Background: ICUs exist to support patients through acute illness that threatens their life. Although ICUs aim to save life, they are also a place where a significant proportion of patients will die with international mortality rates ranging from 15-24%.

Aim: to explore the experience of relatives and staff of patients dying in ICU using qualitative approach

Methods: Consecutive patients were identified who were dying in ICU. The researcher met families prior to the patient’s death. The ICU nurse and doctor most involved were interviewed within 48 hours of the death. The family were interviewed 3-6 weeks later. Interviewees described their experience of the patient’s dying and death. Recruitment until data saturation and thematic analysis occurred concurrently

Results: Ten families, nurses and doctors were interviewed in relation to 10 patients. The main themes are listed below and supported by quotes identified by letters and numbers. In caring for the patient who is dying in ICU and their family, nurses practice to their satisfaction with creativity and autonomy, although concerned about continuity of care at handover. Families appreciate kindness and sensitive regular communication. Families would like more contact with ICU doctors “we were kind of starving for it” (F6). Limiting access to the patient according to ICU protocol is distressing (F7). We were kind of starving for it” (F6). Limited access to the patient according to ICU protocol is distressing (F7). It would’ve been nice if we could’ve all been there together all the time.” (F8)

Family Themes

Personal qualities nurses
“It’s like she was human. I mean she didn’t cry but you could tell it affected her really. You’d have thought he was the only person that they’d ever looked after.” (F3)

Professional qualities nurses
“The nurses were just beautiful, they were just wonderful. I’d say there would be only one that was… nothing wrong with her but just very efficient and not so caring, like just doing her job correctly.” (F7)

“She was very clear, she was very concise, she explained about the machinery.” (F4)

Professional qualities doctors
“We didn’t see the doctors very often. It would’ve been nice to see them to just get some more information.” (F3)

“He was just lovely. The way he explained it all,…. and there was no rush, because I lost the plot…. Information wasn’t passed on while people couldn’t actually hear it.” (F6)

Personal qualities doctors
“He was just very kind and I think you need kindness at a time like that – kindness and understanding of what your family’s going through.” (F4)

Environment
“We thought Dad was going (dying) and there were staff in the corridor laughing… they’d have no idea when someone is going very shortly, maybe you need to be a little bit more aware of what’s actually happening.” (F6)

Communication
“I can’t speak highly enough of the ICU staff. The communication was just spot on… really kept us in the picture.” (F4)

Pastoral Care
“The nurse got in touch with Father R. We had the final blessing with him too. But to be able to get that priest to come was just so wonderful at the end.” (F8)

Limited Access
“You’re only allowed two people beside the bed. When there was only me and my two children it would’ve been nice if we could’ve all been there together all the time.” (F7)

“He sat out in the waiting room for nearly two hours. Which is a bit much when you’ve been told ‘now is the time to call if they want to see her alive’” (F3)

Doctor Themes

Professional Detachment
“We essentially just popped our heads round the curtains and saw that he was still breathing, still obviously alive…. the Consultant actually went into the room and we just stayed outside … We just saw him through the curtains” (D1)

Impact
“It was unexplainable that moment. … you could feel the love inside– but you know with the stoke of their hands and how they talk to him, you know that he is loved.” (N4)

Empathy
“I always say once you’ve got someone who’s kind of in that stage you never leave them… I was just upset that I’d kind of missed that last final prayers… I felt like I’d missed out on something.” (N8)

Continuity of Care
“I always say once you’ve got someone who’s kind of in that stage you never leave them… I was just upset that I’d kind of missed that last final prayers… I felt like I’d missed out on something.” (N11)

Nurse Themes

Empathy
“I always say once you’ve got someone who’s kind of in that stage you never leave them… I was just upset that I’d kind of missed that last final prayers… I felt like I’d missed out on something.” (N4)

Impact
“It was unexplainable that moment. … you could feel the love inside– but you know with the stoke of their hands and how they talk to him, you know that he is loved.” (N11)

Continuity of Care
“I always say once you’ve got someone who’s kind of in that stage you never leave them… I was just upset that I’d kind of missed that last final prayers… I felt like I’d missed out on something.” (N8)

Care of the Body
So I still treat them as though they’re there, that they’re still alive and if we’re rolling them or doing anything to them I’ll tell them what I’m going to do and yet there’s other people who just come in – it’s like they’re being treated like a piece of meat, it’s just a job.” (N10)

Handover
“You bring them to the ward and handover and say ‘bye’ and… you should go down (to the mortuary) and handover to someone.” (N2)

Conclusion: Distress among nurses reported in ICU literature and attributed to disenfranchisement by doctors was not evident. In contrast some doctors struggle to practice what they value. Adherence to ICU protocols needs flexibility when a patient is dying.