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Quality of Life: Changes in Self Perception in People with DS who Participate in *Laliga Genuine Santander*. Self Reports and External Reports

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Abstract: The hypothesis posed was whether participation in *LaLiga Genuine Santander* (competitive football) influenced the quality of life (QL) of the people who participated in it, since their perception of themselves is enhanced by all the aformentioned factors (self-determination, social inclusion, emotional well-being, physical well-being, material well-being, rights, personal development, interpersonal relationships). The objective was to evaluate the QL of people with Down's Syndrome (DS) using their self-perception (n=39) and the perception of the informants (family members, teachers) (n=39). The KidsLife-Down Scale, with a few modifications was used. In general, differences of opinion between the subgroups of participants with DS and informants showed that results were higher in terms of perception for participants in the DS subgroup. Scores for all variables were higher for those participants with DS who said they did engage in practicing competitive football. Despite the perception of informants provides a great deal of information regarding the QL of participants with DS, the latter should be involved in the evaluation process and their self perceptions taken into account. Our research shows that participation in the league modifies the perceptions of the participants with Down's Syndrome regarding their quality of life. However, these perceptions are not shared by the informants.

Keywords: Down's Syndrome, perception, quality of life, sport, age, gender, scale

1. Introduction

The Cordoba Down Centre (CDC) is an NGO concerned with increasing the quality of life (QL) of people with Down's Syndrome (DS) by promoting a healthy, autonomous and independent lifestyle. QL has been defined as a series of objective biological, psychological and social indicators that express a subjective evaluation of the degree to which life satisfaction has been achieved, or the perceived level of personal wellbeing [1, 2, 3, 4]. Schalock et al. [5] proposed a model of QL defined as *the desired state of personal wellbeing from a multidimensional viewpoint, given that it includes both objective and subjective components and is also influenced by environmental factors and personal characteristics.* This model distinguishes eight essential aspects of quality of life and their corresponding indicators which are important for all people: social inclusion (participation, inclusion and support), self-determination (goals, preferences, choice and autonomy), emotional wellbeing (satisfaction, absence of stress, motivation), physical wellbeing (nutrition, health, sport), material wellbeing (economic independence, technology, material support) rights (dignity, respect), personal development (adaptive behaviour, communication strategies, social skills) and interpersonal relations (friendship networks, autonomy). According to Claes et al. [6], the areas of emotional, physical and material wellbeing reflect the general well-being of the person; interpersonal relationships, social inclusion and rights refer to social participation; personal development and self-determination express personal independence. Instruments to evaluate quality of life with a sufficient guarantee of validity and reliability are indispensable for dependent persons [7]. Given that interventions aimed at improving quality of life must be based on evidence, in Spain the KidsLife Scale [8] was developed and validated for the evaluation of children and young adults with DS, using the model proposed by Schalok and Verdugo in 2000 [5].

The CDC includes a group of federated athletes who belong to *the Cordoba Football Club of LaLiga Genuine, Spain.* Currently in Spain, parallel to the Professional Football League, *LaLiga Genuine Santander* consists of a competitive national football league made up of people with intellectual disabilities. This league plays eight-a-side football in a single mixed category.

The objective of the present study was to evaluate the QL of people with DS at CDC using their self perceptions and the perceptions of informants. To this end, we focused on: (1) Analysing the correlation of age in participants with DS and the informants with respect to aspects of QL; (2) Analysing differences in terms of gender in participants with DS and informants with respect to aspects of QL; (3) Verifying if there are differences in aspects of QL between those who practice competitive sport and those who do not, according to the self perceptions of participants with DS and the opinions of the informants, and finally (4) Evaluating differences of opinion with regard to the aspects of QL between groups (people with DS and informants).

With this study we want to emphasize that, in spite of the fact that the perception of informants provides a great deal of information regarding the QL of participants with

DS, the latter should be involved in the evaluation process and their self perceptions taken into account.

2. Materials and Methods

2.1 Participants

A total of 78 people participated in the study, 39 with DS who were users of CDC, with a mean age of 29 years (men n=24; women =15; athletes = 9, non athletes = 30) and 39 informants. Here, "athletes" refers to the federated footballers belonging to the *Cordoba Football Club of LaLiga Genuine, Spain;* "non athletes" were non federated and did not participate in the League. The informants (family members, teachers, coordinators) needed to know the participant well for at least six months and have the opportunity to observe them in different environments for prolonged periods.

Participants with DS presented a predominant moderately high *level of intellectual disability* (according to adaptive behaviour) of 50%; in detail, 56% in conceptual skills, 51.3% in social skills and 54% in practical skills. *Other conditions evaluated* showed that 25.5% had physical disabilities, 44% obesity, 18.3% sensorial disability, 6.3% had serious health problems and 4.9% had sleep disorders.

Both athletes and non-athletes with DS participated in two regular sessions of Physical Education at CDC, in which basic movement patterns were practiced to resolve motor difficulties in daily life using various circuits and posts (jumping, throwing, coordination and balance) as well as improving basic physical qualities: strength, speed, stamina and range of movement. Finally, various sports were practiced (basketball, football etc) which included the use of balls in games modified and adapted to the participants' different levels of ability.

Outside CDC, participants also took part in three 90 minute training sessions a week under the supervision of a coach. Each session consisted of a warm-up period, the main session and cool-down period:

a) Warm-ups were divided into general warm-ups, in which the participants activated the neuromuscular system with group games, followed by specific warm-ups for which the goal keepers were separated from the field players and specific motor activities were practiced.

b) During the main session, balls were used and the specific technical and tactical moves of football were practiced (control, passing, shooting, etc.) Strategic roles were distributed for each side (offense player with ball, offense player without ball, defense player, goalkeeper). Later, real play situations were practiced in short games, changing the rules to meet the objective established for each session.

c) During cool-down, the participants did stretches.

This type of training is more demanding of motor skills than the routine sessions at CDC.

