



JUGGLING CARE AND DAILY LIFE

The balancing act of the rare disease community



A EURORDIS INITIATIVE



EURORDIS.ORG

Survey methodology

Sandra Coubier, EURORDIS

Rare Barometer Voices framework



A EURORDIS INITIATIVE

Participants recruited through Rare Barometer Voices

- Rare Barometer Voices participants participated
- External link disseminated by partners on social media, Google ads, email from patients organisations, helplines...

Socio-demographic Information

- Disease
- Gender
- Age
- Country
- Email

Ethics and security

- Approved by the French data protection authority (CNIL)
- Explicit consent for being recontacted
- Contacts details replaced by an automatically-generated key

Questionnaire design

- Volunteer-based focus group (October 2015), 5 members of the [EURORDIS Council of National Alliances](#).
- The questionnaire was designed in collaboration with:
 - Partners of the INNOVCare project (ZSI, Zentrum für Soziale Innovation, Karolinska Institutet and NoRo Resource Centre, Asociatia Prader Willi, Romania)
 - Academics and corporate partners involved in the Rare Barometer Programme (University of Rouen, Social Science and MAPI, Patient-Centered Research company)
 - EURORDIS members involved in the Rare Barometer programme (Rare Disease Denmark and FEDER, Spanish Alliance for Rare Diseases)



Translation of the questionnaire



In the 23 most used EU languages



Mapi, expert in medical translation and Linguistic Validation, provided the translation in kind



The translation was also checked by volunteer patient organisations

Timing and organisation: 2 stages

1st stage

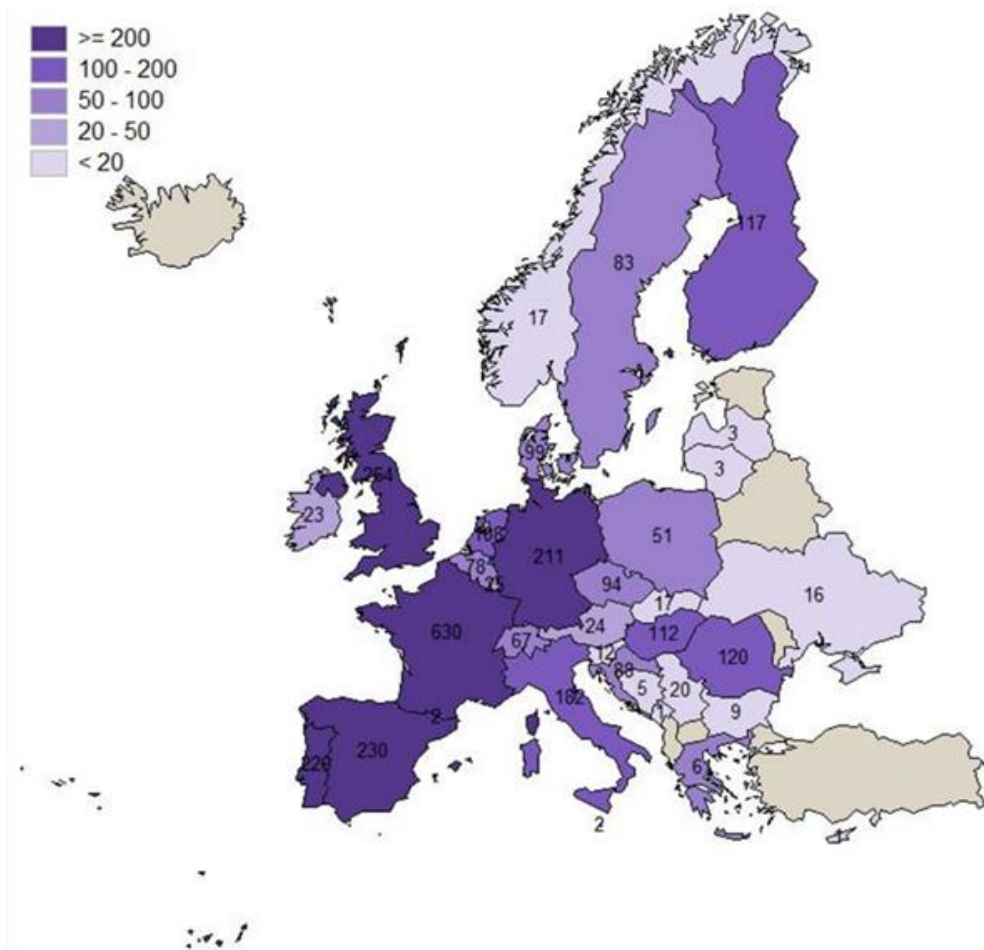
- Care needs, access to care services, coordination of care and the cost of the disease
- 2nd August 2016 to 28th of February 2017
- 3450 answers, including 3071 valid questionnaires

