Analysis of Discrimination and Denial of the Rights of Women with Disabilities with the Help of the Nvivo Software

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Abstract. Discrimination and denial of the rights of women with disabilities continues to be a reality. Women suffer situations of double discrimination, because they are women and because they have a disability. Women are disadvantaged in educational, employment, social, legal and economic terms. The prevalence of disability in Castilla y León (an Autonomous Community of Spain) is 6.86%, 48.2% are women and half of the people with disabilities are 65 years old or older. The objectives of the study were to know the real situation of women with disabilities in in this region, to elaborate their profile from their own perception, and to propose actions that may improve their quality of life. Under a multi-method approach of an exploratory and descriptive nature, the authors elaborated a survey to which 526 women responded, almost all of them were aged 35 to 64, most of them with intellectual disabilities. NVivo software was used for qualitative data analysis. Results: The answers indicate the importance that these women give to the availability of support, need to carry out actions that may improve their quality of life, mainly in self-determination, social relations and emotional well-being, and the need to sensitize the community. Conclusions: In rural and urban settings, self-determination is the most important concern, followed by inclusion and emotional well-being. They demand greater availability of personal assistants, in number and hours, regulated by the administration (59.4% are aware this figure). They do not show a denial of access to maternity (40.7% have children). The study highlights the importance of planning social awareness programs, training women with disabilities and guaranteeing their basic rights.

Keywords: Women with Disabilities; Rights; Discrimination; Quality of Life; Supports; Self-Perception.

1 Introduction

Prejudices and negative stereotypes affecting women and people with disabilities have always been ingrained in society at large. The United Nations (2014) refers to certain social behaviors according to which women and girls are considered inferior to men and boys, which adds to the fact that, in a sexist society, women are mainly measured according to the parameters of beauty and health (Mañas, 2009). On the other hand, as regards people with disability, humiliating stereotypes, stigmas and prejudices cause them to be perceived as a burden to society, as people who are a threat to themselves and to others, people who are suffering and require care, or people who are unfit to care for their children or get married, among others (Carrasco et al., 2014; United Nations, 2018).

According to the data provided by the World Health Organization (WHO), in 2011, it is estimated that 15% of the world's population suffers from some type of disability, with greater prevalence among the most vulnerable population groups such as low-income countries, poverty-stricken people, the elderly and, disproportionately, women. It seems that people with disability have poorer health, worse educational outcomes, less economic participation, higher poverty rates, lower employment rates, less independence, greater isolation and greater restriction on participation in a variety of situations of daily living (WHO, 2021). The recent COVID-19 pandemic has revealed the hidden face of the discrimination and lack of rights of the elderly population, aggravated with serious consequences when these people already had a disability. This group had up to 11 times more likely to die from the disease in the first months of the pandemic compared to non-disabled people (Office for National Statistics, 2020), information was not provided in an accessible way (easy to read, sign language), it was more difficult for them to maintain physical distance as they were the recipients of close care with the higher risk of infection that this entails, together with the insufficient training of support staff (Rotarou, Sakellariou, Kakoullis & Warren, 2021).

Spanish data on disability are obsolete, the latest available official figures being those provided by the Survey on Disability, Personal Autonomy and Dependency Situations of 2008, which reported a figure of over three-and-a-half million people with disability, almost 60% of whom were women (National Institute of Statistics [NIE], 2009). The Social Integration and Health Survey carried out in 2012 (NIE, 2013) reveals that the Spanish population affected by disabilities is characterized by including a larger presence of women (six out of ten). Further data indicate significant differences between men and women after the age of 35 (Esparza, 2011; NIE, 2013), differences that become greater after the age of 80 as a result of the feminization of aging (Department of Family and Equal Opportunities of Castile and León, 2017).

In 2008, in the Autonomous Community of Castile and León, which is where this study is framed, there were 132,529 dependent people, also with a predominance of an elderly-female profile (64.2%); likewise, 59.9% of the dependent elderly population lived in rural areas. In 2012, according to the NIE survey (2013), the disability rate in this community stood at 13.7%, and in 2015 there was a total of 169,637 people with disability, which amounts to a prevalence of 6.86% of the total population. Of these people, 48.2% were women. With a similar profile to the reflected in the global and Spanish data, evidence for Castile and León also shows that, after the age of 65, and especially after 80, women with disability outnumber their male counterparts, and almost one half of them (44.4%) live in rural environments (Department of Family and Equal Opportunities of Castile and Leon, 2017).

Several studies reveal that the situation worsens and becomes more unfair when the variables woman and disability converge, leading to situations of dual discrimination on grounds of both disability and gender (Moya, 2009; Navas et al., 2012). Moreover, they are affected by disadvantaged situations at all levels: educational, occupational, social, legal and even economic, since, according to Gomiz (2017), on the one hand, they are expected to fulfil the socially constructed role of women and, on the other hand, and bearing in mind disability-associated stereotypes, they are regarded as dependent, childish or in need of care, which prevents them from fulfilling such established roles, transforming women with disability into sexless, eternally childish and/or unproductive individuals (Mañas, 2009).

