

What I learned from my illness.

Listen to what a patient tells you about changes in their experience and function, not about their current state

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Summary.

I only realised how much my osteoarthtic hip had altered my life after the operation enabled me to return to activities I did not know I had stopped. Identifying need for and benefit from treatments should focus on relative changes in experience and function, not on a person's absolute state at a particular time.

In March 2011, whilst in a bath in Romania, I noticed my left thigh was wasted. On May 20th 2017 I completed an Oxford Hip Score - my score was probably about 44/48, almost normal and well above the cut-off of 20/48 justifying hip arthroplasty. On June 20th 2017, I saw an orthopaedic surgeon. Initially I was reluctant to have surgery - I did not consider myself significantly disabled, and I only experienced severe pain intermittently and infrequently. However, when I saw the X-ray of my left hip, I immediately agreed to have an operation; I had no visible left hip.

On July 27th I had a left total hip replacement. Over the next six months I realised quite how much my arthritis had affected my life, and how poor standardised measures are either to identify those who need (will benefit from) hip arthroplasty for need or to assess outcome after operation. What are the reasons?

Adaptation.

When asked in the clinic, I replied that I had little pain and no real disability. Although I had marked wasting, I only occasionally had hip pain, which I attributed to loss of muscle. Others remarked on my limping for several years, but I only recognised it in 2015. Even in May 2015, I was still able to walk 10-15 miles a day on the Portuguese Atlantic coast without a problem. January 2nd 2016 was the first time I abandoned a walk due to pain. The only other problem I was aware of was a difficulty cocking my leg over when getting onto my bicycle. I was aware that I could not run, but did not really acknowledge it. It would have been more accurate to have replied that I had adjusted to and accepted my disabilities.

Variability.

I imagined that osteoarthritis of the hip would cause symptoms and disability that were consistent over time. I had not realised how much problems from presumably static tissue damage could vary. For example in early July 2017 on one day I had such severe pain in the morning that a 100 metres walk up and down a slight hill to a beach was difficult, but in the afternoon I walked three miles up and down hills along the Devon Coast path without pain or difficulty.

Denial.

In July 2017 I could still do 25 squats every morning without pain, and so I was convinced I could not have serious hip pathology. When completing the Oxford hip score, I answered on the optimistic side although it was probably reasonably accurate. I just accepted the pain and did not really notice it. I resisted the idea that I had a hip problem.

Identifying changes.

Only since the operation have I appreciated how much my life had been affected. Indeed three months after operation my sister-in-law in Edinburgh, who sees me once a year, said *"Derick, I hope you don't mind me saying, but you look ten years younger now"*.

Looking back, I can see what I had stopped doing. I now:

- walk without a limp
- run for a train, and catch it
- take stairs two steps at a time
- walk down stairs without needing a rail or bannister
- dress without sitting down
- cross my legs easily

- bicycle without risking falls
- carry objects such as chairs or children without pain
- get on a bike by cocking my leg over
- walk 7-8 miles without any pain, and feel confident that I can repeat it, so we can again go on walking holidays in Italy.
- stand for long periods and sit on a sofa, without developing a very unpleasant pain
- sleep with less interruption during the night.

What should we do?

The standard measure, the Oxford Hip score, was devised after asking 20 people seen in a pre-operative clinic; they were asked what problems arose from their hip disease [1]. If I had been such a person, I would not have mentioned most of the areas where I improved. People are not asked after the operation what has improved; they are asked about the problems they mentioned before operation.

I now think we should focus less on patient experience **at a particular time**, and more on **change** in experience and activities undertaken, particularly listening out for change than we did not anticipate. In that way we will learn more about what experiences and losses arise due to progression or reduction in disease.

Measures should be developed differently. Developers should ask what has changed, not what the person notices at a particular time. This approach would be applicable in any situation where change in either direction is likely or the focus of attention. We would also learn more about the real impact of disease.

We need to reverse our emphasis on standardisation, unvarying protocols, and fixed pathways and return to processes focused on the experiences and changing function of the patient. My surgeon did that, for which I am very grateful.

Reference:

- 1 Dawson J, Fitzpatrick R, Carr A, Murray D.
Questionnaire on the perceptions of patients about total hip replacement.
J Bone Joint Surg Br. 1996;78:185-190.