ORIGINAL ARTICLE

Disability evaluation in patients with rare diseases in Spain: the importance of being in accord. BURQOL-RD Project

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Abstract

Most of rare diseases lead to a certain level of disability. In Spain, disabled persons receive long-time benefits, but only if they possess a disability evaluation that officially certifies the degree of their disability. Sometimes, the affected persons can experience disagreement with the obtained evaluation.

Our aim was to analyse the level of agreement among rare disease patients and caregivers in Spain with their official disability evaluation and its possible relationship with their health-related quality of life (HRQoL) and the general satisfaction with the national healthcare system (NHS).

Data were collected from patients (n = 123) and caregivers (n = 74) as a part of BURQOL-RD Project that measured the burden of ten rare diseases in Europe. HRQoL was evaluated by the generic instrument EQ-5D. Satisfaction with NHS was measured on a scale from 1 to 10.

Almost 30% of respondents did not agree with their disability evaluation. These persons expressed less satisfaction with NHS than those who were in accord with their evaluation (5.1 vs 6.8; p <0.0001). Patients' and caregivers' HRQoL was also worse for the disagreement group, but did not reach a statistical significance.

Correctly evaluated degree of disability is fundamental and has many consequences for all affected parties. Disability evaluation rules should reflect the specificities of rare diseases.

Key words

Disability, rare diseases, benefits, satisfaction, health-related quality of life.

Background

According to the WHO definition, disability is a complex phenomenon reflecting the interaction between features of a person's body and features of the societal context where the person lives [1]. Thus, disability is a concept, covering impairments, activity limitations, and participation restrictions. Over 1 billion persons experience some degree of disability in the world [1]. In the European Union, one in six people has a disability that ranges from mild to severe [2].

Most of rare diseases are severe and involve sensory, motor, mental and physical impairment, which leads to a disability if the environment and regulations do not take into account the special needs of people with impairment to participate in society [3]. The specificity of rare diseases is that in many cases the affected person is not seen as a disabled citizen, but just as a patient [4].

All EU countries provide long-term benefits for people who become disabled during working life, in form of disability pensions. Besides, there are also benefits for disabled children, which are mainly family benefits to cover home care, assistance, extra costs and education, as well as specific benefits for people who have never entered the labour market due to disability [5].

Disability certificates are necessary to have rights applicable for disabled persons. These certificates are the result of a complex evaluation process. In Spain, the disability evaluation is a multidisciplinary process that includes medical doctors, psychologists or social workers, who carry out an interview with the disabled person and his/her family members and assess relevant documents. At the end of this process, this committee issues a disability certificate that confirms the disability level or degree. If this

level is more than 33%, the person is considered disabled [6]. However, some benefits, such as long-term care allowance, are provided only to persons with more than 75% of disability [5].

Thus, the certified level of disability has important consequences in the social benefits and support received by the affected families, and an adequate evaluation is fundamental, though not always easy for rare diseases [4]. Some patients with disabilities and their caregivers feel that the evaluation process is subjective or biased, and may experience disagreement with the degree of their disability evaluation and consequently with the received benefits.

The BURQOL-RD Project (Social Economic Burden and Health-Related Quality of Life in Patients with Rare Diseases in Europe), carried out between 2010 and 2013, reached its goal to quantify the socioeconomic burden of 10 rare diseases and also collected data on health-related quality of life (HRQoL), satisfaction, disability level and other outcomes of patients and their caregivers in eight European countries [7-12].

The aim of this paper is to analyse the level of agreement among a group of rare disease patients and caregivers in Spain with their official disability evaluation and its possible relationships either with their own health-related quality of life (HRQoL) or with the general satisfaction with the national healthcare system (NHS).

Methods

We analysed data gathered in a cross-sectional study, BURQOL-RD Project, in 2012 in Spain on persons (patients and their caregivers) affected by one of ten selected rare diseases: cystic fibrosis, epidermolysis, Prader-Willy syndrome, Duchenne muscular dystrophy, scleroderma, juvenile idiopathic arthritis, haemophilia, fragile-x syndrome, histiocytosis or mucopolysaccharidosis. This set of rare diseases was selected in order to represent the broad group of rare diseases, keeping in mind the prevalence (including ultra-rare diseases), availability of treatment or caused physical and/or mental disability [7].

