

## **Meeting RIMS SIG “Patient Autonomy”**

**Aim: Discussion of potential SIG projects to work on  
*September 11, 2019 – 5pm-7pm, RIMS room (K14)***

### **Agenda SIG “Patient Autonomy” in-between meeting**

- 5pm Discussion on the Motherhood choice project (project idea # 3)
- 6pm Discussion of projects addressing patient autonomy in PPMS and severe MS (project ideas # 1 & 2)
- 7pm Conclusion and perspective

### **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).

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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

- Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014;28(8):1000-1025.
- 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.
- Oliver DJ, Borasio GD, Caraceni A, et al. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurology* 2016; 23: 30–38.
- Rietjens JAC, et al. Definition and recommendations for ACP: an international consensus supported by the EAPC. *Lancet Oncol* 2017; 18: e543–51.

### 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:

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- 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

- Rice CM et al. (2013) Primary progressive multiple sclerosis: progress and challenges. *Neurol Neurosurg Psychiatry*;84:1100–1106.
- Feinstein A et al (2015) Progressive multiple sclerosis. *Lancet Neurol*, 14. 194 – 207.
- Venasse M (2018) Exploring Wellness Interventions in Progressive Multiple Sclerosis: an Evidence-Based Review. *Curr Treat Options Neurol* (2018) 20: 13.
- 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

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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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