2nd stage

- Employment, schooling, family and social life and well-being
- 10th November to 28th of February 2017
- 2 2117 answers, including 1953 valid questionnaires

A survey sample which represents the diversity of the rare disease community (1/2)

- 802 diseases
- 42 countries



A survey sample which represents the diversity of the rare disease community (2/2)

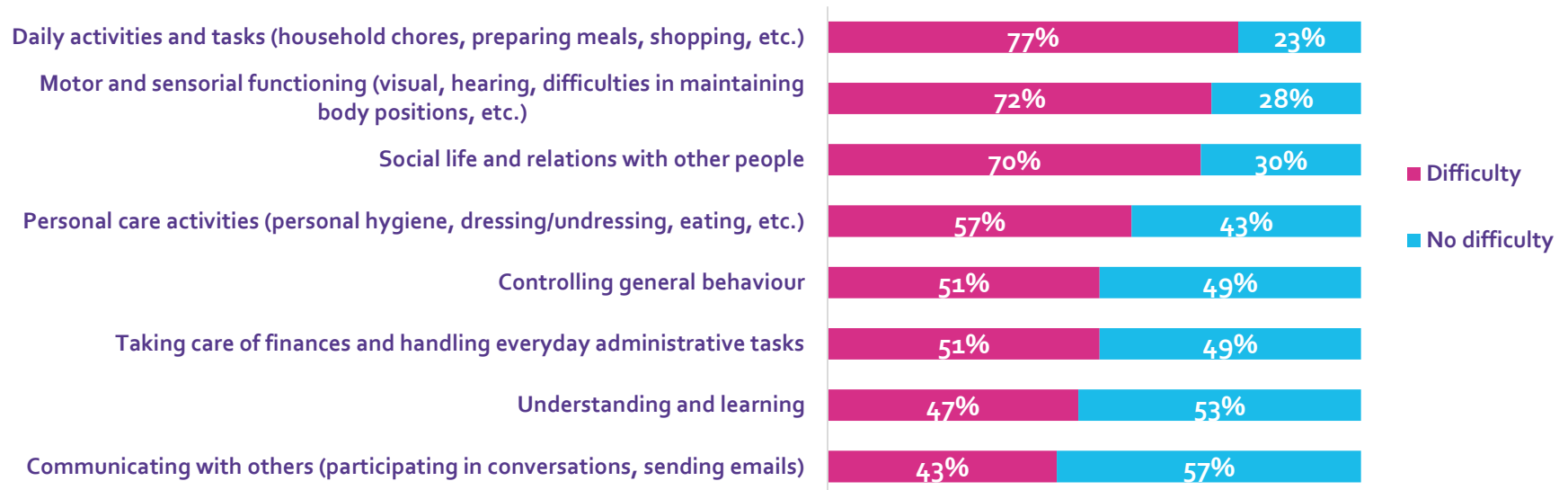
Type	Frequency
Gender	
Male	21 %
Female	79 %
Other	<0,5%
Diagnosis Status	
Diagnosed	92 %
Undiagnosed	8 %
Respondent Status (Several answers possible)	
Patient	62 %
Parent of a child living with a rare disease	37 %
Grandparent of a person living with a rare disease	1 %
Spouse of a person living with a rare disease	2%
Uncle/Aunt of a person living with a rare disease	1 %
Sibling of a person living with a rare disease	4 %
Other	3 %

Impact of rare diseases on daily life and related needs – a heavy impact and burden

Sandra Coubier, EURORDIS

Most rare diseases have a serious impact on patients' everyday life (1/2)

To what extent does the person living with a rare disease have difficulties with...
(n=2689)

