

# ***Quality of life and psychological well-being in parents of children diagnosed with autism spectrum disorder at the Comunica Neurological Development Center in Cochabamba, Bolivia***

***Calidad de vida y bienestar psicológico en padres de niños diagnosticados con trastorno del espectro autista del Centro de desarrollo neurológico Comunica en la ciudad de Cochabamba –Bolivia***

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## **ABSTRACT**

The present investigation aimed to identify the relationship between quality of life and psychological well-being presented by parents of children diagnosed with autism spectrum disorder or its acronym ASD at the Comprehensive Center for Neurological Development (CIDN) Comunica, in the department of Cochabamba. The study corresponds to a descriptive correlational research with a quantitative approach, under a non-experimental design; the population selected for the research is made up of 22 parents, which have children diagnosed with autism spectrum disorder who sequentially attend the CIDN in the city of Cochabamba. The technique used for the collection of data and information was the application of surveys in which two duly validated questionnaires were used as instruments (Psychological Well-being Scale developed by Ryff from its 6 dimensions and the Family Quality of Life Scale developed by Verdugo, Sainz and Rodríguez), taking as a population 22 parents of children with autism from the CIDN Comunica, who agreed to be part of this research. The results obtained regarding psychological well-being fall within the moderate category, while the percentage for family quality of life is moderately high. It was concluded that there is a correlation between the two variables of psychological well-being and family quality of life.

### **Keywords:**

"Autism spectrum disorder"; "Psychological well-being"; "Disorder"; "Adventist University of Bolivia"

## **RESUMEN**

La presente investigación tuvo como objetivo identificar la relación que existe entre calidad de vida y el bienestar psicológico que presentan los padres de niños diagnosticados con trastorno del espectro autista o sus siglas TEA del Centro Integral de Desarrollo Neurológico (CIDN) Comunica, del departamento de Cochabamba. El estudio corresponde a una investigación de tipo descriptivo correlacional con un enfoque cuantitativo, bajo un diseño no experimental, la población seleccionada para la investigación está conformada por 22 padres, los cuales tienen hijos diagnosticados con trastorno del espectro autista quienes asisten de manera secuencial al CIDN en la ciudad de Cochabamba. La técnica empleada para la recolección de datos e información fue la aplicación de encuestas en la que se utilizó como instrumento dos cuestionarios debidamente validados (Escala de bienestar psicológico elaborados por Ryff desde sus 6 dimensiones y la escala de calidad de vida familiar elaborado por Verdugo, Sainz y Rodríguez), tomándose como población 22 padres de familia de los niños con autismo del CIDN Comunica, que accedieron a formar parte de la presente investigación. Los resultados obtenidos en torno al bien estar psicológico se encuentran dentro de una categoría moderado y en cuanto a la calidad de vida familiar, se observa un porcentaje medianamente alto. Se concluyó que si existe una correlación entre las dos variables de bienestar psicológico y calidad de vida familiar.

### **Palabras clave:**

"Espectro autista"; "Bienestar psicológico"; "Trastorno"; "Universidad Adventista de Bolivia"

## INTRODUCTION

Human beings experience psychological well-being when their mental health is good, acting positively when faced with negative problems, accepting them, and knowing how to manage them. To achieve this well-being, each person goes through different learning processes. This is especially significant for parents who have responsibilities for their children, which cause them concern. This situation becomes even more relevant when the child has a neurodevelopmental disorder such as autism spectrum disorder, which hinders their ability to communicate and socialize, and also presents restrictive behaviors, atypical social skills, etc. This could lead to depression, stress, and negative attitudes as a result of little or no knowledge of how to manage these problems, which leads to inadequate psychological well-being at this stage of life for parents or caregivers of children with ASD.

This is also reflected in quality of life, as it's not just about physical health but also mental health. Throughout history, disability has been conceived from an individual perspective, immersed in religious and pathological categories (Palacios, 2008).

For this reason, the World Health Organization (WHO, 1995) defined quality of life as "an individual's perception of their life situation, placed in the context of their culture and value systems, in relation to their goals, expectations, standards, and concerns." The WHO also indicates that psychological well-being is "a state of complete physical, mental, and social well-being, and not merely the absence of injury or disease."