Patients and caregivers were invited to participate through disease-specific patient organizations and completed a self-administered online questionnaire distributed via email [10]. Where patients were not accessible via email, postal survey was used. In case of paediatric patients, the main caregiver was taken as a proxy and answered the questions for the patient. The survey was completely anonymous, as no identification data were collected and the completed questionnaires were automatically saved in the research database.

Part of the questionnaire was dedicated to information about disability evaluation and certification by regional authorities, its level and whether the patient agreed with the evaluation (possible answers "yes" or "no"). Besides, patients' satisfaction with NHS was measured on a scale from 1 to 10, where 1 represented the answer "not at all satisfied" and 10 represented the answer "completely satisfied".

HRQoL of the patients was measured by EQ-5D, a generic instrument validated in Europe, including Spain, and commonly used in economic evaluations of health technologies [13]. This instrument covers five areas: mobility, self-care, everyday activities, pain/discomfort and anxiety/depression. A total of 245 possible health states can be defined in this way and the values oscillate between 0 and 1, where 0 represents the worst imaginable health state (death) and 1 is the value of perfect health. The second part of the EQ-5D consists of a vertical 0-100 scale (VAS), where again 0 represents the worst imaginable health state and 100 the best health state. The respondent marks a point on the scale to reflect his/her overall health on the day of the interview [14].

Barthel Index is a widely used tool for the assessment of disability; it measures the ability of a person to perform ten basic activities of daily living, obtaining a quantitative estimate of the level of dependence of the person [15].

Caregivers also completed the Zarit burden interview (22-item version), which measures their subjective burden. The total score ranges from 0 to 88, with scores under 21 corresponding to little or no burden and scores over 61 to a severe burden [16].

Descriptive analysis were used to present sample characteristics. Means and standard deviations were calculated to describe continuous variables and frequencies were used to describe categorical variables. ANOVA analysis was performed to evaluate differences between groups according to their agreement or disagreement with the disability evaluation.

Data analysis were conducted in SPSS 15 statistical software (SPSS, Inc., Chicago, IL, USA). A level of significance of 0.05 was considered in the analysis.

Results

Data of 123 patients were analysed; 35 of them suffered from fragile-x syndrome, 34 Duchenne muscular dystrophy, 20 Prader-Willi syndrome, 12 mucopolysaccharidosis, 11 epidermolysis bullosa, 6 cystic fibrosis and 5 scleroderma. No data from Spain was available for histiocytosis, juvenile idiopathic arthritis and haemophilia. Besides, 74 main informal (not contracted) caregivers of these patients, mostly parents (87%), responded questions about their situation.

Almost three quarters of the patients were males, because the two most frequent diseases in the study sample (Duchenne muscular dystrophy and fragile-x syndrome) affect more males than females [17, 18]. The average age of the patient group was 18.7 (SD: 13.5) years, due to the fact that most of these rare diseases have onset in the childhood. Average satisfaction with the Spanish NHS was 6.3 (SD: 2.3) points. Average patients' HRQoL was 63.4 (SD: 20.9) points and caregivers' HRQoL was 71.8 (SD: 17.5) points on the visual analogue scale of EQ-5D (VAS).

Characteristics of the patients and caregivers can be seen in Table 1.

Almost 30% of the patients or their representatives (n = 36) expressed disagreement with their disability evaluation (disagreement group), which ranges according to the disease from 8% for mucopolysaccharidosis to 60% for scleroderma (Table 2). The disagreement group had slightly higher patients' average age (23 vs 17 years; p = 0.039) and they were diagnosed later than in the agreement group (8 years old versus 4 years old; p = 0.038) (Table 3). Both groups showed similar level of performance in activities of daily living, with slightly better scores in the disagreement group but without statistical significance (63.8 vs 56.5 on Barthel score, p = 0.301). On the contrary, the subjective caregivers' overburden was higher in the disagreement group, but also without statistical significance (38.6 vs 35.5 on Zarit scale, p = 0.401).

