

Including the patient perspective in education development

Pioneering patient involvement in medical education with AO Spine surgeon Manoj Khatri and patient advocate Claire Thornber

At AO, education programs are designed with the primary goal to improve patient care. While direct patient involvement in education has so far been limited, a number of AO faculty members are committed to integrating the patient's voice at various stages of the education process.

"Reflecting on my early medical training, there was no emphasis on how to communicate with patients. While patient communication is now an integral part of any medical curriculum, we still lack patient perspective in education."

Manoj Khatri



Manoj Khatri, AO Spine faculty and past member of the AO Spine United Kingdom and Ireland Council, has over 15 years experience in including the patient perspective in research and education.

We discussed with Manoj his motivations and efforts to foster collaboration and integrate patients into the education process. He emphasized the importance of including Claire Thornber, founder of the <u>Cauda Equina Champions Charity</u>, in this discussion.



"My mission is to reduce delayed treatment and end the unnecessary suffering of patients with cauda equina syndrome."

Claire Thornber

Understanding the expectations of patients

Manoj recognized that patient expectations often differ from those of surgeons and healthcare professionals, particularly regarding their quality of life following a treatment. He actively engaged patients in research studies to investigate the minimum clinically important difference (MCID)—the smallest measurable change in pain, functional activity, or other relevant measures that patients perceive as significant. This understanding helps healthcare professionals align treatment goals more effectively with patient expectations, ultimately enhancing their quality of life. Manoj's initiatives have led to numerous collaborations with patient organizations, including his work with Claire Thornber and the Cauda Equina Champions Charity.

Manoj and Claire met 10 years ago at a charity event and have been collaborating on patient involvement in education since then.

"People talk a lot about cauda equina syndrome, but as clinicians, we truly do not understand the impact that it has on patients' lives. We had a meeting where we had healthcare professionals, and Claire gave a talk. She actually educated us on the impact, which is not just a technical medical impact. Healthcare and life are beyond medical care, and I think she gave one of the most powerful talks. Then, after that, she showed us a video that helped us, as clinicians, to understand the amount of impact her condition can have on her daily life. I've used that as a driver to make changes in the way we structure our healthcare and therefore ultimately to improve the quality of care and quality of life."

Manoj Khatri



Why Claire got involved in a patient organization

Claire founded the charity after her traumatic experience with cauda equina syndrome, which included delayed diagnosis and poor communication. The charity has grown from a group of 60 to over 4,000 members worldwide, providing education and support for both patients and healthcare professionals.



"I had surgery for cauda equina syndrome in September 2010 and that was an emergency surgery because of a delayed diagnosis. I was in hospital for five days after surgery but not much info was given. I wondered 'ls this permanent?' and the answer I got was, 'Well, we can't really tell.' After I got a prolapse, it took me a further six weeks to get catheters from the hospital which were left in a gift bag on the side by a nurse, who had not instructed me on how to use it. It was a truly traumatic experience that I would not wish for any other patient to go through. So I started to get in touch with other patients like me and to share our experiences and learnings." Claire Thornber

The value of including patients in education design

"There is a lot we can learn from each other," Manoj remarked. He explained how Claire's insights, which would be news to many surgeons as they were to him, provide crucial input for medical education. Claire and Manoj stress the importance of understanding the daily impact of medical conditions.

They acknowledge the role of patient organizations in facilitating patient involvement and education, emphasizing the importance of making patients feel valued, heard, and safe. This approach positively impacts their overall experience and reduces problems such as depression.

"When a person is waitlisted for surgery under my care, we'll talk to them about their condition and also what to expect when they can go home. When can they take a shower, when can they drive. As clinicians, we are not very good at it. So, this is where our role of synergy between a patient comes in. It is medically safe to drive 12 weeks after the surgery, but then the patient can draw on his or her own experience, for example after the surgery, when they sit in the car for the first time. It's about returning to their quality of life or going back to their day-to-day living. And that is where I think the key value of a patient is. I think that is what we are currently lacking."

Manoj Khatri



Should AO consider including patient perspectives in education?

Manoj and Claire's work demonstrates that patient feedback can identify care gaps that can be addressed by education. For instance, the distress and uncertainty experienced by patients post-surgery can often be traced back to insufficient information from the consulting surgeon. Patient stories can create empathy and foster trust.



"If people have a poor experience of treatment, but they feel that healthcare professionals are listening to them afterward and that they're being heard, then they feel safe again. Once they feel safe, those relationships can be rebuilt."

Claire Thornber

We would like to hear your experiences and opinions on including the patient voice in education. Please participate in our survey.

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