

A rare study -

A survey regarding rare diseases in the primary care

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Background

- Two patient-oriented reports;
 - "The Voice of 12000 Patients" by Eurordis
 - "Fokus på vården" by Riksförbundet Sällsynta Diagnoser
 - Patients suffering from rare diseases were generally displeased with their healthcare situation
 - A need for reports on the physicians' perspective
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Shared problems regarding RD

- Rare cases, lack of knowledge → Difficult to diagnose
 - Many simultaneous care givers → Communication problems
 - Little research done, few published studies
 - Expensive and few existing treatments
 - Lack of guidelines for the physicians
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Aim

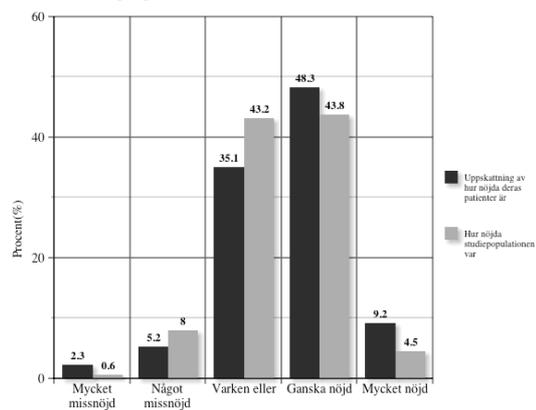
The purpose of this study was to identify:

- Potential needs of education and information about rare diseases for General Practitioners.
 - What prevents the General Practitioners in giving adequate care for RD patients; from the aspect of diagnostics, coordination of the patients' needs and communication in between caregivers.
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Method

- Internet-based survey
- 52 questions
- Aim: 25% of Sweden's General Practitioners, randomly chosen
- We sent 1133 surveys, got: 293 answers (26%)

'Level of satisfaction' (1)



- The study population estimated that their patients with RD were equally satisfied as themselves with the primary care.

'Level of satisfaction' (2)

- In "Fokus på vården" 21% of the patients with RD were dissatisfied with the Primary Care. In our study the GPs estimated the patients dissatisfaction to be 7,5%.
 - 3% of 100 000 Swedes participating in a study in 2009, were displeased with the primary care (SKL, 2009)
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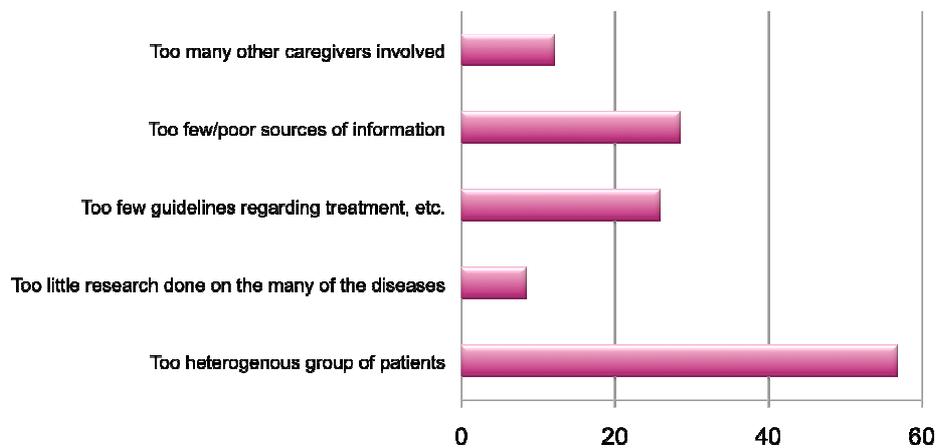
Awareness

- RD patients are more aware about their disease
 - 20% of the respondents were unfamiliar to the term RD
 - 84% were less confident informing a patient with RD
 - At 27% of Primary Care Units, attention is drawn to RD
 - The respondents were less confident about informing a patient at PCUs there was no attention drawn to RD
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Diagnostics

- RD patients take longer time to diagnose correctly
 - Our GPs estimated that they meet 4 patients a year with RD
 - 28% of the RD patients they meet get diagnosed in the primary care
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What do you feel is the biggest problem regarding patients with RD as a group?



Guidelines

- ¼ of the study population felt the absence of guidelines being the biggest problem regarding RD in the primary care
 - Assumption: Less knowledge requires (better) guidelines (?)
 - Effects of absence of a certain guideline
 - The GPs forced to find information on their own
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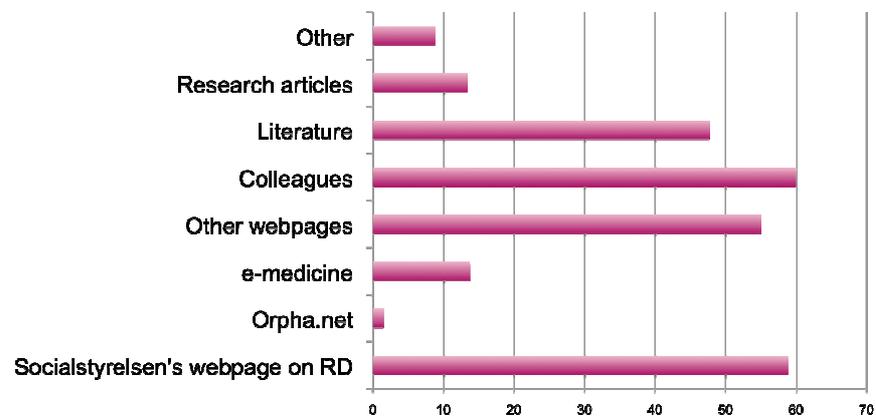
Education and information (1)

- 70% of the GPs get the majority of their knowledge regarding RD "on their own"
 - 20% of the GPs were very dissatisfied with the education they got regarding RD in medical school
 - Almost 50% of the GPs were very dissatisfied with the education they got regarding RD during their resident training
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Education and information (2)

- 35% of the GPs can "never" or "not always" find adequate information about RD
- 69% of the GPs stated they'd be aided by more information about RD in their everyday work

The sources of information the respondent uses for diognostical help in RD patients



Communication

- 57% "sometimes" or "often" experienced difficulties with the communication between GPs and other specialists
 - 27% "always" or "most often" experienced problems in communication concerning RD patients due to separate journal systems
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"Falling through the cracks"

- 35% of respondents considered it "often" or "always" be difficult to coordinate a patient's care adequately
 - Factors that prevent physicians to provide adequate care:
 - 26% a lack of counseling for the patient group.
 - Resource and/or time constraints: only 20%
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Conclusions

- Our study identified several problems the primary care and GPs face concerning the care of patients with RD.
 - Communication between caregivers not satisfactory
 - A lack of knowledge about how to find information on RD
 - Education regarding RD in both medical school and GP residency needs improvement
 - Need for more guidelines
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