



The Importance of Patients When Measuring Outcome Measures

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In this issue Matthew Barber presents a summary of the Ulf Ulmsten lecture he was invited to give at the 2023 Meeting of the International Urogynecological Association in The Hague. “Measuring pelvic organ prolapse: an evolution” is a captivating and thoughtful review of the advancements in quantifying pelvic floor symptoms and anatomical outcome measures after pelvic floor surgery over the years. It intrigues me that Dr Barber has changed his opinion on what is important to our patients before and after pelvic floor surgery after much research. I am especially enthralled that he courageously tells us about his previous misconceptions.

Anyone who is dealing with patients with pelvic floor dysfunction knows that most women do not care about anatomical outcomes. They do not want to have symptoms and many will be happy with a reduction in their symptoms. This has led to many studies investigating preset goal achievements by patients. Whether these goals have been achieved after interventions to treat pelvic floor problems is important to our patients and this knowledge has changed my opinion about what we are able to do as surgeons and what patients want us to do. Quality of life is the key issue but the concept of quality of life is also a dynamic one. The gap between expected and experienced quality of life, also known as the “Calman gap”, may change over time [1]. This corresponds to Matthew Barber’s exploration of the waxing and waning of pelvic floor symptoms, especially bulge symptoms, in women with pelvic organ prolapse. It might be that women are at times more or less aware of their prolapse and it might also be that they care more or less.

Many women adjust their expectations of quality of life given different situations in life. An 80-year-old woman may be very delighted with being able to travel and walk, despite the fact that she may not be able to run anymore. In her fifties this would have been a major problem for her, but

obviously we all have to adjust with ageing. Nevertheless, urinary incontinence, for example, may be a major problem at all times in life. Matt Barber’s suggestion to use continuous outcomes measures over multiple time points is really interesting and a promising tool. It should also take into account this gap between desired and experienced quality of life.

On the other hand, I think we still need to measure objective outcomes as the intention of pelvic floor surgery. However, even the pelvic organ prolapse quantification (POPQ) system is not entirely objective, as it may depend on the amount of straining effort during the examination, the time of the day, whether the rectum is filled with gas or stool, and also on the instructions given to the patient. Obviously, surgeons prefer to see anatomically correct vaginal support postoperatively, as a token of good “craftsmanship”. If the patient still has pelvic floor symptoms, at least we have performed well. Unfortunately, pelvic floor symptoms do not necessarily follow restored anatomy and closing this gap requires further research.

Fortunately, quality-of-life assessment tools, especially disease-specific questionnaires, have improved enormously, which advances women’s health and well-being. There were times when papers described sexual function with terms such as “normal coitus” or “adequate vagina” and urinary incontinence was assessed only during urodynamic studies because the bladder was considered an “unreliable witness”. I fully agree with Barber’s conclusion and suggestion to collect data on symptoms as well as on anatomy. I also think we have to improve our symptom assessment inventory and make it applicable to cohorts around the world. We have already learned that we have to validate and perform appropriate translations and cross-cultural assessments of disease-specific symptom questionnaires. It would be a great achievement if all studies on pelvic floor dysfunction could use similar patient-related outcome measures.

In the recently updated Cochrane reviews [2] we have used subjective patient-related outcomes such as stress urinary incontinence and bulge symptoms as our primary focus when assessing randomised controlled trials. We

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entirely depend on the original studies, but we found that the reporting of symptoms has improved over the years and in all recent trials subjective outcome measures were used. However, not many studies were powered to demonstrate clinically significant differences based on patient-related outcome measures. We also still use the system of success and failure based on the POPQ measures. Most studies used POPQ and reported stages. Most studies considered stage 2 (hymenal remnants plus -1 cm) a failure. Whenever reported, we also included continuous POPQ measurements.

As a surgeon I would prefer to see my work translated into normal vaginal support and of course also subsequently into normal function. An asymptomatic woman with prolapse at the hymenal remnants -1 cm is likely to develop symptoms later in life, especially with confounding factors. We know that the length of the genital hiatus is a risk factor for recurrent pelvic organ prolapse with levator muscle defects contributing to a larger genital hiatus. We also know that obesity as well as smoking, heavy workload and comorbidities such as asthma and connective tissue diseases contribute to pelvic organ disorders [3, 4]. Having said that, we may also have to adjust our counselling and call upon the patients responsibility to take care of her lifestyle. Preventing pelvic organ prolapse should be a major research issue. This also includes changing or improving current obstetrical practices. For pelvic floor health it is contradictory that the average birth weight has increased by 430 g over 80 years according to one study [5]. Increasing longevity of life and more women living longer to the full including sports and travelling call for more urogynaecologists and probably also orthopaedic surgeons, for example. Given limited resources in all economies around the world, we should definitely focus on prevention. And indeed, at the next IUGA meeting in Singapore we will have sessions on prevention of pelvic floor disorders.

In conclusion, estimating the results of interventions to treat pelvic floor disorders is as complex as assessing patient-related outcome measures, just as Matthew Barber has outlined in his Special Contribution and during his lecture at IUGA last year. I would like to thank him for his inspiring lecture and the Special Contribution based on it in this issue. I hope you will also enjoy reading it and trust that we can further improve women's quality of life and measure this effectively.

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