



Maastricht University

*Leading
in Learning!*

Social participation of eight groups chronically ill persons

Angelique de Rijk, Dr. Yvette Bartholomé, Dr. Gonnie Klabbers,
Ingrid Melters, Drs. Bram Rooijackers)

Dept. Social Medicine
Faculty of Health, Medicine and Life sciences

Content

- Introduction (Angelique)
- Methods-general
 - General procedure (Angelique)
 - Approaching the patient organisations (Ingrid)
- Methods & results qualitative study
 - Focusgroup Sarcoidosis (Bram)
- Methods & results quantitative study
 - Survey Sarcoidosis (Gonnie)
- Preliminary conclusion and discussion (Gonnie)

Introduction (1)

- Low labour participation *chronically ill* NL:
 - Work disabled: 39%
 - Partial disability pension: 57%
- (Compare: general NL (≥ 12 hrs pw): 67%; healthy men 35-55 yrs: almost 100%)
- *Chronically ill* have higher sickness absence ($< 10\%$)
- Only 16% of companies hire *chronically ill*
- Social participation (meeting friends, neighbours):
 - High among physically disabled ($>80\%$)

Introduction (2)

- Move from government→market→civil society interventions
- Patient organizations: improved support for
 - Employees with chronic illness or impairment: Stay-At-Work (SAW)
 - People on disability pension: Return-To-Work (RTW)
- Diverse initiatives
 - RTW in medical guidelines (e.g. Cardiac Rehabilitation; Blueprint Cancer and work)
 - Wijzer met Welder: internettool
 - Knowledge and guidelines for vocational experts (RUG and EUR).....

Introduction (3)

- Op Eigen Kracht Aan Het Werk (OEK) (“Working on one’s own resources”)
 - Association of 8 patient organisations (population):

autism (190.000)	Hiv (25.000)
cystic fibrosis (1.400)	chronic headache (500.000),
neurofibromatosis (5.000)	chronic renal disease (40.000)
sarcoidosis (7.000)	visual impairment (320.000)
 - Fase 1: Information on patient needs → UM
 - (Fase 2: Information on current supply; Fase 3: Developing interventions)

Introduction (4)

- UM was approached through interview in *De Volkskrant*
- Proposal → Presentation → comparison with research agency → refined proposal → agreement with budget and legal paragraph (Caphri / UM) (approx. 1 year)
- Communication with co-ordinator of working group that represents OEK

Research questions

- What is the labour participation and social participation?
 - Differences regarding age, educational level and gender?
- Determinants of labour participation, sickness absence and social participation?
- What are the experiences with labour participation, sickness absence and social participation?
- What bottlenecks and success factors are experienced regarding labour participation, sickness absence and social participation?

Literature study (1)

- Patient groups argued on
 - what is the best method to collect new information?
 - What is already known
- Compromise:
 - 4 months literature study
 - 8 months data collection

Literature study (3)

General findings:

- Almost no knowledge from NL
- International studies: old data no longer valid
 - E.g. new hiv medication changed situation tremendously
- Labour participation higher than 39%
- No subgroup analysis (age, education, gender)
- Effect size of determinant?
- Patient perspective? Hardly any qualitative research

Literature study (4)

- Autism:
 - Intelligence related to labour participation
 - Work offers structure and possibilities for social interaction, if well organized
- Cystic fibrosis:
 - Labour participation 50%; jobs that are not physically demanding
 - Determinants: education, age, gender, hospital stay, depression and optimism
- Hiv:
 - Determinants: education, ethnicity, addiction, insecure future, stigmatization

Literature study (4)

- Headache:
 - High labour participation (?)
 - Determinants: severity, low age, gender, education
- Neurofibromatosis and sarcoidosis: no figures
- Renal (kidney) diseases:
 - Transplantation better than dialysis
 - Determinants: age, education, comorbidity, fatigue
- Visual impairments (Goertz):
 - Labour participation: 36.8%
 - Determinants: age, gender, education and married/cohabitating

Conclusion literature study

- Necessity for both surveys and qualitative research among all groups
- Renal disease and visual impairments: Dutch survey data
- Extension of research with 1,5 month and 6 month researcher

Methods: general procedure

- 6 (later 7) surveys with digital questionnaires via website patient organisation (convenience sample) (Gonnie)
- 7 focusgroups and individual interviews with cystic fibrosis patients (Bram)
- In close collaboration with patient organisations (Ingrid)

Approaching the patient organisations (1)

- List of contact persons by OEK
- Contact by telephone (or e-mail)
- Three initial questions:
 - Link on website for survey?
 - Info on website for (focusgroup) interview?
 - Additional activities to draw attention

Approaching the patient organisations (2)

- Different responses and speed
 - Hierarchical: approval of director (many)
 - Interaction: check of questionnaire (hiv)
- If agreed with info on interviews:
 - Contact with interested participants
 - Plan meeting and arrange room, lunch, address info, informed consent, travel expense declaration and present
- Took 1-2 months

Qualitative data collection (1)

- Aims:
 - Focusgroup with 6-8 participants
 - Variety in characteristics
- Procedure
 - Information on website
 - E-mail or phonecall to UM
 - Short questionnaire on gender, age, job, education, type of disorder, positive or negative experiences with work, availability (by Gonnie, Ingrid, Bram)
 - Majority: higher educated
 - Selection on these characteristics of about 12 persons
 - Planning of the interview

Qualitative data collection (2)

- Topiclist
 - the experience of work disability,
 - finding and keeping a job,
 - social support,
 - participation in other activities than work,
 - stigma,
 - encounters with social insurance, occupational health care and re-integration agencies

Qualitative data collection (3)

Analysis

- Transcribed Verbatim (by Prescribe)
- Interpretative
 - NVivo to categorize data
 - Reading manuscript several times
 - Try to grasp the essence
 - Built upon findings of other interviews to find the abstract concepts (and achieve saturation)
 - Use contrasting information to refine interpretation

Preliminary results interviews (1)

Feelings of fatigue as a result of managing their chronic conditions as well uncertainty with regard to their health or their ability to retain employment.