All participants with DS lived with their families.

2.2 Method and ethical approval

Previous to the study, the objective was presented to the directors of CDC to obtain their ethical approval and the consent of those involved or their family members. The authors of this study declare that, based on the Helsinki Declaration, they have taken into account the basic principle of respect for the individual, his/her right to self determination and to make decisions once clearly informed of the pros and cons, risks and benefits of participating in this research study [9]. The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board of DOWN CÓRDOBA, Asociación Síndrome de Down (number 127; 03/09/2020). Once written consent was obtained, a meeting was held with the participants with DS and informants to discuss rules of application and proper use, as well as to warn informants not to influence the responses of participants with DS, though they could clarify points as needed. Participants with DS were told they could request clarification of anything they did not understand.

Institutional Review Board Statement: The study was.

The first author of this study then sent the QL scale to CDC, who distributed it to parents, teachers and coordinators (a printed version and via email). The scales were gathered by a CDC liaison. Once filled out, the researchers compiled the answers in a database and carried out the pertinent statistical analyses. During the process of administering the scale, no personal data was compiled that might identify the person under evaluation. Instead, identification codes were used (such as pseudonyms) that were unknown to the researchers to protect confidentiality, in accordance with Spain's Organic Law 3/2018 on protection of personal data and guarantee of digital rights. These identification codes allowed the results of the evaluations to be returned to CDC to be used in later interventions with the participants [10].

2.3 Instrument

The KidsLife-Down Scale [8] was used to evaluate personal QL results in children and young adults with DS between the ages of 4 and 21, based on a range of 15 to 21 years, with a few modifications consistent with the way the question was presented; participants with DS responded with one of two options, and informants with a Likert scale. All 78 participants (DS and informants) answered the scale.

The scale consisted of 96 items divided into eight aspects of QL (self determination, rights, emotional wellbeing, material wellbeing, physical wellbeing, social inclusion, interpersonal relationships and personal development) [11]. This scale provides standardised scores and percentiles for the eight aspects as well as a QL profile report.

Each aspect was composed of 12 items. There were two versions of the scale used: (a) a self report filled out by participants with DS, with two options (yes/no) and (b) an external report filled out by informants using a Likert scale with four frequency options (never, sometimes, often, always) [12]. The questions asked of informants were the same as those answered by participants with DS, but in the third person.

Direct scores for each aspect of QL are the sum of the scores for the items in each section. The direct scores are then converted to standard scores (M=10; DT=3) following the 15 to 21 year age range provided by the scale. The total standard score is obtained by adding up the standard scores for the eight aspects, which is then converted to the standard composite score or Quality of Life Index (QLI) (M=100; DT= 15) [8], taking into account the aforementioned range.

High scores for the various aspects of QL and QLI indicate a high level of functioning for the person in a given area, greater QL and personal wellbeing. All scores can be shown in a graph of the QL profile [5].

At the time of writing the survey questions, we attempted to avoid any cognitive bias in the two groups of respondents so as to obtain honest information. Also, the sample bias has been taken into account in order to ultimately obtain reliable information of good quality.

A numerical code was assigned to each question, as well as to each answer category. Coding facilitated the subsequent entering of the data into the computer, while preventing errors in this process. An additional advantage was that it allowed the coding done for each response category to be recorded in the response protocol, which is important if the data is reused at a later time. Of course, given that there were two different responses (dichotomy and Likert scale), these were scored so as to obtain (M=10) for all of them.

2.4 Method of Scale Validation

The scale used was validated by Gómez et al. [8]. In order to validate the modifications introduced, the validation process was carried out by a team of professional experts belonging to CDC's board of directors. This committee did not participate as informants. The earliest version of the questionnaire was sent to CDC, who reviewed the possible errors in formulating the questions. They provided feedback that served to reformulate the questions in an appropriate way to avoid confusion among the people surveyed.

Feedback focused mainly on the following issues: wording of questions, vocabulary related to the context of CDC, elimination of ambiguous questions in favour of more specific ones, removal of terminology that could be interpreted as being patronising or offensive, and benefits of some questions regarding the logic of the questionnaire.

The revision of the questionnaire was carried out with in-depth analysis of all contributions, so that it included those that could be considered adequate to allow for the drafting of a definitive model. The improved version was again forwarded to CDC. The questionnaire was considered non-offensive, comprehensible, and suitable for participants.

To validate the reliability of the questionnaire, verify and confirm the matter under investigation, Cronbach's alpha consistency coefficient was used [14;15;16].

2.5 Statistical Analysis

Normality compliance was tested for each group using the variables of gender, age and sport via the Kolmogorov-Smirnov test. The aforesaid hypothesis was not met for all variables studied ($p < .001$ in all cases); therefore, non-parametric or free distribution tests were applied, specifically Spearman's Rho (rank-order correlations) and Mann-Whitney's U-tests. The SPSS programme (v. 25; IBM) was used for all statistical analyses of data.

3. Results

The psychometric properties of the scale were satisfactory. The questionnaire answered by participants with DS obtained a Chronbach alpha coefficient of 0.6 and that answered by the informants obtained a coefficient of 0.87.

3.1 Age

In the analysis of age correlation for both participants with DS and informants with respect to quality of life, the Kolmogorov-Smirnov test showed that normality compliance was not achieved. Therefore, Spearman's Rho (rank-order correlations) was used for the subsample of participants with DS (n = 39) as well as the subsample of informants (n = 39), using the age scale and all aspects of QL implied in the study (see Table 1).

