25th Congress of the European Committee of Treatment and Research in Multiple Sclerosis
24th Annual Conference of Rehabilitation in MS
September 11-13, 2019
Stockholm, Sweden

Meeting RIMS SIG "Patient Autonomy"
Discussion of potential SIG projects to work on

Around 20 MS health professionals and researchers (e.g. neurologists, psychologists, nurses, health scientists) as well as a patient consumer from 8 countries participated in the 2019 SIG interim meeting during the ECTRIMS conference in Stockholm. The meeting was also joined by people from other SIG groups.

We used this meeting to introduce and discuss 3 project ideas devised in the last meetings and with the help of few collaborations (please see the project outlines below for detailed information).

Concerning the motherhood choice project, several people expressed interest to be involved in a multinational survey. We plan to realize the international survey without additional funding.

Further, the projects addressing patient autonomy in PPMS and severe MS were discussed. As the PPMS project would be probably easier to realize within the SIG with limited financial resources, there was also a lot of interest in the advance care planning project.

Therefore, our intention is to submit applications on steps of both projects to the RIMS RiGra grant programme (deadline: December 1, 2019).

The next steps are to e-mail the SIG and all people, who visited the SIG meeting in Stockholm to build groups to proceed the work on the motherhood choice project and the applications on the other projects.

Project idea outlines

Project idea # 1: Advance care planning in people with severe MS

Advance care planning (ACP) is any process that enables individuals to identify their values, reflect upon the meanings and consequences of serious illness scenarios, define goals and preferences for future medical treatment and care, and discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions (Rietjens 2017).

In a recent consensus review on the development of palliative care for patients with chronic and progressive neurological diseases, ACP has been recommended, as follows: 'Communication with patients and families should be open, including the setting of goals and therapy options, and should be structured following validated models (Level C). Early ACP is strongly recommended, especially when impaired communication and cognitive deterioration are possible as part of disease progression (Level C)' (Oliver 2016).

In the MS context, within the Palliative care for people with severe MS guideline, we performed a systematic review in order to identify studies (any design) on ACP for people with severe MS. The evidence is scarce and no intervention has been specifically developed addressing this population.

ACP has mostly been studied for specific groups like patients with terminal diseases or in palliative care. There are few RCTs, mostly conducted in the United States, on the effectiveness of ACP programs like Respecting Choices, Let Me Decide, or different self-developed interventions (Brinkman-Stoppelenburg 2014).

The final aim of the present project idea will be to evaluate an ACP program in people with severe MS, which has been proven effective in other settings and countries, compared to optimized usual care. To this end, we will use a mixed-method approach, following the MRC guidance for development and testing of complex healthcare interventions (Craig 2008).

Results can provide the evidence basis needed for the implementation of ACP in daily practice at the international level.

Steps:

- State-of-the-art and comparison of ACP laws/national programs/prerequisites in different countries;
- Literature review to identify most suitable ACP programs to be implemented in MS.
- Adaptation of the ACP program to be tested in the MS context (e.g. identification of: facilitators, intervention components, etc.);
- Protocol development of an international collaborative trial on the effectiveness of the ACP program in people with severe MS.

→ Organizations to be involved: RIMS, other SIGs, NMSS society of the participating countries; European Association of Palliative Care (EAPC), others?

References

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- Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008;337:a1655.
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Project idea # 2: Information needs of people with PPMS

Around 10-15% of multiple sclerosis (MS) diagnoses could be assigned to primary progressive MS (PPMS). The mean age of onset is around the age of 40. There is often a different symptom onset (usually spinal syndrome or a spastic paraparesis) than in relapsing remitting MS (RRMS) and compared to RRMS there is nearly no difference in gender. According to data from the London Ontario Cohort, people with PPMS reach an DSS score of 6 after 8 years (Rice 2013).

So far, Ocrevus® is the only disease modifying drug licensed to treat people with PPMS showing imaging features characteristic of inflammatory activity.

Therefore, rehabilitation/ symptom management plays an important role in PPMS. While people with PPMS rate balance and mobility impairments, weakness, reduced cardiovascular fitness, ataxia, fatigue, bladder dysfunction, spasticity, pain, cognitive deficits, depression, and pseudobulbar affect as important symptoms, a literature review showed that there are nearly no studies on those symptoms in progressive MS (Feinstein 2015).

A review addressing lifestyle management in progressive MS (SPMS and PPMS) showed the following results:

- Possibly effective: aerobic exercise training on cardiorespiratory fitness (1 study)
- Probably effective: mindfulness training on psychological distress, depression, anxiety, pain, and QoL (1 study)
- Inadequate evidence: dietary modification (2 studies) and combined wellness interventions involving exercise training, meditation, and dietary modification (1 study) (Venasse 2018).

Besides a clear lack in rehabilitation interventions, there is also a lack on evaluated interventions on information provision for people with PPMS. Here, a recently updated Cochrane review included no studies specifically addressing people with PPMS. Besides the evaluation of interventions, there are nearly no studies on information needs of people with PPMS (e.g. qualitative studies or surveys).

Therefore, we propose the following project to the group:

“Information needs of people with PPMS – a multinational project”

Steps:

1. Scoping review to identify the studies on information needs of people with PPMS;
2. Qualitative study (focus groups/interviews) on information needs of people with PPMS in different countries (people with PPMS, significant others of people with MS, health professionals)
3. Development of a questionnaire on information needs of people with PPMS
4. Multinational survey
5. Discussion of possible interventions to address the information needs of PPMS and the next steps to take.

References

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- Köpke et al (2018) Information provision for people with multiple sclerosis. Cochrane Database Syst Rev. 2018 Oct 14;10:CD008757. doi: 10.1002/14651858.CD008757.pub3

Project idea # 3: Motherhood choice in MS

Multiple sclerosis (MS) disproportionately affects young women of child-bearing age (Browne 2014). Therefore, the topic of pregnancy is quite often very important for women with MS.

Women with MS, who are considering pregnancy often express concerns about whether they will pass the disease on to their babies, whether having MS or taking medications will harm the baby, and whether their disease will progress, leaving them unable to care for their babies (Payne 2010, Prunty 2008a). In clinical practice, uncertainties and lack of specific knowledge about pregnancy in MS are common both on the patient and even health professionals' side leading potentially to a decreased realisation of motherhood (Herndon 2004, Thone 2017). What women with MS know about having a baby and how this, along with their personal preferences and risk taking attitude, influences their family planning decisions, however, has not been thoroughly studied.

In Germany (Anne/Christoph/Julia) a mixed-methods study on motherhood choice for women with MS has just started and will be carried out in collaboration with Italy (Alessandra/Andrea). This project aims to develop and pilot a decision support tool and a decision coaching programme on motherhood choice in MS. A new questionnaire on risk attitudes and anxieties (MPAQ) will be developed, and a questionnaire addressing knowledge will be translated-adapted and revised (motherhood choice knowledge questionnaire – revised, MCKQ-R; Prunty 2008b).

Thus, we propose the following project to the group:

"Information needs, concerns, anxieties and knowledge of women with MS who are considering motherhood – a multinational project"

Steps:

1. Qualitative study (focus groups/interviews) on information needs, concerns, anxieties and knowledge of women with MS who are considering a pregnancy.
2. Revision and translation-adaptation of the MCKQ-R following international guidelines; translation-adaptation of the MPAQ.
3. Multinational survey to validate the MCKQ-R and the MPAQ.
4. Discussion of possible interventions (e.g. decision coaching, web-based decision aid) to address the information needs, concerns and anxieties of women with MS who are considering a pregnancy and the next steps to take.

References

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