ASD is a neurological condition that affects the quality of life of those who suffer from it. Thus, people who have a family member with ASD are forced to change aspects of their lives because they must provide specific care to the child with autism. This makes it difficult for them to fully develop their personal, family, and work life, putting the mental and physical health of their direct caregivers at risk. Cuxart (1995) in his book comments that caring for a person with multiple physical and social limitations, such as language and social interaction, prevents caregivers from having the time and money they need to meet their

own needs. The lives of caregivers of children with autism revolve around them, causing a notable decrease in their quality of life, leading to difficulties in the psychological well-being not only of the caregivers but of all family members.

Psychological well-being, based on the development of capacities and personal growth, is evaluated through the six (6) dimensions proposed by Ryff (1989): Self-acceptance, Positive relationships, Autonomy, Mastery of the environment, Personal growth and Meaning of life. Contextually, the subjective evaluation of daily activities and individual characteristics such as age, marital status and offspring influence psychological well-being (Montero & Fernández, 2012; Ryff, 1989 cited by Jeamper, 2019). In the case of ASD, the DSM-V (2014) establishes specific diagnostic criteria.

According to the DSM-V (2014), individuals with ASD must meet the following diagnostic criteria:

A. Persistent deficits in communication and social interaction across diverse contexts, currently or due to history.

B. Restrictive and repetitive patterns of behavior, interests and/or activities.

C. Individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later.

D. Symptoms cause significant impairment in social, occupational, and other important areas of normal functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay; social communication must be below that expected for the child's general level of development.

Upon receiving a diagnosis, parents go through a process of assimilation to having a child with autism, called "Crisis Response." This process consists of various stages that can vary between families and individual members. This diagnosis often modifies the context, expectations, family climate, and relationships, thus affecting the quality of life of parents or close caregivers (Bielfed, 2015, cited by Jampier, 2019). Over time,

and depending on the maturity, psychological stability, and support of the environment, family life can become rewarding and satisfactory (Ortiz S., 2008, cited by Mariandre, 2017). According to Martínez and Bilbao (2008), due to the clinical characteristics of ASD, fathers, mothers, and siblings face a greater risk of experiencing difficulties in their psychological well-being compared to relatives of children with other conditions such as Down syndrome, cerebral palsy, or developmental delay. They emphasize that the mother is the member most emotionally affected, since she bears the greatest responsibility and is often the link between the therapist and the other family members.

In the reviewed background, a paucity of research focused on the psychological well-being and quality of life of direct caregivers of people on the autism spectrum stands out. Among the few studies identified, Morales (2013) conducted a study in Lima, Peru, and Tafur Díaz (2019) and Femenías and Sánchez (2003) in Spain. These studies conclude that the psychological well-being of direct caregivers of people with autism spectrum disorder is more affected than that of those who care for people without this disorder, impacting the daily lives of parents of children with ASD. In relation to psychological well-being, Villagrán (2009), Cruz (2014) and Mariandre (2017) carried out work in Peru and Colombia, indicating that parents show low levels in the total scale of psychological well-being, experiencing personal dissatisfaction, lack of positive attitude towards themselves, hopelessness, little control of the environment, conflicts in problem solving and lack of autonomy, control of the environment, personal growth, positive relationships with others, self-acceptance and purpose in life.

At the national level, Hilda Ojeda's (2017) research in La Paz, Bolivia, stands out. It focuses on mothers of people with motor disabilities. The study sought to determine the relationship between the level of psychological well-being and the parents' quality of life. The findings suggest a relationship between the indicators of psychological well-being and the satisfaction variable, with p-values greater than 0.351.

Under these principles, the interest in

investigating the variables of quality of life and psychological well-being is justified, seeking to determine whether there is a relationship between the two in parents of children diagnosed with ASD. When addressing a disability or mental illness, the focus tends to be on the person suffering from the condition, neglecting those around them, especially the parents. The impact of having a family member with a disability and the mental condition of the parents can significantly affect the quality of life of the direct caregiver. When a parent learns that their child has been diagnosed with ASD, a complex pathology that entails social, behavioral, and language problems, it increases immediate emotions and thoughts that, in most cases, are not functional for the caregiver.