It should not be forgotten that stereotypes are attached to beliefs, attitudes and motivations that create expectations regarding how people should behave, in this case, women with disability. Such expectations are also mirrored in others' behavior towards them, which might lead to discrimination or even a "variety" of forms of abuse, negligence, violence and serious violation of the rights of this group. In turn, stereotypes also influence people's perception of themselves and, therefore, their self-esteem and sense of self-worth, which can lead women with disabilities to develop a negative and biased concept of themselves for not meeting the imposed ideals or not being what society expects them to be (Gomiz, 2017). This, in turn, can have a negative impact on their social and affective relationships.

The 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union (European Disability Forum, 2011) revealed that the roles attributed by society to women with disabilities are different from those assigned to women in general. On its part, the First Integral Action Plan for Women with Disabilities drawn up by the Spanish Committee of Representatives of People with Disabilities (SCRPD, 2005) reports that around half a million women with disabilities in our country live confined to their homes, hardly able to make decisions within the family, not participating in occupational or public environments, not allowed to lead an autonomous lifestyle, and affected by a lack of support. All this becomes further aggravated by old age and by their almost exclusively assuming the role of caring for their parents.

This Action Plan was the starting point for others such as the Action Plan for Women with Disabilities 2007 (Ministry of Labor and Social Affairs, 2007) or the Second Integral Action Plan for Women with Disabilities (SCRPD, 2013), which is a continuation of the first and shows that, as a result of dual discrimination, these women face a prospect of exclusion that can affect their economic, occupational and social situation. Hence, the goal of this Second Plan is to remove obstacles through measures that can guarantee the exercise and enjoyment of their rights and their full participation in social life. With regard to this, it should be noted that article 4 of the Convention on the Rights of Persons with Disabilities (2006) urges states to adopt legal, administrative and other appropriate measures for the implementation of the rights of people with disabilities, specifically focusing on women and young girls with disabilities.

Gender-based discrimination cases intersect with other factors that affect women and girls, particularly those belonging to disadvantaged groups who are, therefore, at a greater risk of being victims of harmful practices. This is the case with women and girls with disabilities (United Nations Human Rights, 2014), who are subjected to practices such as forced sterilization and contraception, genital mutilation, sexual abuse, institutionalization, or economic exploitation (United Nations Human Rights, 2016). The WHO recognizes that women's scarce control over their own sexuality makes them vulnerable to sexual exploitation, violence or unwanted pregnancies.

2 Convergence of negative results

People with disabilities, especially women, report that they face more barriers to participation, the data showing that 14% of them suffer some type of discrimination as compared to 9.9% in the case of men (NIE, 2013). In rural settings, 75% of the women with disabilities believe that their quality of life is worse than that of their male counterparts and, additionally, 67% remark that they encounter more difficulties than the male population when it comes to forging social or sentimental relationships, or to achieve independence (State Observatory on Disability (SOD), 2018).

Academic failure and school dropout rates among girls with disabilities are high (SOD, 2019) and, although their predisposition towards training is greater, there are more women with disabilities who lack academic training than women without such condition and men with or without disabilities (SOD, 2018).

Women with disabilities are also discriminated in the area of access to employment and the right to dignified work (SOD, 2018), with high inactivity rates (64.8%) and lower salaries than women without disabilities and men with disabilities. Likewise, they receive fewer Social Security contributory pensions and those granted involve lower amounts (SCRPD, SCRPD Women Foundation, 2019; NIE, 2018; SOD, 2018). The situation of poverty and precariousness of women with disabilities leads to scarce participation in society and poor access to leisure activities as compared to the general population, especially in rural areas (SOD, 2019; Caballero et al., 2016).

Violations of the health and sexual and reproductive rights of women and girls with disabilities are frequent, ranging from lack of access to information and different primary care services, to lack of support and having their will subjected to that of third parties (SCRPD, SCRPD Women foundation, 2018). As for violence as the major form of discrimination, data reveal that the prevalence of gender-based violence in any of its forms is always greater among women with disabilities (De Miguel Luken, 2015; SCRPD, SCRPD Women foundation, 2016).

Although studies on the specific situation of women with disabilities are few and recent, it is encouraging to find that these women are organized and proactive in the defense of their rights and in the development of proposals to remove the specific forms of discrimination that affect them. The work undertaken by movements of women with disabilities has sown the seed for many proposals and approaches aimed at progress towards improving their living conditions, which are detailed, among others, in the 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union (European Disability Forum, 2011) or, at the national level, in the Second Integral Action Plan for Women with Disabilities 2013-2016 (SCRPD, 2013). Indeed, despite the realities of discrimination, exclusion, lack of visibility, violation of rights and violence against them, many of these women are already members of organized active movements and are determined to fight for their rights, including more inclusive language (Martín-Cilleros, Verdugo Castro and Paredes Cabanzo, 2021)

As expressed in the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Convention on the Elimination of all Forms of Discrimination against Women (United Nations, 1997), it would be interesting for all studies on women with disabilities to include an intersectional approach and analysis that may allow the identification of potential forms of discrimination for reasons such as marital status, type of disability, type of housing, economic situation and other variables, and, in particular, those regarding housing area (rural or urban), which interact and add to discrimination on the grounds of gender and disability.