Both satisfaction with NHS and patients' HRQoL were higher for the agreement group, although only the satisfaction variable reached the statistical significance. Those patients who were in accord with their disability evaluation expressed more satisfaction with the health-care system (6.8 vs 5.1 points, respectively; p <0.0001) and also evaluated higher their HRQoL (65.7 vs 57.8 points on the visual analogue scale of EQ-5D, respectively; p = 0.112), than those who were not in accord. Moreover, the caregivers' HRQoL was affected in the same way: caregivers of patients who agreed with the disability evaluation had somewhat better HRQoL than caregivers of those who did not agree (72.8 vs 69.7 point on the VAS; p = 0.498) (Table 3).

Table 1. Characteristics of patients and caregivers

	Patients (n = 123)	Caregivers (n = 74)
Male, n (%)	90 (73.2%)	14 (11.4%)
Age, mean ± sd	18.7 ± 13.5	45.4 ± 10.5
EQ-5D VAS, mean ± sd	63.4 ± 20.9	71.8 ± 17.5
Barthel index, mean ± sd	58.7 ± 29.5	–
Disability degree, n (%)		
<33%	3 (2.4%)	–
33%-64%	29 (23.6%)	–
65%-74%	29 (23.6%)	–
>75%	55 (44.7%)	–
No reply	7 (5.7%)	–
Years of caring, mean ± sd	–	13.3 ± 10.0
Satisfaction with NHS, mean ± sd	6.3 ± 2.3	–
Zarit scale, mean ± sd	–	36,5 ± 14,4
Relationship to patient, n (%)		
Son/Daughter	–	8 (10.8%)
Mother/Father	–	64 (86.5%)
Other	–	2 (2.7%)

sd: standard deviation; NHS: National Healthcare System; EQ-5D VAS: Visual Analogue Scale of EQ-5D questionnaire.

Table 2. Distribution of the sample (n = 123) by disease: agree vs disagree with the disability evaluation

Disease (n)	Agree	Disagree
Fragile-X syndrome (n = 35)	29 (82.9%)	6 (17.1%)
Duchenne muscular dystrophy (n = 34)	22 (64.7%)	12 (35.3%)
Prader-Willi syndrome (n = 20)	11 (55%)	9 (45%)
Mucopolysaccharidosis (n = 12)	11 (91.7%)	1 (8.3%)
Epidermolysis bullosa (n = 11)	8 (72.7%)	3 (27.3%)
Cystic fibrosis (n = 6)	4 (66.7%)	2 (33.3%)
Scleroderma (n = 5)	2 (40%)	3 (60%)
Total	87 (70.7%)	36 (29.3%)

Table 3. Comparison of groups: agree with the disability evaluation (n = 87) versus disagree with the disability evaluation (n = 36)

	Agree (n = 87)	Disagree (n = 36)	p-value
Patients			
Age, mean ± sd	17.2 ± 12.2	22.7 ± 15.8	0.039
Age at diagnosis, mean ± sd	4.4 ± 5.9	7.5 ± 10.7	0.038
Time of disease exposition, mean ± sd	12.8 ± 9.8	15.3 ± 10.9	0.228
Patient EQ-5D VAS, mean ± sd	65.7 ± 20.1	57.8 ± 22.2	0.112
Patient Barthel index, mean ± sd	56.5 ± 30.0	63.8 ± 28.2	0.301
Satisfaction with NHS, mean ± sd	6.8 ± 2.0	5.1 ± 2.5	<0.0001
Disability degree, no. (%)			
<33%	3 (3.4%)	0 (0%)	NA
33%-64%	20 (23%)	9 (25%)	
65%-74%	20 (23%)	9 (25%)	
>75%	40 (46%)	15 (41.7%)	
No reply	4 (4.6%)	3 (8.3%)	
Caregivers			
Age, mean ± sd	44.1 ± 10.7	48.4 ± 9.5	0.104
Years of caring, mean ± sd	12.0 ± 10.0	16.4 ± 9.8	0.082
Caregiver Zarit scale, mean ± sd	35.5 ± 13.3	38. 6 ± 16.7	0.401
Caregiver EQ-5D VAS, mean ± sd	72.8 ± 17.0	69.7 ± 18.8	0.498

sd: standard deviation; NHS: National Healthcare System; EQ-5D VAS: Visual Analogue Scale of EQ-5D questionnaire; NA: Not applicable.