Table 1. *Table 1. Spearman's Rho correlations between age of participants with DS (n=39) and self perception with respect to the aspects of the study, and the correlation of these ages with informant perceptions (n = 39).*

	Age			
	DS		*Informants*	
Dependent variables	*r*	*p*	*r*	*p*
Social inclusion	-,044	,792	-,057	,728
Autodetermination	-,212	,196	-,081	,622
Emotional wellbeing	-,246	,131	-,093	,572

Physical wellbeing	**-,353**	**,027**	-,012	,942
Material wellbeing	-,062	,708	-,120	,474
Rights	-,083	,614	,114	,490
Interpersonal relationship	-,135	,411	,011	,946
Pesonal development	-,219	,181	,074	,656
Quality life index	-,194	,237	-,204	,212

Results for the subsample of participants with DS indicated a single statistically significant correlation (r = -.353; p = .027) with moderate magnitude and negative meaning with respect to the physical wellbeing variable. No other significant relationship was detected for the remaining variables, including QLI. However, no statistically significant relationship was detected between the age of participants with DS and the opinions of informants in terms of any aspect of the study.

3.2 Differneces in terms of gender

In the analysis of differences in terms of gender, with respect to the aspects studied and QLI of participants with DS and informants, the Kolmogorov-Smirnov test showed that normality compliance was not achieved. Therefore, to contrast the differences between both groups (participants with DS and informants), non-parametric testing was applied, equivalent to Student *t* for independent groups, Mann-Whitney U-tests (see Table 2).

Table 2. Mann-Whitney U tests for independent variables of the study with respect to gender for the subgroup of participants with DS (men n=24; women =15) concerning self perception and perception of informants (n=39).

		DS participants								Informants							
Dependent variable	Gender (DS)	Mean	SD	Min	Max	Average range	U_{MW}	Z	p	Mean	SD	Min	Max	Average range	U_{MW}	Z	p
SI	1	5,58	1,586	4	8	21,85	135,50	-1,350	,177	4,83	1,239	3	7	23,23	102,50	-2,488	,013
	2	4,73	,704	4	6	17,03				3,93	0,961	3	6	14,83			
AU	1	5,71	1,517	3	8	22,69	115,50	-1,899	,058	4,13	0,900	3	5	22,50	120,00	-1,841	,066
	2	4,73	1,387	3	8	15,70				3,60	0,632	3	5	16,00			
EW	1	5,00	1,142	4	7	23,06	106,50	-2,294	,022	5,08	1,412	3	7	23,21	103,00	-2,289	,022
	2	4,13	,834	3	6	15,10				4,07	0,884	3	6	14,87			
PW	1	9,08	,717	8	10	21,98	132,50	-1,463	,143	8,88	0,947	8	10	23,25	102,00	-2,446	,014
	2	8,53	1,125	7	10	16,83				8,00	0,845	6	9	14,80			
MW	1	6,96	1,197	5	9	23,15	104,50	-2,294	,022	6,43	1,273	4	8	24,98	46,50	-3,875	<,001
	2	6,07	1,033	5	8	14,97				4,73	0,704	4	6	11,10			
R	1	4,79	1,817	3	8	20,50	168,00	-0,357	,721	4,88	1,676	3	8	20,42	170,00	-,304	,761
	2	4,27	,961	3	6	19,20				4,40	0,986	3	7	19,33			
IR	1	5,46	1,285	4	7	20,77	161,50	-0,567	,571	5,21	1,141	4	7	21,60	141,50	-1,184	,236
	2	5,20	1,207	4	7	18,77				4,73	0,799	4	7	17,43			
PD	1	5,42	1,248	4	7	23,06	106,50	-2,203	,028	4,46	0,658	3	5	21,60	141,50	-1,229	,219
	2	4,47	,915	3	6	15,10				4,20	0,676	3	5	17,43			
QLI	1	72,71	8,800	63	86	21,75	138,00	-1,238	,216	68,96	7,369	62	80	23,44	97,50	-2,841	,004
	2	67,53	3,701	63	73	17,20				63,00	0,000	63	63	14,50			

NOTE: 1: Man; 2: Woman; DS: People with Down syndrome; SI: social inclusion; AU: autodetermination; EW emotional wellbeing; PW: Physical wellbeing; MW: Material wellbeing; R: rights; IR: interpersonal relationship; PD: Personal development; QLI: quality life index

Results for self perception of participants with DS indicated significant differences for the emotional wellbeing variables (Z = -2.29; p = .022), material wellbeing (Z = -2.29; p = .022), and personal development (Z = -2.20; p = .028). For these three variables, results were higher for men. No statistically significant difference was detected for the remaining variables, nor for QLI (see Table 2).

In the second place, with regard to informants, statistically significant differences were detected between genders for participants with DS for the variables social inclusion (Z = -2.49; p = .013), emotional wellbeing (Z = -2.29; p = .022), physical wellbeing (Z = -2.45; p = .014), Material Wellbeing (Z = -3.88; p = <.001) and QLI (Z = -2.84; p = .004). For all five variables, results were higher for men. No statistically significant difference was detected for the remaining variables (see Table 2).

Therefore, the opinions of participants with DS and informants coincided with respect to emotional wellbeing and material wellbeing.

3.3 Differences between variables in the study and QLI between athletes and those who did not practice competitive sports

To verify if there were differences between variables in the study and QLI between athletes and those who did not practice competitive sports, according to the self perceptions of participants with DS and in the opinion of informants, the non- parametric Mann-Whitney U-test was again applied. Results are shown in Table 3.