Lack of understanding from co-workers, employers, friends and family concerning their illness.

This also impedes their ability to return to work. Social security is experienced as social insecurity due to lack of expertise, incorrect judgements.

Need for flexibility and trust. They are willing and able to work, but in the same way as everyone else.

Forced to choose. Full-time employment comes at the cost of private lives, and vice versa.

Preliminary results interviews (2)

Sarcoidosis: Often long history of vague undefined symptoms (mainly fatigue), sometimes mistaken as mental disorder (it's between your ears) or chronic fatigue. Diagnosis can be seen as relief. Uncertainty caused by the capricious nature of disease.

Renal diseases: Uncertainty if transplants will hold. Demanding, recurring treatments regimes (dialysis) cause absence from work and fatigue; absences damage career prospects.

Preliminary results interviews (3)

Cystic Fibrosis: Defines life from early age. Low life expectancy can dominate career and life choices. Treatments tiring and time consuming. Sense of risk pervades daily life. Decreased stamina dictates hard choices between professional and private life.

Visual impairments: “Normal” tasks require more energy. Feelings of inadequacy coupled with the desire to perform similarly to others often leads to burn-outs. Troubled by digitalization of workplaces and increased reliance on email instead of phone.

Preliminary results interviews (4)

Neurofibromatosis: Progressive nature of disease generates uncertainty. Requires constant acceptance of new conditions and limitations. Future regarded with fear. Sometimes coupled with deafness, benign tumours in face, paralysis.

HIV: Life expectancy concerns, although changed in recent years. Diagnosis requires acceptance: life changing event. Keeping status secret generates unease fatigue, while openness can be liberating.

Preliminary results interviews (5)

Autism: Social interactions require more energy, lack of intuitive understanding of social contexts. Burn-outs frequent. Society seen as less-tolerant of different individuals. Sense of being different and not understanding implicit rules causes stress and uneasiness.

Headaches: Still in planning phase.

Quantitative data collection (1)

- Survey on website during 1 month (Qualtrics by Caphri)
- Hiv: via hiv-panel, later also website
- Inclusion: all with disorder and 18-65 yrs
- Response:
 - Sarcoidosis: 652
 - Neurofibromatosis: 221
 - Hiv: 263
 - Cystic fibrosis: 70
 - Autism: 533
 - Renal disease: 108 (still open)
 - Headache: 755

Quantitative data collection (2)

Variables

- Socio-demographic
- Health (SF-36, comorbidity, care consumption, lifestyle)
- Labour participation, social participation (social participation, IPA)
- Social support (MPSSS)
- Personality and coping (illness experience, self-efficacy, self-esteem); Life events
- Working conditions (work limitations, workability, VOS-D, ERI, JDC); wellbeing at work (engagement, em. Exhaustion); work adaptations, work-home interference
- Sickness absence; return-to-work support; rtw attitudes
- Disorder specific questions

Quantitative data collection (3)

Analysis

- Anova, Chi2
- Logistic regression on work status and sickness absence (y/n, l/s)
- Linear regression on social participation and sickness absence (freq)

Preliminary results survey sarcoidosis (1)

- Age differences: mental functioning (oldest[↑]), labour participation (youngest[↑]), social participation: phys act (oldest[↑]), sp: tasks (oldest[↑]), disruption (youngest[↑])
- Education differences: selfesteem (high[↑]), selfefficacy (high[↑]) working hours (high[↑]), social activities (high[↑]), social participation: tasks (high[↑]), disruption (low[↑])
- Gender differences: age (men[↑]), education (men[↑]), working hours (men[↑]), work experience (men[↑]), social participation: tasks (women[↑])

Preliminary results survey sarcoidosis (1)

- 69% was employed (n=441)
 - about 75% felt supported by their colleagues / supervisor
 - 5% felt discriminated by supervisors because of disease
- Unemployed (n=138):
 - 5.4% not looking for a job
 - 30% experienced serious obstacles in finding one:
 - feeling forced to reveal their health condition and then being turned down,
 - employers not understanding the disease or the consequences thereof for work,
 - being excluded from certain jobs because of their condition.

Preliminary results survey sarcoidosis (3)

- Determinants of work status: mental & physical functioning +, self esteem+, sp: phys act+, care consumption:other HCpros+
- Determinants of sickness absence (yes/no): selfesteem+
- Determinants of sickness absence (long/short):mental & physical functioning-, consults gp+
- Determinants of sickness absence frequency:no of comorbidities -, consults other HC prof +, illness experience: betekenis+, smoking+, bmi+, job control-
- Determinants of social participation, soc act:mental & physical functioning+, self esteem +, illness experience, episode+

Preliminary conclusions & discussion

- New insights
 - Self-management is demanding when searching for / finding paid work
 - Self-esteem important for finding job
 - Supportive work environment = having confidence
 - Social insecurity is disincentive to labour participation
 -etc. → Report available from Sept. 1st on!

Preliminary conclusions & discussion

- Drawbacks:
 - Convenience samples
 - Mainly the voice of the higher educated
 - Time pressure hinders in-depth analysis