

## **Final programme and minutes – SIG in psychology and neuropsychology in-between meeting Barcelona, 16. - 17.11.2012**

Present:

Liina Vahter, EST, chair  
Anita Rose, UK, co-chair  
Bente Osterberg, DK  
Jannie Engelbrecht, DK  
Jana Poettgen, GER  
Stephanie Lau, GER  
Maria Arevalo, ES, local organizer  
Elisenda Anglada, ES, local organizer  
Inma Sanz Gracia, ES  
Michelle Pirard, BE  
Mieke D'hooge, BE  
Ana Ozura, SL  
Wim van de Vis, NL

## **Final programme – SIG in psychology and neuropsychology Barcelona, 16. - 17.11.2012**

### ***16.11.2012 Friday***

9.00 Welcome, introduction

9.15 – 9.45 Ongoing projects in Barcelona – Our experience with workshops in out-patient basis – patients' and their families feedback. Maria

9.45 – 10.15 Ongoing projects in Barcelona – Management of patients with severe cognitive impairment in the rehabilitation treatment. Elisenda

10.15 – 10.45 Red flags“ in cognition. Review of the status of the Melsbroek“ project. Michelle, Mieke

10.45 – 11.15 Cognitive manual – finally finished? Anita, Liina

11.15 – 11.45 *coffee*

11.45 – 13.00 Guided visit for a new Center of Multiple Sclerosis in Catalonia (CEM-Cat)

13.00 – 14.00 *lunch*

14.00 – 14.30 Review of the literature – last 3 years in neuropsychology and MS. Liina

14.30 – 15.00 Neuropsychological Case. Maria and Elisenda

15.00 – 15.30 Review of the literature – latest news in psychotherapy of PwMS. To be confirmed. Anita

15.30 – 15.45 *coffee*

15.45 – 16.15 Social cognition and PwMS – Hamburg study. Jana

16.15 – 16.45 Childhood MS and psychological problems. Anita

16.45 – 17.15 Personality changes and MS. Ana Ozura

17.15 – 17.30 Conclusions for Day 1.

*Dinner*

## **17.11.2012 Saturday**

9.00 – 9.30 Basics of sexual behaviour and the problems MS can give. Wim

9.30 – 10.00 Sexual problems in cognitive impaired PwMS with attentional deficits. Janni

10.00 – 10.30 Counselling of sexual problems. Bente

10.30 – 10.45 *coffee*

10.45 – 11.45 Who we are and what we do? All members of the group

11.45 – 12.00 organizational issues – updating members list, information on the RIMS webpage etc. All members

12.00 – 13.00 planning the next in-between meeting – in spring? In Copenhagen 2. - 5.10.2013 during ECTRIMS? All members

13.00 – 14.00 *lunch, farewell*

## **MINUTES**

**16.11.2012**

Welcome, introduction by dr Xavier Montalban, CEMCAT director

Presentations:

*Ongoing projects in Barcelona – Our experience with workshops in out-patient basis – patients' and their families feedback.* Maria-Jesus Arevalo, ES

Discussion was following. In Denmark specialists go out and do similar things all around the country. There was program in 2009 about cognition and cognitive problems in frames of MS Society, same kind of meetings were organized about physical training (with practical parts), meetings about nutrition are planned. Feedback has been good. In UK small workshops with local PwMS – cognition, fatigue, physio, nutrition, adaption for the house. All around the country similar meetings are taking place. Waiting lists are the longest for the cognitive and emotional issues. Contents: general cognition, biology, special topics - attention, exercises, talk and sharing experiences. Fatigue – similar course structure. Emotional issues – more „lecture“-type, half day. In Hamburg – more lecture type, all PwMS could take part, about relapses and treatment, not about cognition.

*Ongoing projects in Barcelona – Management of patients with severe cognitive impairment in the rehabilitation treatment.* Elisenda Anglada, ES

Discussion. Criteria in BCN – severe cognitive problems or 2 or more therapeutic interventions not being beneficial. Program is carried out 2 times per week for 5 months. In Denmark the group has started, 6 times altogether – is there any consensus how long the treatment should take place before to evaluate the benefit? Discussion about the evaluation of the benefits of the program.

*„Red flags“ in cognition. Review of the status of the „Melsbroek project“.* Michelle Pirard, Mieke d'Hooze, BE

History started from the „cognition“ day in Melsbroek. After that joint meeting of SIGs (occupation, participation, ps and np) took place in Melsbroek in november 2011. No consensus was achieved about the format of report. Preliminary worksheet was set up for collecting information (verbal vs non-verbal, therapists vs elsewhere, different items from different professionals, complaints PwMS has etc.). Final decision – no format for the neuropsychological report, but the use of the worksheet of the „neuropsychological complaints/red flags“ will be recommended. Worksheet will be sent around after the

meeting. Michelle and Mieke will keep us informed about the progress.

