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Quality of Life of Elderly People with Severe Intellectual Disabilities in Chile

Calidad de vida en adultos mayores con discapacidades intelectuales severas en Chile

Qualidade de vida para idosos com deficiência intelectual grave no Chile

Izaskun Álvarez-Aguado, PhD[1]*

Vanessa Vega, PhD[2]

Maryam Farhang, PhD[3]

Leyre Álvarez Aguado, MSc[4]

Félix González, MA[5]

Herbert Spencer, MSc[6]

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1 Facultad de Salud y Ciencias Sociales, Universidad de las Américas (sede Providencia, Santiago, Chile). Millennium Institute for Caregiving Research (ICS2019_024), Chile.

2 Escuela de Pedagogía, Pontificia Universidad Católica de Valparaíso (Chile). Millennium Institute for Caregiving Research (ICS2019_024), Chile.

3 Facultad de Salud y Ciencias Sociales, Universidad de las Américas (Chile). Millennium Institute for Research in Depression and Personality (ICS13_005). Millennium Institute for Caregiving Research (ICS2019_024), Chile.

4 Sistema Nacional de Salud de Navarra (Navarra, Spain).

5 Escuela de Psicología, Pontificia Universidad Católica de Valparaíso (Chile).

6 Escuela de Arquitectura y Diseño, Pontificia Universidad Católica de Valparaíso (Chile).

Izaskun Álvarez-Aguado, ORCID: https://orcid.org/0000-0002-8021-525X
Vanessa Vega, ORCID: https://orcid.org/0000-0003-3333-4798
Maryam Farhang, ORCID: https://orcid.org/0000-0001-6345-6329
Leyre Álvarez Aguado, ORCID: https://orcid.org/0000-0002-5836-9607
Félix González, ORCID: http://orcid.org/0000-0001-7487-0154
Herbert Spencer, ORCID: https://orcid.org/0000-0003-1484-4477

* Correspondence author: ialvareza@udla.cl

Abstract

Introduction: Currently, the concept of the quality of life (QoL) is key to defining health policies aimed at the population with intellectual disability (ID). Most QoL studies in this field have been limited to people with ID with higher functioning levels. This has resulted in a little interest in evaluating QoL interventions among people with ID and a high need for supports, affecting their general well-being and conditioning the care they received. This study seeks to explore the QoL levels of people with severe and profound ID and to examine their differences based on some variables. *Material and methods:* From a quantitative-descriptive approach, the San Martín scale, based on the eight-dimensional QoL Model of Schalock and Verdugo, has been used in 201 Chilean people with severe or profound ID ages between 60 and 86 years. *Results:* Data show how most participants have low QoL levels, with self-determination and social inclusion being the most affected dimensions. When comparing the QoL score with sociodemographic variables, differences in the level of support needs and the type of center they are used are observed. *Conclusion:* Low QoL levels should be carefully considered because of a notable risk that they lead to greater vulnerability situations for this group. Likewise, a higher frequency in the support offered should be advocated, and spaces in which these people operate should be brought as close as possible to the community.

Keywords: Aging; intellectual disability; quality of life.

Resumen

Introducción: actualmente, el concepto de calidad de vida (CdV) es clave para definir políticas de salud dirigidas a personas con discapacidad intelectual (DI). La mayoría de los estudios sobre CdV en este campo se han limitado a personas con DI más leves. Esto ha derivado en un escaso interés por evaluar las intervenciones sobre CdV en personas con DI y grandes necesidades de apoyo, que afectan su bienestar general y condicionan la atención recibida. Este estudio busca explorar los índices de CdV de personas con DI severa y profunda, y examinar sus diferencias según distintas variables. *Material y métodos:* desde un enfoque cuantitativo-descriptivo se ha aplicado la Escala San Martín, basada en el Modelo de CdV de ocho dimensiones de Schalock y Verdugo, a 201 chilenos con DI severa o profunda entre los 60 y 86 años. *Resultados:* los datos muestran cómo la mayoría de los participantes tienen bajos índices de CdV, de los cuales la autodeterminación y la inclusión social son las dimensiones más afectadas. Al comparar la puntuación de CdV con algunas variables sociodemográficas, surgen diferencias según la necesidad de apoyo de los participantes y el tipo de centro del que son usuarios. *Conclusión:* es necesario prestar atención a los bajos índices de CdV, porque existe un riesgo notable de que conduzcan a mayores situaciones de vulnerabilidad para este grupo. Asimismo, conviene abogar por una mayor frecuencia en los apoyos ofrecidos y acercar lo más posible a la comunidad los espacios en los que se desenvuelven estas personas.