The general objective is to determine the relationship between quality of life and psychological well-being in parents of children diagnosed with ASD at the "Comunica" Neurological Center in the city of Cochabamba, Bolivia, in 2023. Thus, the following general hypothesis is formulated:

H1: There is a significant relationship between quality of life and psychological well-being in parents of children with autism spectrum disorder.

H0: There is no significant relationship between quality of life and Psychological Well-being in parents of children with autism spectrum disorder.

The specific objectives proposed are to identify correlations based on the six (6) dimensions presented by Ryff in relation to psychological well-being.

- Identify the relationship between the dimension of life purpose and the variable of family quality of life.
- To clarify the relationship between the autonomy dimension and the family quality of life variable.
- Specify the relationship between the personal growth dimension and the family quality of life variable.
- Determine the relationship between the dimension of positive relationships and the variable of family quality of life.
- Find the relationship between the

dimension of environmental mastery and the family quality of life variable.

- Identify the relationship between the dimension of self-acceptance and the variable of family quality of life.

## METHOD

This research is descriptive and correlational. It is descriptive because it allows for the detailing of situations and events, seeking to specify the characteristics of the study group (parents of children with autism from the Comunica Neurological Center in Cochabamba). The focus is on describing what a phenomenon is like and how it manifests itself, as well as specifying important properties of the individuals, groups, or communities under analysis (Hernández, Fernández, & Baptista, 2010). It is also correlational, since it seeks to understand the relationship between the variables under study.

Furthermore, this research follows a cross-sectional design, since the information was collected at a single moment, in a single time, thus reflecting the natural conditions of the context for subsequent analysis (Hernández, Fernández & Baptista, 2010).

The research approach is quantitative, based on the method used for data management, as it involves statistical procedures in information processing. According to Tamayo (2003), this approach is based on the confirmation of theories based on pre-established hypotheses and requires the use of a sample, which may be random or discriminated, but which characterizes the population or object of study.

The design is non-experimental, since there is no control over the variable. Based on timing, the design is cross-sectional, since data collection is conducted at a single point in time. Cross-sectional research designs collect data at a single point in time with the intention of describing variables and analyzing their impact and interrelationships at that time (Ibid., p. 270).

Furthermore, it is non-experimental, since the independent variables are not freely manipulated; it is based on categories, concepts, variables, events, communities, or contexts that have already occurred (Hernández, Fernández, & Baptista,

2010, p. 21).

The Psychological Well-being Scale, authored by Carol Ryff (1995), is named after the Ryff Psychological Well-being Scale. A Spanish adaptation was carried out by Carranza (2015). Its administration method is collective and/or group, and considering the scope of application, it is deduced that the questionnaire is suitable for parents of the Comunica Neurological Center in the city of Cochabamba. The duration of the application is approximately 20 minutes.

The Family Quality of Life Scale (FQLS), authored by Verdugo, Sainz, and Rodríguez in 2003, aims to determine the satisfaction families experience with each of the quality of life indicators in contrast to the importance they give to such indicators. The Family Quality of Life Scale is the adaptation to the Spanish context of the Family Quality of Life Survey developed at the Beach Center on Disability (2003) and carried out at the University Institute for Community Integration (INICO).

The research population included 22 parents, aged between 35 and 50, belonging to the upper-middle class. These parents have children diagnosed with ASD and regularly attend the Comunica Neurological Center. Most of them have been bringing their children to the center for approximately one year. Most of the parents are still married, so they usually attend their children's sessions as a couple.

The sample for this study is census-based, as it comprises the entire population, that is, the 21 parents of children diagnosed with ASD at the Comunica Neurological Center.

Regarding the procedure, the topic to be investigated was first selected, and the theoretical basis for the research was gathered. Subsequently, the problem was stated and the research objectives were established, defining the study subjects and the institution to be used as the population. To this end, Carol Ryff's Psychological Well-being Scale was retrieved in PDF format from the University of the Americas website in Puebla, Mexico, where standardized scales are shared.

