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Quality of Life in Deafblind People and Its Effect on the Processes of Educational Adaptation and Social Inclusion in Canary Islands, Spain

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Abstract: Deafblindness is a unique and complex disability. Research on the needs and quality of life are scarce; as well as the lack of adequate knowledge, training and lack of qualified professionals to serve this group. All this justifies the sense and interest of this study. This study is derived from the project with reference 2020EDU04. Design: The study is descriptive, cross-sectional and quantitative-qualitative research design was conducted. Objectives: Know and analyze the needs of adult deafblind people in order to contribute to improving their quality of life. Method: Sample of 16 adults with double sensory loss (hearing and vision) residing in the Autonomous Community of the Canary Islands (Spain) was used. Instruments: The FUMAT Scale was used to measure personal development; self-determination; interpersonal relationships; social inclusion; rights of deafblind people; emotional well-being; physical well-being and material well-being. In addition, a semi-structured interview is conducted. Results by dimensions: Personal development: The professionals did not have specialized training to provide an educational response. Physical well-being: 68% of the sample had other health problems associated with deafblindness. Interpersonal relationships: 100% of the sample reported communication problems in the family environment. Social inclusion: They reported difficulties in accessing educational and leisure activities. Material well-being: In general, they stated that they have the material resources necessary for their daily lives. Self-determination: they consider that they have decision-making capacity in basic aspects of daily life. Rights: Deafblind people state that they have limitations in exercising their rights. Based on the interviews, it was observed that the people with the greatest difficulties in daily life are those who presented the greatest visual commitment. Conclusion: The etiology does not determine the quality of life of deafblind people, but communication conditions interpersonal relationships and personal development, and therefore their quality of life.

Keywords: deafblindness; dual sensory impairment; quality of life; social welfare; autonomy; integration; disability



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1. Introduction

Deafblindness is a multisensory, complex and poorly visible disability that prevents the person from using the senses of hearing and sight and does not always lead to a total loss of both senses [1,2]. The loss of one sense or another, its etiology, the degree of loss and the time of appearance, are factors that affect the development of people who present it. The classification of deafblindness is established based on the moment in which the symptoms appear and the level of autonomous functioning of the deafblind person. Visual and hearing loss lead to difficulties in communication, access to information, social interaction, etc. Therefore, specialized services are required to be able to cope with their daily lives [3,4]. Deafblindness is considered a unique disability as recognized by [5]. In

addition to the unique nature of disability, people who are deafblind form a heterogeneous population [6,7].

The literature on deafblindness and its consequences is currently sparse [6,8,9]. The World Federation of the Deafblind in 2018, conducted a census analysis, which included more than 97.6 million people from 22 countries. This analysis showed that 0.2% of the world population had “severe” deafblindness, and 2% had “mild” multisensory loss.

The causes of deafblindness are diverse (neonatal infections, syndromes, metabolic problems, etc.), among them the most common is Usher Syndrome, a hereditary disease, which at the auditory level presents with sensorineural hearing loss, vestibular alterations, and retinitis pigmentosa. In these cases, an effective diagnosis is essential, including genetic studies of deafblind people and their families [10]. Deafblindness poses real challenges, not only for the people who suffer from it, but also for their families and the professionals who work directly with them. One of these is to determine alternative communication methods or systems that allow them to develop functional communication that allows them to improve their quality of life. It is necessary to prioritize the communicative, social, and relational aspects due to the psycho-emotional implications that may derive from their lack, such as depressive processes, cognitive deterioration, and psychological discomfort. In this sense, it is necessary to clearly identify the impact of double sensory loss to offer the best support [11–13].

The moment of appearance of the sensory loss together with the associated difficulties and the socio-environmental context affect social interactions. A better understanding of these aspects improves the intervention programs developed and implemented by professionals who support and help people with deafblindness. Studies such as those by [14] and [4], have revealed that regardless of the origin of these difficulties, people with deafblindness show problems in communication, mobility and functioning in activities of the community. daily life.

Deafblind people can present diverse needs in all areas of development [15,16]. From an educational point of view, they require qualified professionals specialized in alternative communication models, especially focused on technological aids and support through digital communication applications and tools [17–22].