Palabras clave: calidad de vida; discapacidad intelectual; envejecimiento.

Resumo

Introdução: atualmente, o conceito de qualidade de vida (QdV) é fundamental para a definição de políticas de saúde voltadas às pessoas com deficiência intelectual (DI). A maioria dos estudos de QdV neste campo foi limitada a pessoas com DI mais leve. Isso gerou pouco interesse em avaliar intervenções de QdV em pessoas com DI e altas necessidades de suporte, afetando seu bem-estar geral e condicionando os cuidados recebidos. Este estudo busca explorar os níveis de QdV de pessoas com DI severa e profunda e examinar suas diferenças de acordo com diferentes variáveis. *Material e métodos:* a partir de uma abordagem quantitativo-descritiva, a Escala de San Martín, baseada no modelo de QdV de Schalock e Verdugo em oito dimensões, foi aplicada a 201 chilenos com DI severa ou profunda entre 60 e 86 anos de idade. *Resultados:* os dados mostram como a maioria dos participantes apresenta baixos níveis de QdV, sendo a autodeterminação e a inclusão social as dimensões mais afetadas. Ao comparar o escore de QdV com algumas variáveis sociodemográficas, surgem diferenças de acordo com o nível de necessidade de apoio dos participantes e o tipo de centro de que são usuários. *Conclusão:* deve-se atentar para os baixos níveis de QV, pois há um risco notável de que levem a maiores situações de vulnerabilidade para esse grupo. Da mesma forma, é aconselhável advogar por uma maior frequência no apoio oferecido e aproximar os espaços de atuação dessas pessoas o mais próximo possível da comunidade.

Palavras chave: deficiência intelectual; envelhecimento; qualidade de vida.

Introduction

For some years now, the construct of the quality of life (QoL) has become a key concept not only for the planning and provision of support for people with intellectual disabilities (ID) but also for the definition and evaluation of specific health policies (1,2).

In the field of ID, the QoL model proposed by Schalock and Verdugo (3) prevails due to its multidimensionality. The model indicated that this construct is understood as a desired state of personal well-being that (a) has universal properties and properties linked to culture, (b) has both objective and subjective components, and (c) is influenced by personal characteristics and environmental factors. The QoL concept consisted of eight domains: self-determination, emotional well-being, physical well-being, material well-being, rights, personal development, social inclusion, and interpersonal relationships. The relevance of these domains for QoL and their close association with the general health of people with ID has also been empirically and cross-culturally validated (e.g., 4).

The progressive measurement of this construct in the population with ID has shown the influence of some variables on their QoL levels. For example, people with ID who live in small neighborhoods present greater satisfaction with their QoL than those who reside in big cities (5). Likewise, people who have a job or occupation, regardless of the modality, experience higher average QoL levels than those who do not work (6). Similarly, other studies identify QoL differences of this population based on their financial situation (7). In addition to these variables, the literature suggests an important association between the QoL of this population and the severity of the ID diagnosis (8-10). When comparing the QoL based on the disability level, people with mild or moderate ID have a better QoL (11). However, most studies on QoL in the field of disability have been limited almost exclusively to those people with ID who have higher functioning levels. This has resulted in a little interest in assessing the interventions carried out to people with high support needs in terms of improving their QoL or personal results, affecting their general well-being and conditioning of the care they received (12).