The focus of the research detailed in this study was to examine the situation of women with disabilities according to their own perception, with the intention of drawing practical implications to improve their quality of life. The study follows a biopsychosocial approach to the understanding of disability, where it is viewed as a condition that involves multiple factors that interact and contribute to it. Thus, rather than understanding disability as something that only affects the person, it is interpreted as the result of the interaction between the person and his or her environment (World Health Organization, 2001; Schalock, 2018; Verdugo, 2018; Verdugo et al., 2013). Also in accordance with the established by the United Nations (2006), the approach advocated here is based on the inherent dignity of people with disabilities who, as legal subjects, should have the opportunity of enjoying all fundamental rights on equal terms and without discrimination (United Nations, 2018). More specifically, as observed by the Committee on the Rights of Persons with Disabilities, article 6 is a binding provision on non-discrimination and unequivocally forbids discrimination against women with disabilities while promoting equality of opportunities and results (United Nations Committee on the Rights of Persons with Disabilities, 2016).

On the basis of the above, the main goal of this research was to develop a profile of the woman with disability in Castile and León that may allow the identification of potential forms of discrimination in different areas. The specific objectives were:

1. To learn the circumstances in which these women live, considering the following areas of interest:
    a) access to love relationships, motherhood, forming a family,
    b) availability and use of a variety of housing resources, both family dwellings and other specific community or residential options,
    c) access to education and to a variety of advanced education levels,
    d) occupational and employment status and access to various forms of work, both paid and unpaid,
    e) economic situation and possibility of having their own economic resources, both the product of paid employment and of the use of social benefits,
    f) use of services provided by the National Dependency System (assessment of disability, specific housing and occupational services, personal care assistant, home help…).
2. To learn how women with disabilities perceive the impact of their disability on the different areas of their quality of life and well-being.
3. To learn how they perceive potential areas where they are discriminated.
4. To identify potential variables (rural or urban setting, age, type of disability…) that are related to the results in the analyzed areas.
5. To learn the demands of women with disabilities and suggest improvements for the system of dependence.

3 Methodology

3.1 Data collection

The sample included five hundred and twenty-six women between the ages of 35 and 64 ($X=46.94$) affected by intellectual disabilities ($n= 102$), multiple disabilities (n=

105), physical disability (n= 72), mental health problems (n= 46), cerebral palsy (n= 13), hearing disability (n= 8), brain damage (n= 6), visual disability (n= 4), rare diseases (n=2), autism disorder (n= 2), unspecified (n= 166) from the following provinces of the region of Castile and León (Spain): Valladolid (24.3%); Salamanca (17.3%), Palencia (13.3%), Ávila (13.3%), Soria (8.6%) León (7.0%), Zamora (8.3%) Segovia (5.0%) and Burgos (3.3%). More than half of the sample (57.3%) lived in urban areas (municipalities with more than 50,000 inhabitants), 32% in rural areas (less than 10,000 inhabitants) and the remaining 10.9% in intermediate areas (between 10,000 and 5,000 inhabitants). Regarding their marital status: single (63.2%), married (25.8%), divorcee (7.4%), widow (2.3%) and other (1,3%). 40.7% of had children, 37.8% were childless by their own choice, 8.7% had not had the opportunity, 7.1% were childless by others' decision, and 5.8% were childless by a consensus decision with their partners.

As regards dependents, 34.5 have none, and those who do are distributed as follows: 19.4% have three, 17.8% have two and 17.1% have four. The kinship relationship they have with the people under their care is: mother (23.2%), daughters (17.3%), unspecified relationship (30.8%) and wife (5.4%).

A majority of them reside in the family home (66.1%), followed by residences for people with disabilities (13.4%), sheltered housing (9.7%) and shared flats (5.4%). In relation to the number of people who live with them, it stands out that 26.2% live with three, 21.8% with two, 19% with four and 5.4% with one. In turn, most of them belong to associations (70.7%). Regarding their level of studies, the category "without studies" predominates in 33.7% of the sample, followed by primary studies in 20.8%, complete high school studies in 18.3% and incomplete high school studies in 16.5%, university categories being a minority (6.5%)

In relation to employment, the highest percentage corresponds to the condition of pensioner in 33% of the cases, followed by that of self-employed worker (12.2%) and student (11.2%).

Concerning their annual income, it should be noted that 74.1% of the total receive less than 11,500 euros, 16.2% receive between 11,501 and 15,000, and only 4.2% are in the 20,000-30,000 range.

3.2 Instrument

An 83-item survey was elaborated containing four main sections: i) general information, ii) occupational and professional data; iii) data related to disability, and vi) quality of life. The questionnaire was hosted on the SurveyMonkey platform.