The Family Quality of Life (FQL) scale, derived from a previous national research project, was also used. Authorization was then requested



from the directors of the Comunica Neurological Center to contact the parents of children with autism at the institution. Parents were contacted, scheduled for a specific day, and informed consent was provided before administering the Ryff Psychological Well-being Scale and the FQL scale. After collecting all the data, the scales were scored and the results interpreted. The results were analyzed using Excel and SPSS software, conclusions and recommendations were drawn, and the final report was prepared.

## RESULTS

### Correlation analysis between quality of life and dimensions of psychological well-being:

Below are the results from highest to lowest correlation score between the family quality of life variable and the six (6) dimensions of psychological well-being according to Ryff.

**Table 1.** *Correlation of family quality of life and the dimension of life purpose*

Quality of life		Satisfaction
Purpose in life	Pearson correlation	0.819
	p-value	0.057
	N	42
Source: Prepared by the authors, 2023		

Within the first results table, it is identified that the life purpose dimension is the one that presents the highest correlation among the other dimensions, showing a Pearson correlation of 0.819.

This correlation has a significance that indicates a strong positive relationship. This demonstrates that the clearer parents are about their life purpose, the better their quality of family life will be in their environment.

**Table 2.** *Correlation between family quality of life and the self-acceptance dimension*

Quality of life		Satisfaction
Self-acceptance	Pearson Correlation	0.680
	p-value	0.033
	N	42
Source: Prepared by the authors, 2023		

Regarding the second dimension, we find self-acceptance, which refers to the attitude one has toward oneself, consistently accepting one's flaws and virtues, without judgment or blame. A moderate positive Pearson correlation is observed, with a score of 0.680.

This indicates that it is the second dimension with a high correlation score. This demonstrates that the greater the self-acceptance parents have—that is, their acceptance of themselves, including their personal flaws and virtues—the better the quality of life they experience with their family.

**Table 3.** *Correlation between family quality of life and the dimension of environmental mastery*

Quality of life		Satisfaction
Environmental mastery	Pearson correlation	<b>0.612</b>
	p-value	<b>0.004</b>
	N	<b>42</b>
Source: Prepared by the authors, 2023		

Within the environmental mastery dimension, a score similar to that obtained in the second dimension (self-acceptance) is observed, reaching a score of 0.612. Again, a strong positive Pearson correlation is present. This reveals that when parents have adequate environmental mastery,

which implies the ability to manage a complex environment and skills to choose, manipulate, and adjust their environment according to their personal needs, including the ability to adapt to adverse circumstances and handle complicated situations, their family quality of life will be better.

**Table 4.** *Correlation between family quality of life and the personal growth dimension*

Quality of life		Satisfaction
Personal growth	Pearson correlation	<b>0.574</b>
	p-value	<b>0.574</b>
	N	<b>42</b>
Source: Prepared by the authors, 2023		

Table 4 shows that the correlation score between family quality of life and the personal growth dimension is 0.574, indicating a moderate positive correlation. This shows that if a parent engages in an adequate, ongoing, and dynamic process of personal development and improvement in various areas of life—that is, an internal journey that involves exploring beliefs, values, attitudes, skills, and strengths to reach their full potential and achieve a more fulfilling and satisfying life—they will experience personal growth. This growth will contribute to a better family quality of life,

considering that there is a correlation with this dimension.

**Table 5.** Correlation between family quality of life and the autonomy dimension

Quality of life		Satisfaction
Autonomy	Pearson Correlation	0.449
	p-value	0.120
	N	42
Source: Prepared by the authors, 2023		

Regarding the correlation results between family quality of life and the autonomy dimension, a moderately weak correlation was observed, with a score of 0.449. This indicates that the autonomy dimension influences parents' family quality of life, although not significantly, as the correlation is not very high. Considering that autonomy implies

the ability to develop tasks, make decisions, and act independently on matters related to oneself, controlling and making decisions about how to live according to personal norms and preferences, it can be concluded that, despite the importance of personal autonomy, it is better to consider the family than to act completely independently.

