Report meeting triple joint SIG meeting

SIG Communication & Swallowing, SIG Occupation and SIG Participation & Integration
Masku, Finland 20-21 November 2009

Theme: "Participation of people with MS by empowering communication"

Empowering communication of people with MS: assessment and management

Chair: Eric Kerckhofs (B)

Participants

There were 22 participants of 7 different countries and 10 different centres (see list of participants attached). It was an interdisciplinary meeting with 11 occupational therapists (OT), 4 social workers (SW), 3 medical doctors (MD), 2 speech and language therapists (SLT), 1 head of the rehabilitation and 1 person who is physical therapist (PT) and psychologist.

Programme

For the complete programme, see attachment.
The following topics were presented and discussed with all participants:

- Presentation of results of survey
- Scales to assess communication in daily life. Review of the scales available
- Overview of assistive devices for communication
- Interdisciplinary management of AAC (alternative and augmentative communication).

Conclusions

Based on the presentations and discussions, the following "take home messages" were formulated by all participants:

- effective communication = sending AND receiving information
- it takes at least 2 to communicate
- there are many factors involved in communication performance (like speech, cognitive performance, behaviour, mood, employment, family roles, mobility, hearing & vision deficits, fatigue …)
- all rehabilitation professionals are involved in communication, however they should have more focus on communication (assessement + training)
- there should be a communication about communication within the rehab team
- specialists in rehabilitation need training in effective communication with clients
  →it is possible to organise a workshop dealing with this during RIMS conference?
- use of scales ameliorates the relationship between therapist and client
- there is a lack of written procedures/processes (e.g. advise of alternative and augmentative communication (AAC))
- group sessions in communication seem to be useful to:
  - stimulate communication
  - lower resistance in using AAC in already existing users and potential users
  - produce new ideas
- it is not easy to succeed in advising AAC due to resistance, practical limitations etc.
- importance of considering clients' needs and wishes

- importance of considering caregivers' needs and wishes
- new technologies should be considered within the "new" world of communication (shatting, sms, email etc.)
- communication is both technique and content
    - clients' needs to be motivated
    - clients' needs to have things to talk about (sometimes limited world)
    - music, arts, dance can play an important role to facilitate communication
- it is all about empowering communication!

Plans for the future
We discussed how we would like to do to deal with this topic in future. We have agreed on the following actions:

- to produce recommendations on the process of advising AAC
- to create a database of AAC (frequency of advise and profile of clients)
- to repeat the survey in order to look for changes in assessing and managing communication limitations
- to register all assessment instruments
- to discuss the possibilities of group sessions
- to create an algorithm of AAC advise
    - include clients and family in the creation process
    - include students to work on it and make a literature review (under supervision)

To do

1. Distribution of documents on advise of assistive devices already produced by SIG Occupation and by colleagues in Melsbroek as a basis for a draft of the algorithm (Pascal and Daphne). This will be sent to all contactpersons (see below).
2. Give feedback on the first draft by all participants and their colleagues within the rehab team, and by clients and their environment.
3. Integrate all comments at RIMS meeting in Gotheborg (Sweden) October 15-17 2010 (contactpersons should preferably be present)
4. Send survey in May 2010 (Daphne) – integrate a question on frequency of advising AAC
5. Communicate with SIG Pyschology & Neuropsychology (Tarja)
6. Contact with students who want to collaborate (Daphne)
7. Explore what has already done – looking for databases, CMSC … (all participants and students)
8. List of information sources (where do you get your information from?) (send it to Pascal)
9. Marta will send the assessment scales (extended and short version) in English to all participants, who will give feedback on them.

Contactpersons

- Stephanie Remy, Fraiture (B)
- Pascal Van der Beeten, Melsbroek (B)
- Gita Berzina, Latvia
- Zorana Sicherl, Slovenia
- Christoph Heesen, Germany
- Jeanne Hansen, Haslev (DK)
- Lene Kallmayer, Ry (DK)
- Tarja Huilla, Masku (FI)
- Marta Renom, Barcelona (ES)
- Daphne Kos, Artesis (B)

Separate SIG meetings

A. SIG Communication & Swallowing Disorders

Participants: Marta Renom (ES) and Antonella Nota (B)

Both participants agreed on the success formula for the joint meetings. SIG Communication's future will be ascertained especially in that joint formula.