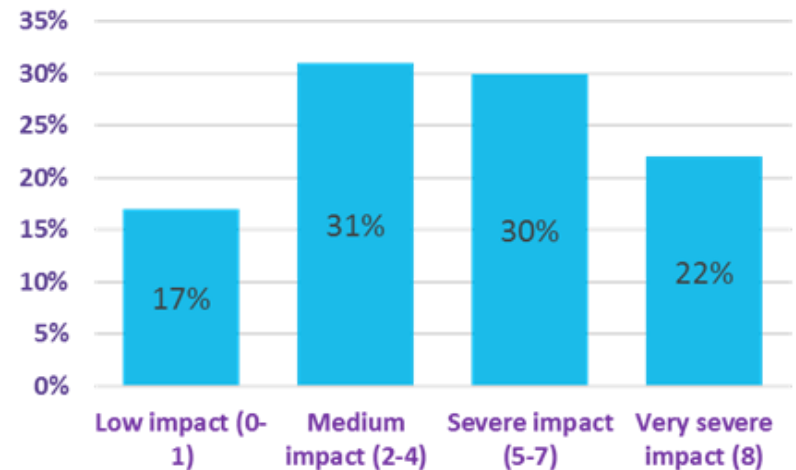


Some modalities have been grouped:
Difficulty=Completely unable + A lot of difficulty + Some difficulty

Most rare diseases have a serious impact on patients' everyday life (2/2)

- Most rare diseases have an impact on several aspect of the patients' everyday lives
- Diversity of the diseases represented in terms of impact

Graph. 2. To what extent does the person living with a rare disease have difficulties with. Number of difficulties expressed (n=2689)



Most rare diseases are complex and often invisible

“The difficulty lies in the impossibility of carrying a routine. When you do not have episodes you can do a normal life, but when episodes occur, it often interrupts what the person is doing. The problem arises when one day you appear completely healthy, the next day you are sick, and two days later you appear completely normal again. Many people find it difficult to understand the disease and the process, and the absenteeism that entails.»

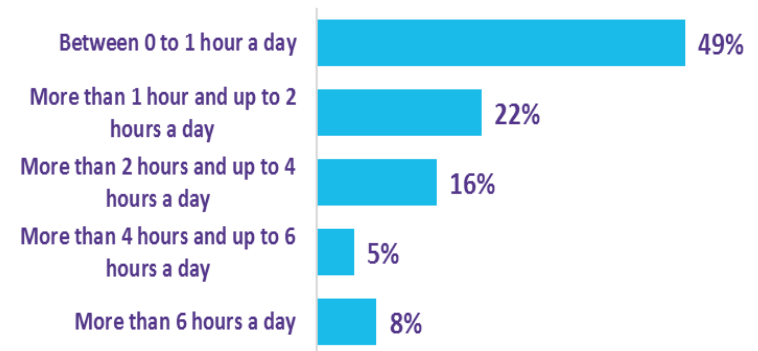
Female, Spain

- 85% says that the disease impacts upon several aspects of the health and everyday life
- Symptoms can go back and and forth
- The disease is often invisible in many ways

A heavy time burden on daily life (1/2)

- Self-caring represents a heavy time burden for patients: 52 spend more than 1 hour a day
- Comparison with diabetes patients: over a 24-hour period, diabetes patients spend 86 minutes

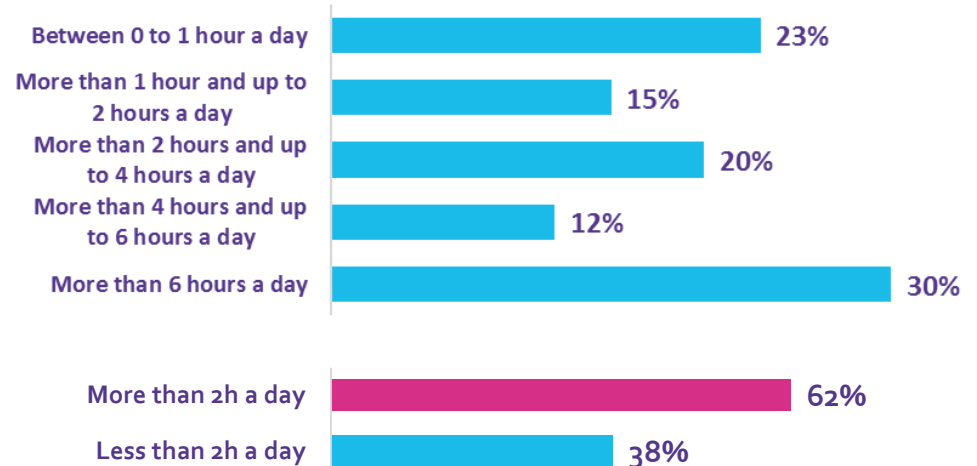
How much time do you invest in an average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)? [For patients] (n=2009)