3.3 Data analysis

A mixed-method approach through a concurrent design (QUAN+QUAL) was chosen and descriptive statistical analyses were performed (i.e., frequency analysis, measures of central tendency and dispersion), as well as content analysis (CAQDAS Nvivo 12 PLUS) for the related open questions. The qualitative research methodology was used in this study. It can be characterized as inductive, understanding the context and the people under a holistic perspective, being sensitive to the effects that the researcher causes to the people under study, and understanding study participants within their frame of reference, in which all perspectives are valid. It is a humanistic method that emphasizes the validity of the research, and that all contexts and people are potential study subjects (Quecedo & Castaño, 2002). This has implied that data collection and analysis were done simultaneously (Sánchez Gómez, Martín-Sevillano, Martín-Cilleros, Marcos & García-Peñalvo, 2021)

Furthermore, a quasi-experimental study with one non-randomized study group was conducted using a one-group post-test design. Data were scrutinized under Factorial Analysis (ANOVA), Student's t-test and Chi Square. Eighteen open questions were analyzed in the qualitative analysis. The constant comparative method of Strauss and Corbin (1994) was taken as a reference. This model allows three essential actions to be carried out: open, axial and selective coding to identify the relevant categories of the participants' comments, which were grouped into metacategories to build the theory-generating concept map. In the process, the quality criteria in qualitative research have been guaranteed at all times (Sánchez-Gómez, Palacios-Vicario and Martín-García, 2015). For this reason, the coding was carried out by the research team to be able to guarantee credibility (internal validity). The qualitative content analysis procedure began with an examination of the data and imposition of a structure, conducted to identify several specific themes that would later be grouped into general categories, or meta-categories. Within these categories, sub-categories were created based on existing themes (Sánchez Gómez, et al., 2021). In order to prove the dependence (reliability) of the category system, an explanatory codebook was elaborated. At the end, the objectivity (confirmability) was endorsed in the results by means of literal fragments of the participants' text. Furthermore, the analysis required an in-depth understanding of the context surrounding the information collected to reconstruct facts and stories to link the results with available knowledge and generate a theory based on the data (Sánchez Gómez, et al., 2021).

4 Results

4.1 Results of the quantitative analysis

Regarding support and services used, the findings show that 67.2% of the women report that they do not need help from others, and, while 59.4% are aware of the figure of the personal care assistant, only 20.1% uses this professional’s help. On the other hand, the healthcare center is the service that the women use the most (41.4%), followed by the occupational center (2.4%), while the least used are home help (0.9%) and telecare (2.3%) services. As shown in Table 1, there are statistically significant differences in the use of these services according to whether the women live in rural or urban settings, differences that are especially marked in the case of healthcare center, occupational service, housing, leisure, social services, and daycare and leisure center.

Table 1. Percentage of demand for services by living environment

	Rural		Urbano		Intermediate		Total		Mn	SD %	P-Val.
	n	%	n	%	n	%	n	%			
Health Care Centres	33	44,0%	53	44,2%	6	22,2%	92	41,4%	1,70	,461	,022
Occupational Centres	26	34,7%	31	25,8%	14	51,9%	71	32,0%	1,76	,425	,005
Residential Care Centres	26	34,7%	32	26,7%	8	29,6%	66	29,7%	1,78	,414	,025
Leissure Services	14	18,7%	28	23,3%	15	55,6%	57	25,7%	1,81	,392	,000
Social Care Services	22	29,3%	25	20,8%	2	7,4%	49	22,1%	1,84	,369	,048
Night Care Facilities	11	14,7%	26	21,7%	1	3,7%	38	17,1%	1,87	,332	,151
Employment Services	8	10,7%	21	17,5%	7	25,9%	36	16,2%	1,88	,325	,137
Rehabilitation and Physiotherapy	12	16,0%	16	13,3%	4	14,8%	32	14,4%	1,89	,308	,679

Educational Services	8	10,7%	13	10,8%	3	11,1%	24	10,8%	1,92	,271	,941
Personal Assistance Services	18	24,0%	6	5,0%	0	0,0%	24	10,8%	1,92	,271	,143
Day Centres	18	24,0%	6	5,0%	0	0,0%	24	10,8%	1,92	,271	,000

The variable related to discrimination on grounds of the personal condition of disability deserves special attention, the results showing that 63.8 % of the sample report not having suffered it, 18.8% have been discriminated when seeking employment and 17.3% have been discriminated at work. It is worth emphasizing that there are significant discrimination values according to the setting they live in, their annual income and whether they are holders or not of an official disability certificate.

As for the quality of life dimensions, the results reveal that women, especially those with multiple disabilities and those with intellectual disability, show greater needs in the areas of self-determination and inclusion, while they are less concerned about personal relationships and physical well-being. Regarding emotional well-being, women under the age of 18 report feelings of low self-esteem, harassment, or insecurity until the age of 24. For some of them, depression problems begin after the age of 25, or even a little earlier.

4.2 Descriptors for impact on quality of life according to setting they live in

Table 2. Impact on quality of life by living environment (nc 95%)

	Rural		Urbano		Intermedio		Total	M	SD	P-Valor
	n	%	n	%	n	%	n			
Physical Well-being Affectation	81	34,9	121	52,2%	30	12,9	232	2,19	1,147	,625
Emotional Well-being Affectation	81	34,9	121	52,2%	30	12,9	232	2,45	1,131	,835
Rights Affectation	80	34,8	120	52,2%	30	13	230	2,04	1,091	,649
Social Inclusion Affectation	80	34,9	119	52,0%	30	13,1	229	2,28	1,121	,257
Interpersonal Relations Affectation	79	34,5	120	52,4%	30	13,1	229	2,38	1,185	,706
Self-determination Affectation	79	34,6	121	52,6%	30	13	230	2,50	1,159	,002
Material Well-being Affectation	81	34,8	122	52,4%	30	12,9	233	2,55	1,166	,600
Personal Development Affectation	80	34,5	122	52,6%	30	12,9	232	2,61	1,087	,020

There is a clear statistical difference in service use according to whether the women live in rural or urban settings. Specifically, significant differences are found in the following services: healthcare center, occupational center, housing, leisure, social services, daycare and leisure center.