Table 3. *Mann-Whitney U-tests for dependent variables with respect to practicing competitive sports on the part of participants with DS (Yes, n=9; No, n=30) according to the opinions of the subgroup with DS and informant perceptions (n=39).*

		DS participnats								Informants							
Dependent variable	Sport (SD)	Mean	SD	Min	Max	Average range	U_{MW}	Z	p	Mean	SD	Min	Max	Average range	U_{MW}	Z	p
SI	1	7,44	0,726	6	8	34,89	1,00	-4,695	<.001	4,56	1,130	3	6	20,94	126,50	-,315	,781
	2	4,60	0,621	4	6	15,53				4,47	1,252	3	7	19,72			
AU	1	7,33	0,707	6	8	33,89	10,00	-4,249	<.001	4,22	0,833	3	5	23,83	100,50	-1,222	,255
	2	4,73	1,143	3	8	15,83				3,83	0,834	3	5	18,85			
EW	1	6,33	0,500	6	7	34,67	3,00	-4,757	<.001	4,78	1,481	3	7	20,56	130,00	-,172	,883
	2	4,17	0,648	3	6	15,60				4,67	1,295	3	7	19,83			
PW	1	9,78	0,441	9	10	31,39	32,50	-3,645	<.001	8,67	1,000	8	10	20,67	129,00	-,217	,857
	2	8,60	0,855	7	10	16,58				8,50	1,009	6	10	19,80			
MW	1	8,33	0,500	8	9	34,33	6,00	-4,525	<.001	6,25	1,389	4	8	23,69	86,50	-1,235	,235
	2	6,10	0,803	5	8	15,70				5,63	1,351	4	8	18,38			
R	1	6,89	1,054	5	8	34,44	5,00	-4,465	<.001	4,67	1,581	3	7	19,17	127,50	-,263	,806
	2	3,90	0,845	3	6	15,67				4,70	1,442	3	8	20,25			
IR	1	7,00	0,000	7	7	33,00	18,00	-4,138	<.001	5,33	1,323	4	7	22,17	115,50	-,692	,522
	2	4,87	0,973	4	7	16,10				4,93	0,944	4	7	19,35			
PD	1	6,67	0,500	6	7	33,83	10,50	-4,308	<.001	4,33	0,866	3	5	20,39	131,50	-,129	,909
	2	4,57	0,898	3	7	15,85				4,37	0,615	3	5	19,88			
QLI	1	83,33	1,500	81	86	35,00	0,00	-4,594	<.001	67,78	7,225	62	79	20,83	127,50	-,298	,806
	2	66,93	3,423	63	73	15,50				66,33	6,283	63	80	19,75			

NOTE: 1: Practicing sport (Yes); 2: Practicing sport (No); DS: People with Down syndrome; SI: social inclusion; AU: autodetermination; EW emotional wellbeing; PW: Physical wellbeing; MW: Material wellbeing; R: rights; IR: inter-personal relationship; PD: Personal development; QLI: quality life index

The opinion of participants with DS showed statistically significant differences between the group with DS that practiced competitive sports and those that did not. These results for all variables, including QLI, were higher for those participants who said they practiced competitive sports (in all cases, p = < .001; Table 3).

In the second place, with reference to informant opinion, no statistically significant difference was detected for any of the variables as regards the practice or not of competitive sports on the part of participants with DS.

3.4 Differences of opinion between particpnats with DS and informants

Differences of opinion were also evaluated concerning the variables studied and QLI between participants with DS and informants. A new series of Mann-Whitney U-tests was applied to contrast differences between both groups of participants, those with DS and informants. Results are shown in Table 4.

Table 4. *.Mann-Whitney U-tests for dependent variables studied with respect to groups (participants with DS, n=39; Informants, n =39).*

Dependent variable	Group	Mean	SD	Min	Max	Average range	U_{MW}	Z	p
Social inclusion	1	5,26	1,371	4	8	46,50	487,50	-2,889	,004
	2	4,49	1,211	3	7	32,50			
Autodetermination	1	5,33	1,528	3	8	50,08	348,00	-4,246	<,001
	2	3,92	0,839	3	5	28,92			
Emotional wellbeing	1	4,67	1,108	3	7	39,42	757,50	-,031	,975
	2	4,69	1,321	3	7	39,58			
Physical wellbeing	1	8,87	0,923	7	10	43,62	600,00	-1,681	,093
	2	8,54	0,996	6	10	35,38			
Material wellbeing	1	6,62	1,206	5	9	46,03	467,00	-2,880	,004
	2	5,76	1,364	4	8	31,79			
Rights	1	4,59	1,551	3	8	38,44	719,00	-,430	,667
	2	4,69	1,454	3	8	40,56			
Interpersonal	1	5,36	1,246	4	7	42,05	661,00	-1,053	,292
Relationship	2	5,03	1,038	4	7	36,95			
Personal development	1	5,05	1,213	3	7	45,28	535,00	-2,389	,017
	2	4,36	0,668	3	5	33,72			
Quality life index	1	70,72	7,643	63	86	47,41	452,00	-3,268	,001
	2	66,67	6,441	62	80	31,59			

NOTE: 1: People with Down syndrome; 2: Informants

In this case, the results show statistically significant differences (Table 4) between participant groups with reference to social inclusion (Z = -2.89; p = .004), self determination (Z = -4.25; p = .001), material wellbeing (Z = -2.88; p = .004), personal development (Z = -2.39; p = .017), and finally QLI (Z = -3.27; p = .001). In all aspects mentioned in QLI, results were higher in terms of perception for participants with DS.

4. Discussion

Evaluation of QL for CDC users was carried out using the modified KidsLife Scale [8] (Gomez et al., 2017), which allowed the compilation of in-depth distinctions for those who responded to the questionnaire from two points of view: that of those with DS and that of informants. Though the number of participants in the study was relatively small, important results were found.

The result for Cronbach's Alpha coefficient in the informants' questionnaire shows high reliability for each question. On the other hand, the result in the questionnaire for participants with DS is lower. According to Devellis [14] and Nunnally and Bernstein [15], for this coefficient to be considered acceptable it must have a value of 0.7 to 1. Other authors declare that the acceptable range is between 0.65 and 1 [16]. The questionnaire for participants with DS reached a value of 0.6; from a statistical viewpoint this can be interpreted as a low relationship between questions. However, this value is not far from 0,65 or 0.7. It must be borne in mind that sociodemographic data show that the level of intellectual disability (according to adaptive capacity) of participants was moderate. Scientific literature shows that persons with DS have certain limitations associated with cognitive capacity which show up in adaptive capacity (conceptual, social and practical skills) [17, 18]. Adaptive skills coincide with the level of intelligence, which implies that there are no severe limitations on functionality, as long as the degree of intellectual disability is not profound or severe [19; 20]. In adulthood, the person is expected to be able to deal with the demands of daily life and, in turn, those demands corresponding to relationships with family, friends and CDC staff. However, people with DS present behaviour that is sometimes classified as atypical [21].

