EAPM Main Conference - Thursday, June 20 2019 - Parallel sessions 2 - 17.45 - 19.15
Patients’ Experiences, Expectations and Decisions

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Experience Sampling Method for patients with endometriosis

Aim
Endometriosis symptoms have a significant social and psychological impact, decreasing quality of life. Assessment of symptoms is relevant to evaluate the natural disease course over time and to follow-up treatment efficacy. However, currently used assessment methods are mainly retrospective, which have important limitations such as recall- and ecological bias. The Experience Sampling Method (ESM), an electronic questioning method characterized by random repeated momentary assessments, overcomes these limitations with taking into account contextual and psychological factors [1].

Methods
Based on the international guidelines on the development of Patient Reported Outcome Measures (PROMs), items from validated questionnaires were selected during focus groups. Furthermore, participants were instructed to bring forward other items they considered essential. Qualitative data analysis was conducted by ATLAS.ti and the final items were selected during a multidisciplinary expert meeting.

Results
Momentary assessment items contained questions about endometriosis symptoms, general somatic symptoms, psychological symptoms, contextual/social information and use of food and medication. Additionally, a morning questionnaire was included containing information about sleep and sexuality. Items will be repeatedly assessed with the MEASURE (Maastricht Electronical Abdominal Symptom REporting) application.

Conclusion
There is a need for a modern assessment tool for endometriosis which overcomes the limitations of today’s retrospective questionnaires. Therefore, this ESM tool is being developed following the FDA PROM development guidelines to measure real-time symptoms in the context of daily life.

Reference

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The Treatment Expectation Questionnaire (TEX-Q) – a generic multidimensional scale measuring patients’ treatment expectations

Aim
While patient expectations are a relevant predictor for health outcomes and a central mechanism of placebo and nocebo effects, the lack of conceptual clarity and generic assessment tools impedes an integrated understanding of expectations across treatments. The aim of this study was to develop and validate a generic, multidimensional scale measuring patient expectations of medical and psychological treatments.

Methods
The Treatment Expectation Questionnaire (TEX-Q) was developed based on the integrative model of expectations (Laferton, Kube, Salzmann, Auer & Shedden-Mora, 2017). Its multidimensional structure assesses three expectation constructs (probabilistic expectations, value-based expectations, process expectations) across three outcome domains (benefit, adverse events, impact). The development steps include systematic literature review, expert ratings, and cognitive patient interviews. Item characteristics, factor structure, internal consistency and construct validity are examined in 300 individuals prior to receiving different medical and psychological treatments.

Results
After systematically reviewing the literature, content validity of 78 preliminary items was rated by 13 experts according to item fit, comprehensibility, and clarity. The best 53 items where evaluated for comprehensibility, acceptability, phrasing preference and consistence of understanding by interviewing 11 patients prior to treatment using the “think aloud”-technique. Psychometric properties of a 35-item pilot-version developed from this analysis and the validated final version of the TEX-Q will be presented.

Conclusion
The TEX-Q is a generic, multidimensional self-report scale measuring patient expectations of medical and psychological treatments. Overcoming the constraints of adhoc scales and disease-specific assessment methods for expectations, it allows comparing the impact of expectations across different conditions and treatments.

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Evaluation of a decision coaching program for structured decision support in preference sensitive decisions of risk-adapted prevention for BRCA1/2 (BReast CANcer) gene carriers: Study of a German Multicentre Study

Aim
Around 70,000 women are newly diagnosed with breast cancer and 7,800 women with ovarian cancer each year in Germany. In around 30% of these cases there is a familial clustering for these cancer types. 25% of these women carry a BRCA 1/2 gene mutation. Women with this gene mutation have an elevated risk for breast and ovarian cancer throughout their lifetime. These women have multiple options of preventive care. For example, they can have their breasts or ovaries surgically removed or participate in an intensive mammography screening program. To make a decision about their preventive options, women need to be fully informed and counseled.

The current project aims at supporting affected women with an individual decision coaching (DC) session. The goal is to improve understanding of benefits and risks of all preventive options. This should lead to a higher decision competence and quality.