Tabla 3. Percentage of demand for services by living environment

	Rural		Urbano		Intermedio		Total		M	SD	P-Valor
	n	%	n	%	n	%	n	%			
Health Care Centres	33	44,0%	53	44,2%	6	22,2%	92	41,4%	1,70	,461	,022
Occupational Centres	26	34,7%	31	25,8%	14	51,9%	71	32,0%	1,76	,425	,005
Residential Care Centres	26	34,7%	32	26,7%	8	29,6%	66	29,7%	1,78	,414	,025
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Social Care Services	22	29,3%	25	20,8%	2	7,4%	49	22,1%	1,84	,369	,048
Night Care Facilities	11	14,7%	26	21,7%	1	3,7%	38	17,1%	1,87	,332	,151
Employment Services	8	10,7%	21	17,5%	7	25,9%	36	16,2%	1,88	,325	,137
Rehabilitation and Physiotherapy	12	16,0%	16	13,3%	4	14,8%	32	14,4%	1,89	,308	,679
Educational Services	8	10,7%	13	10,8%	3	11,1%	24	10,8%	1,92	,271	,941
Assistance Personal Services	18	24,0%	6	5,0%	0	0,0%	24	10,8%	1,92	,271	,143
Day Centres	18	24,0%	6	5,0%	0	0,0%	24	10,8%	1,92	,271	,000
Respite Care Services	2	2,7%	7	5,8%	3	11,1%	12	5,4%	1,96	,196	,027
Supported Employment	2	2,7%	5	4,2%	3	11,1%	10	4,5%	1,97	,179	,137
Tele-asisstance	3	4,0%	2	1,7%	0	0,0%	5	2,3%	1,98	,128	,353
Home Care Services	1	1,3%	1	,8%	0	0,0%	2	,9%	1,99	,089	,801
Total	96	100,0%	173	100,0%	33	100,0%	302	100,0%			

4.3 Discrimination

One of the variables that is worth noting is that of discrimination on grounds of the person's condition of disability. In this regard, it may be confirmed that 63.8 % of the sample express that they have not suffered discrimination, while 18.8% have been discriminated when seeking employment, and 17.3% have been affected by discrimination at work. On the other hand, there are significant discrimination values according to the setting they live in (p-value= .005), annual income (p-value= .01) and whether they hold an official disability certificate (p-value=.05). No statistically significant values are found for the marital status, profession, level of education, need for help, reduced mobility, dependence or unemployment variables.

4.4 Impact on quality of life

The impact of the condition of disability can be observed in different areas. There are significant differences in means in favor of the urban environment according to whether the women live in rural or urban settings in the different variables of the quality of life subscale: self-determination (p-value= 0.00) and personal development (p-value=0.02). Similarly, there is a significant difference in impact on quality of life according to the provinces where the women live in the following variables: physical well-being (p-value=0.02), rights (p-value=0.01), inclusion (p-value=0.01), interpersonal relations (p-value=0.00); self-determination (p-value=0.00), personal development (p-value=0.00) and emotional development (p-value=0.02).

4.5 Qualitative analysis results

The fusion of the main ideas obtained from the open responses and the reviewed theory on the topic led to the definition of two central categories (support and impact on quality of life) and 11 subcategories.

This resulted in the development of a concept map focused on support, whose subcategories were defined in a comprehensive and contextualized way as demands, utility, benefits and impact on quality of life; the latter, in turn, represented by the eight dimensions suggested by Schalock and Verdugo (2003, 2007). The categories that emerge from the comments made by the participants are included in Figure 1.

Fig. 1. Conceptual map of categories (key ideas)

Below are the data obtained from the search of word frequency in the comments made by the participants (see Figure 2). This semantic analysis shows that the word disability is the most frequently quoted as the axis of their quality of life, also conditioning access to employment and to a variety of activities.

Fig. 2. Most frequent words cloud

The word support usually appears in comments related to their needs, aimed at meeting basic needs of their daily lives such as being accompanied when going to places. The women who participated in the study regard support as essential to enhance their autonomy and provide respite for relatives, to attend medical examinations, to help them arrange their plans…; in general, they consider it important in all aspects of their lives. They claim that the people who are employed to provide support should be given more working hours, and that there should be greater availability of both professionals and appointment times, also stating that more training is required and that such support should be facilitated by administrations. Moreover, on various occasions they refer to the need for psychological and emotional support due to the circumstances they are faced with.

