Solutions to participate in work: Perspectives of people with a chronic disease

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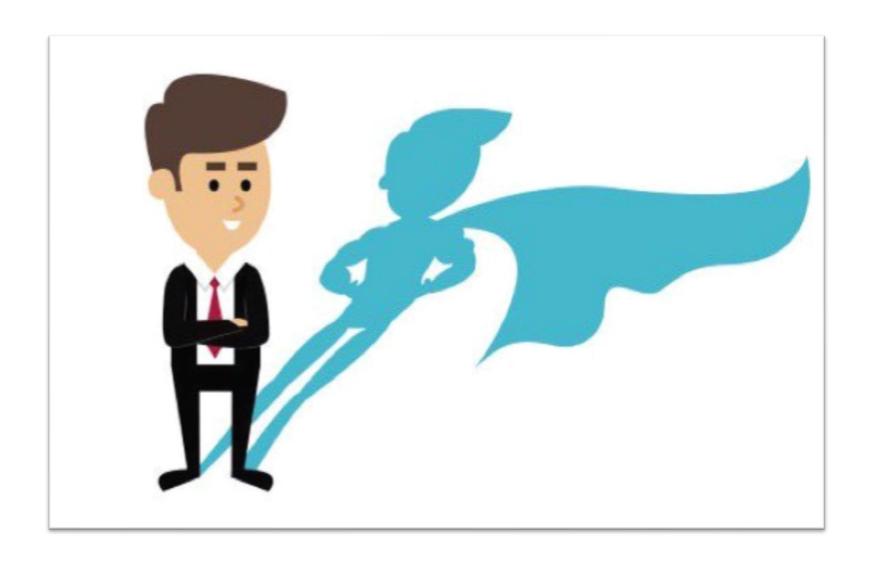
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I declare no conflict of interest







Methods

Research questions:

- Which solutions do you use to be able to participate in work?
- Which support (type / by whom) do you need to find or use these solutions in daily practice?

Methods



Five focus group meetings:

Included people with a chronic disease;

- Either working or actively looking;
- Rheumatic disease, kidney disease, visual handicap, mental illnesses, heart condition, Lyme disease, diabetes, back problems etc.

Recruited via GPs, patient associations



Solutions to participate: Focus group meetings

Acceptation and coping

- Start from scratch to rebuild life
- Focusing on what they could still do

Quote: 'But you need to focus on what you can do, rather than on what you can't do. That is my motto in life'.



Insight into abilities and limitations

Learning what is possible and what is not

Quote: 'It's mainly about finding your own limits. The saying goes "Once bitten, twice shy" – well ... I think I've been bitten at least ten times already..."



Communication work environment

Disclosure

Quote: 'So, being open allows you to let other people see what you can or can't manage and what your needs are'.



Communication work environment

Learning and communication of boundaries

Quote: 'Whenever I work too long, may supervisor says 'Time to go home!'. Then she simply says: 'Since you've been worked half an hour more today tomorrow you can leave half an hour earlier.' So no she's really the one who sets my limits'.



Active management

- Managing energy levels
- Asking for help (colleagues and organisation)
- Obtaining information

Quote: 'Simple keep negotiating over the tasks to be done and, with a bit of help from your colleagues, you can manage'.



Self-efficacy

- Believing and communicating qualities
- Knowing skills and abilities

Quote: 'Eight years ago, during a job interview, I said 'I know perfectly well what I'm capable of. Once I'm hired, you'll see that I'm an extremely good worker. Except that, in this situation, I also have certain limitations'.



Skills development

- Social skills training
- Job application skills

Quote: 'I've received training on applying for jobs where I learnt how to write application letters. An during those sessions, I also learnt to take things step by step: not expecting to immediately get the job'.



Work environment

- Autonomy
- Adaptations to the work environment

Quote: 'If a deadline is set for Friday, for me it automatically shifts to the preceding Tuesday or Wednesday so that if I have a bad day, I can still finish it on time'.









Emotional support

- Need for understanding / empathy / interest
- Help in learning to accept the disease and to gain overview in 'everything'



Informative support

- Providing low-threshold information concerning regulations
- Information about which companies accept people with a chronic disease



Instrumental support

- Adaptations / aids
- Training programs
- Supporting in obtaining and maintaining work

Type of support

- Active, personal and based on requests of the individual
- Proactive

Social environment

Important source to learn to accept / cope with disease

Manager / colleagues

Social support and understanding in work, thinking along with solutions

Patiënts associations

Contact with others (with same disease), information, practical tips

GP / medical specialist

Most often contacted for advice regarding illness and work

Occupational health professionals

Practical tips, advice to employer, supporting retaining and returning to work



Solutions and support: Conclusion

- Acceptance, support by family and friends, is a first step towards work participation.
- Disclosing the disease is important in work, for the use of other solutions such as setting boundaries, asking for help and autonomy.
- Emotional, informative and practical support of various stakeholder is required.



What can stakeholders do?

- Ask what the individual wants and needs
- Ask the individual which solutions they have to retain or return to work
- Providing support in finding solutions
- Employers: Providing empathy and facilitating the employee in work adjustments

What can individuals do?



- Learn to accept and to cope with the disease
- Find and use solutions, such as believing in oneself, asking for help, energy management
- See a professional who can provide support and information on additional solutions/interventions
- When feeling save, explain situation to employer



Thanks for your attention!

Are there any questions?

