Design and feasibility of integrating patient centered-outcome dashboards in endometriosis care

Alba Nicolas-Boluda, Marc Even, Jérôme Bouaziz, Arnaud Fauconnier

ONE CLINIC

alba.nicolas-boluda@one.fr

Introduction

The worldwide prevalence of endometriosis is of 10% on average in women of fertile age. Patients suffering from endometriosis manifest a varied symptomatology including pelvic symptoms, dysmenorrhea, chronic pelvic pain, dyspareunia, intestinal or urinary tract problems, and infertility. Evidence has shown that the systematic use of information from Patient Reported Outcome Measures (PROMs) in different domains contributes to better communication and decision-making between clinicians and patients, consequently improving patient satisfaction of care. This, transposed to endometriosis care, could significantly improve care. The recent development of digital tools facilitate the collection of PROMs and their routine use in clinics. PROMs can be collected digitally prior to the consultation at the patients' home or in the waiting room and results can readily be displayed to the clinician on a dashboard ready to be used as a support during consultation. The objective of this study is to design and evaluate the feasibility of the integration of a patient centered-outcome dashboards in endometriosis care. To do so, we engaged patients, physicians and design experts in the design of patient centered-outcome measures dashboards, that allow visualizing PROMs and clinical data (Clinician Reported Outcome Measures, CROMs) for endometriosis.

Methods

We designed and assessed the feasibility of integrating dashboards into endometriosis care.

We performed this in 3 steps:

1. understand the needs of patients and physicians through focus groups;
2. build and refine a dashboard prototype;
3. test dashboards with patients and physicians in endometriosis care.

The PROMs and CROMs included in this dashboards were those selected by an international Delphi study. An initial feasibility test was performed to compare the digital data collection method with respect to traditional paper-pen method in a small cohort of patients (n=10). The rate of missing data and concordance between data collection method.

Results

Three focus groups, two physician focus group (n = 11) and one patient focus group (n = 8) took place to prioritize the needs and preference for the design of a dashboard visualizing PROMs and clinical data for endometriosis. Different dashboards designs with different types of charts were proposed to the participants of the different focus groups, their comments and preferences were considered. Given their needs, we built a refined prototype of dashboard that allows visualization of the different PROMs and CROMs as well as the evolution of PROMs in time, highlighting significant events in the care pathway (surgery, change of therapeutic protocol). Pilot testing of the dashboard to determine the feasibility of its use in particular the digital data collection method with respect to traditional paper-pen method was performed in a small cohort of patients (n=10). The proportion of missing data did not vary from digital to traditional data collection, the missing rate was of 10%. Moreover, the rate of concordance between both data collection methods was of 72%.

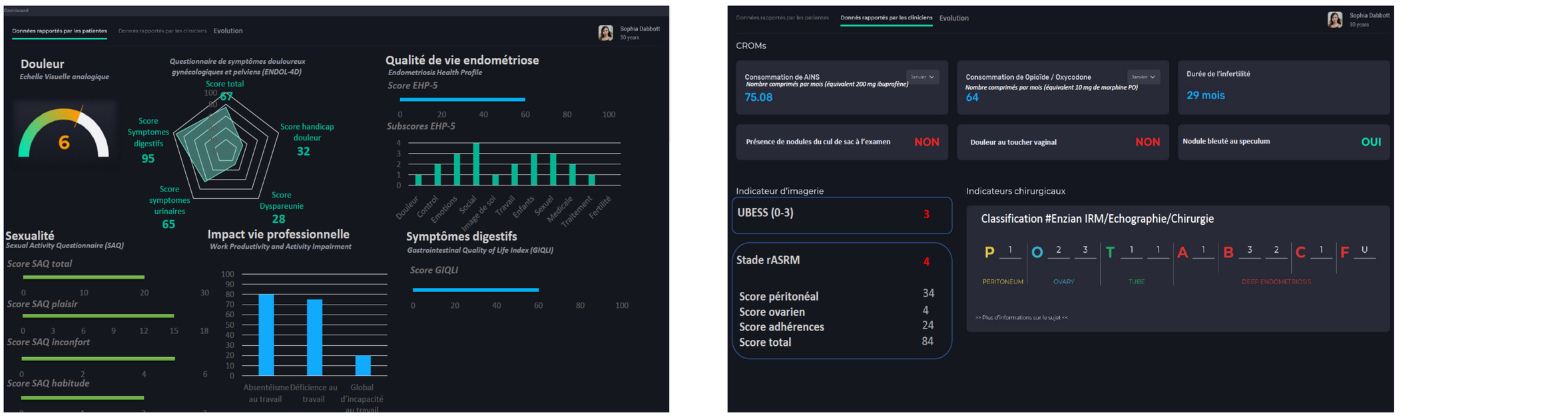

Figure 1. Two screenshots of the proptype of the dashboard that allows the visualization of the different PROMs and CROMs .

Conclusion

Preliminary data shows that the digitalization of PROM and CROM data collection and their visualization in simplified dashboard is a promising approach solution for the integration of patient-reported data into endometriosis care. This will allow physicians to complement their traditional medical consultation with the patients' view on their disease, transitioning towards a patient-centered care and the use of PROMs as shared-decision making tool. The key to a successful implementation of this kind of approach is the participation of patients and physicians in the design of the dashboard, allowing its tailoring to fit their daily needs. We have approached this challenge applying a multiple stepwise method to "ask" users for input on visual outcome. The next steps of this project is performing a feasibility study on a bigger cohort (n=128) patients focusing on measuring the usage rate both by patients and the medical team.

Ethics approval

This study has received ethics approval from the *Comité d'Ethique de la Recherche end Obstétrique et Gynécologie (CEROG)* in 2021 (number 2021-GYN-1203)

ICHOM 2022
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