In terms of the content analysis represented in the concept map, as already mentioned, there are several focal points that underlie each central topic and that are addressed by the participants. As regards the dimensions of quality of life (Figure 3), broadly, the most frequently mentioned refer to self-determination (e.g., they reflect experiences associated with total dependence on relatives) and to inclusion (e.g., architectural barriers mentioned in the comments of people with multiple disabilities, 29%, and mental barriers), whereas the least approached are interpersonal relationships (e.g., difficulties in starting or maintaining a relationship) and physical well-being (e.g., comments on their health problems and the need for medication). On the subject of material well-being, they refer, for example, to necessary modifications to their home that have involved economic costs; in the personal development category, they consider that their limitations arise from their disability; and, finally, they draw attention to the importance of fulfilling the rights of people with disabilities.

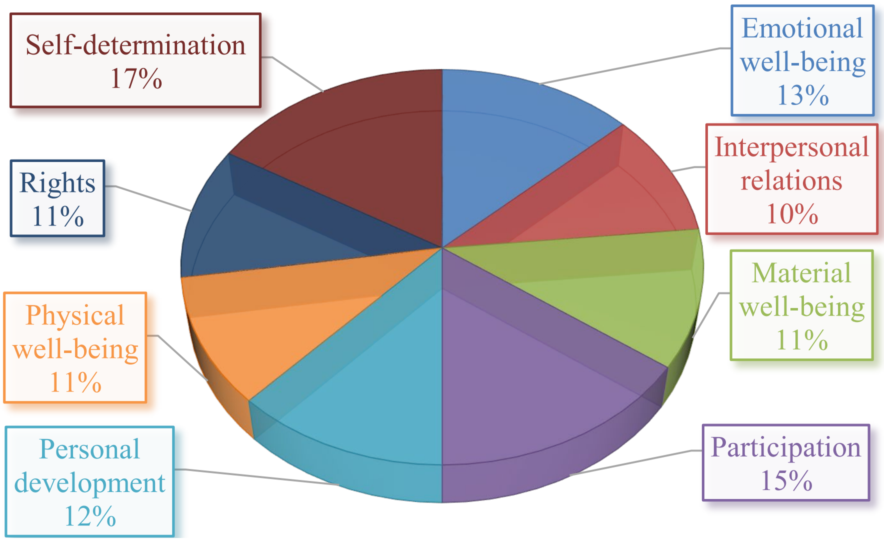

Fig. 3 Coding references related to quality of life indicators

Although all the dimensions encompassed by quality of life are interconnected, cluster analysis revealed that certain results indicate that certain dimensions are more closely related to each other (see Figure 4).

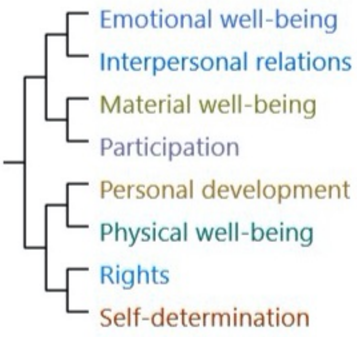

Fig. 4. Clustered elements by similarity of coding

The first similarities appear between interpersonal relations and emotional well-being, showing that the loss of friendships has made the women feel more rejected, affecting their mood, as suggested by comments such as “My work environment and friendships are the areas that are growing worse, this has brought me much suffering and a very poor quality of life in general”, “If you lack support, you can’t get ahead in certain situations, you grow much more vulnerable and might develop depression…”, “With friends, a lot, because they come and go, travel and don’t count on us, at least as they used to”, “Young people with so many health problems are seen as strange. You are a burden”, “I avoid all those people who are given basic notions to make communication easier and ignore them, and those who see it as something funny”, “I don’t have any relationships, because of rejection”, “My biggest problem has been with my friends, I’ve had their support during the illness, but when I’ve resumed “normal” life, (the life I must lead now, not partying, going out, etc.) it seems that I no longer fit in their lives”, “Insecurity when dealing with others” or “I feel discriminated”.

Participation is indexed alongside material well-being, becoming reduced by, among other aspects, a lack of financial possibilities, either to afford leisure and free time activities or to hire a support person that may provide them with the autonomy required to carry them out. These aspects are reflected in comments such as “Not having any income has made it difficult for me to participate in things that I like, such as going to see the Mirandés, travelling, … if I had worked, I could have done more things”, “Because I can’t work I only have my pension and since it’s not very high I have to spare on expenses”, “… since not having a pension means that I have to pay at the center and I have little money left for recreational activities, camps, leisure”, “That I can’t make ends meet”, “I don’t go to any activities, not being able to go on my own, I can’t enslave my husband to do so many things, he must have his free time”, “Not arranging to meet friends in advance because I don’t know if I’m going to be able to make it”.

These two similarity groups are also related because material well-being clearly helps towards greater participation in activities, which usually provide the setting where social interactions take place, the latter being one of the keys to emotional well-being.