Routines become real challenges for deafblind people. The degree of isolation in their family circle, friends or at work complicate the integration processes. One of the priority aspects to compensate for the sensory disconnection they suffer is based on addressing communicative functions, for which the figure of the Spanish Sign Language (SSL) interpreter is essential, especially in cases in which people they are signers and do not dominate the oral language. The independence acquired through the support of interpreter guides of SSL, or of the relatives themselves, is fundamental and becomes a priority and basic task for this group [1,6,23–25].

Another fundamental aspect that has focused the interest of research in the field of deafblindness has been quality of life. As [23] define quality of life as a multidimensional phenomenon that encompasses personal development, self-determination, interpersonal relationships, social inclusion, rights, emotional well-being, physical well-being, and material well-being. They consider that these aspects vary and present different characteristics depending on the personal characteristics and environmental factors that surround deafblind people.

According to [26], if we want to know the real needs of deafblind people, it is necessary to evaluate the Quality of Life based on the dimensions and indicators described by [27], (Emotional Well-Being; Physical Well-Being; Self-Determination; Interpersonal Relations and Personal Development). This evaluation would allow us to have a general vision of the situation of people with this type of disability, however, individual differences cannot be dismissed because those personal, social, and educational factors may have on it [28,29].

Authors [30] have related positive self-perception to social acceptance and greater autonomy; and a negative self-perception with social isolation, etc. The deterioration of health associated with age, its vulnerability and economic and labor variability, as well as a

negative awareness of the way in which society perceives its condition, substantially affects both its personal image and its self-concept [28,30–32].

Autonomy is another aspect to consider in the study of Quality of Life, as it affects personal autonomy. The promotion of an autonomous and independent life supposes not only having the capacity, but also the possibility of making decisions and choosing freely, counting on the respect of others and towards others [28,33,34].

People with Usher syndrome have more difficulty maintaining their independence as they age [35]. The vulnerability of this group to exercise their right to decide is greater if families and professionals are not able to understand what they want, think, and want to do at a given moment. For this reason, it is important to support independence in three main areas; mobility, communication and access to information [33].

Interpersonal relationships are another relevant aspect in relation to quality of life, since it affects social inclusion. When deafblind people participate in activities, they feel less isolated and alone and improve control of their lives, feeling more useful [36–38]. In this way, the role of the associations that represent this group has become fundamental in terms of promoting participation and social integration activities.

The heterogeneity of the population, difficulties in functional assessment, communication barriers and deafblindness require changes that favor accessibility and adaptation to jobs [39,40].

The need for research in the field of deafblindness with the aim of improving the quality of life and social policies that favor the integration and adequate response to the needs of this group is becoming more and more evident. The social inclusion of this group continues to be a challenge today.

The main objective of the research was to assess the QoL of a sample of deafblind participants. Specific objectives:

1. Documentar about physical and emotional well-being. H1 and H3.
2. Explorar interpersonal relationships and social inclusion. H2.
3. Explorar about personal development. H4.
4. Identificar into personal and material resources.
5. Know the perception of their rights

Therefore, we developed the following hypotheses:

1. Using oral language and being oral-sign bilingual is associated with a better QoL compared with sign language.
2. Daily living with other people is better than living alone.
3. Having separate causes of deafblindness will be associated with better QoL compared to Usher syndrome.
4. To determine if social well-being is associated with health-related problems in people with Usher syndrome.

2. Materials and Methods

The main objective of the research was to assess the QoL of a sample of deafblind participants. Specific objectives:

The study is descriptive, cross-sectional and quantitative-qualitative research design was conducted.

2.1. Participants

Sample of 16 deaf-blind adult volunteers, 9 males and 7 females, aged between 18 and 27 years ($M = 22.7$, $SD = 3.04$).

Likewise, the selection of the people under study was made by contacting the different ONCE offices in Canary Islands. Regarding the sociodemographic data, 43.75% were women and 56.25% men, regarding age, 25% were between 18 and 20 years old, 31.25% between 21 and 23 years old and the 43.75% have an age between 24 and 27 years. Regarding marital status, 12.5% were married, 87.5% said they were single. In relation

to the employment situation, 18.75% were active and 81.25% were studying. Regarding the etiology, 6.25% were diagnosed with Usher Syndrome type I, 81.25% had separate causes and 12.5% unknown cause. According to the degree of hearing impairment, 22.72% had moderate hearing loss, 18.19% severe hearing loss and 59.09% profound hearing loss. Another aspect that was considered was visual functionality, 22.72% had total blindness and 77.28% had partial blindness. It should be noted that 50% used oral language, 31.81% used Spanish Sign Language and 18.19% were bilingual.