A heavy time burden on daily life (2/2)

- Caring represents a heavy time burden on carers
- Intense caring (more than 6 hours a day) is provided by 29%
- 47% of those who care for severely affected people spend more than 6 hours a day

Graph. 4. How much time do you invest in an average day for illness-related daily tasks (hygiene, helping the patient with house chores, helping the patient to move, administration of treatments)? [For carers] (n=1147)



Organising care increases patients' care related time burden

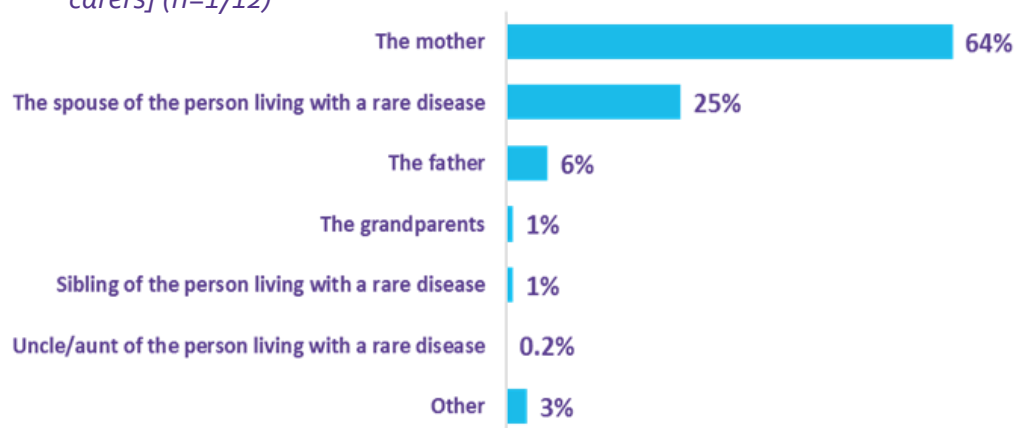
Finding the necessary information on the disease, finding the right professionals, arranging and attending appointments with different service providers and traveling to and from appointments etc.

- ➔ **75% of the respondents declare that it is time-consuming**
- ➔ **64% consider that it is difficult to manage**

A burden that heavily relies on woman

- 79% of the survey respondents are woman

Graph. 6. Who is the main carer in your household ? [For carers] (n=1712)



Impact of rare diseases on well-being and mental health

Erwan Berjonneau, EURORDIS

A decline in social and family life...

- **#1: Isolation from friends and family.**
 - 54% declare that it was caused or amplified by the rare disease
- **#2: Tension between family members**
 - 52% declare that it was caused or amplified by the rare disease
- **#3: Members of the family feeling neglected**
 - 46% declare that it was caused or amplified by the rare disease

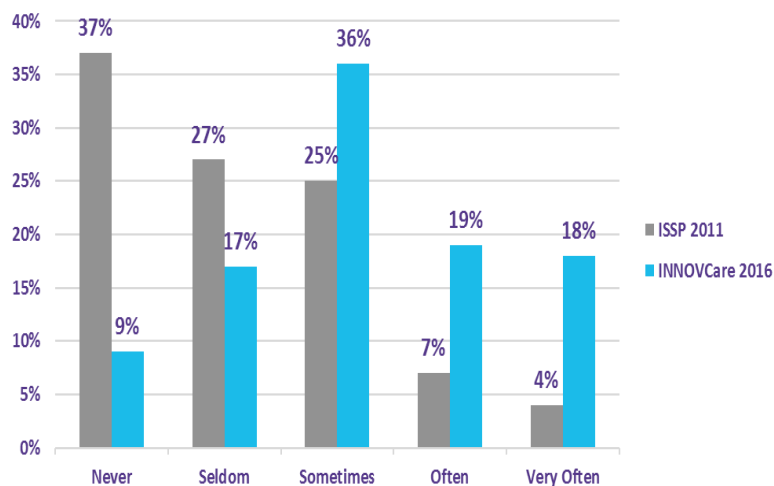
...But the family survives most of the time and its bonds can even be strengthened.

- Most families **stay together** while facing this situation:
 - Only 15% reported that a divorce or separation was caused or amplified by the disease.
- The disease can also have a **positive impact** on some families:
 - 45% declare that it has strengthened the family unit.