There are two reasons that could explain the scarcity of research regarding the QoL of people with high support needs: (a) very few standardized instruments have been used to assess the QoL in this very specific population and (b) no scientific and organizational consensus has been established in characterizing who constitutes this population group that receives very different denominations (13). This affects both the identification and quantification of this population group and the generation of knowledge about good practices in providing support.

Despite the lack of consensus, currently people with ID requiring high support needs (also called "people with severe or profound ID") are those who "have a very limited intellectual and adaptive functioning, generally accompanied by sensory deficits and other types of disabilities (in their majority of physical type), resulting in the generation of a high degree of dependency" (14, p. 12). Highlighting some of the scarce research regarding the group characteristics, the intensity of the required support deprives them of the enjoyment of new service models (15), they have difficulties in meeting their wishes because they depend almost entirely on others' interpretation (16), they do not receive the appropriate support to significantly participate in activities of their interest (17), they find it more difficult to exercise their self-determination (18), and, in general, they face greater situations of the exclusion than their peers with less severe ID or with milder support needs (19).

Due to the difficulty in measuring something as subjective as QoL in a population with clear communication difficulties, the existing little information on this construct in this very specific group is based on the objective assessment provided by others (generally health professionals) (13). Some most relevant data from these investigations show how people with ID and high support needs present, to a greater extent than their peers with less intense needs, a series of sensory and physical difficulties or difficulties related to the nervous system that can condition their physical well-being (20). Specifically, as they age, these people tend to develop high-frequency cardiovascular problems (21), sleep apnea or thyroid problems (22), and diabetes or obesity (23). In addition, some epidemiological studies estimate the prevalence of psychiatric disorders in this population at 30%–35% (24), with depression and anxiety being the most common mental health problems during late adulthood. Combined with having more health problems than their peers with milder disabilities, people with ID and who require high support needs experience more barriers in receiving routine medical care (25,26).

Similarly, people with significant disabilities are more likely to remain in segregated environments, being excluded from experiences that foster a transition process to life in the community and negatively impacting their well-being (13). In these settings, only a third of people with severe or profound ID have someone in their relational network who is not associated with the field of disability or is not part of the family environment (15).

In Chile, 2% of the total population was diagnosed with ID. Among all people with ID, >40% of patients require high support needs and a grade of ID diagnosed as severe or profound (27). To guarantee the provision of a timely support to this group, laws 20.422/2010 and 21.168/2019 have been enacted. Precisely, these laws advocate equal opportunities and preferential care in the field of health for the population with ID and who require high support needs. However, no evidence has evaluated the impact of these procedures on the QoL of this group and their satisfaction with the support they received.

Considering all of the above-mentioned evidence, to learn how the disability severity can condition the support provided to the person to improve their well-being and general health, a recent study suggests further examination of the QoL of the population with ID and high needs for support (2,9,13,24). To advance the study of this phenomenon, we aimed to explore the indicators related to eight-domain QoL in people with severe and profound ID and to examine differences in QoL among the participants with different sociodemographic variables and correlations among different domains included in the QoL. Based on these objectives, this study assumes the following hypotheses: (a) people with ID and high support needs have low QoL levels and (b) there are significant differences in the QoL levels of the population with ID and high support needs based on sociodemographic variables.

Although good and healthy lives should be ensured, the QoL analysis in people with severe or profound ID is still only slightly addressed in the international literature and is practically nonexistent in the Latin–American context. Therefore, this study offers an innovative scenario by providing knowledge in a very unexplored area that helps clarify what contextual and personal elements must be considered when planning supports that help increase the QoL levels and the general well-being of this population. In addition, identifying which domains are necessary to delve into makes it possible to guarantee successful interventions that result, as far as possible, in improvements in the health conditions and general well-being of these people.