2.2. Ethical Statement

The Ethical Committee of University of La Laguna approved this study (reference number CEIBA2021-0462). All participants gave informed consent and were treated according to the Declaration of Helsinki (1964–2013).

2.3. Instruments

The FUMAT scale [27] was used to obtain the quality-of-life index of the participants. Based on the heuristic model of quality of life proposed by [24]. This scale is made up of eight dimensions related to quality-of-life indicators.

All raw scores were converted into percentiles [41]. The eight dimensions and their corresponding indicators are then determined (see Table 1):

Table 1. Dimensions of the Fumat Scale and indicators [1].

Emotional Well-Being	Absence of Stress/Anxiety/Negative Feelings, Self-Concept, Social Relationships, Personal Satisfaction/Satisfaction with Life.
Relationships	Family, friendship, and social relationships.
Material well-being	Community relations, income, finances, possessions, belongings, community services, and housing (compliance).
Personal development	Work, education, and activities of daily living.
Physical well-being	Health (consequences, energy, and vitality), general health, health services and sleep.
Self determination	Autonomy, decisions, choices, goals, and personal preferences.
Social inclusion	Integration in the community, social participation, and social support.
Rights	Human and legal.

Through a semi-structured interview, sociodemographic data were collected: age, sex, etiology, time of onset of disability, age at which they began to lose hearing and vision, and prosthetic adaptation (hearing aid and cochlear implant) and inquired about quality of life based on the dimensions established by [27], in order to complete and contrast the results of the questionnaire (see Table 2).

Table 2. Dimensions, Definition, items.

Emotional Well-Being	Are You Satisfied with Yourself? How Do You Feel in Your Day to Day? Are You Satisfied with Your Life?
	How do you relate to others? Do you think people understand you? How do you relate to your family? What limitations do you encounter when communicating with other people?
Relationships	Does your home fit your needs? What is your income? Do you have help to move?

Table 2. Cont.

Emotional Well-Being	Are You Satisfied with Yourself? How Do You Feel in Your Day to Day? Are You Satisfied with Your Life?
	What is your educational level? What limitations have you encountered during your schooling? What jobs have you done? Do deafblind people have the same opportunities as normal-hearing people in the workplace? How do you relate to the workplace? And in daily life? In case of a problem, how would you solve it? Is your work adapted to your disability?
Material well-being	Explain when you start losing your hearing and vision. And what other health problems do you have?
It is based on the life project of the person, taking into account their individuality: Goals, values, preferences and interests. In this way the subject develops its autonomy as a fundamental right.	How do you get along in your daily life (home, street, work...)?
Personal development	Do you belong to any association? Do you interact more with deafblind and hearing people?
	Do you consider that people with disabilities have the same rights as the rest.

Source: Own elaboration.

2.4. Procedure

Data collection was carried out by specialized and trained personnel (MCRJ, IPA). After being invited, all participants were asked to sign an informed consent to enroll in the study. At the second visit, a week later, the participants met with the investigators, with the assistance of a sign language interpreter when participants were signers and non-oralist. During the visit, the researchers tried to develop an atmosphere of trust, confidentiality of the answers was assured, and the participants were told that there were no right or wrong answers.

All interviews were recorded for later transcription. Subsequently, a second researcher compared the transcriptions made to verify their accuracy.

2.5. Data Analysis Strategy

2.5.1. Qualitative Data Analysis

The MAXQDA Plus 2020 qualitative analysis software was used. The interviews were literally transcribed and entered for analysis, establishing the categories considered in the questionnaire (Personal development; Interpersonal relationships; Physical well-being; Emotional well-being; Material well-being; Social inclusion); Self-determination; Law). These categories were used to identify segments of the text in relation to the research questions and hypotheses. To identify the responses of the participants, an identification code with a general name “Px” was used, where the term “x” refers to the participant number (P1 = participant 1).