Perception of the aspects on which QL is based varies with reference to each specific person's QL. Therefore, significant differences have been found when participants evaluate their own QL versus when informants give opinions regarding third parties, particularly those with DS, which coincides with studies carried out by [22] and [23]. This confirms that, in line with CDC's purpose, this population's QL must be fomented. As proposed by Shalock and Verdugo [11], QL is composed of the same aspects and indicators, having the same degree of importance, for all people [23]. However, the results of the present study do not coincide with the studies of QL carried out by Córdoba et al., [24]; Bagnato et al., [25]; Vega et al., [26]. Consequently, the importance of having two viewpoints must be reflected in order to properly evaluate the QL of these persons.

Regarding age, on the one hand participants with DS perceived that with respect to all aspects of QL, physical wellbeing diminishes as age increases. This perception on the part of participants with DS may be due to the fact that adults in this population suffer from "accelerated aging", which implies experiencing certain physical conditions common among people of advanced age in the general population. The reason for this is not fully understood, but is related in large part to the genes of Chromosome 21 associated with the aging process [10]. Perhaps they perceive their physical wellbeing in a negative way due to physiological changes which can increase the risk of chronic degenerative diseases [27].

On the other hand, informants did not share this perception. Preoccupation with physical wellbeing, and health in particular, is an outstanding and determining indicator of QL for aging persons with intellectual disabilities. The explanation can be found in the fact that the subject's perception of is radically modified when he or she presents serious health problems [28]. Perhaps the informants did not take into account the associated pathologies suffered by users with physical disabilities: obesity, sensorial disability, serious health problems or sleep disorders. In this study, as in Aja et al. [29] and Badía et al., [12], it was shown that age has no significant relationship to quality of life. However, the results obtained by other researchers differ [30; 31].

In the present study, statistically significant differences were shown with respect to gender as perceived by participants with DS for the variables of emotional wellbeing (personal satisfaction, motivation, absence of stress), material wellbeing and personal development (adaptive behaviour, competence, social skills and development of communication); these were higher in men than in women. These results coincide with [32; 33; 34; 35] , which also pointed out that men had higher emotional wellbeing than women. However, we differ from the foregoing authors who state that women have a lower quality of life than men, since in this research we found no significant differences in QLI. Significant differences with respect to emotional wellbeing may be due to the fact that women are more expressive of emotion and more aware of life events [36]. Emotional wellbeing is a balance between feelings, desires and emotions. A great difference is often found between emotional age, cognitive development and chronological age. Infantilizing people with DS puts them at risk and marginalises them [37]. Differences in material wellbeing can be attributed to the fact that women attain greater job placement, as well as being more protected by family members than men; they exchange free time for family support [38]. Greater personal development in men may indicate that they have learned better skills and habits that make them more competent [11].

Informants showed significant gender-related differences in social inclusion, emotional wellbeing, physical wellbeing, material wellbeing and QLI, with men being favoured; this coincides with participants with DS with respect to emotional and material wellbeing. The differences and biological peculiarities of men and women are taken into account, as well as their interaction with gender-related social factors such as identity, roles, responsibilities and strengths which are reflected in emotional and material health as well as social inclusion for both sexes [39; 40].

In spite of playing in a single mixed category, by chance *LaLiga Genuine Santander Football League* includes no female users of CDC. In the opinion of CDC, their users' participation in this league not only contributes to the stimulation of motor skills of those members with DS, it also includes those health, cultural and social aspects which accompany sport and reinforce a healthy lifestyle, values and attitudes in participants. Besides, it is a way to optimise social skills as well as emotional, psychological and physical health [41].

No agreement was verified in terms of the perceptions of participants with DS and informants regarding aspects of QL between those who practice competitive sports and those who do not. While informants did not show significant differences in any of the aspects evaluated in athletes and non-athletes, the results obtained from participants with DS showed statistically significant differences for all variables including QLI. All variables obtained higher values for participants in sports versus those who did not participate in sport. This result was very striking, as we had thought that informants would perceive an improvement in QL fomented by participation in *LaLiga Genuine*, since team sports are an activity that increases the majority of variables contributing to quality of life [41], providing an opportunity to interact and share with others and therefore integrate into society [42]. As shown in other studies [43; 44; 45; 46; 47], sport foments mutual awareness and cooperation, making it an ideal way to create social capital. In particular, football is a socio-motor sport of cooperation/opposition, which within the context of attack/defence represents a form of social activity that demands high levels of coordination as well as encouraging communication between teammates (passes, support, etc.) and opponents (scores, charges, intercepting the ball) [48]. We agree with other authors [49; 41] that sport foments interpersonal relationships, social inclusion, self determination and quality of life. Competitive team sports are characterised by intense social and physical contact. The context of sport represents society's virtues and defects on a large scale which may serve to reflect the socialisation of the athlete in the relationships formed with teammates, coaches, family and peers [50] as well as improving quality of life [51].

Finally, upon comparing QL variables between participants with DS and informants, it is clear that the former have higher perception compared to the latter. The results obtained coincide with those of [35], who concluded that the perception of people with intellectual disabilities was higher than the perception of the professionals in charge of them. However, in 1999 Stancliffe [52] found no significant differences between different informants. In 2017, Flórez [53] stated that the immense majority of people with DS are happy with their lives, appearance and personality. This may have caused them not to answer the questionnaire in an objective way.