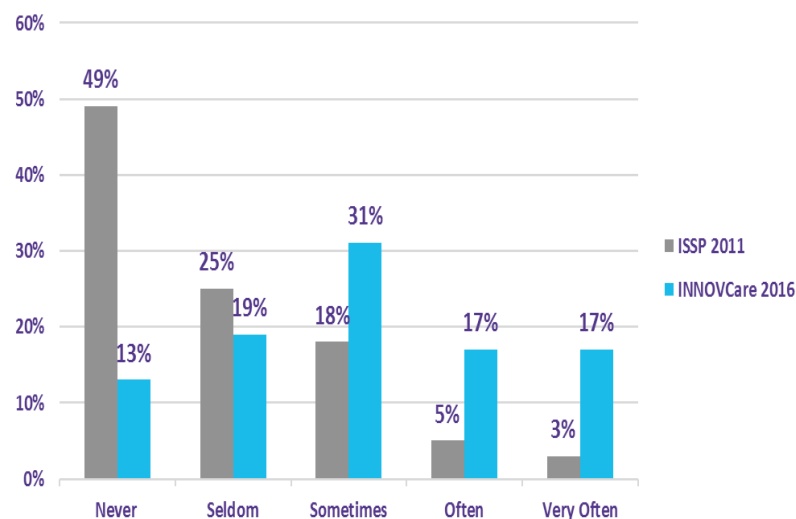
It is important to remember that, as difficult as it can get, a disease can also bring positive aspects.

Deteriorated mental health compared to the general population

In the past 4 weeks, how often have you felt unhappy and/or depressed ?



In the past 4 weeks, how often have you felt you could not overcome your problems?

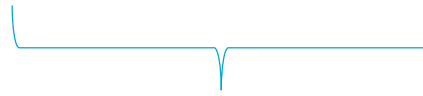


- Rare disease patients and carers are **3 times** more likely to often feel unhappy and/or depressed than the general population
- Rare Disease patients and carer are **4 times** more likely to often feel they could not overcome their problems than the general population

The particularities of rare diseases are detrimental to the mental health of patients and carers

22% need respite care but do not benefit from any

Diagnostic wavering
Unappropriated health assessments
Lack of treatment
Endless explanations



Anxiety
Financial difficulties
Stress
Depression
Loss of confidence and self-esteem

38% need psychological support but do not benefit from any

The challenge of working while living with a rare disease

Sandra Courbier, EURORDIS

The difficulty to combine rare diseases and work life

“The worse time, was the time we were looking for a diagnosis. (which took roughly 6 years). It was also the time I had two young children. By asking a year "non paid break" (to pursue my diagnosis journey and to take care of my children, one of them also having similar symptoms) I received a refusal from the employer. So I decided to give up my job and stayed unemployed for 4 years. At least I had the time to find out exactly what disease I had enough energy to take care of my children. Strangely, feeling stronger after the diagnosis and the information about the disease (which my husband I and I sought by ourselves), I decided to pick up work again. One year: part-time and thus earning half as much as before. Later on and until now: working less then a part time and earning even less; but the job is my dream job and I still have a husband who is the main "breadwinner". That's how we manage to make ends meet.»

Female, Luxembourg

- high absence rate at work: 58% were absent more than 15 days a year
- having to make the decision to leave or reduce employment: 13% of parents faced it
- facing the fact that the child is starting school later than average: 23% of parents face it
- difficulty in accessing higher education: 19% declare reported these difficulties

Most rare disease patients remain employed but the disease decreases employment quality

Decrease of employment quality

- 35% part time compared to 17% in the general population
- Interrupted careers

Less fulfilling job careers

- 76% were limited their professional choices
- 67% were limited in being promoted

“ I was studying for a degree in software engineering, and spent a year in industry after the first two years at university. By the end of that year, my mental and physical health both had collapsed and I had no choice but to suspend my studies and move back to my parents' because I wasn't well enough to work or cope on my own. I spent three years applying for every job I thought I had any chance of doing, and over that time went from ambulatory, to a stick, to crutches, and then to a manual and then a powered wheelchair. Every time my disability got more obvious, the look of "oh. you're wasting my time" when I went to an interview got more obvious.»

Other gender, United Kingdom

An unsatisfied request of flexible employment practices

Is/was your current/last work environment specially adapted for you, in terms of:

