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A survey about rare diseases among Swedish General Practitioners

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Conflicts of Interest

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Background

- Survey based on two patient-oriented reports
 - "The Voice of 12000 patients" (EURORDIS)
 - "Focus on care" (Rare Diseases Sweden)
 - RD patients were dissatisfied in general with their care situation.
 - Perspectives of the physicians needed to complete the picture
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Objectives

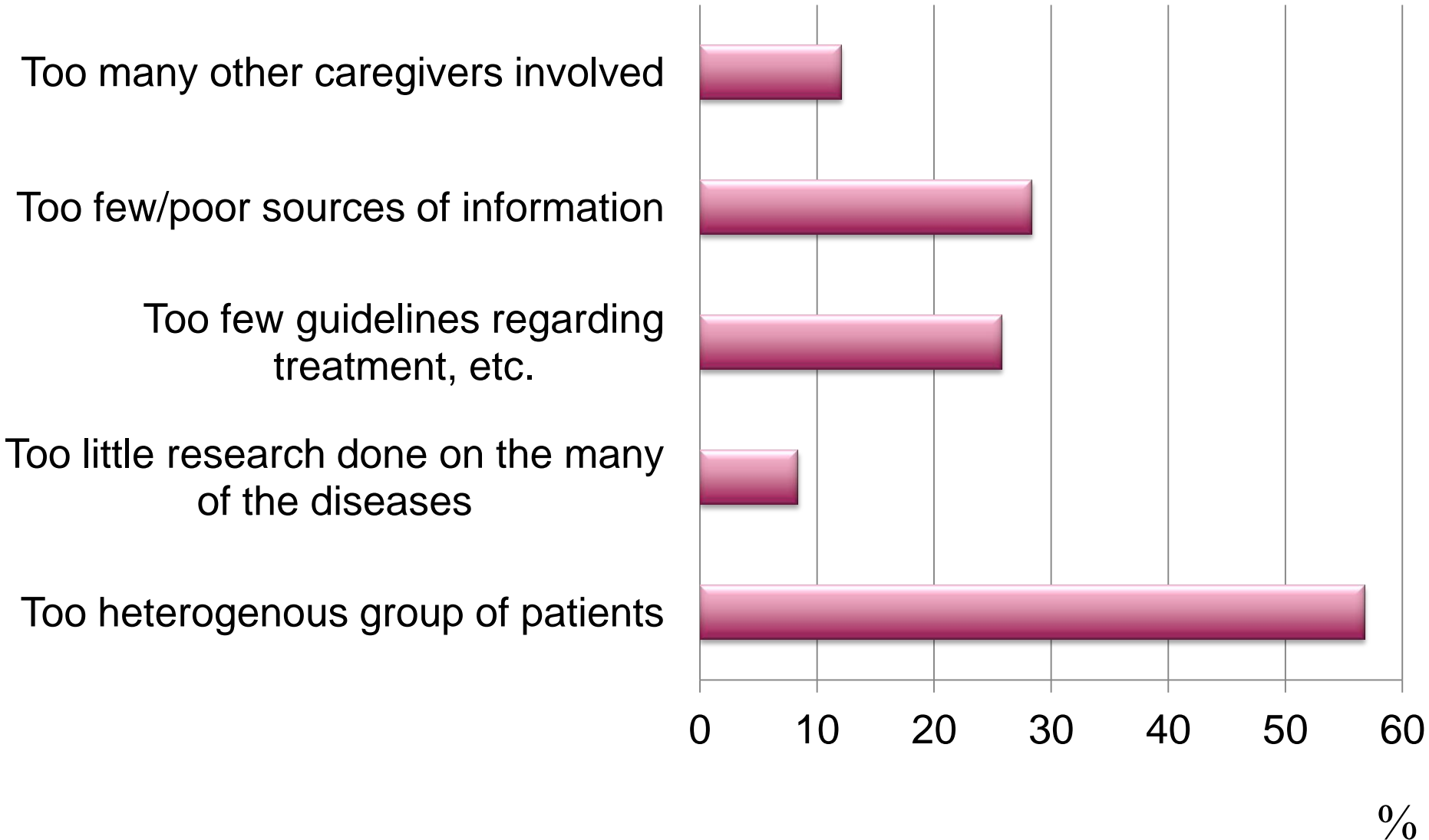
To identify

- Potential needs of general practitioners for education and information about rare diseases
 - What factors that hamper efficient diagnostics and adequate treatment and care of RD patients
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Method

- Internet-based survey
 - 52 questions
 - 293 responses from Swedish General practitioners
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What is your biggest problem regarding the group of patients with a rare disease?