These significant differences affected the variables of self determination, material wellbeing, personal development and QLI in which the opinions of informants do not coincide with those of participants with DS. The informants acknowledged the difficulties people in their care have to take responsibility for themselves, participate independently in their environment, become economically independent and make autonomous decisions; this is in line with the findings of other researchers who indicate that the disabled perceive themselves as less self-determined than their peers without disabilities[32; 54; 55; 35].

Perhaps the value of quality of life evaluated by participants with DS may generate debate regarding the reliability and validity of their responses [56]; however, knowing their opinions is necessary since quality of life has a very personal (subjective) side [57]. Some authors agree that subjective factors must be evaluated from the viewpoint of those with intellectual disabilities; to this end, abstract questions must be avoided in order for the members of this population to understand [58;59]. According to [60], there are significant differences between the perceptions of the disabled and those of informants.

There are some limitations to the present study; one of these is sample size. Another is the fact that in spite of the league being mixed, no women participate in the Cordoba Football Club; therefore, gender based comparisons could not be made. It must be borne in mind that the impact of the practice of sport on different aspects of quality of life may be modulated by environmental or intrapersonal factors: age, sex, social skills, adaptive behaviour and degree of disability, as well as the kind of sport and access to other leisure activities [61; 62]. Finally, other variables were not included, such as the need for support, living in assisted living facilities, or inclusion in a job placement programme.

We suggest that future research should broaden the scale to include other Spanish teams of *La Liga Genuine* to contrast the opinions of participants with DS and informants regarding sports practice.

5. Conclusions

Participants with DS perceive that as they age, their physical wellbeing tends to decrease. However, informants do not share this perception. The opinions of participants with DS and informants regarding gender showed significant differences, coinciding only in terms of emotional and material wellbeing.

Scores for all variables were higher for those participants who said they did engage in practicing sports. However, informants did not perceive that QL depended on the participants with DS practicing sports or not.

In general, differences of opinion between the subgroups of participants with DS and informants showed that results were higher in terms of perception for participants in the DS subgroup.

In spite of the fact that the perception of informants provides a great deal of information regarding the QL of participants with DS, the latter should be involved in the evaluation process and their self perceptions taken into account. Therefore, self-reporting is a necessary tool for this population to be able to evaluate their own QL; avoiding abstract questions is fundamental to aid understanding. The ideal is a combination of self-reporting with reports by informants.

Authors contribution

Conceptualization, Rocío Camacho, Francisco Requena and Estrella I. Agüera; Data curation, Arturo Gallego and Roberto Espejo; Formal analysis, Arturo Gallego and Roberto Espejo; Investigation, Rocío Camacho, Cristina Castejón-Riber, Francisco Requena, Julio Camacho and Estrella I. Agüera; Methodology, Rocío Camacho, Cristina Castejón-Riber, Francisco Requena, Julio Camacho and Estrella I. Agüera; Supervision, Estrella I. Agüera; Writing – original draft, Rocío Camacho and Julio Camacho; Writing – review & editing, Rocío Camacho, Cristina Castejón-Riber, Francisco Requena, Julio Camacho, Amaranta De Miguel-Rubio, Begoña M. Escribano and Estrella I. Agüera.. All authors have read and agreed to the published version of the manuscript.

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5. References

1. Diener, E. Subjective well-being. *Psychol Bul* **1984**, 95(3), 542-575.
2. Blanco, A. La calidad de vida: supuestos psicosociales. In: *Psicología Social Aplicada*; Morales, J.F.; Blanco, A.; Huici, C.; Fernández J.M. Desclée de Brouwer Eds; Bilbao, Spain; 1985.
3. De Haes, J.C. Quality of life: Conceptual and Theoretical Considerations. In: *Psychosocial Oncology*. Watson, M.; Greer S; Thomas. Pergamon Press. Oxford, England, 1988.
4. Chibnall, J.T.; Tait, R.C. (1990). The quality-of-life scale*:* A preliminary study with chronic pain patients. *Psychol Health* **1990** *4*, 283-292.doi.10.1080/08870449008400397
5. Schalock, R.I.; Keith K.D., Verdugo M.A., Gómez E.I. Quality of life model development in the field of intellectual disabilities. In: *Quality of life for people with intellectual disability*. Kober R. dir; Springer, New York, USA**.** **2010**, 17-32.
6. Claes, C.; Van Hobe, G.; Vandevelde, S., van Loo, J., Shalock, R. The influence of support strategies, environmental factors, and client characteristics on quality of life-related personal outcomes. *Res Dev Disabil* **2012a**, *33(1*), 96-103. Doi.10.1016/ridd.2011.08.024.
7. Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia. B.O.E. núm 229, de 15/12/2006. Available online: https://www.boe.es/eli/es/l/2006/12/14/39/con (accessed on 24th November 2020).
8. Gómez, L.E.; Verdugo, M.A.; Rodríguez, M.M.; Arias, V.B; Morán, L.; Alcedo, M.A.; Monsalve, A.; Fontanil, Y. (2017). *Escala KidsLife-Down: evaluación de la calidad de vida de niños y adolescentes con síndrome de Down*. INICO: Salamanca, España, 2017.
9. World Medical, A. World Medical Association. Declaration of Helsinki: Ethical principles for medical research involving human subjects JAMA **2013** *310,* 2191–2194.
10. Moran, J.; Hogan, M; Srsic-Stoehr, K.; Service, K., Rowlett S. Aging and Down Syndrome. A health a well-being guidebook. National Down Syndrome Spicety. (s.f.) Available online: https://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf (accessed on 16th November 2020). **undated**
11. Schalock R.L., Verdugo M.A. *Handbook on quality of life for human service practitioners*. American Association on Mental Retardation, Washington, DC, U.S.A, 2002.
12. Badía, M.; Carrasco, J.; Orgaz, M.B.; Escalonilla, J.M. Calidad de vida percibida por personas adultas con discapacidades del desarrollo versus la informada por profesionales. *Siglo Cero* **2016** *47(1),*7-21.
13. Gómez, L.E.; Alcedo, M.A.; Verdugo, M.A.; Arias, B.; Fontanil, Y.; Arias, V.B.; Monsalve, A.; Morán, L. *Escala KidsLife: Evaluación de la calidad de vida de niños y adolescentes con discapacidad intelectual*. INICO, Salamanca 2016.
14. DeVellis, R.F. *Scale development: Theory and applications*. SAGE, London, U.K. 1991.
15. Nunnally, J.C.; Bernstein, I.H. *Psychometric theory*, 3rd ed., McGraw-Hill, New York, U.S.A. 1994.
16. Threvethan, R. Self-assessment of Foot Health: Requirements, Issues, Practicalities, and Challenges. *J Am Podiatr Med Assoc* **2009**, *99 (5),* 460-471 .doi. 10.7547/0990460
17. Bildt, A.; Sytema, S.; Kraijer, D.; Sparrow, S.; Minderaa, R. Adaptive functioning and behavior problems in relation to level of education in children and adolescents with intellectual disability. *J Intellect Disabil Res* **2005**, 49(9), 672-681. doi.org/10.1111/j.1365-2788.2005.00711.x
18. Sparrow, S.; Cicchetti, D.; Balla, D. *Vineland-II adaptative behavior scales* (2a ed.). Pearson Bloomington, Minnesota, U.S.A. 2005.
19. Montero, D. Conducta adaptativa y discapacidad aquí y ahora: algunas propuestas para la mejora de la práctica profesional. *Siglo Cero,* **2003** *34(206),* 68-77.
20. Villar, E. Aprendizaje, motivación y conducta adaptativa: La búsqueda de empleo de los titulados superiores. Tesis doctoral. Universidad de Barcelona, Spain. 1991.

