Patients’ Needs and Expectations concerning Access to Health Services.

The EurordisCare 3 study

Yann Le Cam
EURORDIS’ Chief Executive Officer
RAPSODY’ Project Leader

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Why do this survey?

• This survey was launched to provide evidence on rare disease patients’ need for adapted health care.
• We needed to go beyond patients’ anecdotes or patient groups’ views in order to find out patients experience-based opinions with solid quantitative data.
• This will help develop public health policies further at a time when several European countries are involved in the (re) organisation of their health services for rare diseases.
Objective

To describe and compare patients’ experiences and expectations regarding access to health services for a variety of significantly relevant rare diseases across Europe
The approach is unique because it is based on a scientific methodology to collect data from people identified through the patient group network.
EurordisCare 3: Facts & Figures

- One questionnaire
- Adapted
  - to 16 rare diseases
  - to 23 countries
- Translated into 15 languages
- 20 022 copies sent to 130 committed patients’ organisations
- 5 963 received at Eurordis (30% response rate)
- 1 020 000 data recorded
- Adapted to 16 rare diseases
  - Marfan syndrome
  - Fragile X syndrome
  - Williams syndrome
  - Ehlers-Danlos syndrome
  - Cystic fibrosis
- Translated into 15 languages
  - Hungarian, Italian, Norwegian, Romanian, Slovak, Spanish, Swedish
- Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Malta, Netherlands, Norway, Romania, Slovakia, Spain, Sweden, Switzerland, United Kingdom
Rare disease patients need complex health services
Rare diseases require complex care

On average, patients needed 9 different types of care or medical services over a period of 2 years.
Access to essential medical services

Access to the 8 most needed medical services was difficult or impossible for patients in 26% of cases.

- 25% very easy
- 12% easy
- 11% difficult
- 3% very difficult
- 1% impossible
Lack of referral is the main reason for not accessing medical services, followed by unavailability of services and waiting time.

On average, lack of access is due to at least 2 reasons.
Who does not have access?

Lack of access (%)

- Primary education
- Secondary education
- Low income
- Medium income
- High income
- University income

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Did medical services respond to patients’ expectations?

20% of patients were not satisfied with the medical services offered (9% poorly satisfied and 11% had no access)
Satisfaction according to type of medical consultation

For some types of medical services, patients were particularly dissatisfied

- Rheumatology: 26% fully, 8% partially, 15% poorly, 37% not at all, 9% not at all
- Pain control service: 37% fully, 3% partially, 9% poorly, 13% not at all, 0% no access
Rejection by health professionals is a major issue for rare disease patients
Rejection is a major issue

Based on their experience, 18% of rare disease patients were rejected by health professionals because of their disease.

The main reason for rejection given to patients is the complexity of their disease (69%) ... rather than linked to themselves (31%).
Rejection and its causes vary according to the disease

Percentage and reasons of rejection (%)
Female patients are more discriminated

20.1% females experience rejection by health professionals as opposed to 15.0% of males

⇒ Females were 34% more likely to be rejected than males

The main reasons for rejection should be the same for females and males... but clearly they are not
Patients needing pain control are even more rejected

42.4% of patients needing pain control services are rejected as opposed to 15.5% of patients not needing pain control

⇒ Patients needing pain control services are about 3 times more likely to be rejected

The reasons for rejection should be the same for patients regardless of their need for pain control...

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Patients with lower income are more rejected.

![Bar chart showing the relationship between income and education. The chart indicates that patients with lower income are more rejected as the level of education increases. The labels on the x-axis are 'lowest', 'medium low', 'medium high', and 'highest', and the y-axis represents the percentage (%). The legend includes 'income' and 'education.'
Rare disease patients need social assistance, as much as medical care.
29% of patients needed to meet a social worker over the last 12 months
The need for social assistance varies according to the disease

Percentage of patients needing social assistance in the last year (%)
32% of patients said it was difficult or impossible to access social assistance.
Patients do not access assistance at the right time

On average, it takes more than 5 years to access social assistance.

Social assistance is less available when patients need it most during first 5 years after diagnosis.
Assistance needs to be adapted to rare diseases

The more specific the needs, the less satisfied with the assistance

Information on social, legal and financial rights

61%

Assistance for exceptional financial support (purchase of wheelchair, home adaptation, medical consultation abroad…)

43%

fully  partially  poorly  not at all
Rare disease patients agree that specialised centres are essential to address their needs.
Communication between professionals

95% of patients say that medical information sharing and coordination between all professionals who care for her/him in the specialised centre is useful or essential.

Patients who say this sharing is essential
- Were more frequently rejected by health professionals,
- Need more frequently pain control services
92% of patient say that training of local professionals in responding to the specific needs of patients is essential or useful.

- Were more frequently rejected by health professionals,
- Needed more frequently social assistance,
- Needed more frequently pain control services
93% of patients say that the mission of a specialised centre is to inform patients about their rights and to guide them towards services, schools, leisure activities, etc.

Patients who say training of local professionals is essential:
- Were more frequently rejected by health professionals,
- Needed more frequently social assistance,
91% of patients say that the mission of a specialised centre is to creating material for teachers, employers, social services, insurance companies and the general public to inform them about patients’ needs and improve social integration of patients.

Patients who say training of local professionals is essential
- Were more frequently rejected by health professionals,
- Needed more frequently social assistance,
- Needed more frequently pain control services
Conclusion

In order to address the major issues of:

- lack of access to needed medical services,
- poor satisfaction of medical services,
- rejection by health professionals,
- delays in accessing social assistance,
- lack of specific social assistance,
Conclusion

Rare disease patient expect specialised centres which:

- Know their disease well and accept to treat it
- Have a multidisciplinary approach
- Share and coordinate patients’ medical information between professionals
- Integrate medical care and specific social services linked to the rarity of the disease
- Provide training for local professionals
- Provide information material about their disease and guide them in order to improve social integration
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