Discussion

The European Commission has a long-term strategy on disability, which determines the main policy developments in the disability sector [2]. In the field of rare diseases, the adoption of the Commission Communication in 2008, the Council Recommendation in 2009 and the Directive on cross-border healthcare in 2011 have created a solid basis to place rare diseases in a privileged position in the health agenda of the Member States [19].

However, major and arbitrary disparities exist between countries, and even between regions, in the allocation of financial aid, income support and reimbursement of medical costs [3]. Treatment costs incurred by a rare disease are often higher than they are for other common chronic diseases because of the rarity of the disease, the limited number of specialised centres and the need for continuous care. In most cases, a significant proportion of these expenses is born exclusively by the families. Travel costs to specialised centres are also high in terms of productivity losses and financial costs.

Families affected by a rare disease and health care workers frequently complain about the extreme difficulty in taking the necessary administrative steps required to receive social benefits [3]. The investigation performed by RehabCare with families and patients in Ireland brought also other elements into evidence and discussion [20]. Due to the lack of information and support for people with rare disorders many of the participants initially had great difficulty getting information on their entitlements. Some participants also felt that the caregiver's allowance was insufficient to replace the loss of a fulltime income and that they were struggling to survive.

There are many factors that can affect negatively the quality of life of a person with a rare disease [21]. Health state is certainly one of the most important factors, but others can also play a role, such as access to school or employment, existence of specialized social services or financial support and social benefits.

Our study discovered that almost one third of families affected by a rare disease in Spain were not satisfied with their officially certified disability degree. This figure is in line with the results of a survey carried out by Federación Española de Enfermedades Raras (FEDER) in 2009 [4], which observed that 35% out of 715 respondents affected by one of 29 rare diseases did not agree with their disability evaluation. The main reason, for which the patients think they did not receive a correct evaluation, is the lack of knowledge of the evaluators about the specific rare disease, its symptoms and limitations, which can lead to an underestimation of its burden and therefore a lower certified degree. Indeed, the study discovered that those patients with more prevalent rare diseases received higher disability degree than those with ultra-rare diseases (p = 0,002) [4].

Based on our results, we could add to these findings that the doubts about the correctness of the disability evalua-

tion may lead to a significantly worse perception of NHS among patients and their caregivers. Also the HRQoL of patients and caregivers from the disagreement group was affected, although not reaching a statistical significance; this impairment was not caused by the dependency level, measured by Barthel index, which was slightly higher in the agreement group. However, we cannot assure a direct connection of these variables, since there may be some confounding factors, like a higher patients' age or a higher age at diagnosis in the disagreement group. This latter variable may have a special significance, since the delayed diagnosis in rare diseases is apparently a common problem across countries [22, 23] and there is also evidence about the negative effects of this delay, which can have severe irreversible, debilitating or even life-threatening consequences [24-26]. Unfortunately, our data do not provide sufficient information to determine whether there was a delay in the diagnosis of the participants in our survey.

Other limitation of our study is the small number of participating patients and even less caregivers, without clinically confirmed diagnosis, which is a common problem of socio-economic research in rare diseases field [10] and it can limit the significance level of the analysis. The fact that BURQOL-RD project was not primarily designed to gather information on disability or satisfaction limits drawing reliable conclusions.

Conclusions

Our results suggest that the level of agreement with the disability evaluation could affect people's overall satisfaction with NHS. We also observed a non-significant impairment in patients' and caregivers' quality of life. The consequences of the correctly certified degree of disability are many: from the possibility to receive certain financial benefits, to the entitlements to social services and aids for activities of daily living. The fact, that about one third of affected persons are not in accord with the certified disability degree, is striking. Policy makers across Europe should bear in mind this fact in the moment of creating or modifying rules for disability evaluation, not only in rare diseases area.

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Authors' contribution

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Renata Linertová had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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