

Family integrated therapy: Parent experiences of neonatal therapy participation

Sarah K Edney, Lancashire Teaching Hospitals NHS Foundation Trust (sarah.k.edney@gmail.com)

Gretl McHugh, University of Leeds

Core category:

Neonatal therapies as a means of regaining parental autonomy in a context of trauma

Phase 1 — Loss of autonomy and control:
“At the mercy of the doctors”



Transition point:
“Something to look forward to”



Phase 2 — Re-gaining autonomy and control: “I was actually helping”

“It's a situation where you're just not in any control at all. You have to totally rely on doctors and nurses and specialists. You have no real control over how your baby is going to progress” (Participant 6)

“I think by the time we were a few weeks on we were much more positive. It's sort of something even to look forward to, all this talking about feeding and things like that.” (Participant 2)

“In that time where you're a bit lost, the more you know, the more you feel like you can help her, and the quicker you can help her get better.” (Participant 6)

Barriers to parental participation

“When I did come, it was a bit late, like everything had been done.” (Participant 3)

“It was sort of like not on the parent's terms. There were a couple of times when [my baby] was asleep that I'd go down to the café to get some lunch, and then I'd go back and somebody had been. Well if I knew they was going, I wouldn't have gone.” (Participant 2)

Impact of these barriers

“I think [not being able to access the therapist] may have been what affected my confidence. So for me it was how do I do this? Do I do it this way, or that way? The nurses only know what's wrote down” (Participant 7)

“[Community therapists] showed me ways of trying to help him. If the [neonatal therapists] would have told me that from the beginning, ... he might be more developed now.” (Participant 8)

Clinical recommendations for therapy services

Welcome and facilitate parental participation
Provide a means to directly contact therapists

Recognise where parents may be in their journey
Staffing for frequent, flexible, face-to-face contact