The dendrogram also shows a relationship between physical well-being and personal development, and between rights and self-determination. In the case of the former, the problems derived from disability, the side effects of the required medication or the disability itself, limit the person’s ability to engage in personally fulfilling activities. Examples of this can be observed in the following comments: “I can hardly do anything I like for some or another health problem”, “I can’t do more of the things that I want to”, “Much of it because of the pain and exhaustion when doing the slightest thing”, “Every step I take, all I do in my life is for the sake of the lymphedema or at least so that the lymphedema or my body are not harmed, insomnia, fasciitis”, “… doing little activity has made me gain weight and that makes my activities more difficult”. Such activities are commonly related to the person’s work environment, examples being: “It has made me unable to develop a professional career”, “I’m no longer eligible for the jobs I could opt to before, either because I’m not physically who I used to be or because the disability that I have been left with limits me in many aspects”, “I have hearing impairment and find it increasingly difficult to perform my job”, “… trying to work in that state was impossible, I couldn’t manage my 90kgs, I didn’t sleep, I would become dizzy…”, “… not being able to do anything related to the activity I used to do”; or the possibility of acquiring knowledge, as in “Less trained because of disability”. Concerning rights and self-determination, certain institutions still disregard this population group, which is clear from comments such as “Very difficult to access spoken information, which is what all public information services mostly provide”, “Not being able to access certain places”, “…we have achieved things in terms of rights, but there is still much to achieve, access to public services is sometimes complicated”. Work-related rights are also undermined, which becomes consequently reflected in greater dependence, as shown by the following comments: “I became unemployed because I couldn’t do it because of my disability”, “I haven’t had the chance of having a job and earning money independently”, “Fired because they would not change my job post”, “Nobody demands that you say what your disability is, but if you don’t say what it is, forget about being hired", "At the company I used to work for, when I said I had cancer, they fired me, and as a reward to their wonderful behavior, the judge said that it was a perfect decision", "It is much more difficult to find a job when you have a disability". In certain cases, this non-recognition of rights, also affects education; as stated by one of the women: "I have sometimes had problems for them to adapt things for me and to be fairly assessed".

5 Conclusions and discussion

The goals of this research focused on understanding the circumstances that women with disabilities in Castile and León live in, their perception of personal well-being, the differences between living in a rural or an urban setting, the analysis and consequences of their dependence, and what they demand from the public care system.

5.1 Circumstances which women with disabilities live in

According to the comments expressed by the women that participated in the study, we might conclude that all the dimensions of quality of life are affected, with greater emphasis on lack of autonomy, which is attached to a constant feeling of dependence and an inability to make choices that leads them to adapt to the desires of their caregivers or guardians. Although their presence in the community is growing, it is an issue that remains pendant, be it because of architectural barriers or because of those that are harder to remove, namely, mental barriers. Their circle of friends is reduced, so it is hard to build new social networks because of the difficulties they face to achieve greater participation in the community, as mentioned before, and because of the loss of friends when the disability surfaces in the person's life or family.

As regards personal development, comments tend to place more emphasis on the professional area since, on the one hand, it is difficult to find a job and, on the other hand, disability very often leads to unemployment. This has a major impact on material well-being, which is further affected by expenses resulting from disability such as healthcare, modifications to reduce architectural barriers or other types of necessary support.

Although not very often broached in the answers, physical well-being is also conditional on their dependence situation, since they are a population group that is affected by numerous health issues, some of them associated with medication side effects. Among such problems, mental health is deeply affected, and the older the woman, the greater the impact.

As reported in other studies (Gomiz, 2017; Shum and Conde, 2009), the participants exhibit emotional problems, such as low self-esteem, that are not addressed by professionals until they develop into depression or other more serious mental health issues. Emotional support should be provided from the early stages of the onset of the disease, when it appears in the person's evolving capacity, and, when the disability is present at birth, this aspect should be addressed from early childhood. Such aspect is both eclipsed and boosted by their economic problems, since one of the main needs they believe is not covered is associated with expenses derived from their disability, such as healthcare costs, or those aimed at obtaining physical or architectural support. These basic needs are the cause of their not being able to afford other recreational activities which, added to the discrimination they face when it comes to participating in the community and, in certain circumstances, a negative self-image, have a damaging impact on their emotional well-being, which is expressed very frequently in comments such as "I suffer from depression" or "I feel anxious".

5.2 View of women with disability regarding their full and inclusive development

The findings are consistent with what is stated by the World Health Organization (2015). People with disabilities achieve worse results in the area of education, with only

11% of the sample having training in higher education against the 33.7% who have no studies or the almost 21% who have only completed primary education. Poverty rates are also higher, the annual income of 74% of the sample being under 11,500 euros, and employment rates are lower, 33% being pensioners as a consequence of their disability. Likewise, they are less independent, as expressed by the participants in their comments, regardless of their disability, self-determination being the most repeated topic. They suffer greater isolation and are affected by greater restrictions in participation in several situations, as they report when referring both to inclusion and to interpersonal relations. As reflected in the results, isolation appears both associated with participation in the community and with employment, 17.3% stating that they have felt discriminated at work.

Against what the United Nations reports (2018), the results of this study do not show a denial of motherhood, since 40.7% have children and the 37% who do not, state that it was their own choice. It would be interesting to further explore whether such idea is truly their own or has been prompted by others.

5.3 Differences in the situation of women with disabilities in rural or urban settings

As regards quality of life, there are no noticeable differences between rural and urban settings, concerns in both contexts revolving around self-determination, inclusion and emotional well-being. There are, however, age-related differences, since it is a topic that is more frequently mentioned by women between the ages of 56 and 64 and less expressed by those between 18 and 24.