**Table 6.** Correlation between family quality of life and the dimension of positive relationships

Quality of life		Satisfaction
Positive relationships	Pearson correlation	0.297
	p-value	0.212
	N	42
Source: Prepared by the authors, 2023		

Regarding the final correlation, the positive relationships dimension obtained a score of 0.297. This indicates that it is the dimension with the lowest correlation score, demonstrating that there is a correlation between the two variables, but it is weak. This suggests that having positive relationships may have a tendency to improve family quality of life, but due to the weakness of the relationship, it cannot be completely relied upon. It follows that, despite the importance of a father having positive relationships in his environment, this does not significantly influence family quality of life.

#### **Analysis between the variables of family quality of life and psychological well-being:**

Below are the results of the correlation between the two research variables: quality of life and psychological well-being.

**Table 7.** Correlation between family quality of life and the dimension of positive relationships

Quality of life		Satisfaction
Psychological well-being	Pearson correlation	0.584
	p-value	0.053
	N	42
Source: Prepared by the authors, 2023		

When analyzing the correlations between the two variables of family quality of life and psychological well-being, a score of 0.584 was observed, indicating a moderately positive correlation. This means that there is a relationship between a father's psychological well-being and an adequate family quality of life. The higher a father's psychological well-being, the better his quality of life with his family is. Furthermore, positive correlations were found in all dimensions of psychological well-being with the family quality of life variable.

## DISCUSSION

Below is a discussion of the results of this research, which aimed to determine the relationship between psychological well-being and quality of life in parents with children, diagnosed with ASD who attend the CNC (Centro Neurológico Comunica). Psychological well-being is categorized as an important aspect in human beings, since it encompasses the understanding of the person and how functional their life is. According to the author considered for the research, Ryff (1995), psychological well-being is not only limited to happiness or positive emotions, since it is considered multidimensional and encompasses six (6) dimensions, including self-acceptance, positive relationships, mastery of the environment, purpose in life and personal growth.

According to the results obtained in this research, it is observed that high scores were obtained in the correlations based on the six dimensions proposed by Ryff. This indicates a positive correlation between all dimensions of psychological well-being and the family quality of life variable. It demonstrates that well-being in all the dimensions proposed by Ryff contributes to an

increase in the family quality of life of parents. These findings are consistent with the research of Tafur Díaz (2019), who examined the level of psychological well-being in mothers of children diagnosed with autism spectrum disorder. His study concludes that fathers have a moderate level of psychological well-being, which translates into a better family quality of life.

Through the analysis of the research results, the general hypothesis is confirmed, demonstrating a positive and significant correlation with both the dimensions of psychological well-being and the quality of life variable. A general correlation is also evident between these two variables, specifically family quality of life in terms of satisfaction and psychological well-being. This is perceived from the parents' perspective, indicating the existence of a consistent and positive foundation in the family, with adequate psychological well-being to cope with the behavior of their children with autism. This should translate into more effective support for children with autism in their educational development, contributing to an appropriate family quality of life for both parents and children. This finding is in line with the research of Chávez (2015), who examined the quality of life and psychological well-being of people with motor disabilities in a disability integration center in Trujillo, highlighting the importance of the people with whom they live for adaptation and readaptation to a new lifestyle, seeking satisfaction at a social, work and personal level to achieve psychological well-being and, therefore, a better quality of life.

On the other hand, there is also the research by Pérez (2005), who studied Psychological Well-being in parents of children with mental



retardation, using the Psychological Well-being Scale (PWS) as an instrument. Unlike the present research, she obtained different results, since when analyzing the results, it was established that the majority of parents who have children with mental retardation have low psychological well-being, suffering from stress, depression and anxiety. On the other hand, it is observed that parents of children with ASD present a low level to moderate psychological well-being, showing deficiencies in the sense of continuous development, lack of progress, little openness to new experiences and skills such as control of activities. Similarly, difficulties are identified in creating or choosing favorable environments, competence over themselves and their environment, assertiveness, coping with social pressures, self-regulation and maintaining their own individuality in different contexts. There is also evidence of a limited ability to maintain stable social relationships, relate to peers, and a poor or nonexistent acceptance of positive and negative aspects of themselves, as well as a limited understanding of their own limitations. This research also agrees with the study by Ortiz (2008), who conducted his research in Spain, setting out to determine the levels of overload experienced by primary caregivers of children diagnosed with Autism, in addition to determining their physical and psychological health status, as well as its relationship with the experienced overload. The results indicate a high level of overload among caregivers, as well as poorer mental and physical health compared to the general population. Positive and significant correlations were found between levels of overload and elevated psychopathological and health dimensions.