2.5.2. Quantitative Data Analysis

Age and FUMAT scale scores were summarized as mean (standard deviation), and categorical sample characteristics were summarized as frequency (percentage). Whole sample percentile scores (subscales and total) were compared against the expected reference values N (50,34) from the scale validation sample [41] using one-sample Student’s t test. Additionally, subscales and total QoL scale percentiles were compared between oral and bilingual vs. sign language speakers, and between separate-cause vs. Usher etiologies,

using two-sample Student's *t* test. Effect sizes of the differences were calculated using Cohen's *d* formula: $d = (M1 - M2)/SD$. The benchmarks for effect size interpretation were: 0.20, small; 0.50, moderate; 0.80 large. Significance level was set at 0.05 for all comparisons. All the analyses were performed using Stata 15.1 (StataCorp, College Station, TX, USA).

3. Results

After comparing QoL scales in percentile values with the standard reference, our sample of deafblind participants scored significantly lower in multiple subscales and the overall FUMAT scale. Thus, the sample averaged 37.16 (SD = 13.32) in Emotional Wellbeing subscale percentile, $p < 0.001$, $d = -0.96$, which was significantly lower than the reference. Interpersonal Relationships percentile, $M = 15.32$ (SD = 10.39), $p < 0.001$, $d = -3.34$, and Material Wellbeing percentile, $M = 4.60$ (SD = 6.1), $p < 0.001$, $d = -7.44$, showed very low scores (very large effect sizes) compared with the expected values. Self-determination percentile, $M = 40.24$ (SD = 11.07), $p < 0.001$, $d = -0.88$, and Rights, $M = 26.36$ (SD = 17.81), $p < 0.001$, $d = -1.33$, were also shown to be significantly lower than the reference. Finally, the analysis of FUMAT QoL percentiles showed and overall poor reported QoL in our sample of deafblind participants: $M = 23.60$ (SD = 7.72), $p < 0.001$, $d = -3.42$. However, no statistically significant differences were found in Personal Development, Physical Wellbeing, Social Inclusion percentile subscales compared with the reference.

The comparison based on the ability for oral language used (Table 3) shows that oral/bilingual speakers scored significantly higher in Personal Development scale ($p = 0.013$, $d = 1.03$). They also showed moderate effects (not statistically significant) in—already very low—Material Wellbeing scores, and Social Inclusion. However, a moderate effect size was found in the opposite direction regarding Rights scale.

Table 3. Differences in QoL percentiles due to oral language use.

Scale	Oral and Bilingual (<i>n</i> = 17)	Sign (<i>n</i> = 8)	<i>p</i>	<i>d</i>
	<i>M</i> (SD)	<i>M</i> (SD)		
Emotional Wellbeing	37.76 (14.06)	35.88 (12.38)	0.748	0.14
Interpersonal Relationships	15.29 (10.39)	15.38 (11.10)	0.986	−0.01
Material Wellbeing	5.53 (7.00)	2.63 (3.02)	0.276	0.48
Personal Development	56.88 (10.4)	43.63 (13.7)	0.013	1.03
Physical Wellbeing	44.82 (22.55)	40.00 (19.43)	0.608	0.23
Self-determination	39.41 (8.04)	42.00 (16.34)	0.596	−0.23
Social Inclusion	51.65 (15.42)	43.25 (20.95)	0.269	0.48
Rights	23.53 (17.95)	32.38 (17.05)	0.255	−0.50
FUMAT QoL	24.53 (8.69)	21.63 (5.04)	0.392	0.38

Note: differences between groups were assessed using two-sample Student's *t* test. Source: Own elaboration.

When QoL was compared based on etiology of deafblindness, no statistically significant differences were found between Separate Causes and Usher. Emotional Wellbeing, Personal Development and Self-determination scales showed moderate-effect sizes (not statistically significant) in favor of separate causes.

Only two participants reported living by themselves: both were female, used oral language, and their etiology was separate causes; one worked and the other one was single. Their overall QoL scores were very low, consistent with low Emotional Wellbeing and Social Inclusion, very low Interpersonal Relationships and Self-determination, and extremely low Material Wellbeing. However, they scored normal in Personal Development and Physical Wellbeing (see Table 4).

Table 4. Differences in QoL percentiles due to deafblindness etiology.

