

POST POLIO SYNDROME

– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

The value of investigating patient perspectives:

Fitness And Cognitive behavioural Therapies for Fatigue and Activities in PPS

Karen Schipper, MSc/ PhD student, VUmc

Prof. Tineke Abma, VUmc

Prof. Frans Nollet, AMC

Program

1 **Background -**

2 **FACTS-2-NMD study -**

3 **Results -**

4 **Conclusion**

5 **Questions -**

Program

1 Background -

2 FACTS-2-NMD study -

3 Results -

4 Conclusion -

5 Questions -

1 Background: patients central

- Patients are nowadays more and more invited to have an active role in managing their disease and life
- Their knowledge and experiences are nowadays more and more acknowledged
- New trend since the knowledge of patients was often seen as subjective and emotional and therefore ignored.

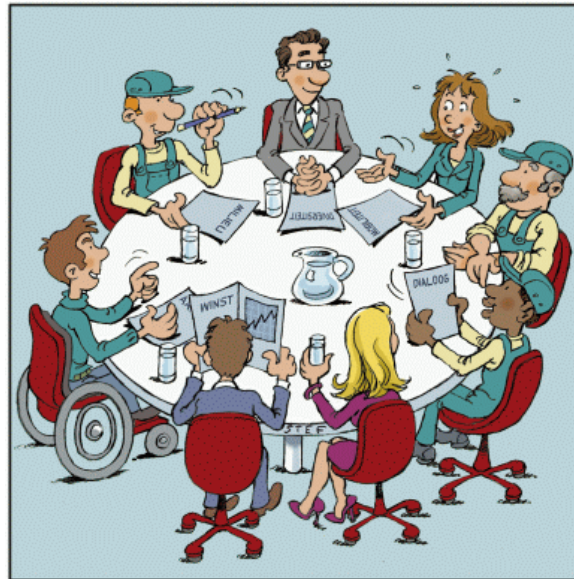
1 Background: patients central

- Changes as a result of:
 - 1) Societal developments (less respect to figures in authority, more assertive and critical, less hierarchical relations, doctors are not heroes anymore et cetera).
 - 2) Changes in views about knowledge.
(it is no longer seen as subjective and emotional)



1 Background: patients central

- It is now more and more acknowledged: patients bring in new themes to the table that are underexposed and otherwise would not be taken into consideration (substantial argument of patient participation).
- Patients bring in an unique perspective due to their illness (experiential knowledge) that professionals do not have.