For his part, Cabanillas (2010) found that the behavior of individuals with autism is a major factor that diminishes the psychological well-being of their parents. Therefore, he recommends implementing methodologies for addressing each member of the nuclear family in specialized centers. Parents who seek to regulate the emotional consequences that arise from a stressful situation, such as receiving a diagnosis and coping with a child's autism, have greater psychological well-being (Pozo et al., 2014).

Quality of life satisfaction, in addition to psychological well-being, is influenced by other factors, such as socioeconomic status. Parents' perceptions of their child with autism are closely related to their perceptions of their daily mood, the financial and material income they receive through their efforts, the work life they face daily, and the life they may be experiencing with their partner. These factors can generate satisfaction or dissatisfaction in their personal lives. This assertion is corroborated by Carballar, Estévez, García, and Pernas (2012), whose study, titled "Factors Influencing the Psychological Well-being of Patients with Rheumatoid Arthritis," focused on 180 patients in the rheumatoid arthritis protocol clinic. They used the Well-being Questionnaire (CAVIAR) to assess psychological well-being and evaluated the activity index (DAS28) and functional capacity index (HAQ), according to the rheumatoid arthritis protocol of the Rheumatology Department of a Cuban hospital. Disease activity and rheumatoid factor positivity were not associated with psychological well-being. Functional capacity was positively correlated with almost all psychological well-being variables and was associated with several of the 72 variables, including satisfaction, the affective component, and the general well-being index. They concluded that psychological well-being in patients with rheumatoid arthritis is affected and significantly associated with the degree of functional disability. In other words, it is affected by the disease.

Regarding the limitations of this research, it is important to note that these results may have been influenced by the number of parents included in the population, as the center has a limited number of parents of children with autism. Another limitation is that, by answering the self-administered questionnaires, the parents surveyed could have expressed what they consider the correct answer to each question, rather than responding according to the reality of how they behave with their autistic children. Finally, to date, in the national context, there is no research addressing the relationship between psychological well-being and family quality of life of parents of children with autism within the CNC.

## CONCLUSIONS

The conclusions of the research are then presented, addressing the established objectives of identifying correlations between the family quality of life variable and the six dimensions of psychological well-being. The results are presented in order of score, from highest to lowest, for each dimension's correlation with the variable. Finally, in response to the overall objective, the results of the correlation of the two variables: quality of life and psychological well-being are presented.

Responding to the first specific objective posed in this research, we conclude that there is indeed a significant relationship between the quality of life variable and the life purpose dimension. This demonstrates that when a father has a clear sense of his life purpose, his family's quality of life is more satisfactory.

Regarding the second specific objective, a high positive correlation is required between the family quality of life variable and the self-acceptance dimension. This demonstrates that if a father has the ability to consistently accept his flaws and strengths, his quality of life with his family will be better.

For the third objective, it is specified that there is indeed a moderate positive relationship between the quality of life variable and the environmental mastery dimension. The conclusion is that if a parent has the ability to positively manage and confront complex situations in their environment, the quality of life they have with their family improves.

Regarding the fourth specific objective, it was determined that there is indeed a positive relationship between the family quality of life variable and the personal growth dimension. This indicates that when a parent has aspirations for personal growth and improvement, the family quality of life improves.

Regarding the fifth specific objective, it is concluded that a moderate and weak positive relationship was found between the variable of family quality of life and the autonomy dimension.

In response to the sixth and final specific objective, a positive relationship was identified between the quality of life variable and the positive

relationships dimension. It should be noted that, despite the existence of a relationship, it is weak; leading to conclude that the correlation is not entirely reliable.

Finally, considering the general objective of the correlation between both variables of family quality of life and psychological well-being in parents of children with autism at the CNC in Cochabamba, it is concluded that there is indeed a moderate positive relationship between the two variables. Therefore, the first general hypothesis is accepted, and the null hypothesis is rejected.

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