Scale	Separate Causes (n = 13)	Usher (n = 11)	p	d
	M (SD)	M (SD)		
Emotional Wellbeing	40.62 (15.09)	34.18 (10.6)	0.248	0.48
Interpersonal Relationships	15.54 (10.41)	13.09 (8.73)	0.544	0.26
Material Wellbeing	3.54 (5.58)	6.09 (6.89)	0.327	−0.41
Personal Development	57.00 (10.09)	50.00 (13.0)	0.152	0.59
Physical Wellbeing	41.62 (25.81)	43.45 (15.79)	0.839	−0.09
Self-determination	41.15 (9.48)	36.00 (6.68)	0.145	0.60
Social Inclusion	51.15 (13.16)	47.45 (22.26)	0.619	0.21
Rights	25.08 (15.76)	28.00 (21.41)	0.704	−0.16
FUMAT QoL	24.15 (9.47)	22.55 (5.66)	0.627	0.21

Note: differences between groups were assessed using two-sample Student's t test. Source: Own elaboration.

Results of the Semi-Structured Interviews

Personal Development Dimension (work, education, and activities of daily living).

The participants reported that the teachers had no training in deafblindness, were not prepared to teach them, and were unaware of the adaptations required for an adequate educational response. Of those interviewed, 83% had studied vocational training and 17% had studied compulsory education. Educational centers did not have the personal and material resources to adapt the educational response (teachers did not use sign language, but oral language, and as a consequence they could not access the curricular content).

"...In my school sign language was not used, very oral methods..." P6.

"...I have been limited due to my communication problems; I did not have the necessary academic help..." P7.

"...I had problems with my eyesight since I was a child, since I was in school, I already had numerous problems, together with a lack of attention from my teacher, which led to poor grades..." P2.

Regarding work, all active work participants stated that they had difficulties in carrying out their professional performance, because the work space was not adapted to their needs, there were significant physical and access barriers that hindered their autonomy and independence, and the workday did not adjust to the limitations imposed by their disability.

"...I had many problems because my job was not adapted, I had to work in a small space, but as I had the need to earn money, I continued..." P6.

Regarding activities of daily living, it should be noted that all the participants stated that they had mobility difficulties outside their immediate environment, although 72% stated that they encountered fewer difficulties in household activities, since it was a more familiar environment for them. 28% stated that they needed assistance for mobility in the environment and at home.

"...Well, I use my visual remains to get by in my day to day, I have problems if I spend time in busy areas because it causes me fatigue..." P8.

"...I don't go out alone, I feel insecure, and a girl comes to help me..." P23.

"...Well, I clean, I make the food, I put the washing machine on, and my family knows my problem and they don't leave things lying around or out of place..." P16.

Dimension: Physical well-being (general health, health services and sleep).

Regarding this dimension, associated health problems were observed (68%). Only 32% did not present other diseases. 84% stated that they were well cared for by their doctors, they attended their visits with sign language interpreters. 16% of the participants stated that they had difficulties in detecting associated pathologies that affected their health.

"...regarding sight, as a baby I had some visual problems in which I was not correctly identified where the origin was, they triggered some cataracts, which had to be operated on and all that..." P1.

"...I have retinitis pigmentosa with Usher Syndrome I..." P13.

"...first was the audition, a situation in which I became completely "deaf". Regarding the eye, I began to experience difficulties and I had some vision problems, which I have already gotten used to..." P3.

Dimension: Interpersonal relationships.

Regarding this dimension, difficulties were found in relation to communication in the family environment, 16% of the participants stated that they did not share the same communication code. In the social sphere, all the participants stated that they had difficulties integrating or interacting with others.

"...when they don't speak LSE, I ask someone to sign or speak for me..." P10.

"...little sign language and oral language, especially with my relatives, I have quite a few communication problems due to my production problems. So, they use supported sign language or very short messages. Also, another resource that we use is remote sign language..." P6.

"...depends on the person, on their way of communication, due to my visual problems the others have to speak more slowly, otherwise I can't fully capture the information and I get lost. Another factor is that the person is aware of the difficulty..." P7.

In addition, all reported difficulty in interpreting information from hearing people and expressed frustration.

"...My family does not know sign language, so communication is difficult and other methods are used, such as messages in the palm of the hand or written messages..." P8.

Dimension: Social inclusion.