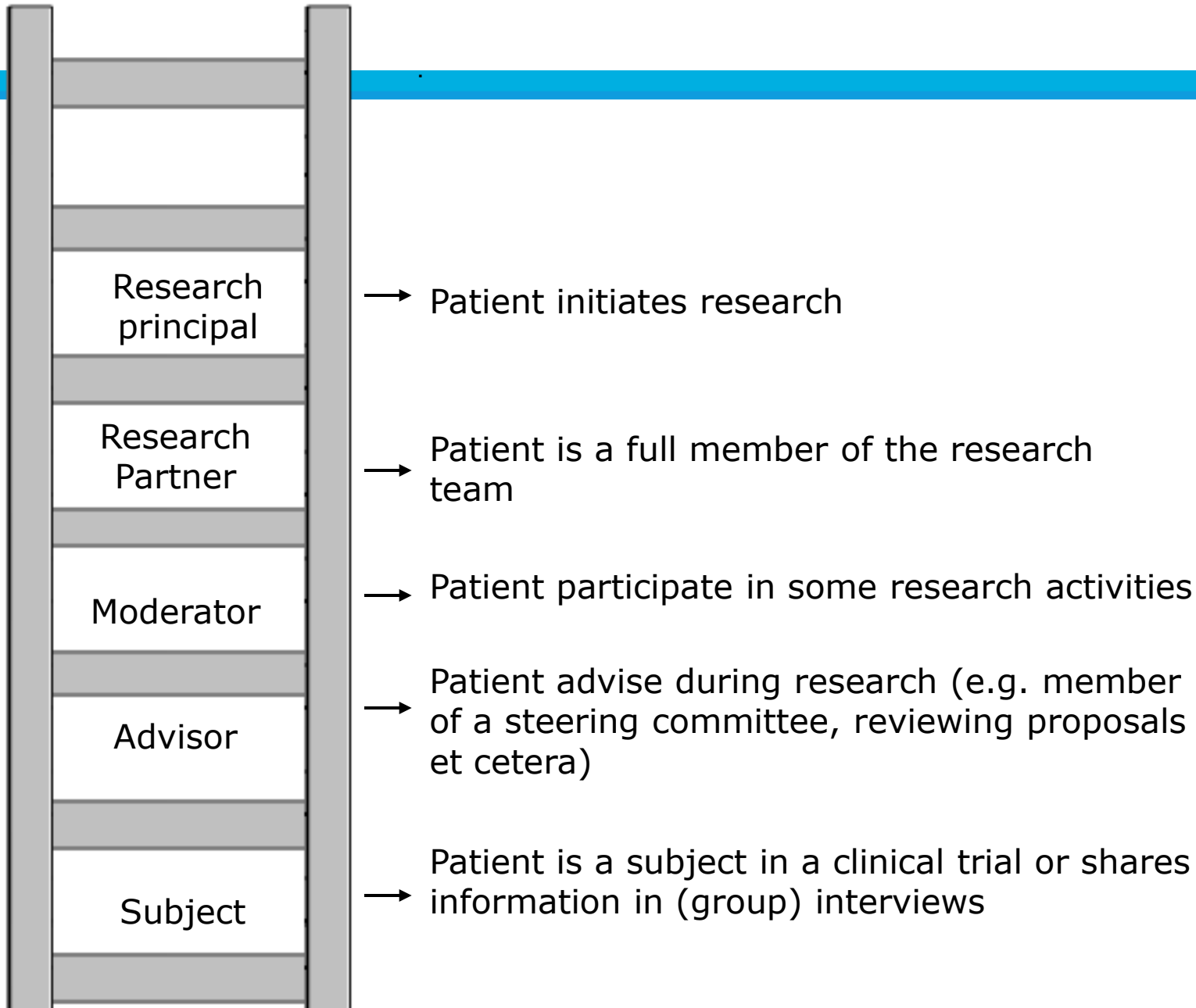
1 Background: patients central

- Patients should furthermore have the right to become involved in research because they will be affected by the outcomes (normative argument).



- Participation also leads to better implementation (instrumental argument)
- Thus several arguments that plea for involvement of patients: with in stead of about us!

1 Background: How to involve patients?



1 Background: patients as subjects

- Quantitative methods (like questionnaires or measurements) have been used more often and have a longer history in comparison with qualitative methods (like interviews or focus groups).
- Qualitative methods were regarded with sceptism and were being accused of their subjective nature and absence of facts.
- It is now more and more recognized that both methods can supplement each other whereby qualitative methods are described as leaving more room for patients. These methods give them the possibility to bring in their own perspectives and experiences without being led by a certain questions.

Program

1 **Background -**

2 **FACTS-2-NMD study -**

3 **Results -**

4 **Discussion - *Conclusion and Key points***

5 **Questions -**

2. FACTS-2-NMD study

- FACTS-2-NMD study: RCT in combination with qualitative research (see www.facts2nmd.nl).
- Aim RCT:
 - 1) To study the efficacy of exercise training (ET) and Cognitive Behavioural Therapy (CBT) for improving activities and quality of life in patients with post-polio syndrome (PPS), amyotrophic lateral sclerosis (ALS) & fascioscapulohumeral muscular dystrophy (FSHD).
 - 2) To identify generic and disease-specific determinants of effects.

2. FACTS-2-NMD study

- Primary outcome measurements RCT:
 - 1) Fatigue (CIS)
 - 2) Activities (SIP-68)
 - 3) Quality of Life (SF-36)

2 FACTS-2-NMD study: qualitative study



- Aims qualitative study:
 - 1) To obtain insight into patients' expectations and experiences and those of the professionals with both interventions and to compare these with each other.
 - 2) To improve healthcare practice by enhancing personal and mutual understanding of a situation by fostering a dialogue about relevant issues among stakeholders.
 - 3) To improve the final interventions by adapting those to the experiences of patients and professionals

2 FACTS-2-NMD study: qualitative study

- Participatory observation
- Reading ego-documents and literature
- In-depth interviews with patients before and after the treatments. (Using a topic list , making transcripts, content analysis by tow coders and working till saturation).
- In-depth interviews with professionals before the treatments started and half way the trial.
- Homogeneous and heterogeneous focus groups with patients and professionals.
- Integration quantitative and qualitative data

Program

1 **Background -**

2 **FACTS-2-NMD study -**

3 **Results -**

4 **Conclusion -**

5 **Questions -**

3 Results: participants

	ET	CGT
PPS	4	6
ALS	0	3
FSHD	4	9

3 Results: overview

- Information about how all three patient groups experience ‘being part of a trial’.
- Information about how PPS patients experience the interventions and their effects.