Material and methods

A descriptive-quantitative study was proposed. The study participants were Chilean people with ID ages between 60 and 86 years. The participants were selected based on the following two convenience criteria: (i) being between 45 and 90 years and (ii) have a diagnosis of severe or profound ID based on the standards established in the DSM-5.

To collect the evidence, after obtaining approval from the bioethics committee of the university (BIOEPUCV-H 270/2019), the National Disability Service databases in Chile that recorded the number of institutions dedicated to providing support to adults with severe or profound ID were reviewed. After contacting 10 institutions, three accepted the invitation. These institutions had some specific characteristics: (a) they developed specific programs to support independent living, (b) they carried out actions aimed at promoting the autonomy of users, and (c) they based their interventions on a rights-based approach. The types of institutions that contributed the sample were permanent residences of the participants (93 participants), day centers where they went to perform leisure activities (80 participants), and occupational centers where they participated in personal empowerment programs (28 participants). The residence and the day center were located in urban environments in two central regions of the country (Metropolitana and Valparaíso), whereas the occupational center was located in a rural environment in southern Chile (La Araucanía). In general, in different participating institutions, the care ratio for people with ID is one professional for every five users.

In the participating institutions, the initial contact persons were their directors, who were established as intermediaries between the research team and the study participants. Subsequently, an agreement on data handling and treatment was drawn up. Through this agreement, based on the Chilean Personal Data Protection Law (No. 19,628), security and confidentiality measures were established to protect the data from unauthorized access or improper use. In addition, the roles and responsibilities of researchers and other potential stakeholders in data processing were defined. The agreement also addressed aspects related to the preservation and subsequent disposal of evidence once the investigation was completed.

In each institution, the intermediaries were supported by one professional from the research team who oversaw the verification and control of the information provided by institutions on the diagnosis and sociodemographic characteristics of the participants (prior authorization from the people with ID or their families, if applicable) and supervision of the application of the questionnaire. The scale implementation process was phased based on the availability of institutions that agreed to participate in the study. Before the application of the instrument, informed consents of the participants (professionals and people with ID) were obtained. This process was structured in three stages: presentation of research objectives, impact of the research on the lives of people with ID, and implications derived from the study participation. These three stages (Table 1) were conducted through informational workshops in each institution that accepted the invitation.

Table 1. Stages of the informed consent process for participants with ID

Stage	Action	Adaptation
Stage 1	Explanation of the objectives and scope of the project Presentation of the research team Presentation of data collection techniques and instruments Simulation of the application of techniques and instruments (fictitious)	Documents in easy reading Cognitively accessible documents Use of pictograms Use of visual support
Stage 2	Explanation of the impact of the investigation Consequences of the research for your life Explanation of the benefits of participation Information about the risks of participation	
Stage 3	Explanation of the type of participation Explanation of the form of participation Submission of informed consent or assent document Review consent document or informed assent Simulation of the signature of a consent or assent (fictitious)	

Data sources/measurement

For data collection, the San Martín scale was used (28). This scale allows evaluating the QoL of adults with significant disabilities from 18 years (e.g., people with ID who require extensive and generalized support, with other possible associated conditions). The San Martín scale provides an individual profile on the QoL that helps personalize the support. Among the sociodemographic data collected using the scale is the level of need for support required by the person (extensive or generalized).

It is a self-administered questionnaire administered to professionals who work in the participating institutions regarding observable questions about the QoL of people with ID. The professional (a) must work directly with the person whose QoL is to be evaluated, (b) must have known the person for at least 3 months and be able to observe them in different contexts, (c) must have completed at least 3 years of university studies, and (d) be familiar with the QoL concept.