100% of the participants stated that they needed the support of institutions and their families to overcome barriers, both communication and architectural. Both the family and the associations they attend, support them, and help them make decisions for themselves. They have greater difficulty accessing educational, training or leisure activities, since most of them are not adapted to their communication needs.

"...it's not very hard. We are marginalized in society in general..." P10.

"...no, we have the same job opportunities as hearing people, due to numerous communication problems..." P5.

"...yes, I am affiliated with ONCE..." P1.

"..., in addition to being an association for deaf people, is a place where I go to see my friends, and I do different leisure activities, my needs are well attended to here..." P5.

Dimension: Material well-being.

The participants stated that they needed material goods to cover the specific needs associated with deafblindness, for example: a cane or a guide dog for mobility, or technological adaptations for the use of different electronic devices (mobile phones, computers, etc.) as well such as the adaptation of physical spaces. In relation to housing, the majority stated that they lived in their own house, which was generally adapted (ramps, lights, etc.).

"...I have some modifications in my mobile, contrast, colors, sounds, talk-back. As for the computer, more or less the same modifications..." P4.

"...yes, with the help provided by ONCE (guide dog or cane) I use it to do so..." P2.

"...I live in a house with the necessary adaptations to be able to move independently, there is an elevator and ramps in the building..." P1.

Dimension: Self-determination.

97% of the participants expressed having decision-making capacity in basic aspects of daily life, choosing what to study, where to work, what leisure activities to participate in, etc. Only 13% stated that they could not make decisions autonomously.

"...I recently moved..." Q4.

"...I changed my address near my association..." P3.

"...I live with my wife and children..." P1.

Dimension: Rights.

The participants considered that they had the same rights but highlighted that they had limitations when exercising them (100%). They also expressed that they did not participate in the design of specific policies to guarantee equal opportunities with other people.

“...I can vote, because they inform me, but I need a family member to give me the ballot I want, so I don’t have privacy to do it...” P4.

“...When I go to the ATM, I can’t do the operations, by myself, I have to be accompanied...” P11.

4. Discussion

This study has made it possible to identify the main difficulties and conditions that affect the daily life of deafblind people in the Canary Islands. The combined use of the FUMAT scale and the answers obtained from the semi-structured interviews have allowed us to approach a reality quite unknown at the social level.

In relation to personal development, an improvement in the training and qualification of teachers and professionals who care for these people is required. The possibilities of progress in studies seem to be conditioned by limitations in resources and professional training and qualification. Likewise, they perceive that work environments are not adapted to their needs and that they lack communication tools and motivation to communicate with this group by other colleagues. The jobs and the contexts that encompass labor relations are not adequate and favor the isolation of this group.

Regarding interpersonal relationships, it is evident that there are no communication difficulties when deafblind people spoke orally, however, this communication was severely affected when they used other languages such as sign language, palm dactylology, etc. As [1,42] and [23], these difficulties are present and lead to the isolation of this group both in the family and social circle. As [36] stated, interpersonal relationships influence the processes of social inclusion of deafblind people.

Regarding physical well-being, participants reported having associated diseases. Physical well-being is a fundamental aspect that must be controlled by health professionals who care for these people. Ensuring access to health information by making available the necessary means and support is essential to prevent the effects and changes resulting from the aging of these people. As stated by [35] and [26] the provision of means and resources for an aging person with quality of life is essential for this Group.

Regarding social inclusion, the need to offer opportunities to access training or leisure activities stands out, for the most part these activities are not adapted to their communication needs. Associations and groups can be an alternative in which deafblind people feel comfortable, but it is not a situation that favors true inclusion. Most of the participants expressed their preference for associations, which from our point of view is not enough. Social inclusion influences the emotional well-being of people with deafblindness, but as [36,37] and [38] stated, they must occur in natural and non-segregated contexts and environments. Deafblind people need the support of institutions and families to overcome the difficulties that prevent them from feeling included in society [43].

In relation to the emotional dimension, low scores are shown in emotional well-being, interpersonal relationships and rights through interviews. It is noteworthy that in the personal development, physical well-being and social inclusion dimensions the results were not significantly different from those of people without disabilities, however the interviews did not confirm this fact since their answers did not reflect dissatisfaction with respect to this dimension in the results of the scale, but it did in the interviews carried out.

