W14: Shared Decision-Making: Patient Experience and Priorities in Urology and Pelvic Pain Management

Workshop Chair: Pedro Blasco Hernández, Spain
24 October 2024 15:00 - 16:30

Start	End	Topic	Speakers
15:00	15:05	Introduction	Pedro Blasco Hernández Katrine Petersen
15:05	15:20	What does SDM mean?	Francisco Cruz Miranda Rodrigues
15:20	15:30	Pelvic health, presenting less invasive options, timing and quality of life issues	Katrine Petersen Helena Frawley
15:30	15:50	Pelvic pain, the patient experience and priority setting?	Judy Birch
15:50	15:55	Questions	All
15:55	16:10	Why do we need SDM?	(Mary) Lynne Van Poelgeest-Pomfret
16:10	16:25	SDM steps and procedures	Pedro Blasco Hernández Alicia Martín Martínez
16:25	16:30	Questions	All

Description

The main goal of this workshop is to introduce the shared decision-making procedure and approach. Gaining an insight first into the concept of what SDM is, leading to the development and implementation of SDM as a standard element of a patient's roadmap to treatment.

This workshop will explore:

- What meaningful patient experiences can look like and how they can affect treatment outcomes
- How to leverage the voice of the patient in creating interventions whilst understanding and presenting alternative options in line with patient priorities
- What KPIs are important and how best to measure them.

Pelvic pain management:
To ensure that clinicians and patients can have a productive conversation and engage in shared decision-making, both parties must have a clear understanding of the various treatment options available, along with their associated risks and benefits. Our goal is to present the priorities of the patient and emphasize the importance of conservative treatments, such as physiotherapy interventions, which can help improve the patient's quality of life.

The prevalence of chronic pelvic pain varies in the literature, with estimates ranging between 15% and 25%. However, there are fewer studies on this subject from less developed countries (Latthe et al., 2006). Pelvic pain accounts for up to 20% of gynaecological appointments, and it poses a significant challenge for clinicians (Vincent and Evans, 2021). Pain has often been viewed because of tissue dysfunction. EAU guidelines highlight pelvic pain syndromes which may not resolve with pharmacological or surgical interventions. We have emerging research and evidence for the mechanisms that maintain persistent pain. Although pain is far from being fully understood, we know that pain education can improve our own and the patient's understanding of their condition. It is helpful to explain that pain can exist without tissue damage, changes in the nervous system can improve, and there are strategies to help with pain management and function. This can improve the chances of the patient making well-informed choices as part of SDM.

SDM has always been an integral component of evidence-based practice, described as "the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care" (Sackett 1996). Patients' preferences and actions remain an integral part of the more modern concept of clinical expertise and evidence-based practice (Haynes, 2022).

Patient priorities in pelvic pain:
We need more relevant research that addresses the priorities and needs of the patients in pelvic pain. Research that has made the patient voice central, and for endometriosis-associated pain, for example, has reported a need for more conservative management options (NHS Scotland (2023). There needs to be a focus on self-management methods to help with the emotional/psychological impact of living with symptoms of endometriosis (James Lind Alliance 2022).
A meta-synthesis reported that 'poor quality of life is prevalent and recurrent' in people with chronic pelvic pain, highlighting priorities of addressing the impact of pain, providing holistic care, and fostering coping skills (Ghai et al., 2021), and this was echoed by Giese et al. (2023) in an Australian study of people affected by endometriosis.

Priority setting in Australia and New Zealand similarly identified treatment of symptoms as the highest priority, and effect on lifestyle intervention such as exercise came eighth out of ten priorities (Amour et al., 2023)

Patients with lived experience have their individual experiences, but the Pelvic Pain Support Network in the United Kingdom offers further perspectives on what matters to patients in their consultations with the results of a very recent survey.

To facilitate meaningful conversation and SDM, it is, of course essential that both clinicians and patients have a grasp of alternative options, risks and benefits of a range of potential treatments.

Physiotherapy in the management of pelvic pain:

All healthcare professionals should take a trauma-informed biopsychosocial approach with each patient and consider the effectiveness and potential risks of non-invasive and invasive treatments. It is important to address any fears or unhelpful beliefs that may prevent the patient from maintaining their health.

Physiotherapists have the necessary skills to reduce the severity of pain the impact of pain on a person's life and improve patients' physical function. Those with expertise in managing pelvic pain can provide personalised interventions and education to help patients maintain mobility, relationships, bladder, bowel, and sexual function. They can also assist with managing flare-ups. There is now strong evidence of the effectiveness of physiotherapy treatment in women with chronic pelvic pain (Starzec-Proserpio 2024).

It is crucial to focus on reducing harm and providing services that align with patients' individual needs. This can be achieved through co-designing interventions with patients.

It is not enough to consider a treatment successful based on objective measures alone. Clinicians should also ask questions about the patient's well-being and the impact of the treatment on their daily activities. Early consideration of holistic and low-risk interventions is important and should not be a last resort.