Awareness

- RD patients are more aware about their disease than common patients
 - 20% of the physicians were unfamiliar to the term RD
 - 84% were less confident informing a patient with RD
 - At 27% of Primary Care Units, special attention was drawn to RD
 - The physicians were less confident about informing a patient with a rare diagnosis at PCUs where no special attention was drawn to RD
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Education and information

- 20% of the GPs were very dissatisfied with the education they got regarding RD in *medical school* and about 50% during their *resident training*
 - 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
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Conclusions

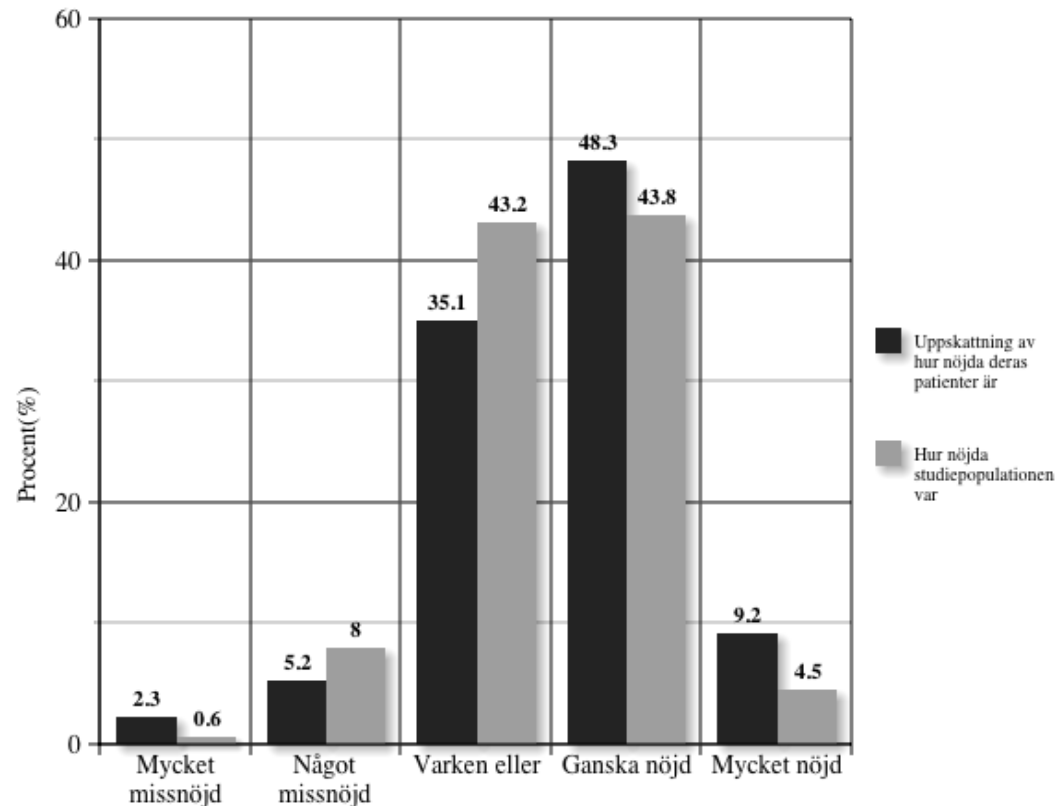
- GPs ask for
 - better information
 - education and
 - care guidelines for rare diagnoses
 - RD care centres may give support the physicians
 - the coordination between different care units can be improved
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Welcome to Poster 47!

