

## Changing experiences of paediatric services in rural Africa

Most of us have experienced the frustration of lengthy waits to see a doctor. But it doesn't usually mean turning up at 4.00am to find 300 people ahead of you in the queue. For women bringing their children to a specialist malnourishment and HIV clinic in north western South Africa, this was the norm.

Facing this situation with a child who was not only malnourished but likely suffering from complications such as HIV, TB, gastroenteritis or pneumonia, visiting the clinic was a highly stressful experience.

### Understanding the issues

Family doctor Claire van Deventer was already aware of some difficulties with the service and she wanted to find out more. As she explains, "I was doing a PhD in Involving patients in quality improvement projects and EBCD kept coming up in the literature. It seemed like a fascinating approach as it's so centred on the patient experience, but also well structured. I wanted to see if it could be successful outside of the developed world."

Claire decided to focus on the experiences of mothers and family carers. She recruited ten participants – nine mothers and one grandmother – who were happy to take part once they were reassured that their interviews would only be shared within a small circle of people. She also recruited 14 members of staff, which was straightforward as Claire was well known and trusted locally

Claire began by using the EBCD toolkit to familiarise herself with the process and downloaded all the forms. She then took time to read through all the documentation with the participants, to make sure they felt clear about what they were taking part in.

### Staff were shocked

Claire took audio recordings of staff and videoed patients. When staff saw the films documenting the experiences of patients, some of them were very shocked. "I had to provide some counselling for them, as some staff were extremely distressed," she explains.

"They had thought they were doing a good job – and they were, but within the medical model. So, if you got the right diagnosis, the right medication and were discharged, your care was considered "good". But there was a blind spot in terms of how patients actually experienced care. The EBCD process really shifted their attitudes."

The findings focused on factors such as the need for better communication, more positive attitudes and better administrative processes, with some overlap between staff and carer views. The parents also shared moments of high emotions, including experiences when they had been reprimanded or made to sleep on blankets on the floor, but also shared positive experiences – especially warm, friendly interactions with staff.

Claire was unsure how well the co-design groups would work: 'Here, the economic and power gap between patients and staff is especially high, with many local families living in severe deprivation,' she explains. "When we had invited patients to meetings in the past, they were often quite intimidated and sat in the corner. But in the co-design groups, it was different. We put on snacks and provided toys for the children to play with, and people really made very practical and positive suggestions."

"It was important that we had a good mix of participants. It wasn't just white staff and black parents/carers – some of the staff were black too, and all but one participant spoke fluent English or Afrikaans, which helped overcome cultural and language barriers."

The project resulted in 25 changes to the service being made, covering emotional, practical and organisational areas – for example:

- a point-of-care blood machine purchased to reduce the amount of time waiting for blood results in the emergency department
- a play area for children attending the HIV clinic
- staff attending psychologist-led positive attitude workshops
- emotional support both for paediatric staff and for mothers/carers
- three standard operating procedures being developed to improve handover and waiting times
- screens installed to improve privacy in reception
- a school in the afternoons run by the university so children don't miss out on vital education

### Understanding the people behind the patient

"I enjoyed doing this project so much," says Claire. "As doctors, we can be so busy curing people's bodies that we miss their lives. But EBCD brings out their stories, and they're not only fascinating but they can inform how we change our systems. The woman who queued around the block for care at 4.00am, worrying if she would get to work on time; the woman who asked her neighbour to give her child medication and then the neighbour seeing that it was HIV medication, and her reaction to that; the grandmother who was told she should go to court for allowing her grandchild to get so ill."

"It's all so much more user friendly now. Now, when a woman arrives, the staff explain to her what is going to happen and at what time – and why, for example, there are beds on the floor for some mothers and not for others. EBCD was bullseye in terms of what I wanted to achieve. But it's also shown me that EBCD can be done in a really low-resource setting. It's a universal possibility."