches relate to material aspects of life or monetary indicators, including income, expenditures, savings, and producing goods and services. It has been proposed that the assessment of the QoL should consider various aspects of life, including financial status, the standard of living, housing, health and personal safety, marriage or partnership, family life, relationships with relatives and friends, neighborhood or community, leisure and recreation, work, self-efficacy, personal development, and national issues.

In occupational science, Harvey (1993) defines the QoL as the mutual interaction between humans and their environment, and occupational stress may decrease workers' QoL. The other vital aspects that may contribute to the QoL are the relationships with each other and the changes in daily living. Some measures are proposed to evaluate the QoL, such as variety, diversity, enhancement of activity choices, tension, and satisfaction. However, it has to be congruent with the individuals' daily life activities and depends on their environment, preferences, and behaviors.^[34] Furthermore, Ruževičius (2007) explained that QoL is interrelated with happiness, life satisfaction, and subjective well-being. It is impacted by job satisfaction, work engagement, motivation, productivity, health, workplace safety and well-being, stress, workload, and burnout.^[35]

Later on, the concept of QoL was adopted in health science. The WHO (1997) proposed several domains to reflect individuals' perceptions of their lives, such as physical well-being, mental condition, individual convictions, social connections, and environmental engagement.^[6] The initial emphasis of the QoL concept was primarily on the adult and elderly demographic. QoL was defined as possessing a car within the household, having recently availed dental services, being free from chronic illnesses and medication, engaging in physical activities, not being a smoker, having attained higher education, and being married.^[36,37] Afterward, many studies investigated QoL of the adult population with chronic diseases perceived QoL as improving functional characteristics, having social support, diet satisfaction, and improving general health.^[38,39]

The context of QoL is also suitable for children and adolescents in a healthy population and, in comparison, with ADHD. Healthy children and adolescents perceived good QoL as having good communication with parents, parental bonding attitude, caregiver availability after school, and relationship with peers as social indicators and school life satisfaction regarding academic achievement.^[8,9] In contrast, parents of school-aged children with ADHD in special schools perceive their children to have a poor QoL in various categories, including physical function, emotional function, social function, and school function. The QoL of school-aged children with ADHD is also impacted by having less family support and more family anxiety.^[26]

Determining the Defining Attributes

In general, there are three attributes of QoL in school-aged children with ADHD that is repeated in the literature and define

the concept. The defining attributes of QoL including (1) the perspective of parents and children about the life experience of children with ADHD, (2) identification of parents and children's satisfaction regarding physical, emotional, social, and school aspects of their lives related to ADHD, and (3) availability of the measures to evaluate parents and children's perception of QoL among children with ADHD (Table 1). The physical domain includes aspects related to physical functioning, role/ social restrictions, bodily pain, and general health perception. ^[18-23,26,40-42] Emotional-behavioral difficulties, self-esteem, mental health, and general conduct are manifest in the emotional domain.^[18,20-23,26,43-46] The social domain includes interpersonal interactions with parents, siblings, classmates, social support,^[18-23,26,40,41,44-46] and academic domain or school functioning, including school attendance, attention while learning, completion of assignments, and memory capacity.[18-20,26,40,43,45,47]

Identifying Model Case

R, 28 years old, the mother of D, a boy who was diagnosed with the combined type of ADHD, perceived her son as an active boy; he never complains of being tired after walking and running, he loves to participate in soccer with his friends, but sometimes, he becomes angry because his needs are not fulfilled, mostly when he is hungry. His mother said that the school feedback is relatively good. D is also active in his class; sometimes, it disturbs the others, but he still can be directed to keep silent during the learning process. D is still doing his homework, although sometimes, he is easily distracted. It is also not difficult to give D medication; he takes it very well. Mrs. R also put D's medication in his bag and asked the teacher to give it to him. Mrs. R believes that medication, family, and school support help D control his behaviors. The entire family remains relatively unperturbed by D's antics and consistently assists and supports him during his challenging periods. Overall, Mrs. R rated her son's QoL reasonably, and her husband and his older sister agreed with her.

Identifying Additional Cases

Three additional cases are offered, including the borderline, related, and contrary cases. A borderline case is an example case in which only some attributes are presented; meanwhile, a related case presents the case of a related concept often used interchangeably with the concept of QoL. The contrary case presented the example cases that do not reflect the attributes of QoL.

Borderline Case

M is an 8-year-old girl diagnosed with the inattentive type of ADHD. She stayed with her grandmother after her parents passed away from the accident. Her grandmother perceived M as a shy girl with difficulty following directions, and usually, she would understand after more than three times explanations. She never finishes her homework and is afraid of many things, especially darkness and the sound of thunder. However, she is a physically healthy girl without any complaints. Her grandmother is supportive, pays a tutor, and teaches her at home. Her uncle and aunt frequently visit her and bring her favorite foods. Her grandmother is happy with her but worries about her learning ability. In this case, M has no problem with the health domain and is fully supported by her grandmother, uncle, and aunt. Nevertheless, she has problems with emotional, social, and school functioning.

Related Case

P is a 12-year-old boy diagnosed with hyperactivity type ADHD. His father perceived him as a "never tired" boy because he always had more energy to do something. He loves athletics so much and never misses athletic competition. After failing three athletic competitions, he won the second medal in the past competition. His father believes that P is so proud and satisfied with himself because he always talks about his winning, and he never stops talking and demonstrates how he runs in the competition. He always takes his medal with him when sleeping and wherever he goes. In this case, the concept of QoL is used interchangeably with the concept of children's life satisfaction, and one aspect of satisfaction with life in children is to achieve something essential for themselves.^[48] The focus on satisfaction, in this case, is only about achievement; the other defining attributes, such as emotional, social, and school functioning, are not presented. The familial and school supports are also not mentioned clearly.