Methods
The effectiveness of the DC will be evaluated in six centers for familial breast and ovarian cancer Germany-wide through a randomized-controlled trial funded by Innovation Fund of the Federal Joint Committee. Around 400 women with a BRCA ½ gene mutation will be recruited through the attending physician and randomized into experimental or control group. Women in the control group will receive standard routine care. Women in the experimental group will receive the DC by specialized breast care nurses.

Results
First results could be reported in three years.

Conclusion
If the decision coaching program will reliably improve the decision quality, it can be integrated into routine care.

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Affective symptoms in patients with endometriosis: A systematic review and meta-analysis

Aim
Severity of endometriosis is not directly related to the degree of symptoms. Therefore, an association with psychological distress such as depression and anxiety is suggested. A systematic review informs about the strength of the associations between these affective disorders and endometriosis.

Methods
After literature search 1499 records were identified. Thirty articles were included describing an association between endometriosis and depression or anxiety using validated assessments.

Results
Affective symptoms are more common in patients with endometriosis-related pain comparing to pain-free endometriosis patients and healthy controls (pain-focused hypothesis). No positive association was found comparing patients with endometriosis related pain and patients with chronic pain from other conditions (disease-focused hypothesis). A meta-analysis with articles using the Hospital Anxiety and Depression Scale comparing 196 endometriosis patients and 147 controls, revealed a not statistically different increased risk for anxiety (odds ratio 1.30 p0.656) and depression (odds ratio 1.15 p0.689) in endometriosis patients.

Conclusion
This review confirms the pain-focused hypothesis and rejects the disease-focused hypothesis for the increased risk of anxiety and depression in endometriosis patients. Due to heterogeneity in methodological issues, meta-analysis for these specific hypothesis was not possible. In this meta-analysis pain-free endometriosis patients were also included. Therefore it is possible that analysis did not reach significant difference in risk for affective symptoms in endometriosis patients. Standardized research groups and assessment tools are necessary. This review confirms the importance of psychiatric screening in patients with endometriosis-related pain, as this may influence the perception of symptoms, prognosis, compliance with treatment and quality of life.

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Having a co-morbid CVD at time of cancer diagnosis severely impacts HRQoL: results from the profiles registry

Aim
To examine the relation between co-morbid cardiovascular disease (CVD) at the time of cancer diagnosis and health-related Quality of Life (HRQoL) among cancer survivors diagnosed with colorectal, thyroid, prostate, endometrium, ovary cancer, melanoma, (non-)Hodgkin lymphoma, chronic lymphocytic leukemia (CLL), or multiple melanoma (MM).

Methods
Secondary analyses were based on data from the PROFILES registry. Data on co-morbid CVD at cancer diagnosis was extracted from medical records. HRQoL was measured at a median 4.6 years after cancer diagnosis. General Linear Model Analyses were run for the total group of cancer survivors and for each malignancy.

Results
In total, 5,930 cancer survivors (2,281 colorectal, 212 melanoma, 1,054 prostate, 280 thyroid, 177 endometrium, 194 Hodgkin, 874 non-Hodgkin, 242 CLL, 227 MM, and 389 ovarian cancer survivors) were included. For the total group, survivors who had a CVD at the time of cancer diagnosis (n=1,441, 23.4%) reported significant and clinically important lower scores on global QoL, physical functioning and dyspnea (p's <0.05) compared to those without CVD. Co-morbid CVD at cancer diagnosis has a negative impact on global QoL, the six functional scales and the symptoms fatigue and dyspnea across malignancies (i.e. colorectal, prostate, endometrium, ovary cancer, melanoma, non-Hodgkin lymphoma, and CLL). No significant relations were found among thyroid and endometrium cancer, Hodgkin lymphoma and MM survivors, likely due to small numbers.

Conclusion
Care givers should pay attention to the vulnerable group of cancer survivors with comorbid CVD at diagnosis when it comes to their HRQoL, even years after cancer treatment is finished.

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