B. SIG Participation & Integration

"Where are we with our SIG and where do we want to go?"

Participants:
Rina Verdoodt (chair, SW, (B) Melsbroek), An van Nunen (co-chair, MD, (B) Melsbroek , Hanna-Mari Hyvönnen (web-pages responsible, SW, (Fi) Masku), Eric Kerckhofs (Psychologist, physiotherapist, professor VUB (B) Brussels), Cristina Vetoret (SW (SP) Barcelona), Inge Gjerrild Soegaard, (Head rehabilitation (DK), Ry), Jeanne Hansen (Nurse, (DK) Haslev, Gita Berzina (MD, Latvia)

Program

1. As a warming-up for this meeting and to draw a framework for the new SIG core members, an overview was given of the SIG activities, participants and core members over the last 5 years.
2. During the RIMS annual conference in Genua, april 2009, we had a joint workshop with our SIG and the temporary SIG "patient information and shared decision making". Goals of this workshop were multiple, and report of it was given:
    a. We wanted to sort out to what extent cooperation/merger of both groups would be appropriate for now and for the future. At this time a close cooperation between both SIG's is chosen.
    b. Objective of this new SIG for the future (selection)
        i. Systematic review of educational concepts, patient information and decision support tools in MS Rehab centres, preferably in cooperation with the MS Societies.
        ii. Develop strategies of EBPI and shared decision making in MS Rehabilitation setting.
        iii. Development of EBPI tools and study of effects of different formats (eg booklet, group session, face-to-face interview).
3. Participants were asked to formulate what they see as positive and negative in the functioning of the SIG. The need remains for a more extended and more stable core group. The lack of continuity in the core group impedes deepening of topics and setting up long-term projects. 6 of the participants wanted to become or to continue to be a core member of the SIG. This gives us certainly a more solid base for the future.
4. Participants were asked to bring suggestions for future meetings topics, preferably with a long-term character. The use of ICF as an assessment tool and/or outcome measure in the field of Participation and Integration was generally felt as a very interesting and actual topic. More information about the actual status of the development of an MS specific assessment tool based on ICF will be looked for. In Denmark, some centres have already some experience in working with ICF. The topic is putted forward as very interesting to have an inbetween meeting on.
5. An van Nunen expressed her intention to withdraw as co-chair of the SIG. Jeanne Hansen (DK) is willing to take the vacant place. An will inform the board about her decision.

6. A warm congratulation to Hanna-Mari Hyvönen with her baby coming in the beginning of 2010. This means that also a new web-pages responsible needs to be found. There are no applications up till now.

Conclusions

1. Rina will ask the board if there is financial support to organise an inbetween meeting before the general RIMS meeting in autumn (yes, there is, 1 inbetween meeting a year can be organised by every SIG)
2. Rina and Jeanne will consult by email about subject, appropriate period, possible locations and program of an eventual inbetween meeting in spring 2010.
3. Vacant position of web pages responsible remains. Rina will ask the board to give a more clear “job-description”. (OK, this will come in a later stage)

C. SIG Occupation

Chair : Daphne Kos (B)
Participants: Marianne Dhem (B), Stephanie Remy (B), Pascal Vanderbeeten (B), Jaana Kivilahti (FI), Zorana Sicherl (SLO), Jytte Rose Jakobsen (DK), Lene Kallmayer (DK), Annukka Mäkitalo (FI), Tarja Huilla (FI), Karen Verbeek (B)

Apologized: Stephan Ilsbroukx (B) (co-chair)

Agenda:
- Recommendations on advise of assistive devices
- Research using AMPS
- Future plans
- Preparation RIMS meeting Oct 2010

1. Recommendations on advise of assistive devices

During the RIMS conference in Genoa (May 2009) the group provided feedback on the proposal of a scheme on advising assistive devices (incorporating all important factors playing a role in the advise). Stephan planned to integrate the feedback and produce a definite version which would be published on the RIMS website. Daphne will inform about the state of the art and send the definite version to all SIG Occupation members for a last check. After that, it will be posted on the RIMS website.