‘Level of satisfaction’ (2)

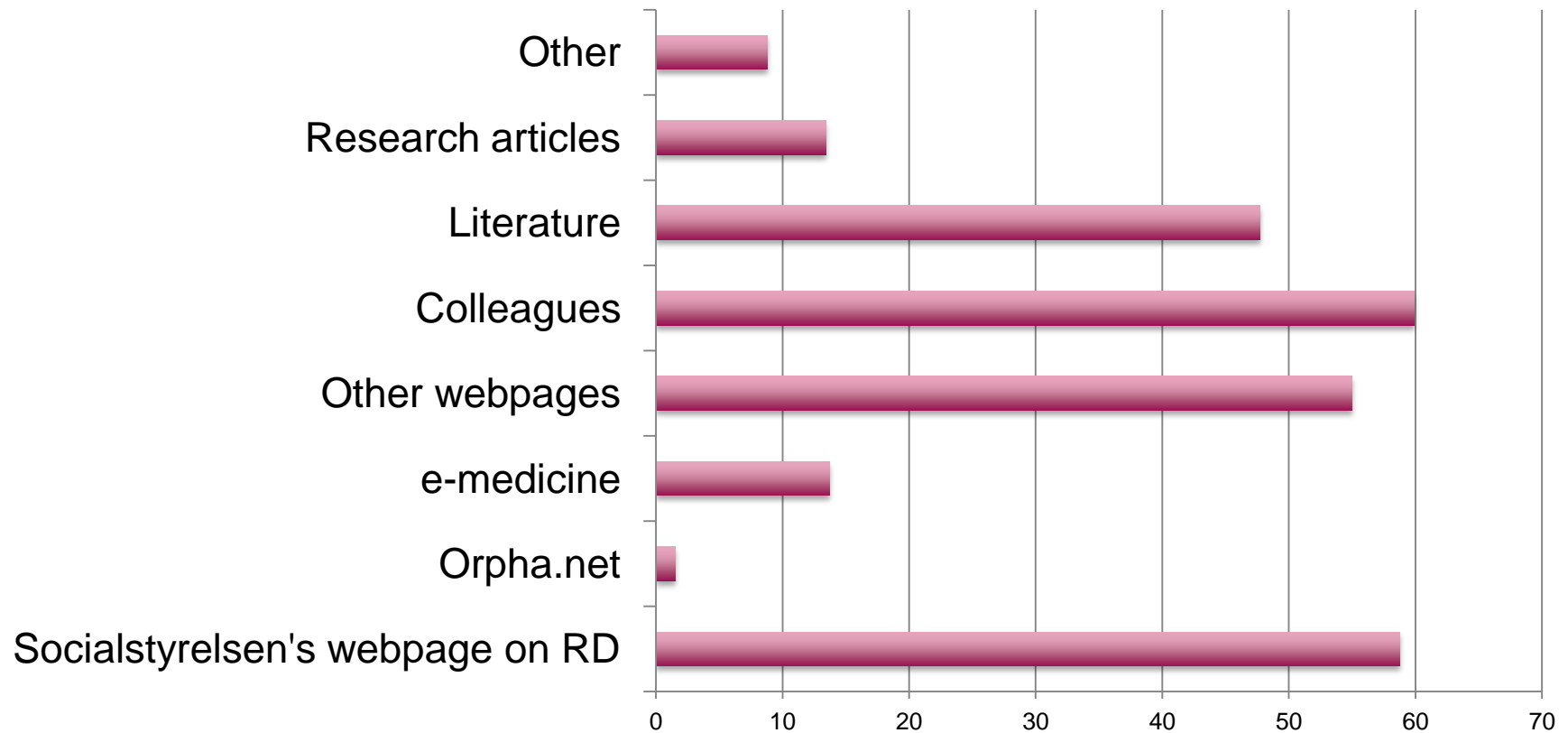
- In “Fokus på vården” 21% of the patients with RD were dissatisfied with the Primary Care. In our study the GPs estimated the patients dissatisfaction to be 7,5%.
 - 3% of 100 000 Swedes participating in a study in 2009, were displeased with the primary care (SKL, 2009)
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'Level of satisfaction' (1)



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

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



Guidelines

- $\frac{1}{4}$ 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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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: 20%
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Conclusions

Our study identified issues in the primary care that 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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