21. Vega, M. Incidencia de un Programa de Actividad Recreativa y Deportiva, sobre la Conducta Adaptativa y la Motricidad en las Personas con Síndrome de Down, desde la Perspectiva de los Padres. Tesis Doctoral. Puerto Rico. **2014**

22. Holburn, S.; Cea, C.D.; Coull, L.; Goode, D. What is working and not working: Using focus groups to address quality of life of people living in group homes. *f Dev and Physl Disabil* **200**, 20(1), 1-9.

23. Vega V.; Jenaro C.; Flores N.; Cruz, M.; Ataza, C. Calidad de vida de adultos con discapacidad intelectual institucionalizados en Chile desde la perspectiva de los proveedores de servicios. *Universitas Psychologica*, **2013**, *12(3)*, 923-932.

24. Córdoba, L.; Gómez, L.; Verdugo, M.A. Calidad de vida familiar en personas con discapacidad: un análisis comparativo. *Univ Pshychol* **200**, *7*(2), 369-383.

25. Bagnato, M. J.; Jenaro, C. Aplicación de la Escala de Calidad de Vida (Schalock y Keith, 1993) con tres grupos de informantes: evidencias adicionales sobre su utilidad. *Siglo Cero* **2010** 41(2), 81-98.

26. Vega, V.; Jenaro, C.; Morillo, M., Cruz, M.; Flores, N. Servicios residenciales en Chile, calidad de vida y apoyos: aproximación a una realidad desconocida. *Psicol. conoc. Soc*. **2011** *1(3*), 52-70.

27. Hayflick L. *Cómo y por qué envejecemos*. Herder, Barcelona, Spain; 1999.

28. Schalock, R.L.; Verdugo, M.A. Revisión actualizada del concepto de calidad de vida. In: *Cómo mejorar la calidad de vida de las personas con discapacidad. Instrumentos y estrategias de evaluación.* Verdugo M.A. (dir). Amarú. Salamanca, Spain 2006**,** 29-41.

29. Aja, R.E.; Gerolin, M.; Canto, A.; Vidorreta, I. Análisis de la incidencia de factores personales y ambientales de calidad de vida en 224 personas con discapacidad intelectual en Bizkaia. *Siglo Cero* **2014** *45 (251),* 47-61.

30. Gómez, M.; Verdugo, M.A.; Canal, R. Evaluación de la calidad de vida de adultos con discapacidad intelectual en servicios residenciales comunitarios. *Rev. psicol. gen. apl.* **2002**, *55*, 591-602.

31. Badía, M.; Rodríguez, P.; Orgaz, M.B.; Blanco J.M. Calidad de vida en los pacientes con parálisis cerebral en proceso de envejecimiento. *Rehabilitación* **2013**, *47,* 194-199.

32. Gómez-Vela, M.; Verdugo, M. El cuestionario de evaluación de la calidad de vida de personas de educación secundaria obligatoria: descripción, validación inicial y resultados obtenidos tras su aplicación en una muestra de adolescentes con discapacidad y sin ella. *Siglo Cero* **2004,** *21*, 5-17.

33. Meneses, C. Género, desigualdad e inclusión. Séptimo Catálogo Español de Buenas Prácticas, **2009.** Available online: http//hábitat.aq.upm.es/boletin/n41/acmen.html (accessed on 16th November 2020)

34. Verdugo, M.; Gómez, L.; Arias, B.; Navas, P. Evidencias de validez del modelo de calidad de vida de ocho dimensiones y aplicación de la escala integral en distintos países. In: *Aplicación del paradigma de calidad de vida a la intervención con personas con discapacidad desde una perspectiva integral.* Verdugo, M.R , Canal; Jenaro, C., Badia, M.; Aguado, A., Eds.,INCO. Salamanca, España, 2012a**,** 11-26

35. Castro, L.; Cerda, G.; Vallejos, V.; Zuñiga, D.; Cano, R. Calidad de Vida en personas con discapacidad intelectual en centros de formación laboral. *Ava. en Psicol. Latinoam.* **2016** *34 (1*), 1-12. doi: 10.12804/apl34.1.2016.12

36. Cardenal, V.; Fierro, F. Sexo y edad en estilos de personalidad, bienestar personal y adaptación social. *Psicothema* **2001** *13(1),* 118-126.