Contrary Case

B is a 10-year-old girl diagnosed with a combined type of ADHD. She is so active and talkative. Her mother said that B is careless and quickly gets hurt when she runs around the house. She likes to scream aloud and argue with her younger sister. She never had a close friend; the last time when her friend came, she bit her badly. Her mother always receives negative feedback from her teachers. She never finishes her homework and only stays 5 min to study; after that, she starts running again. Her mother worries because the whole family is disturbed by her loud voice and her messy house. Her mother perceived B as having a poor QoL, and she had no idea how to help her daughter. This case reflects that B does not show any positive attributes of QoL, and her family is bothered and confused about how to care for B.

Identifying Antecedents and Consequences

The antecedents of QoL in school-aged children with ADHD are mostly related to their situations. It was found that clinical

factors are significantly related to QoL, including the symptoms of ADHD (the presence of inattention, hyperactivity, and impulsivity), conduct problems, peer relationship problems, and other physical issues can be observed in youngsters,^[18-23,41,43,44,47] as well as gender and self-concept of children.^[22,45] Additional factors include familial circumstances, such as single-parent households, parental mental health issues (anxiety) resulting from children's illnesses, maternal smoking during pregnancy, and family support.^[20,23,26] There are two consequences of QoL in school-aged children with ADHD, such as consequences caused by good QoL and consequences caused by poor QoL.

The impact of a good QoL on children with ADHD includes better cognitive behaviors, better psychological conditions, and better social relationships if children have better self-concepts.[45] Otherwise, the lower QoL experienced by schoolaged children has a significant impact on the daily lives of the children, their parents, and their families as a whole. Poor QoL in children, as perceived by both children and their parents, has several consequences such as physical problems (pain, lower general health, impaired physical function, and less energy),^[18,21–23,26,40,41] academic problems (lower school performances/achievement and lower school attendance),^[40,42,43,45] emotional problems (poorer mental health, low emotional well-being, low self-esteem, distressing/poor emotion, and mood),^[19–23,26,43,44,46] and social problems (poorer social relation, fewer friends, and poorer family relationship).^[19–23,26,40,41,44,46,47]

Identify Empirical Referents

Walker and Avant (2019) defined empirical referents as tangible manifestations or measurable indicators of a concept's presence.[27] There are many instruments developed and widely used in previous studies regarding QoL among children with ADHD. Pediatric QoL Inventory TM (PedsQLTM) is the most well-known instrument to measure QoL in the children population^[7] and applied by two studies, including in the Indonesian population. There are two kinds of PedsQLTM: child self-reporting ages 8–12 and parent proxy reporting ages 8–12. The PedsQLTM consists of four dimensions: physical functioning, emotional functioning, social functioning, and school functioning. These dimensions are then summed into three scores: Overall scale score, physical health summary score, and psychosocial health summary score. At present, two modules are available: The generic module and a diseasespecific module, including asthma, rheumatology, diabetes, cancer, and cardiac conditions. However, the ADHD-related module is still not available.^[7]

The other frequently used instruments in some previous studies, to evaluate QoL among children were the Child Health Questionnaire (CHQ self-report and parent-report),^[21-23,46] Kidscreen-52,^[43] Child Health and Illness Profile-Child Edition (CHIP-CE), Child Health and Illness Profile-Child Edition (CHIP-CE),^[20] Kinder Lebensqualita⁻⁻tsfragebogen (KINDL) questionnaire,^[19] The "Block E: QoL" assesses HRQoL of the child population,^[40] the Questionnaire of QoL for Children in Pictures; AUQUEI,^[41] The Inventory of QoL in Children and Adolescents (ILK)^[47] with mainly focused domains are physical health, psychological/emotional health, social domains, and school functions.^[18,20,23,40-44] However, those instruments are generic and not specifically related to ADHD.

Moreover, the following studies described and applied specific ADHD-related instruments to evaluate QoL. The study of Landgraf, Rich, and Rappaport (2002) proposed that the ADHD Impact Module Children (AIM-C) consists of a child scale and a home scale. Parents consider their children's success at home, in addition to their emotional and social wellbeing, as an indicator of a decent QoL. This instrument does not only evaluate The effects of ADHD on both children and their families.^[44] Dolgun, Savaşer, and Yazgan's (2013) study applied another specific ADHD-related instrument, the ADHD QoL Scale. Similar to AIM-C, this instrument mainly focuses on the psychological and social domain and focuses more on cognitive behavior as a critical aspect of school-aged children's developmental tasks.^[45]

Conclusion

Concept analysis is an essential process for the new researcher before conducting research. It will help researchers to improve their understanding of the concept by adopting Walker and Avant's analytical process involves several steps, including the selection of a concept, identification of the analysis's objective, examination of the concept's usage in literary works, definition of its attributes, presentation of a model case, consideration of additional cases (borderline, related, and contrary), determination of antecedents and consequences, and identification of empirical referents. This concept analysis highlights the importance of considering children's and parents' perceptions and satisfaction when examining the QoL among school-aged children with ADHD. Specifically, attention should be given to the physical, emotional, social, and academic dimensions of their lives, especially among the Indonesian children population. Regarding the appropriate instruments, health professionals, especially nurses, should take a look at the ones that may fit in their cultural background. In the end, the enhanced understanding of the concept will lead to the decision of whether to develop a new instrument, nursing diagnosis, or nursing intervention and differentiate the overlapping concepts and logical thinking regarding the QoL among school-aged children with ADHD in Indonesia.

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