Guilt and shame in People with rheumatoid arthritis

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University Twente The Netherlands
Thank you for inviting me to this congress
And to your famous and magic city of Lahore
Guilt and shame in RA

• What is rheumatoid arthritis?
• What does it mean to have RA?
• Feelings of guilt
• Shame
• Solutions?
Rheumatoid arthritis

- Joint inflammation and destruction
- Pain, stiffness, loss of function
- Fatigue
- Deformation, nodules
Rheumatoid arthritis

Beginning RA
Progression of RA

RA nodules
Complications
Course of RA

*Rasker en Cosh*

1981
Course of RA

- Differs per individual
- Life expectation 5 years reduced
- With complications even 10 – 15 yrs
- Explanation: more often cardiovascular diseases

*Minaur ea J Rheumatol 2005*

- Prognosis improved since methotrexate

*Choi Lancet 2002*
Guilt and shame in RA

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• What does it mean to have RA?
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Problems in daily life

• 2/3 have difficulty on street
• Loss of job, cannot perform house duties
• Many ADL dependent (dressing, washing, toilet)
Some problems of RA

- Disease varies from hour to hour, from day to day or longer
- Environment does not understand
- Uncertainty about the effect of drugs
- And about future
- Whole life has changed
Some problems of RA

• Role pattern changed
• Cannot make plans for future
• Increasing dependency, less autonomy
• Deformations, changed self image
Main problems RA patients

- Being dependant on others: 32%
- Not being able to do things: 36%
- Pain: 17%
- Other: 22%

Cornelissen et al Ann Rheum Dis 1984
Guilt and shame in RA

- What is rheumatoid arthritis?
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- Feelings of guilt
- Shame
- Solutions?
Guilt

In this individualized society people feel permanent guilty as they are not young, beautiful, sporty, slender and healthy

Doris Nauer 2005
RA patient feels guilty for getting the disease?

• If I had gone directly to rheumatologist I would not have been as bad off as I am now

• I should not have been sitting in the draught
Other people blame the patient

• Punishment of God? Allah? Other people think: “he/she must have done something terrible to be punished like this”
• Temptation by God (Job)
• Complementary healers: family blames patient: “when you are not going to this healer, it is your own fault and I am not going to help you anymore”.

Others are guilty?

- Wrong treatment by doctor
- My parents should not have forced me to work so hard as a child
- They should not have let me sleep in a damp room as a child
External factors are blamed for RA

• The draught
• Damp climate (UK)
• Food
• (Psycho) trauma
• Operation / accident
Psyche and RA

• RA not caused by psyche
• Stress has influence (like in all people)

Study in 200 RA patients feeling guilty?

- All 200 felt “somehow” guilty
- I feel guilty for tensions in my relation, “my wife had to quit her job to care for me and that always causes frictions”
- “even without pain, I am in a bad mood”
- “I feel guilty regarding my children, I just sit doing nothing”.

Rasker et al reuma hebben 1984
Feelings of guilt in RA

- Patients (n=229) and controls in Twente, Friesland and Rotterdam
- Age 59.3 years (12.8)
- Disease duration 18.7 (10.6)
- 68% women

Riemsma et al 1997 Aspect 56: 42-43
Feelings of guilt in RA?

Questionnaire:
I feel guilty:
• As I am a burden for the others
• As I am not doing enough to improve my disease
• When others are helping me
• That I have got RA

Crohnbach alpha = .74 (N= 229)

Riemsma et al 1997 Aspect 56: 42-43
Feeling guilty scale 1-10

Patients (N=229)  1,8 (2,3)
Controls (N=133)  1,0 (2,0)

Riemsma et al 1997 Aspect 56: 72-73
Feelings of guilt in RA

Conclusion:

Few adult RA patients have feelings of guilt

Riemsma et al 1997 Aspect 56
Do young arthritics feel guilty?

K Timmers et al
(master thesis)
Do young arthritics feel guilty?

