

National Institute for Public Health
and the Environment
Ministry of Health, Welfare and Sport

Empowerment of patients in online discussions about medicine use

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National Institute for Public Health and the Environment
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• Independent knowledge institute
• Research and knowledge integration
• Public health, nutrition, safety and environmental management

RIVM Project e-Medication



Influence of internet on medication use:

Opportunities and risks

Sub-projects:

1. Purchase of medicinal products via internet
2. **Social media as data source on medication use**
3. Self-management of medication use with aid of apps

Medicines in social media discussions

- Online discussions on chronic medication use: which issues?
- Different categories of chronic diseases: different issues?
- Online interaction about medicines use :
  - Influence on patient empowerment?
  - What do people advice each other?



Medication use and empowerment

- More emphasis on self-management disorder
- Yet, low adherence with prescribed medication is common (50%)
- Empowered patients better manage their care process
- Quality of information important for empowerment and self-management



Question

Do online discussions on medicine use contribute to patient empowerment and subsequently more effective use of medicines?



Selection of three chronic conditions

Chronic condition with clear treatment options : Diabetes

Condition with less clear role of diagnosis and medicines and less (societal) consensus: ADHD

Life-threatening condition without treatment options: ALS



Selection of social media and posts

- Interaction on medication use particularly on online message boards

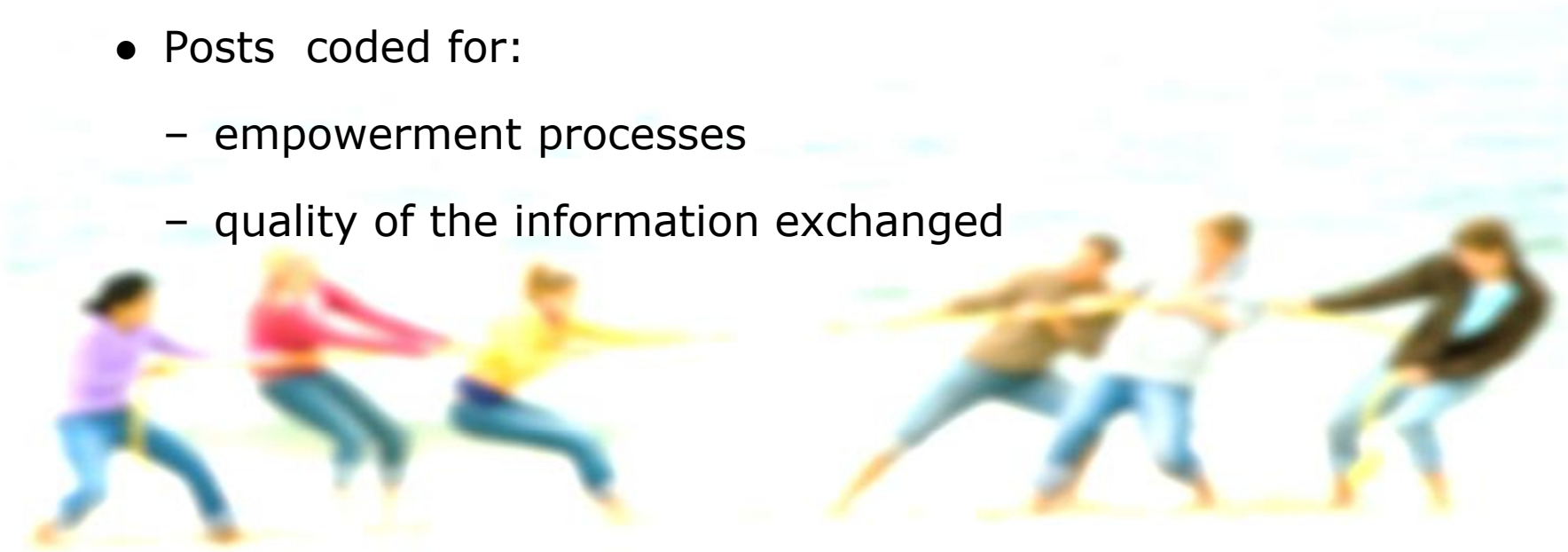
- Overview:
  - most active Dutch online message boards
  - where medication use is discussed
  - with respect to
    - ADHD (3)
    - Diabetes (3)
    - ALS (1)