Take home message:

Patients with persistent pelvic pain may require multidisciplinary options for effective management. This aspect must be included in Shared Decision Making (SDM) discussions. To achieve fully informed consent, patients should have an opportunity to gain a better understanding of their pain and alternative options. To consider patients' preferences and priorities. In the case of pelvic pain, SDM involves working within a scientifically established protocol, which healthcare professionals must know and apply. We understand that not all healthcare organisations may have access to a multidisciplinary pelvic pain team. However, we encourage exploring available resources, such as physiotherapy options, and involving patients in the development of services to ensure a co-productive and patient-centred approach. SDM is not only an stablished way of working and taking decision but for sure a way of working that will change our everyday work and healthcare system structures as will be shon during the workshop

Aims of Workshop

Shared Decision-Making (SDM) is a process whereby clinicians and patients work together to make decisions about patients' care based on reliable information. To become proficient in SDM, clinicians must prioritise patient preferences during the clinical encounter. They must also know all available treatment options and their associated risks and benefits. While treatments for painful conditions are often aimed at repairing tissue dysfunction, pelvic pain syndromes may not be resolved with pharmacological and surgical interventions. This workshop will provide you with insights directly from patients and highlight alternative treatment options and communication skills required to improve the patient's quality of life.

SDM process is well defined and with concrete steps that must be considered. It is NOT only a matter of taking into account the patient's opinion but also establishing a working method that allows, following specific steps established in the scientific literature, to carry out shared decision-making between the parties involved: professional and patient. Throughout the workshop, we will describe what are the steps of the shared decision-making process and all that this implies at the level of clinical care. Steps include.

1. Seeking patient collaboration
2. Help patient explore and compare treatment options.
3. Assess patient´s value and preferences.
4. Reach a decision together.
5. Evaluate decisions and processes to improve them in the future.

Educational Objectives

This workshop's aims are:

1. Introducing attendees to SDM's importance in treatment planning. Participants will learn practical strategies for implementing SDM and assessing its effectiveness. Chronic pelvic pain, affecting 15-25% of individuals, is addressed, emphasising non-pharmacological and non-surgical management options highlighted by research focusing on patient priorities.
2. Explain the steps involved in a shared decision-making process. The way to develop them and the necessary tools. We will present the necessary checklist to verify that a real shared decision-making process is being carried out. New training needs require developing a shared decision-making process (communication, empathy, the transmission of information, listening, etc.) as well as showing examples of tools to help the SDM procedure.

3. The workshop integrates insights from a patient's lived experience, published research and relevant physiotherapy interventions to inform decision-making and support patients with pelvic pain. Attendees will explore reducing harm and aligning interventions with patient needs, advocating for co-designed services to enhance patient-centred care.

4. Developed with input from a multidisciplinary team, including medical doctors, patients and healthcare professionals, the workshop addresses challenges in initiating SDM conversations. Led by a patient and experienced physiotherapist, it provides practical tools for improving quality of life and fostering collaboration between clinicians and patients. Through discussions participants will gain a deeper understanding of informed consent and SDM in action, leaving them empowered to integrate these principles into their practice.

Learning Objectives

1. What meaningful patient experiences can look like
2. Patient perspectives, alternative and conservative options for pelvic pain, and understanding of patient priorities
3. Outcomes/KPIs/benchmarking and getting it right

Target Audience

Urology, Urogynaecology and Female & Functional Urology, Bowel Dysfunction, Pure and Applied Science, Conservative Management

Advanced/Basic

Basic

Suggested Learning Before Workshop Attendance

1. Armour M, Ciccia D, Yazdani A, Rombauts L, Niekerk LV, Schubert R, Abbott J. Endometriosis research priorities in Australia. Aust N Z J Obstet Gynaecol. 2023 Aug;63(4):594-598. doi: 10.1111/ajo.13699. Epub 2023 May 24. PMID: 37226362.
2. http://uroweb.org/guidelines/chronic-pelvic-pain/

3. Ghai, V., Subramanian, V., Jan, H. et al. A meta-synthesis of qualitative literature on female chronic pelvic pain for the development of a core outcome set: a systematic review. Int Urogynecol J 32, 1187–1194 (2021). https://doi.org/10.1007/s00192-021-04713-1

4. Stannard C, Bernstein I. NICE guideline NG193 for chronic pain: reasons to be cheerful. Br J Gen Pract. 2021 Oct 28;71(712):489-490. doi: 10.3399/bjgp21X717425. PMID: 34711558; PMCID: PMC8544154.

5. Vincent K, Evans E (2021) An update on the management of chronic pelvic pain in women, Anaesthesia, 76 (Suppl. 4) 96-107 https://doi.org/10.1111.anae.15421

6. http://uroweb.org/guidelines/chronic-pelvic-pain/https://www.jla.nihr.ac.uk/priority-setting-partnerships/endometriosis/top-10-priorities.htm

7. https://www.gov.scot/publications/endometriosis-lived-experience-insight-report-2023/

8. https://d56bochluxqnz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Chronic-Pelvic-Pain-2023.pdf

9. Latthe, P., Latthe, M., Say, L. et al. WHO systematic review of the prevalence of chronic pelvic pain: a neglected reproductive health morbidity. BMC Public Health 6, 177 (2006). https://doi.org/10.1186/1471-2458-6-177Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence-based medicine: what it is and what it isn't. BMJ. 1996 Jan 13;312(7023):71-2. Doi: 10.1136/bmj.312.7023.71

10. Haynes RB, Devereaux PJ, Guyatt GH. Physicians' and patients' choices in evidence based practice. BMJ. 2002 Jun 8;324(7350):1350. doi: 10.1136/bmj.324.7350.1350.

11. Starzec-Proserpio M, Frawley H, Bø K, Morin M. Effectiveness of non-pharmacological conservative therapies for chronic pelvic pain in women: a systematic review and meta-analysis. Am J Obstet Gynecol. 2024 Aug 12:S0002-9378(24)00827-5. doi: 10.1016/j.ajog.2024.08.006. Epub ahead of print.