*Cognitive manual – finally finished?* Anita Rose, UK, Liina Vahter, EST. We will finish the manual within next 2 weeks (final parts from Jannie and Nicolas, some addition from Liina), send then around for final editing, Anita will correct the english. Manual will be ready at the end of the 2012. After that we will publish it on the RIMS website. All the members of our group are encouraged to promote the manual as the helping tool for psychologists working with PwMS in their own countries and neuropsychological societies.

*Guided visit* for a new Center of Multiple Sclerosis in Catalonia (CEM-Cat) was performed.

*Review of the literature – 2011 – 2012 in neuropsychology and MS.* Liina Vahter, EST. Summary and keywords for further interest will be sent around (+ „Gorilla“ article)

Neuropsychological Case. Maria Jesus Arevalo, Elisenda Anglada, ES. Discussion followed.

*Review of the literature – latest news in psychotherapy of PwMS (nov 2011 – nov 2012).* Anita Rose, UK. Slides and references will be sent around.

*Social cognition and PwMS – Hamburg study.* Jana Poettgen, GER  
Hopefully will be published in JNNP;) Impaired social cognition might explain high rate of divorces in the beginning of MS.

*Childhood MS and psychological problems.* Anita Rose, UK  
Overview about the topic, UK sample cases.

*Personality changes and MS.* Ana Ozura, SL  
Overview of the topic. Study about Rorschach test conducted in Slovenia. One study was published in 2010 by Ana and colleagues, results of the other study were presented to us.

## **17.11.2012**

*Basics of sexual behaviour and the problems MS can give.* Wim van de Vis, NL  
Biological background was covered, in the presentation was a video about the experiences PwMS has experience in her sexual life. Discussion followed about how and how is counselling PwMS in different centres around Europe.

*Sexual problems in cognitive impaired PwMS with attentional deficits.* Jannie Engelbrecht, DK.

Case was presented together with the neuropsychological profile. Discussion followed.

*Counselling of PwMS.* Bente Osterberg, DK.  
In Denmark there is a webpage about different issues MS may give, incl sexual problems. There is also a discussion in Denmark – is the personal assistant of PwMS obliged to help PwMS to go to the prostitute (i.e. prostitutes who are specialized to neurologically impaired people). It would be illegal in many other European countries. In Melsbroek there has been a working group established for the topic „Sexuality and MS“. Anita shared her experience about getting „trained“ in the field of similar problems. Professional knowledge, comfort and limites were discussed.

*Organizational issues*

- members list has been updated
- information on the RIMS webpage has been forwarded (NB! No information about the next RIMS meeting available on the RIMS webpage – it takes place together with next ECTRIMS, Copenhagen, oct 2013)
- newsletters and banners have been advertised – people have tried to register but not succeeded due to technical problems on the website, will continue trying
- planning the next in-between meeting has been done
  - 19. - 20.04.2013, Ljubljana, Slovenia (Ana volunteered and is happy to organize, no pressure)
  - In Copenhagen 2. - 5.10.2013 during ECTRIMS
  - In 2014 Melsbroek?
  - Topics for next meeting in Ljubljana:
    - „Sexual problems and couple issues in MS for psychologists and neuropsychologists“ (Wim, Jannie and Bente to be in charge)
      - possible plan for booklet
      - article different from booklet (review, International Journal of Rehabilitational Medicine)
      - review from the literature (Anita and Ana to be in charge)
      - cases (Jannie, Wim, Bente, Michelle to be in charge)
      - discussion (all members of the group)
      - SIG in bladder and bowel to be contacted? (Liina)
      - general session for RIMS conference to be prepared at the same topic (all members)
    - computer based rehabilitation programmes, cell-phone etc based rehab strategies, applications (for example „Tap to Talk“) etc – us to be more informed. Small video cameras in use all of the time of the day for training recognitional memory.
    - research and further publication planning
    - preparation for the RIMS/ECTRIMS in Copenhagen – open and more general session prepared by our SIG

Some additional topics to be covered in the future:

- early diagnosed and benign PwMS – psychological and neuropsychological problems
- PwMS in advanced stages – psychological and neuropsychological problems
- suicide and MS
- palliative care and MS
- to continue with cases and discussion („grand round“)
- adapting tests (Rey figure copying in Ipad etc)
- how to test people who cannot write and see
- how to test very young people – big change in „hardware“