The San Martín Scale consists of 95 items distributed to 8 subscales that correspond to the dimensions of the QoL model: self-determination, emotional well-being, physical well-being, material well-being, rights, personal development, social inclusion, and interpersonal relationships (3). All items are stated in the third person, with a declarative format, and are answered using a scale frequency of four options (from “never” to “always”). It is a validated scale with good reliability indices for Spanish-speaking contexts (e.g., 12,29). Regarding the data processing and analysis, to transform the direct scores into standard scores and percentiles, the scales provided in the questionnaire manual have been used. Furthermore, averages of the indicators associated with each subscale were calculated using the descriptive statistics. The existence of significant differences in QoL scores based on sociodemographic variables were also analyzed. To determine the significance of differences between scores, the normal data distribution was checked using the Kolmogorov–Smirnov test as a previous step of the analysis of variance calculation (F). Finally, the correlation between variables was carried out using Pearson's correlation coefficient (r).

Results

The sample size in this study consists of 201 people with ID. Most participants are between 60 and 75 years (n = 101), were males (n = 125), had a diagnosis of severe ID (n = 160), received an extensive support[7] (n = 123), and live in the family home (n = 108) in urban environments (n = 152). In addition to the ID diagnosis, almost all participants (n = 176) have some of the following conditions: hearing impairment (n = 11), visual impairment (n = 3), mental health problems (n = 32), epilepsy (n = 3), Down syndrome (n = 3), behavioral problems (n = 4), several previous pathologies (n = 112), or other different conditions (n = 8). All participants were members of associations for the care of individuals with ID. These entities oversaw providing the researchers with the data related to the diagnosis, level of the support need, and the socio-health file of participants. Table 2 shows some of the sociodemographic characteristics of the participants.

Table 2. Sociodemographic data of the participants

Variable	Indicator	Frequency	%
Age	60–75 years	101	50.2
	76 years or older	100	49.8
Gender	Male	125	62.2
	Female	76	37.8
Degree of disability	Severe	160	76.6
	Profound	41	20.4
Level of support need	Generalized	78	38.8
	Extensive	123	61.2
Place of residence	In the family home	108	53.7
	Outside the family home	93	46.3
Living environment	Urban	152	75.6
	Rural	49	24.4

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[7] The information on the "level of support need" of the sample was a sociodemographic data provided by the institutions participating in the study. These entities used the Support Intensity Scale (Verdugo, Arias & Ibáñez, 2007) to determine the level of index need for each person's support. This index classifies the support needs into four consecutive levels ranging from lesser to greater dependency: intermittent, limited, extensive, or generalized.

QoL index in people with severe intellectual disabilities

In this study, the calculation of Cronbach's alpha for all items of the scale (α = .972) yielded acceptable levels of internal consistency. Table 3 shows the internal consistency values of different subscales in the instrument.

Table 3. Cronbach's alpha for instrument subscales

Subscale	Cronbach's alpha
Self-determination	.843
Emotional well-being	.852
Physical well-being	.810
Material well-being	.912
Rights	.890
Personal development	.960
Social inclusion	.929
Interpersonal relationships	.919

To analyze the QoL levels of the sample, the percentiles of the scale were divided into three ranges (low, medium, and high). The QoL levels of most participants (48.8%) were in the low range. The rights ($\bar{x}$ = 3.25; standard deviation [SD] = .596) and material well-being ($\bar{x}$ = 3.09; SD = .697) subscales have the highest means, whereas social inclusion ($\bar{x}$ = 2.09; SD = .791) and self-determination had the lowest ($\bar{x}$ = 2.46; SD = .615). Table 4 shows the averages for each indicator of the subscales.