- 7 message board: 25 threads

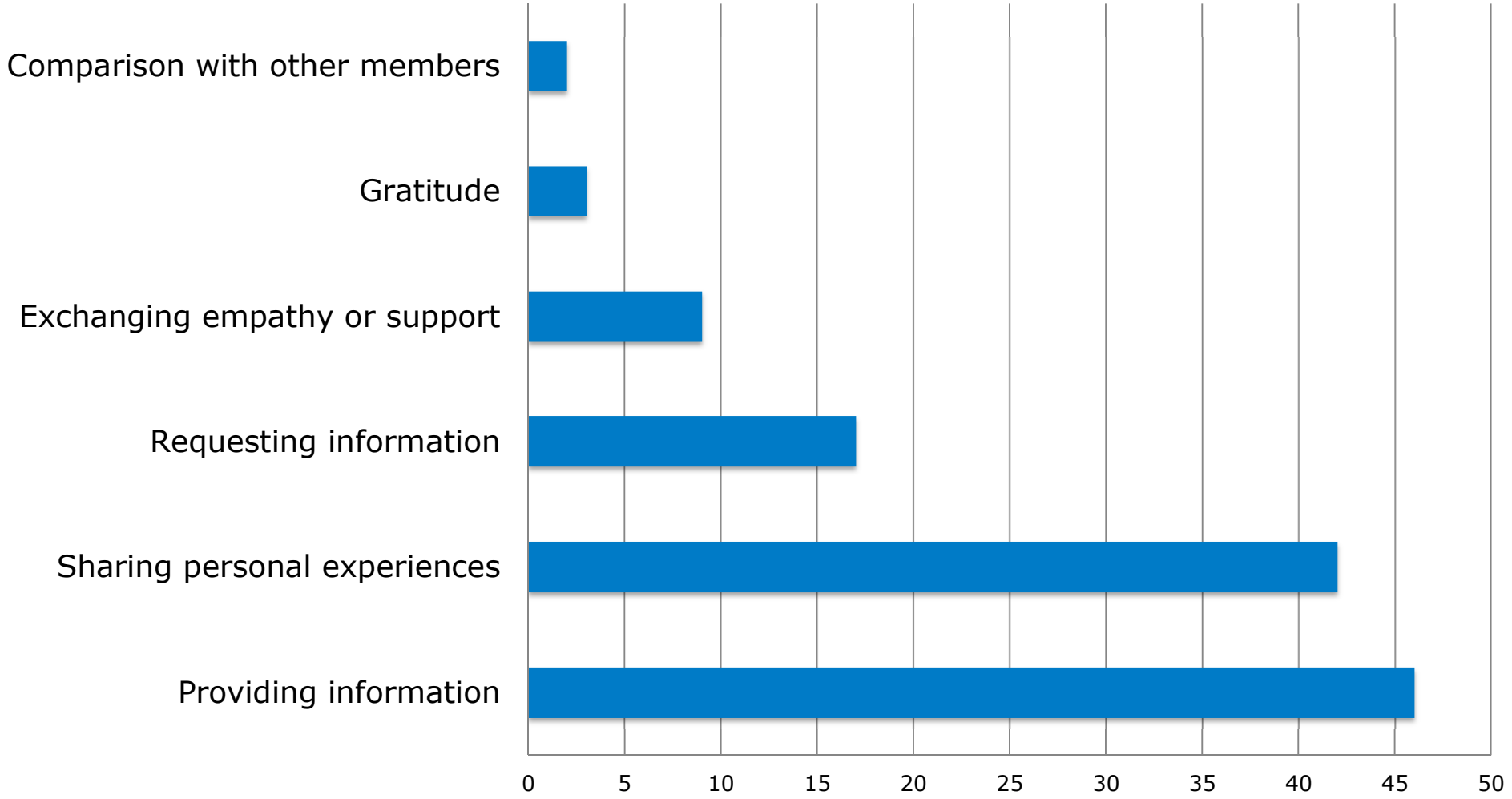
- Total 5532 posts analyzed for

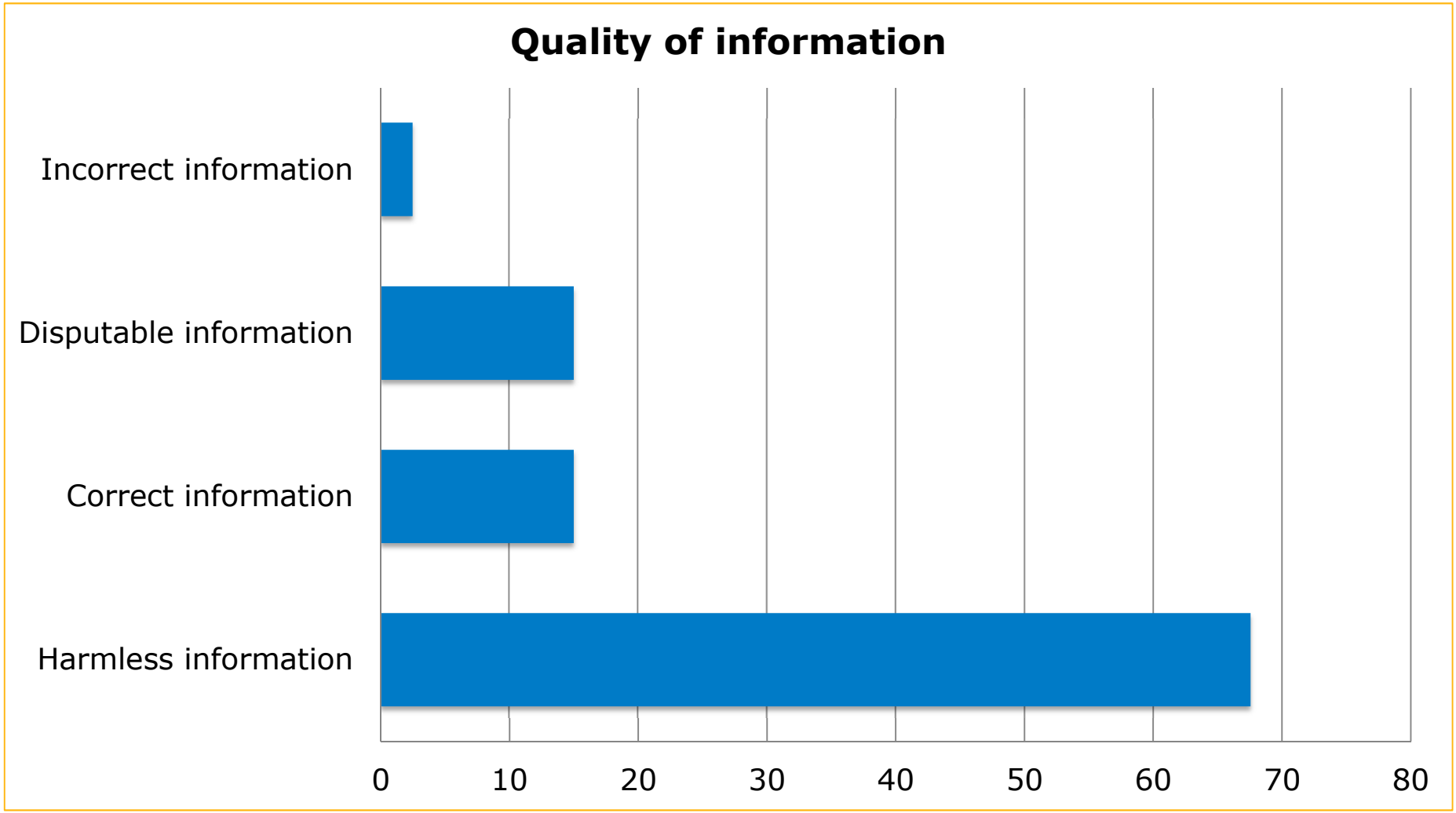
Analysis

- Deductive thematic analysis
- Based on categories defined by Uden-Kraan et. al. and Perron
- Posts coded for:
  - empowerment processes
  - quality of the information exchanged



Empowerment processes




Quality of information
Incorrect information
Disputable information
Correct information
Harmless information
0
10
20
30
40
50
60
70
80

Referral to healthcare professional

"Instead of experimenting with medicines on your own, it might be a good idea to go to a doctor."



ADHD

Most important issues:

- Medication options
- Effectiveness of medicinal products
- Access to medication

Other issues:

- Appropriate dosage schemes (rebound)
- Is ADHD a real disorder?
- Medicines for ADHD are (not) drugs



Quotes ADHD

"There are other types of medicines besides methylphenidate, perhaps Strattera is better suited for you. Discuss this with your psychiatrist and try to find an alternative".

"Dexamphetamine is garbage; ask for a prescription for methamphetamine"

Diabetes

Most important issues:

- Best blood glucose levels
- How to live with insulin treatment
- Diagnosis of diabetes



No issue:

- Choice for medicinal products
- Effectiveness of medicinal products

Quotes diabetes

"Maybe one of you has experienced this as well, where just the fact that you drink a lot was an indication of diabetes?"

"When in doubt, just throw it away. Feeling unwell as a result of spoiled insulin is not worth the cost of a new vial".

ALS



Important issues:

- Effectiveness and availability of (new) medicines
- Despair:
  - No access to clinical trials
  - No access to experimental medicinal products
- Exchange of information on self-experiments (e.g. food supplements)

Quote ALS

"Will non-participants [in the trial] also receive Dexpramipexol in October and how do I obtain access to this medicine? Do I need a prescription from the doctor or neurologist? I'm curious!"

Conclusion

Patient empowerment processes occured in posts related to all three disorders (ADHD, diabetes and ALS)

The type of information shared in these processes can contribute to the self-efficacy of the patient when it comes to medicine use