3 Results: being part of a trial

- Method of communication used by researchers to inform patients about inclusion decisions.
- Confronting nature of certain items in questionnaires.
- How patients fill in questionnaires

3 Results: communication

- Patients may not appreciate the method of communication used by researchers to inform patients about inclusion decisions

*'I received an email from the doctor.....I am not allowed to join since **I am not tired enough**. It hurts me. How can a questionnaire say something about my tiredness? I think they should not communicate by mail about the exclusion. Furthermore they should not say: you are not tired enough. **Patients feel the tiredness, but it isn't bad enough.....***



3 Results: confronting items

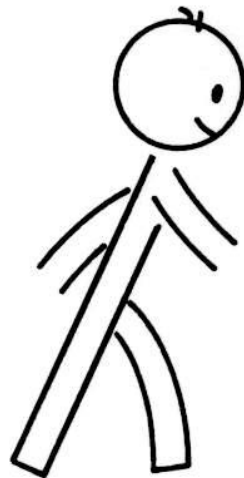
- Some patients have problems with some confronting questions in the questionnaires they receive at home.

*‘ The questions irritated me and my son, enormously! “I feel sad”” is not that bad, but ‘I would suicide myself if I had the possibility’ is **shameful!** And what does the researcher do with my answers? What if I say yes? I think you should not ask these questions by a questionnaire. My son has trown away the whole research proposal and **he will never ever participate** in a study from this hospital. Is this the way we want it? I don’t think so! Who’s idea are these questions? Are they from a researcher who doesn’t have a clue about the possible effects of these questions?!’*

3 Results: using questionnaires

- Patients may adjust their answers in order to fulfil inclusion criteria

‘There was a question: are you able to walk for 10 minutes without any help. I can’t, but I really wanted to participate, so I said yes. I really hope that I don’t have to do this later on!’



3 Results: using questionnaires

- Patients may not fill in the questions correctly

*‘The questionnaires consisted of many many questions and some were more or less the same. Questions were repeated in just another formulation. This made me fill in the questionnaires faster and less accurate. I **wanted to get rid of the questions and started to work routinely.** I’m not sure if I have filled in the questions exactly as I felt myself...but I wanted to end it!’*

3 Results: some adjustments

- The experiences were discussed with the research team, resulting in procedural changes (like informing by phone, enclosed letter) and a better understanding of patients' experiences.



To remember.....

- Primary outcome measurements RCT for PPS:
 - 1) Fatigue (CIS)
 - 2) Activities (SIP-68)
 - 3) Quality of Life (SF-36)

Effect CBT: patients with PPS



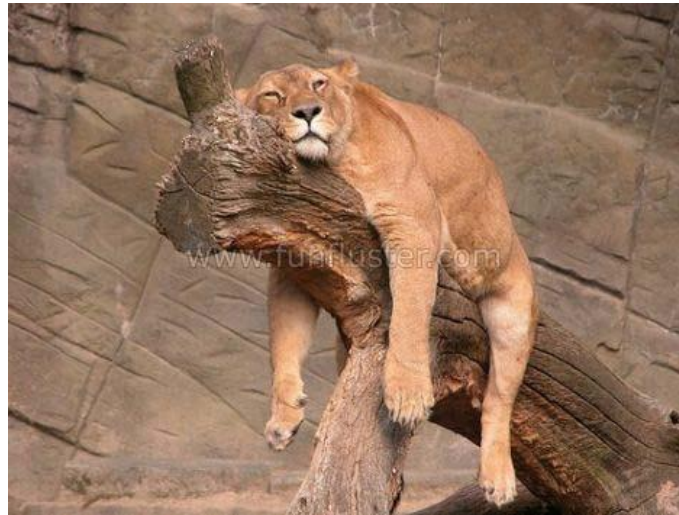
CLINICAL
PSYCHOLOGIST

3 Results: experienced effects: CBT

- Tiredness?

*‘We have **hardly** talked about tiredness.’*

*‘I’m **less tired**. The tiredness in my head, my mental tiredness has changed in a positive way... ‘*



3 Results: experienced effects: CBT

- Balance between activities and rest

*‘She has learned me **to restrict explosions** of activities and **to avoid peak performances**. Taking some rest can be better.....’*

*‘I have learned **to use my energy** in an appropriate manner.’*



3 Results: experienced effects: CBT

- Recognition

*‘The therapist told me about the experiences of other patients. It was nice to hear their experiences and to hear that I’m not unique in my feelings and experiences. I’m **not the only one.**’*

3 Results: experienced effects: CBT

- Acceptation of feelings

'I have learned to accept my feelings. I may be angry and rebellious. I used to become angry if things didn't work out as I wished they should. And afterwards I became angry because of my anger.'

- No toning down anymore

'I used to tone down my problems and emotions if some else told about anyone with more serious or difficult problems. I have learned to accept my feelings and I do not relativize them anymore.'