Table 4. Descriptive statistics of the subscales

Dimension	Mean	Standard deviation
Self-determination	2.46	.615
Emotional well-being	3.00	.611
Physical well-being	2.96	.545
Material well-being	3.09	.697
Rights	3.25	.596
Personal development	2.62	.846
Social inclusion	2.09	.791
Interpersonal relationships	2.92	.684

If attention is focused on QoL indicators related to different subscales, it can be observed how often the centers or entities utilized by people with ID are concerned about respecting their rights (e.g., the right to privacy, confidentiality, and autonomy, free from unwanted interference or intrusion) (item 51: $\bar{x}$ = 3.55; SD = .774). Also quite frequently, professionals who provided them with support know the communication systems used by people with ID (item 84: $\bar{x}$ = 3.32; SD = .817) and give them love, affection, and physical contact when they need it (item 22: $\bar{x}$ = 3.47; SD = .768). However, participants have little opportunity to decide how to organize their private spaces (item 9: $\bar{x}$ = 1.67; SD = .1.045), know the rights they have in the institutions they use (item 52: $\bar{x}$ = 1.74; SD = .1.055), or participate in activities outside those centers or entities with people outside their immediate support context (item 76: $\bar{x}$ = 1.80; SD = 1.015).

To determine which indicators were most related to each other, Pearson's correlations were utilized. Here, providing the person with their technical aids is highly related to the use of community settings (r =.716; ρ <.001) and the acquisition of new skills or experiences through participation in activities (r =.701; ρ <.001). Taking specific measures to improve their communication skills is strongly associated with a person's participation in the development of their individualized support plan (r =.726; ρ <.001) and with learning things that make them more independent (r =.679; r <.005). Developing strategies or taking measures to prevent or treat pain is related to a greater tendency to have opportunities to learn about environments other than the person's residence (r =.679; r <.005).

Variables affecting the QoL of people with severe intellectual disabilities

The Kolmogorov–Smirnov test calculation (Z =.671; ρ =.904) showed normally distributed data. When comparing the general mean QoL score with different sociodemographic variables, significant differences are found based on the type of center used by the person or in which they participate (F = 14.715; ρ = 000) and their level of need for support (F = 4.267; ρ < .040). However, no differences were found in the QoL levels based on the age of participants, their gender, their degree of ID, their place of residence, their living environment, or other diagnosed conditions.

The comparative analysis between means shows how people with ID with extensive level of support needs ($\bar{x}$ = 95.14; SD = 16.83) have higher QoL levels and generalized level of support needs ($\bar{x}$ = 90.28; SD = 15.85). Regarding the type of the center, the study of *post hoc* contrasts shows which intergroup means are statistically more different from: participants who stay in their residences ($\bar{x}$ = 85.86; SD = 17.14) present significantly lower QoL levels than those who participate in day ($\bar{x}$ = 97.20; SEM = −11.340; ED = 2.34; ρ <.000) or occupational centers ($\bar{x}$ = 98.75; SEM = −12.890; ED = 3.31; ρ <.000).

To determine the extent of the level of support needs and the type of the center to predict the QoL index of the participants, a linear regression analysis was performed. The results show that only the level of support needs is a good predictor of the QoL index. Specifically, the analysis of this variable in the multiple linear regression model explains approximately 70% of the variance (adjusted R2 = 0.698; ρ <.000).

An analysis of variance has been carried out with the means of the subscales to determine any significant differences based on sociodemographic variables. This analysis shows how the QoL levels in some of the instrument's subscales vary significantly based on the living environment of the participants, their place of residence, and the presence of other diagnosed conditions (Table 5).