- Young people with juvenile idiopathic arthritis
- N = 141
- Age 24 (16-30)
- Women 72%
- Disease duration: 10 years (sd 5.9)

Karin Timmers (Master Thesis)
Young arthritics
Do young arthritics feel guilty?

Questionnaire

I feel guilty:

• As I am a burden for others
• I think that I am to blame that I got arthritis as I am doing too little to get rid of the disease
• As I am afraid that I am boring when I talk about arthritis with others

Crohnbach alpha 0,63 (n=141)

K Timmers et al (unpublished data)
Do young arthritics feel guilty?

M  sd  min  max
Feelings of guilt  1.9  0.8  1.0  4.7

(Scale 1- max 5)

*K Timmers et al (master thesis)*
Denial and feeling guilty

- Denial explains 11% of the variation of feeling guilty (and 3% of emotional wellbeing)

K Timmers et al (master thesis)
Young arthritics

More feelings of guilt when more dependant upon others
Egyptian RA patients feel more guilty than Dutch

- Four items scale assessing feelings of guilt related to RA
- Egyptian (n=36) (score 1-5) 2.9 sd 1.0
- Dutch (n=140) (score 1-5) 1.8 sd 0.9) p <0.001.
- In the Dutch patients a weak correlation of guilt with feelings of loneliness (0.22) but not in the Egyptian patients.

Tarek El Mansoury Clin Rheum 2008
Egyptian RA patients feel more guilty than Dutch

Although no data are available from other countries, this study may indicate that in developing countries feelings of guilt (and shame) may play a larger role in RA patients than in the Netherlands

Tarek El Mansoury 2008
Egyptian patients feel more guilty

- Possible explanations:
  - In Holland all patients insured
  - Women are more dependant of husband and family
  - Women are scared for marriage
  - Other?
Guilt and shame in RA

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Shame in RA

- Mrs de B: “I feel ashamed that I did not go to the rheumatologist earlier”
- For my deformities (?)
- Orthopaedic shoes
- Wheelchair
- For what others say / think
Shame

- Fatigue
- Shoes
- Deformities
- Rollator
Shame
For wheelchair,
being dependant
Shame for what others think
Shame for hands

Solution: striking rings
Shame

• “I am slowly when paying in shops, everyone has to wait for me”
• “I let fall the dinner service”
• “I cannot put on my shoes”
Shame (in Pakistan?)

- You are a burden for the family, a good for nothing, dependant
- You cost the family money (for medication and treatment)
- You are a shame for the family
New study on guilt and shame in RA

Aim of the study:

• Cross sectional study in RA patients and controls
• To look for determinants age and sex, pain, function, anxiety and depression
# Guilt and shame in RA

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Controls</th>
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<tbody>
<tr>
<td>N</td>
<td>86 (F 77%)</td>
<td>72 (F 78%)</td>
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<tr>
<td>Age</td>
<td>62.2 (sd 13.9)</td>
<td>59.9 (sd 12.5)</td>
</tr>
<tr>
<td>Dis dur</td>
<td>16.0 (sd 13.5)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Not different</td>
<td></td>
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<tr>
<td>Social situation</td>
<td>Not different</td>
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Shame and guilt in RA patients and peers (ESS)

<table>
<thead>
<tr>
<th>@</th>
<th>Items</th>
<th>Pat</th>
<th>peers</th>
<th>p</th>
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</thead>
<tbody>
<tr>
<td><strong>Experience of Shame Scale</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characterol shame 1 – 4</td>
<td>0.91</td>
<td>12</td>
<td>1.3</td>
<td>1.3 ns</td>
</tr>
<tr>
<td>Behavioural shame 1 – 4</td>
<td>0.92</td>
<td>9</td>
<td>1.5</td>
<td>1.6 ns</td>
</tr>
<tr>
<td>Bodily shame 1 – 4</td>
<td>0.95</td>
<td>4</td>
<td>1.5</td>
<td>1.4 ns</td>
</tr>
<tr>
<td>Total scale score 1 – 4</td>
<td>0.90</td>
<td>25</td>
<td>1.4</td>
<td>1.4 ns</td>
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</tbody>
</table>

