

SIG Participation, patient information and shared-decision making

At the **GENUA CONFERENCE, 23-25 APRIL 2009** an initiative for a possible new SIG was started in an emerging field of care-oriented research. Included in this discussion were the chairs of the SIG participation. It was decided to have a close exchange and possibly visits to interim meetings of the other group until the RIMS conference in 2010.

Why is information relevant?

Knowing risks and benefits of interventions, value of diagnostic tests and facts about prognosis gives the patient the opportunity to match these factors with his/her own values and increases the ability of shared decision making with physicians. Therefore, evidence-based patient information (EBPI) that, similarly to a drug treatment, is rigorously developed, regularly updated and tested for effectiveness should be a major area of clinical research.

Why focussing on participation?

Integration and participation is the major goal of all medical and rehabilitative efforts referring to the International Classification of Functioning, Disability and Health (ICF, WHO 2001). By addressing participation we emphasize that it is the ultimate target of health care, and improvement of impairment or surrogate markers are noteworthy provided that they are related to participation changes. Furthermore, most studies on chronically ill patient management have shown that not only participation in family, job and society but the active engagement of patients in their care is of major relevance to improve outcomes. Therefore, addressing participation means empowering patients to gain mastery over their lives (J. Rappaport 1982).

Why is education relevant?

While health might be more adequately conceptualized as the ability to adapt than complete physical, psychological and social well-being, measures to increase adaptive behaviour are training and education. Therefore, we believe that education is a major topic in rehabilitation. Other behavioural-educational interventions might focus psychological factors as e.g. disease coping, training groups or mindfulness-based meditation, neuropsychological dimensions as meta-cognitive training or physical dimensions as exercise training. These are areas of stimulating overlap with other SIGs, nevertheless they are complex interventions whose content and effectiveness need to be fully documented.

Education may lead to deeper processing of self-concept, more elaborated perceptions and weighting of symptoms and goals as well as judgement on the health care process. Furthermore, any health care intervention should improve quality of life. Therefore, patient-reported outcome measures are at the core of this approach.

Overall goals

✓ To establish EBPI as a first step in MS rehabilitation at the beginning of the disease

- ✓ To make EBPI devise and provision a central quality criterion in the management of people with MS (PwMS)
- ✓ To show that EBPI enhances active role realisations and possibly affects health behaviours and health status

Objectives

To review educational concepts, patient information and decision support tools of MS rehab centres in Europe

To assess unmet PwMS needs in the area of patient information in Europe starting international collaborations

To systematically review, develop and test effectiveness of new MS information tools. Of primary relevance are diagnosis, prognosis, relapse management and immune therapy. Our final aim is that these tools are integrated in a comprehensive multi-cultural modular system of standardised and up-to-date educational instruments in MS.

To assess, develop and validate in different cultures MS risk knowledge tools. Again, of primary relevance are diagnosis, prognosis, relapse management and immune therapy.

To review, develop and validate in different cultures MS specific patient-reported outcome measures to assess involvement in health care and empowerment.

To initiate European comparative studies on MS risk knowledge and autonomy preferences and their matching to realized roles in medical decision making.

To initiate collaborative randomised controlled trials (RCTs) with other SIGs on educational interventions in MS.

To study factors relevant in MS decision making, especially in cooperation with the SIG neuropsychology.

To offer a methodological platform for other SIGs to study complex interventions (e.g. devise and validation, design, conduct and analysis of RCTs).

First steps

Systematic review on PwMS information tools and their effectiveness, and definition of urgently needed areas. A Cochrane Review has already been applied for.

Consensus approach on relevant MS risk knowledge in different disease stages. Translation and exchange of existing instruments has been started, a review among health professionals and PwMS in different European centers is to be initiated.

Assessment of role preferences of PwMS in different cultural settings tailored to disease stage and decisions to be taken. A revise of the Control Preference Scale (CPS; Degner 1997) is under development. Administration of different versions of the CPS in collaborating centers is planned.

Translation and adaptation of existing EBPI tools into different languages/cultures. This could be soon initiated for the Evidence-Based Self-management In Multiple Sclerosis (EBSIMS), a structured educational program on relapse management in Multiple Sclerosis.

Development of new EBPI tools and study of effects of different formats (and combinations): booklet, face-to-face interview, group session, and internet-based. A follow-up meeting should discuss the area of utmost importance and initiate a systematic review of the evidence.

Next steps

An interim meeting in addition to the SIG meeting Participation in Jan/Feb 2010 in Hamburg is planned. We aim at involving university and hospital MS centers from Europe as well as the MS Societies for this meeting.

Topics for the interim meeting:

- Systematic review on patient information tools;
- Risk knowledge consensus;
- Presentation of an EBPI example and discussion of adaptation and implementation in other countries;
- New tools - what is needed?
- Update on ongoing projects.

At a SIG meeting in Goteborg we aim to present **the following**:

- **Preliminary results** of the systematic review **on patient information tools**;
- Consensus strategy on risk knowledge questionnaire;
- **a translated, adapted EBPI tool (f.e. EBSIMS) with pilot evaluation data**

A session on "Behavioural interventions in MS" is planned in the main programme as well.

We want you!

But as our core group is still small, we invite you to join us.

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