Table 5. Averages for the subscales according to sociodemographic variables

Indicator	SDE		EW		PW		MW		RI		PD		SI		IR	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Urban context	2.42*	.614	2.98	.589	2.97	.546	3.05	.686	3.22	.610	2.57	.902	2.05	.806	2.93	.721
Rural context	2.62*	.599	3.07	.677	2.95	.549	3.20	.725	3.33	.549	2.75	.630	2.22	.733	2.90	.562
In the family home	2.64*	.608	3.19*	.615	3.01	.542	3.31*	.546	3.09*	.469	2.86*	.767	2.23*	.767	3.06*	.575
Outside the family home	2.27*	.564	2.78*	.515	2.91	.547	2.84*	.766	3.44*	.652	2.33*	.846	1.93*	.793	2.77*	.767
Hearing impairment	2.34	.656	3.07	.639	2.94	.531	3.15	.668	3.29	.442	2.78	.675	2.44	.681	2.89	.613
Visual impairment	1.94	.210	2.50	.741	2.64	.835	2.42	1.01	2.67	.846	1.69*	.675	1.45*	.091	2.67	.882
Mental health problems	2.48	.587	3.02	.528	3.05	.469	3.30	.510	3.44	.592	2.58*	.830	1.76*	.669	2.75	.636
Epilepsy	2.53	.192	3.56	.241	2.69	.674	3.11	.529	3.56	.096	3.00	.577	2.12	.430	3.61	.048
Down syndrome	2.69	.048	3.44	.337	2.83	.144	3.56	.385	3.69	.048	2.31	.770	2.03	.892	2.86	.625
Behavioral problems	2.73	.734	3.08	.204	2.52	1.08	3.23	.362	3.27	.249	3.10	.542	2.30	1.07	3.13	.160
Several pathologies	2.42	.636	2.92	.619	2.97	.524	3.02	.752	3.16	.637	2.57*	.883	2.06*	.780	2.91	.735
Other conditions	2.30	.339	3.22	.661	2.86	.726	3.02	.565	3.32	.623	2.14*	.675	1.78*	.663	3.6	.623
None	2.76	.615	3.15	.672	3.04	.576	3.12	.711	3.31	.445	3.03*	.744	2.66*	.798	3.08	.593

SDE: Self-determination; EW: Emotional well-being; PW: Physical well-being; MW: Material well-being; RI: Rights; PD: Personal development; SI: Social inclusion; IR: Interpersonal relationships.

*The difference is significant at the level of $\rho < .001$ (bilateral).

Regarding the living environment, differences between averages were found to be significant in the subscale of self-determination (F = 4.073; ρ = .045). People who live in rural contexts show higher QoL scores ($\bar{x}$ = 2.62; SD = .599) than those who reside in urban areas ($\bar{x}$ = 2.42; SD = .614). Considering the place of residence in all the subscales, except for physical well-being, those who live in the family home have significantly higher averages in their QoL than those who live in the facilities.

In addition to the ID diagnosis, the presence of other diagnoses among the participants is a variable that conditions the personal development (F = 2.047; ρ = .043) and social inclusion (F = 3.350; ρ = .001). The analysis of post hoc contrasts shows how in both subscales the differences exist between participants without any other diagnosis and those with visual impairment, mental health problems, various pathologies, and other conditions or diagnoses different from those included in the instrument. In all cases, both in the personal development and in the social inclusion subscale, the participants who did not have any other diagnosis presented significantly higher averages than the rest of the groups.

Discussion

Based on the study results, the QoL levels among people with ID and high support needs should improve markedly. In addition, developing skills related to self-determination and increasing their social inclusion should be strengthened, because they are two of the dimensions with the lowest QoL scores in this population.

Furthermore, some factors that may be intervening in the low levels of self-determination and social inclusion of the participants should be identified. For example, when these people did not consider the necessary technical aids or measures to prevent or treat pain, they participate in fewer community activities, less likely use collective environments, and have fewer opportunities to discover new spaces.

This study also shows how the level of support need and the type of institution where these people live or participate are the only two variables that influence the QoL indices of the population with ID and high support needs. In this study, people with a higher level of support needs, that is, with a higher degree of dependency, present worse results in the evaluation of their QoL levels.

In some studies, differences between the QoL levels have been identified based on the type of support received by people with severe or profound ID (29,30). These studies suggest combining family cares and professional health supports with other technological ones (e.g., alternative communication systems) because they can be associated with improvements in people's well-being. To date, no study has been found to analyze the incidence of the intensity or frequency of the support received with the QoL levels.