2. Research using AMPS

We plan to perform a research project investigating the effect of OT on performance assessed with AMPS. Jelka Jansa (Slovenia) will explore the possibilities for similar OT interventions in every interested partner institution.

3. Future plans

We discussed the expectations, wishes and needs of the group related to (future) meetings and actions.
Members of SIG Occupation wish to:
- have guidelines/recommendations on OT in several domains in people with MS (eg now: communication)
- have regular contact with other OT’s in order to exchange experiences
- have new information when available
- use appropriate assessment instruments (by screening the ones available on quality and usefulness)
- stimulate international teamwork

    - create consensus on what is needed to assess

Possible themes for future meetings:

- management cognitive performance (computer, games, ADL training, devices, group sessions, interdisciplinary work, interference with life domains, ethical approaches/dilemma's etc.)

  → we would like to have a joint meeting with SIG Psychology & Neuropsychology on this topic (Tarja will inform about the possibilities and agenda of the SIG P&NP)
- handfunction and sensibility
- balance
- wheelchairs

Two options for the next meeting:

- a joint meeting about cognitive performance (1 day joint meeting, 1 day separately)
- a SIG Occupation meeting: 1 day on cognitive performance, 1 day on hand function

The next in-between meeting will be either between RIMS conference in October 2010 and March 2011 (so January/February 2011) or in Oct/Nov 2011. This also depends on whether the next meeting will be a joint meeting with SIG Psychology & Neuropsychology.

4. Preparation RIMS meeting Oct 2010

See report joint SIG meeting

Evidence based patient information and shared decision making

Chair: Rina Verdoodt – An van Nunen (B)

"What can we learn from these insights about communication in rehabilitation?"
Forum for interaction and reflection (impulse by Dr. An van Nunen)

Report Meeting Evidence Based Patient Information in Rehabilitation:
Prof. dr. Chris Heesen introduced to us his research on evidence based patient information and shared decision making in MS. His interesting work on f.i. the role of EBPI in relapse treatment and his papers on shared decision making were a suitable starting point for reflections on how we deal with information transmission and decision making in MS rehabilitation.
Evidence based patient information (EBPI) deals with communication of evidence concerning a medical condition (diagnosis, prognosis and therapy) to patients. This **dialogue** goes between patients and doctors or other health care professionals.
It has as ultimate goal to **empower** people in caring for their health by helping them to be involved in decision making. Even when no evidence is available to base our clinical practice on, informing patients in a systematic way about treatment options is the best way to **increase quality of care.**
Patients present themselves with different **preference styles** in medical decision making, depending on f.e. personality, actual mental status, disease history, cultural influences and the type of the decision to be made. Obviously, cognitive problems in MS may have an impact on the level of involvement of patients in decision making.
In the scala of role preferences, Prof. dr. Chris Heesen and his research group described 5 styles that patients can identy with : **autonomous style - informed decision - shared decision – professional as agent – paternalistic style.** Professionals should realise that their own preference style in decision making don't necessarily match those of their clients and that their ,estimations about what patients want often fail.

Role preferences are no static charachteristics of persons but can change during life and differ in specific situations. It is also our experience that there is an automatic shift to more paternalism when **communication limitations** occur. We should commit ourselves to remain as close as possible to patients‘ preferences, even if communication is problematic due to motor, sensory or cognitive disabilities.
It is therefore crucial to **check** with PwMS to what extent they themselves want to be involved in decisions concerning (rehabilitation) therapy, the implementation of aids or home care profs,… . In rehabilitation practice the principle of autonomy in decision making is common fundamental. The explicit action of making the decision process more visible facilitates participation of patients in the whole of their care process.
Shared decision making could be seen as the ideal model in (medical) decision making in MS. This seems logical since the chronic condition itself (and the therapy involved) demands for a continuous process of adaptation in patients lives. Shared decision making creates in its two-way exchange of information a fruitful ground for the best decisions. In decisions that ask for adaptations in patients‘ lives, we should nevertheless check which role the PwMS prefers to play.
Preference styles can be explored by using the Control Preference Scale (Kryworucko et al., 2008). This is a useful tool of getting a quick view on a person's viewpoint in this matter. More difficult is it to assess whether -in a real situation**-** patients perceive the same involvement as the professional observes. Also can there be a discrepancy between which role a patient prefers and the **actual role** he takes on in the meeting with his doctor. The communication style of the professional is one of the probable influencing factors in this concrete realisation of role preferences.
In providing information to patients some **quality characteristics** should be taken into account. The information provided has to be easily accessible and understandable, leading to insight in the