In relation to material well-being, the results showed a lack of materials that cover the specific needs of this group derived from their condition. Technological adaptations for the use of different electronic devices (mobile phones, computers...) as well as the adaptation of physical spaces are claimed elements that are not found in the environment or spaces through which they pass.

Technology has the potential to transform the lives of people who are deafblind. Deafblind people have problems with mobility, access to information and communication. Without adequate technological support, people who are deafblind may become increasingly withdrawn and isolated, which will affect their quality of life [18,44,45].

Appropriate support and guidance are required to promote self-determination in deafblind people. Some deafblind people have been able to decide on basic aspects of their daily life, they have been able to choose studies, work, leisure activities, etc. This reality is not frequent and requires an important effort and work on the part of professionals and families. Autonomy, independence, and decision-making are aspects to promote the true inclusion of this group.

Despite being aware of their rights, deafblind people must have the means and resources to exercise them and make them effective. In this sense, they claim the development of policies that guarantee their fundamental rights with equal opportunities as the rest of the people.

The reality of deafblind people is complex, not only because of the special living conditions derived from their sensory condition, but also because of the conditions of their day-to-day life [45]. It is necessary to implement actions that focus on the provision of means, support and technological resources that allow overcoming the barriers of their condition. Deafblind people are an unknown group for which we must work and develop policies focused on their own needs that allow access to spaces, resources, training, etc. if we really want them to have an adequate quality of life.

5. Conclusions

It is not clear that the etiology of deafblindness can determine significant differences in quality of life.

Communication determines and conditions interpersonal relationships since the means, resources or support that guarantee effective communication are not always available.

It is necessary to provide adequate support to deafblind people (LSE guides-interpreters, communication mediators, etc.), so that they can access education, the world of work and society in general. To this end, the professionals who care for them must receive specific training on deafblindness and information on the specific resources available to carry out their work.

Social participation improves the emotional well-being of people with deafblindness, despite the fact that institutions and associations promote participation and insertion through activities and workshops that encourage communication between equals, this should not be the only resource or space for participation.

Deafblind people have the same fundamental rights as other citizens to achieve full integration and equality and it is necessary that they be able to exercise them autonomously, and that they have guaranteed equal opportunities and thus avoid discrimination.

The discussion of this study is presented based on the dimensions that have been used to order and describe the results based on the characteristics of a disability whose complexity requires a multidimensional approach. Knowing the quality of life of deafblind people will allow us to respond individually and appropriately to their needs [26,27].

It has been evidenced in the results of this and other previous studies, deafblindness is a disability, the special nature of the combination of two disabilities as complex as deafness and blindness, complicates the adjustment processes of the psychosocial and educational response [1,2,6,8,10].

This study has made possible to identify the main difficulties and conditions that affect the daily life of deafblind people in the Canary Islands. This is the first study carried out in the Canary Islands, whose incidence [10] and special reality focus the interest of the results of this study. Especially significant is the fact that it is one of the Spanish autonomous communities with the highest rate of deaf and deafblind people in Spain. The very prevalence of this disability marks differences in terms of the level of functioning and functionality [4].

The dimensions studied through the FUMAT scale and the first-hand opinions of those affected provide a realistic perspective focused on the story of the vital experiences of these people who have seen their vital experience condition by a still unknown disability

that generates fear and insecurity in the people who must relate or interact with them on a day-to-day basis.

One of the keys and most relevant aspects in relation to the improvement of the training processes of this group is related to the adequacy of the educational response and therefore with an adequate qualification of the teachers [46].

Well-trained and qualified teachers are better qualified to promote the personal development of a group that is especially conditioned by its particularities [11–13,39]. The possibilities of progress in studies seem to be conditioned by the limitations in resources and the training and qualification of this group [16]. Likewise, work environments have not been adapted to them given that deafblind people's colleagues lack communication tools and communicative intention [17,18,20–22].

The jobs and human environments that make up labour relations are not adequate and favour isolation.

Regarding interpersonal relationships, it is interesting to differentiate a concrete fact related to the preservation of the oral language, which in the case of people who suffer late vision and hearing loss, does not lead to specific difficulties, however it is not the same in the case of people who used sign language, palm dactylology, etc. In this sense, these authors [1,23] confirm that relationships and social interaction are affected in these children, which ends up isolating them from both the context and the family [36,38]. As [36] stated, interpersonal relationships influence the processes of social inclusion of deaf-blind people and in the case of the participants in this study this has been significantly affected, especially in the implications it has on in relation to the perception they have about their social acceptance [31].