3 Results: experienced effects: CBT

- Taking initiative in stead of complaining

*'I have learned **to stop complaining** about my restrictions. Nobody ever asked questions about my restrictions and I felt lonely. People didn't ask me for events since they thought it would be too enervating for me. I have learned to say: "I also want to join." I should **not be dissapointed** if people don't invite me and I **have to take more initiative** by myself but that's still a hard job to do.'*

3 Results: experienced effects: CBT

- Being mentally stronger

*'I have also learned **to handle awkward comments** of my environment.'*

- Enrichment

*'I can't explain it....but the therapy was **an enrichment of my life**. I experience the value of our talks everyday. It just fitted with my situation at that moment. It was the cherry on the cake'*

3 Results: experienced effects: CBT

- Increased self-confidence

*‘People often rejected me because of my body and **I experienced that as a total rejection** of myself as a person. This has been **changed** as a result of the treatment!’*

- Increased self-acceptation

*‘I did not want to wear a shirt without sleeves because of my odd shoulders but I have done it now!!! People were seeing my shoulders but they didn’t reject me because of my body! **I’m not less valuable because of my body but I acted as if I was less valuable!** ‘*

3 Results: experienced effects: CBT

‘I’m better able to accept my restrictions and my dependency. I needed to switch my thoughts but I wasn’t able to do that before. I’m better able to focus on my possibilities in stead of restrictions right now! ‘

‘I don’t need to devise any apologies anymore. I’m now able to admit my restrictions without listing all my poor excuses.’

3 Results: experienced effects: CBT

- Showing vulnerability

'I don't have to be strong anymore and I have learned to show my vulnerability. I'm allowed to be vulnerable since people will mention it anyhow.'

'If people asked me something I used to overstate myself: of course.....I'm able to do anything I want.....'Now I able to be honest and I don't need to overstate myself anymore.'

Effect ET: patients with PPS



3 Results: experienced effects: ET

- Tiredness?

'I have not experienced any development or progression. Bicycling was difficult and enervating at the beginning and at the end. I didn't feel any progression....I expected progression so I'm dissapointed.'

*'My tiredness **did not improve** at all.'*

'I still don't understand my tiredness at all.'

*'I feel a **little bit less tired** I think.'*

3 Results: experienced effects: ET

- Knowing and accepting limits

*Finding and recognizing your limits isn't easy. I'm familiar with not feeling them.....
But I know my limits now a little bit more and I try to communicate about my limits. The talks with my physiotherapist have learned me that it isn't "and and" but "or or". I have to make choices.'*

- Having any idea about your future

'I have gained insight in my future and the perspectives and that's what I wanted and needed.'

3 Results: experienced effects: ET

- Increased self-acceptation

'I'm better able to accept myself as a result of listening to the stories of other patients with PPS. As a result of that I have asked for a wheelchair. It will be difficult but I have to admit my limits if I want to enjoy things.'

3 Results: experienced effects: ET

- More positive relation with partner

*‘My husband worried about my negative mood and my tendency to ignore my limits. **The treatment forced me to realize my limits** and we were, as a result, **able to talk about these limits and my husband’s worries.**’*

Program

1 **Background** - *Introduction and Study purpose*

2 **Methods** - *Participants, Study design, Measurements, and Statistical analysis*

3 **Results** -

4 **Conclusion** -

5 **Questions** -

4 Some conclusions

- More interviews and focus groups are needed but.....
- The experiences of patients have provided useful insights into how the research process can be improved.
- Patients mention various effects of the interventions. These effects will not be measured with the quantitative questionnaires. Patients may thus show no progression on the primary outcomes of the quantitative study but this does not mean that a therapy does not work for patients!!

4 Some conclusions

- A combination of quantitative and qualitative methods is preferable since “measuring is not always the same as knowing everything.”
- Please stay curious to the experiences of patients since they can help us to improve health care!





Program

1 **Background** - *Introduction and Study purpose*

2 **Methods** - *Participants, Study design, Measurements, and Statistical analysis*

3 **Results** -

4 **Discussion** - *Conclusion and Key points*

5 **Questions** -



Karen Schipper

k.schipper@vumc.nl

Thank you!

Mange tak, Grazie, thank you, faleminderit,
благодаря, gràcies, danke, tänan,
kiitos, merci, σε ευχαριστώ, köszönöm,
hvala ti, paldies!, ačiū!, grazzi,
bedankt, takk, спасибо, dziękuję,
obrigado, mulțumesc, хвала ти,
d'akujem ti, hvala, gracias, děkuji ti,
teşekkür ederim, tack!