different factors playing a role in the specific decision to make. If evidence exists concerning therapeutic options the information should include the strength of evidence, patient relevant outcome measures, and absolute risks with a balanced presentation of effects and side effects.

After delivery of information it is important to check whether the information was well understood and sufficient for the PwMS to be prepared for a decision. This leads to an exchange of information in both directions.

Since information is an **unmet need** in MS, developing balanced patient information is a challenge for all health care professionals. Since our focus in rehabilitation lies on empowerment, matching risks and benefits to personal preferences and values of PwMS helps them to keep mastery over their lives.

In conclusion we agreed that the lack of strong evidence to support (complex) interventions in rehabilitation in MS, must not restrain us from **producing high quality information materials** on rehabilitation aspects and providing it in a more **systematic** way. We are convinced that decisions made on basis of balanced information joined with the specific preferences and values, lead to the best decisions.

Finally we concluded that EBPI deals not only with information transmission to patients but has to be seen itself as a **complex intervention** with effects and probable side-effects. The professional experience and communication style of health carers lead to more or less space for PwMS to play an autonomous role in decision making.

Shared decision making could be the ideal model of empowerment but it is nevertheless crucial for all professionals involved to adapt to the preference of each PwMS in each specific decision situation.

Closing the meeting

For the last part of the meeting, we had a guided tour in the nice rehabilitation centre of Masku and all participants were able to do rehabilitation in practice, either in the pool and sauna, or performing team games or outside sports.

Report: Daphne Kos, Rina Verdoodt, An van Nunen, Marta Renom & Antonella Nota

Programme meeting triple joint SIG meeting

SIG Communication & Swallowing, SIG Occupation and SIG Participation & Integration
Masku, Finland 20-21 november 2009

Theme: "Participation of people with MS by empowering communication".

Thursday 19.11.2009
19.00-21.00 Welcome party, hotel lobby (Turku)

Friday 20.11.2009 (Turku)
"Empowering communication of people with MS: assessment and management"
Chair: Eric Kerckhofs (B)

9.00 Welcome and introduction
9.20 Presentation of results of survey – Daphne Kos (B)
10.00 Scales to assess communication in daily life. Review of the scales available – Marta Renom (ES)

10.45 *Coffee/tea*

11.00 Overview of assistive devices for communication – Karen Verbeek (B)
11.40 Discussion

12.15 *Lunch*

13.15 Interdisciplinary management of AAC (alternative and augmentative communication)
Forum for interaction and reflection (impulse by Antonella Nota & Pascal Vanderbeeten (B))

14.30 *Coffee/tea*

14.45 Separate SIG meetings
- SIG Participation & Integration
- SIG Communication & Swallowing Disorders
- SIG Occupation

17.00 End

19.00 *Dinner*

Saturday 21.11.2009 (Masku)

8.15 Leaving the hotel to the bus station
8.30 Bus trip to Masku

“Evidence based patient information and shared decision making”
Chair: Rina Verdoodt – An van Nunen (B)

9.00 Masku in numbers – Eija Luoto (FI)
9.30 “Insights in research” – Christoph Heesen (D)
10.15 Questions

10.30 *Coffee/tea*

10.50 “What can we learn from these insights about communication in rehabilitation?”
Forum for interaction and reflection (impulse by An van Nunen (B))
12.00 Take home messages

12.15 *Lunch*

13.00 Look around the house in small groups
13.30 Rehabilitation in practice, 2-3 choices:

1. Pool and sauna
2. Team games
3. Outside sports (depends on the weather)

14.30-15.30 After exercises refreshments and good bye

Participants triple joint meeting SIG Communication, SIG Integration & Participation and SIG Occupation

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