Likewise, the characteristics of the entities in which these people participate also affect their QoL. Unlike the day or occupational centers, in this study as in others, collective residences of people with ID and high support needs who remain institutionalized indefinitely have a negative impact on their QoL (31). Specifically, residences offer very few opportunities for these people to participate, as far as possible, in planning their health itineraries, self-managing their grieving processes, establishing significant social relationships, and receiving care according to their wishes, religious, or cultural beliefs (32).

However, although no differences were found in the general QoL levels based on the age of the participants, their gender, their degree of ID, their place of residence, their living environment, or other diagnosed conditions, some dimensions of the QoL construct have been affected by some of these variables. Specifically, people who live in rural settings and in the family homes are more self-determined. Those who live with the family, in fact, also present greater emotional and material well-being, better social inclusion, greater interpersonal relationships, and better personal development. Beyond this research, no studies have predicted the higher QoL levels in people with severe or profound ID living in rural areas or in the family home.

In this study, another variable that affects the levels of self-determination and personal development is the presence of other diagnoses or health conditions in addition to ID. Despite not finding specific studies that clarify the impact of comorbidity on self-determination and personal development of people diagnosed with severe and profound ID, some indications suggest how the presence of mental health problems among people with ID and high support needs (e.g., anxiety or addictive disorders) notably limits their abilities for self-regulation and their personal competences for learning things that interest them (9,33).

One of the main findings of this study is related to the nonexistence of variations in QoL levels depending on the degree of ID. Contrary to this study, a general tendency to find lower QoL indices in people with more severe ID diagnoses is observed (34). Although the literature indeed shows an important association between the QoL and the degree of disability, this relationship is complex and is not necessarily significant when other factors are considered, such as the lack of support or opportunities (2). In fact, research has shown how and when the right support is provided, i.e., some skills, such as recognizing one's own strengths or the ability to solve common problems, can be developed among the population with ID and high support needs (9).

Limitations

This study also has limitations: (a) as participants were recruited using convenience sampling, the results are not generalizable; (b) the data obtained have been provided by other informants and not by the people with ID themselves, thus, the results should be cautiously interpreted and to complement them, when possible, with the participants' perceptions; (c) the low variability between the ages of the sample may have made it difficult to consider it as a determining factor of QoL in this population. However, people with ID generally age prematurely, and thus, a qualitative longitudinal study should be conducted to observe whether the QoL levels deteriorate as age advances; and (d) the scarcity of studies on the subject complicates the elaboration of a well-founded discussion on the phenomenon to be investigated. Therefore, these results must be considered from an exploratory perspective.

Conclusion

Considering the hypotheses of this study, the population with ID and high support needs does not have a good QoL, with dimensions self-determination or social inclusion being severely affected. In addition, a higher frequency in the support offered should be advocated to bring the spaces in which these people operate closer to the community, as much as possible.

The results of this study yield some implications that may be of interest to advance in the evaluation of the QoL of the population with ID and high support needs: (a) when identifying that the level of support needs is a good predictor of QoL among this population, standardized measurements on the QoL should be applied simultaneously with evaluations on the support index in these people, which will allow defining health support plans more precisely; (b) considering the disparity of results, deepening the link between the degree of ID and the QoL in this population should be continued to anticipate appropriate supports that allow to compensate for personal limitations and enhance existing capacities; and (c) spaces and environments should be created that facilitate the application of the current multidimensional QoL paradigm and avoid the development of purely healthcare practices.

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Author contributions

Conceptualization: IAA; Methodology: IAA, VV, and MF; Software: IAA, FG, and HS; Validation: IAA, VV, MF, LA; Formal analysis: IAA, VV, LA; Data curation: IAA, VV, FG, HS; Writing (original draft): IAA, VV, and LA; Writing (review and editing): IAA and MF; Visualization: IAA, VV, and MF; Funding acquisition: IAA.

Conflicts of interest

None declared.

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