*Pearson chi-square, † Independent t-test

<sup>a</sup>High scores indicate worse outcome
### Shame and guilt in RA patients and peers (TOSCA)

<table>
<thead>
<tr>
<th>Test</th>
<th>Items</th>
<th>Pat</th>
<th>peers</th>
<th>p</th>
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</thead>
<tbody>
<tr>
<td><strong>Test of Self Conscious Affect</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shame,</td>
<td>1 – 5</td>
<td>0.82</td>
<td>16</td>
<td>2.8</td>
</tr>
<tr>
<td>Guilt,</td>
<td>1 – 5</td>
<td>0.67</td>
<td>16</td>
<td>4.2</td>
</tr>
<tr>
<td>Externatisation</td>
<td>1 – 5</td>
<td>0.56</td>
<td>16</td>
<td>2.3</td>
</tr>
</tbody>
</table>

<sup>a</sup> High scores indicate worse outcome

*Pearson chi-square, † Independent t-test*
Multiple linear regression analyses for shame and guilt in RA patients

<table>
<thead>
<tr>
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<th>ESS (shame)</th>
<th>TOSCA</th>
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<td>Charact</td>
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<td>behav</td>
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<td>bodily</td>
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<tr>
<td>Total</td>
<td></td>
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</tbody>
</table>

|                      |             |       |       |
|----------------------|-------------|-------|
| Sex (male)           | 0.23        | 0.37  |
| Age                  | -0.21       | -0.25 | -0.20 |
| Affect               | 0.32        | 0.24  |
| Social interact      | 0.32        | 0.26  | 0.26  | 0.31  |
| Self-blame           | 0.30        | 0.34  | 0.39  | 0.36  | 0.38  |
Conclusion

- This elderly group of patients with longstanding RA have no more feeling of shame or guilt than their peers.
- Only those who placed the guilt of the disease upon others had more shame (externalization)
Conclusion

• Female patients experienced more bodily shame
• Younger patients experienced more character and bodily shame
• Worse affect (anxiety and depression) is predictor for behavioral shame
Conclusions

• Worse social functioning and more self-blaming are the strongest predictors of feelings of shame.

• Shame (TOSCA) was associated with more self-blame.

• Female patients were more prone to feelings of guilt.
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The garden as metaphor of RA

• If you remove weeds and vermin from your garden and add manure, you will not get beautiful flowers.
• For a really beautiful garden you need a healthy surrounding with sufficient sun and shade.
• So in order to have happy patients you indeed have to treat the disease and symptoms but especially have to give the patients the chance to flourish.
RA patiënt society

- Aims:
- Education by patients
- Social contact
- Political ‘pressure group’
- Swim in warm water
- Good relationship with doctors

(Hekman, 1976)
Painting
Role RA patient

• Changes frome “doctor knows what is good for me” to
• Co-ordinator of own care
• Advocate of disease
• Teacher of doctors
• Researcher
Modern Patient:

“Doctor, here you have some information about my disease; take your time to read it, next week I will return to answer your questions.”
Autonomy, participants in international rheumatology congresses
Patients as advocate

- **Personal:** own experience
  Groups advocate: collective power of a large group
- Making aware of rheumatism
- Call for changes on individual level, society and government level, to improve the life of the rheumatic patients.
- People have the right to make their own choices regarding health care.
Patient partners

Patient as teacher of doctors and students
(made possible by Pfizer)
Patient as scientist
RA patient as scientist

- More critical (no guinea pig anymore)
- Questions about financial relationship of the researcher
- Patients member ethical committee
- Not convinced with ‘scientifically proven’
- Patient as hands-on expert
Conclusions

• Feeling s of guilt and shame play a role in the life of many RA patients
• Differ in different parts of the world
• Positive approach may help
• Autonomy may help, is not an answer
• Further research is needed
• As long as we cannot heal RA the problems will persist
Autonomy is possibly part of the solution.
Thank you