

Special Session 6 EFNA/EAN: Eliciting patient's preferences for effective shared decision-making

SPS06_1

Information: How to support patients to take evidence-based decisions

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Patient information is a prerequisite of patient involvement in decision making founded in the bioethical right of patient autonomy. It is therefore at the core of patient centred medicine which is increasingly developing as a paradigm in medicine. In clinical guidelines but also legal advices patients gain more right but also duties to be informed. While a plethora of medical information exist very few follow rigorous development guidelines. Evidence-based patient information (EBPI) is probably the most elaborate approach in this area which means including patients in the development process and communicating study findings in numbers and graphical formats at best based on systematic reviews. At best EBPI is tested in clinical studies from phase 1-3 comparable to drug developments with the ultimate goal to improve disease adjustment. EBPI is especially relevant in chronic conditions with ambiguous management options. Clinical Neurology includes therefore many scenarios in which this approach can be regarded as the ideal management concept. Examples include decision making on prophylaxis in migraine, decision making on antiepileptic treatment, choice of anticoagulation after cardioembolic stroke, decision making on L-Dopa or apomorphin pump or brain stimulation in Parkinson's disease and immunotherapy in multiple sclerosis. However, as reasoning and decision making might be substantially impaired in neurological conditions neurology imposes considerable challenges f.e. in decisions on treatments in dementia or palliative care. However, fueled by research from oncology and psychiatry evidence is increasing that even here substantial patient involvement is possible. While medical information traditionally has been given via physicians especially the internet has revolutionized patient information, not always at the sake of patients. But as well physicians receive a wealth of information but often from pharmaceutical companies which is often biased. This underlines the need of information based on transparent development guidelines. But EBPI includes other challenges, a major one is communication of medical data which are often difficult to understand even for physicians. Another one is updating which needs considerable resources. Web-based information modules such as lectures, podcast, educative videos offer many opportunities. Combining web-based at best individually tailored information with face-to-face information in structured decision making processes might be perspective. But in general the developments are slowly and even more so in neurology. In most areas in neurology EBPI virtually do not exist. Some efforts have been made in multiple sclerosis.

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SPS06_3

The impact of carer 'shared (disease management) responsibility' on 'shared decision making' for older persons managing multimorbidity.

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Introduction: For older persons with multimorbidity (PwMs), self-management is a complex process that involves integration of knowledge and tasks for multiple, and often interacting, chronic diseases (1). Shared decision making (SDM) refers to clinicians working together with patients and/or their caregivers to decide which care plan best fits individual patients and their lives, when there is more than one reasonable option (2). The current study aimed to understand the role of caregiver support related to SDM for older PwMs (aged over 65). The data presented were collected as part of an extensive requirements gathering exercise to inform the design of ProACT, a digital health ecosystem that aims to support self-management and improve integration of care for older PwMs.

Methods: Semi-structured qualitative interviews and focus groups were conducted with 38 older PwMs, 17 informal carers and 22 formal care workers across the Irish and Belgian health systems. Interviews and focus groups were transcribed and analysed using thematic analysis.

Results: PwMs in Belgium availed of higher levels of carer support and 'shared responsibility' for disease management with their carers. This was reported as having a potentially positive impact on SDM.

Conclusion: Increased support from caregivers to PwMs may have a positive impact on improving SDM, due to the enhanced 'shared responsibility' between PwMs and carers to disease management.

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2. Van der Flier, W.M., Kunnemann, M., Bouwman, F.H., Petersen, R.C., Smeets, E.M.A. (2017). Diagnostic dilemmas in Alzheimer's disease: Room for shared decision making. *Alzheimer's and Dementia: Translational Research and Clinical Interventions*, 3(3), 301-304.