37. Garvía, B. Avances y retos en el Síndrome de Down. Perspectivas desde la calidad de vida. *Rev. psicol. gen. apl.* **2019** 32, 1-2.

38. Abella, B. La discapacidad tiene rostro de mujer. *Periódico Semanal de la Discapacidad*. Cermi.es. 2013.Available online: http://semanal.cermi.es/noticia/Igualdad-genero-entidades-discapacidad-reportaje.aspx (accesed on 13th November 2020).

39. Sabo, D. Comprender la salud de los hombres. Un enfoque relacional y sensible al género. Organización Iberoamericana de la Salud. Harvard Center for Population and Development Studies, **2000**.

40. Courtenay, W.H. Constructions of masculinity and their influence on men well-being: a theory of gender and health. *Soc Sci Med* **2000** *50*, 1385-401. doi.org/10.1016/s0277-9536(99)00390-1
41. García-Moltó, A.; Ovejero-Bruna, M. Satisfacción vital, autodeterminación, y práctica deportiva en las personas con discapacidad intelectual. *RPD* **2017** *26,* (2), 13-19.
42. Quero A. Deporte y síndrome de Down. Trabajo de Fin de Máster. Universidad de Almería, España, 2016.
43. Carl, J. Social capital and sport participation. Dissertation Abstracts International, ASection: The Humanities and Social Sciences, **2003** *63(11)*, 4097-A.
44. Jarvie, G. Communitarianism, sport and social capital: Neighbourly insights into Scottish sport. *Int Rev Sport* **2003** *38:2*,139-153. doi.org/10.1177/1012690203038002001
45. Spaaij, R. The glue that holds the community together. Sport and sustainability in rural Australia. *Sport in Society* **2009** 12(9), 1132-1146. doi.org/10.1080/17430430903137787
46. Stempel, C. Gender, social class, and the sporting capital-economic capital nexus. *Sociol Sport J* **2006,** *23*, 273-292. doi.org/10.1123/ssj.23.3.273
47. Walseth, K. Bridging and bonding social capital in sport -experiences of young women with an immigrant backgroun. *Sport, Educ Soc* **2008** 13 (1), 1-17.
48. Pino, J. Análisis funcional del fútbol como deporte de equipo. Wanceulen Editorial Deportiva, S.L. Sevilla, España. 2002.
49. Haigh, A.; Lee, D.; Shaw, C.; Hawthorne, M.; Chamberlain, S.; ...., Beail, N. What Things Make People with a Learning Disability Happy and Satisfied with Their Lives: An Inclusive Research Project. *J Appl Res in Intellect Disabil* **2013** *26*, 26–33. Doi.10/1111/jar.12012
50. Smith, R.E.; Smoll, F.L. Behavioral research and intervention in youth sports. *Behav Therapy* **1991** *22*, 329-344.
51. Ramírez, W.; Vinaccia S.; Suárez G.R. El impacto de la actividad física y el deporte sobre la salud, la cognición, la socialización y el rendimiento académico: una revisión teórica. *rev estud soc* **2004** 18, 2-8.
52. Stancliffe, R. J. Proxy respondents and the reliability of the Quality-of-Life Questionnaire Empowerment Factor. *JIDR* **1999** *43,* 185–193. doi.org/10.1046/j.1365-2788.1999.00194.x
53. Flórez, J. Síndrome de Down. Comunicar la noticia: primer acto terapéutico. Fundación Iberoamericana Down21, 2017.
54. Wehmeyer, M.; Agran, M.; Hughes, C.; Martin, J.; Mithaug, D.; Palmer, S. Promoting self-determination in students with intellectual and developmental disabilities. In: *Discapacidad e inclusión manual para la docencia*. Amaru: Salamanca, España 2007.
55. Santamaría, M.; Verdugo, M.; Orgaz, B.; Gómez, L.; Jordán de Urríes, F. Calidad de vida percibida por trabajadores con discapacidad intelectual en empleo ordinario. *Siglo Cero* **2012** *43(2)*, 46-61.
56. Hatton, C.; Ager, A. Quality of life measurement and people with intellectual disabilities: a reply to Cummins. *J Appl Res in Intellect Disabil* **2002** *15(3),* 254-260. doi.org/10.1046/j.1468-3148.2002.00124.x
57. Corral, S. La ventaja del síndrome de Down en la Calidad de vida individual y familiar. Trabajo de Fin de Máster. Universidad Pontificia ICAI ICADE Comillas, Madrid. 2016.
58. Cummins, R. A. Assessing quality of life for people with disabilities. In *Quality of life for people with disabilities: models, researchs and practice*; 2nd ed., Brown R.I.,Ed.,, Stanley Thornes, Cheltenham, England, 1997, 116-150.
59. Cummins, R. A. The validity and utility of subjective quality of life: a reply to Hatton & Ager. *J Appl Res in Intellect Disabil* **2002** 15(3), 261-268. doi.10.1046/j.1468-3148.2002.00123.x
60. Claes, C.; Vandevelde, S; van Hove, G.; van Loon, J.; Verschelden, G.; Schalock, R.L. (2012b). Relationship between self-report and proxy ratings on assessed personal quality of life-related outcomes. *J Policy Pract in Intellect Disabil* **2012b** *9(3),* 159–165. doi.org/10.1111/j.1741-1130.2012.00353.x

61. Nota L.; Ferrari, L.; Soresi S.; Wehmeyer, M. Self-determination, social abilities, and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research* **2007** *51(11*), 850-865. doi.org/10.1111/j.1365-2788.2006.00939.x
62. Wehmeyer, M.L.; Gamer, W. The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *J Appl Res in Intellect Disability* **2003** 16, 255-265. doi.org/10.1046/j.1468-3148.2003.00161.x