5.4 Demands and possible improvements to the dependency system

When addressing support, only 59.4% was aware of the existence of the personal care assistant option, which is only used by 21.1%. The results show that it is necessary to continue work on independence and autonomy, the personal support option being regarded as highly beneficial to both the person with the disability, whose autonomy and planning capacity become enhanced, and for relatives who can use it for respite. Currently, personal care assistants are only called for basic needs such as help with dressing and going with the person to medical appointments; thus, one of the demands is that there be greater availability of these workers, both in terms of numbers and appointment hours. The comments convey the need for more administratively regulated and specifically trained personal care assistants.

The responses gathered in the study allude to constant bureaucratic hurdles and refusals from the administration in their attempts at achieving recognition of economic rights because of their status of disability, which undermines their situation in this regard and adds to their difficulty in finding employment or being accepted in their workplace.

The results and conclusions, which are supported by article 8 of the International Convention on the Rights of Persons with Disabilities (2006), reveal the importance of maintaining public awareness campaigns aimed at eliminating stereotypes and prejudices, allowing women with disabilities to become more involved in public representations and presenting a positive image of them, facilitating contexts where their merits and abilities may be acknowledged.

This raising of awareness must be targeted at groups that represent all evolutionary stages, starting with the early ones by promoting inclusive practices at education centers and conveying messages on the benefits of diversity, where the support that is crucial to students with disabilities is extended to all those who share spaces (González et al., 2020; Martín-Cilleros and Sánchez-Gómez, 2016). According to the findings, emphasis must be placed on raising awareness among business professionals and public bodies, creating guidelines and engaging in training initiatives for such purpose. The proposal provided in article 23 of Royal Legislative Decree 1/2013, of 29 November, on "the adoption of internal regulations at companies or centers that may foster and stimulate the removal of disadvantages or general situations of discrimination towards people with disabilities, including reasonable adjustments", should be encouraged and favored.

As well as developing actions aimed at eliminating mental barriers, it is necessary to continue work on the elimination of architectural barriers, implementing measures that may guarantee mobility and accessibility to buildings and settings or public roads and streets, paying special attention to leisure spaces and open or public use places, both in urban and in rural areas, to ensure equal opportunities and foster not only the presence, but, taking it one step further, also the participation of this population group. To this effect, building contexts modelled on universal design and/or providing a wider range of personal support such as assistants should be encouraged. Concerning the support professional, attention should be paid to his/her training, which should be official and include specific contents and also be aimed at the end-users of such support. The availability of these professionals should also be broadened so that their use might become more common and go beyond the coverage of basic needs.

Disability is a challenge for the person affected by it, who is forced to adapt to the situation. Not only does it sometimes make performing everyday tasks so trying that they might require personal support, but they are also faced by discrimination, which is augmented by their personal condition as women. The findings of this study show that the rights of women with disabilities are indeed undermined, not only their right to make choices regarding minor everyday events, but also others such as the right to benefits or to a decent job. The violation of these rights triggers economic problems that mainly affect their material and physical well-being, and their personal development and self-determination.

Guaranteeing the rights of women with disabilities is based both on the training of the affected people themselves and on that of their family, guardians or relatives, who are to play an important role towards achieving this. The engagement of institutions such as universities, education centers or non-profit organizations could be fostered through a learning-service methodology that favors civic responsibility in catering for the specific needs of a certain population group, in this case women with disabilities, and fostering civic values and an inclusive culture.

Adverse situations are best approached with adequate emotional control. As reflected in the results, women refer to mental health problems that begin in early childhood with low self-esteem and deficits in skills to confront harassment, to develop into depression or anxiety, which can eventually escalate into serious mental health problems. The availability of an emotional support service where women with disabilities might learn strategies to maintain emotional balance and thus improve their perception of their own image and worth, while preventing more serious mental health problems, would not only serve as prevention, but would also help them to build the foundations required to boost other quality of life dimensions, even becoming an observatory against possible ill treatment or gender-based violence.

Finally, the media play an essential role by having a responsibility to disseminate a positive image of women with disabilities, contributing to a positive shift in attitudes towards them. In this regard, it should be noted that the 2nd Manifesto on the Rights of Women and Girls with Disabilities mentions the need to foster the use of positive language among professionals when approaching subjects on women and girls with disabilities. Moreover, according to Law 7/2010, of 31 March, General Law on Audiovisual Communication, "Audiovisual communication service providers will endeavor to offer in their broadcasts an adjusted, normalized, respectful and inclusive image of people with disabilities (…) avoiding the dissemination of perceptions that are stereotyped, biased or the product of prejudices that might subsist".

5.5 Study limitations

The study is based on a large sample of women with disabilities from the Autonomous Community of Castile and León and yields significant results. Nevertheless, further research is required to provide data that are differentiated according to type and severity of the disability and other explanatory variables. Likewise, it is advisable to engage in multiple studies at the local levels so that the relevant administrations may gradually improve the dependence system and their support responses to this population group.

The views of women with disabilities themselves and of their family environment are the ones that allow progress in the definition of the causes and solutions to the limitations of rights that they suffer. Therefore, they should be given due value and awareness of them should be actively promoted.

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