Physical well-being is a fundamental aspect that must be supervised by the health professionals who care for these people; their special conditions and associated multiple pathologies make them a highly vulnerable group [35]. Ensuring access to health information by making the necessary means and support available is essential to prevent the effects and alterations caused by aging [26,43]. Aging and the limitations derived from it condition the limitations inherent to disability, in this sense, the means and resources must be guaranteed so that they can age with dignity.

Resources must be guaranteed to secure the processes of social inclusion. In this sense the training or leisure activities must be adapted to their needs for communication, orientation or relationship and interaction. Associations and groups today represent an alternative in which deafblind people feel comfortable and integrated, however we consider that they continue to be spaces of a reductive inclusion model that does not favor real inclusion. The best way to respond to the needs of the group of deafblind people is to know their needs and offer spaces for interaction and relationship as natural and real as possible [33]. The reality manifested and reported by the group in this study show the need to change the model for the relationship and social interaction.

Social inclusion is key to improving the emotional well-being of people with deaf-blindness as stated by [36,38], they must occur in natural contexts and environments and not in circles closed, such as those represented by associations or groups of disabled people. Deafblind people need the support of institutions and families to overcome the difficulties that prevent them from feeling included in society, for this reason it is necessary to generate social awareness and make their reality visible, especially invisible in the Canary Islands, where there is only one association serving this group.

Emotional development has been a dimension in which the participants of this study evidenced emotional difficulties, difficulties in interpersonal relationships and recognition of their rights.

Significantly curious is the fact that in dimensions such as; personal development, physical well-being and social inclusion the results were not very different from those found in people without disabilities, however the interviews reflected dissatisfaction regarding these dimensions. We cannot consider that the reality experienced by the group is really the most optimal for favoring adequate emotional development [46]. The insularity and

the scarcity of resources limit the possibilities of interaction and relationship with others, the evidence manifested by both relatives and by the affected ones themselves mark the need to reorient the formation and emotional development of the group.

The special conditions and the peculiarities and specificities of deafblind people require significant efforts to provide them with the resources and materials they need. The statements in relation to material well-being show the lack of materials to cover the specific needs derived from the condition [17–20]. Technological adaptations for mobile phones, computers, etc., as well as the adaptation of physical spaces are examples of common claimed aspects of the environments or spaces through which they travel. Technology has proven to be the most important ally for the elimination of barriers, deafblind people have problems with mobility, access to information and communication, without adequate technological support, this group could be increasingly isolated, a fact that, it would certainly affect their quality of life [18].

Adequate support and guidance are required to promote the self-determination of these people. Although some deafblind people have been able to choose studies, work, leisure activities, etc., this is not often the case. An important effort and work are required on the part of professionals and families and the administration itself to support and guide the self-determination processes. Autonomy, independence, and decision-making are aspects to be promoted if the true inclusion of this group is to be promoted, decision-making processes must be favoured by making families understand the relationship with the self-determination process [28,33,34].

Knowing their rights does not guarantee that they can exercise them, even if deafblind people know their rights, they show great difficulties in exercising them. Aspects such as limited material, technical or human resources are, among others, some of the elements that condition their motivation to exercise them. They feel that they continually fight because others are aware of their reality and facilitate the exercise. Feeling doubly isolated makes them especially vulnerable and limits them in essential aspects of life. They demand the development of policies that guarantee the same opportunities as the rest of the people.

The reality of deafblind people is complex, not only because of the special living conditions derived from their sensory condition, but also because of the conditions in which they are translated for the day-to-day life of these people [46]. It is necessary to implement actions that focus on the provision of means, support and technological resources that allow overcoming the barriers of their condition. Actions to improve their personal, emotional, and social development must be focused on an individualized and personalized response developed and implemented by truly qualified and trained teachers. The educational response model must lead this group to feel fully included, breaking down both physical and ideological barriers regarding the real possibilities of deafblind people.

Deafblind people are an unknown group for whom we must work and for whom we must develop policies focused on their own needs, so that in this way they can access spaces, resources, training, etc. if we really want them to have an adequate quality of life.

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