**Listen to THIS - Episode four: Improving critical care with lessons from the pandemic**

Tara Lamont: Welcome to Listen to THIS, where we have conversations examining how we can improve the quality and safety of healthcare.

In this series, we'll dive into both current and long standing healthcare challenges and shine a light on some of the work that is being done to address them.

I'm Tara Lamont, Fellowship Advisor at the Healthcare Improvement Studies Institute. We want to find out today about the very particular environment of critical care and what that means for improvement research. Over a quarter of a million people enter critical care every year. They'll be the sickest patients needing the most advanced care and highly skilled staff with close monitoring. In this episode, we'll focus on what's distinct about that setting and the particular challenges for improving services and carrying out research.

We'll hear about the extraordinary shock of COVID where critical care was at the heart of a new and unfolding crisis, and the experience of that for patients and for staff.

What did we learn from this crisis and how do we take that forward to deal with future uncertainties and demands? We'll also explore what we mean by quality and safety in the critical care environment and the balance between protocolised care and responding to the needs of patients. Joining me today are three this Institute Fellows.

Jo McPeake: I'm Jo McPeake and I'm based at the University of Cambridge and Cambridge University Hospitals. I'm an intensive care nurse by trade and my background is understanding what happens to patients following critical illness and in the long term.

Debbie Clark: Hello, my name's Debbie. I'm a PhD student at the University of Leeds, but I'm also a critical care nurse and a lecturer in nursing at Sheffield Hallam University. I'm currently doing a project looking at standardisation and adaptation from standards, which covers different areas in acute hospital settings.

Annelieke Driessen: My name is Annelieke Driessen. I’m an anthropologist currently working as a postdoctoral researcher at the University of Amsterdam. I'm interested in healthcare practices and in how patient knowledge might be used for healthcare improvement. And in this Fellowship research at THIS Institute, I did research on patient and family experience on COVID 19 and intensive care.

Tara: Great, thank you. And we'll look forward to hearing more about those projects. I wonder, Jo, first if you could just tell us what it's like to work in ICU [intensive care unit], what a critical care ward feels like.

Jo: Critical care is quite different to other places in the hospital. It's different in how it's set out, it's different in how it's staffed and it's different in how patients are cared for. So patients in intensive care are the sickest in the hospital. And many of them – you’ll hear quite often on TV – they’re on the life support machine. And there isn't actually anything…there's no such thing as a life support machine.

But what we have in intensive care is quite often ventilators or breathing machines. And quite often people in intensive care will be on breathing machines. And certainly people who were admitted during the pandemic, the vast majority of them were admitted, the primary reason to go into a breathing machine.

The big difference within intensive care is also the staffing. So in intensive care, certainly in the UK, every intensive care patient will have one-to-one nursing. Each patient will have their own nurse. And what that means is that they get round-the-clock care. There's always somebody there's always somebody supporting them. So what I would say differentiates intensive care is they're very sick, they'll require really advanced treatments, quite often a breathing machine. And the staff there are skilled in that enhanced technology. But also there's a lot of staff there because of the severity of illness that you see.

Tara: Do you have anything to add, Debbie, about what it feels like?

Debbie: So I think Jo's touched on the point of the one-to-one care and that's, you know, quite unique. But that doesn't mean it's not a really busy environment because those patients require so much support, really.

So there is an awful lot of equipment to be managed and there's a lot of staff. So it's not just the teams of nurses, teams of doctors, physiotherapists and visiting specialities coming there.

So there's a lot of activity that goes on within intensive care and consequently it's noisy. There's lots of machines and monitors and equipment beeping all of the time, causing distractions and trying to grab your attention. And I also think the thing that always stands out to me is intensive care patients are often asleep.

So your relationship might be more with their family members and their carers than with the patient in terms of the kind of conversations that you can have. And that's fairly unique compared with the environments where I think I've worked before.

Tara: And I suppose too that brings its own challenges in terms of finding out about areas to improve or carrying out research when there's issues of capacity and consent. Is it a very different world to do research in?

Jo: I'm quite happy to come in there. It is a different type of place because of the issues that you're seeing there, Tara, around capacity, so the usual consent process…and when lots of patients are sleeping…although there's now a movement to having patients more awake.

But actually patients are still quite often under certain medicines, sedatives to support the use of technologies. And because of that, the consent process isn't as straightforward as it is on a ward where you'll check if a patient has capacity and then you will go through the nuts and bolts of a research project.

Quite often it's capacity…then it’s given through different means. During the pandemic it was different again because it was public health measures, but there's that capacity component to it that makes it that much trickier.

The other part of it is quite often we're given emergency care. So these are not that…we're changing a medicine and we're going to see how that affects you in the next six to 12 months, like you might see in a long-term conditions trial.

And again, we've seen this during the pandemic. These were emergency treatments which were about mortality, short term, life or death. And that itself can introduce challenges around the correct information to give, how you give it and what you do with it. Ultimately, in terms of the consent process… makes it a little trickier.

And the other thing to say is, internationally it's really different how we consent patients in critical care, which again, with patients and family members, when you're talking to them about consent, they'll often contextualise that with something they've seen in a TV programme. And it is different internationally in terms of consent processes and how families are involved in that across different contexts.

Tara: We've already started to talk and we can't really avoid it, about the pandemic and the huge shock that was.

And Annelieke, your project goes to the heart of what it was like for patients to be intensive care during the pandemic. Do you want to tell us a little bit about what you did and what you found out?

Annelieke: My project entailed that I interviewed patients as well as family members, including bereaved family members of patients who'd died in COVID. I've spoken to 45 people in total, 30 patients, 15 family members and family members, that is in the widest sense of the term. So we've also included very close friends.

And I need to say that I did this project together with Dr. Lisa Hinton, who thought through some of these narratives with me.

What it entailed is that I spoke to people, spoke to them on video conferencing platforms, sometimes up to three hours long interviews retrospective about the experience in ICU or for family members at home.

The things that really stood out from these interviews was…we've already touched on the visitor restrictions and the unintended consequences of them…So all the listeners will be aware that they were put in place to deal with low supplies of PPE (that’s personal protective equipment), as well as to contain the spread of the virus at the time when not much was known about it, primarily.

So I think the lesson that we drew from these stories really was the importance of relationships that family members have, not just with patients, but also very much with staff.

There's this terminology that's used in ICU, which is ‘patient visits’ when family members come and visit patients. But what the pandemic really showed is that when family members come to the ward, it isn't really only about visiting their patient, but it's also very much the relationships that family members have with staff members to provide them with information.

And this was known before the pandemic, but I think the pandemic really brought that home and really made that all the more clear how relevant family members are on the ward to complementing clinical information like medical histories, but also the giving staff a sense of who the patient really is when they're sedated or unconscious.

Tara: Thank you. And I don't know, Jo and Debbie, if you wanted to add anything, just about your own experience or also what we know about staff experience at that extraordinary time.

Jo: I suppose the other thing to say is or staff, there was a huge impact on the visiting restrictions because patients, as we've heard, can sometimes be sedated, and even those that aren't sedated will be delirious quite often. We have about 80% of patients in intensive care who will suffer some type of delirium during their intensive care stay.

And so quite often, as an ICU nurse, you'll get to know the patient through their family, and the family will tell you what their hobbies are. They'll bring in music for them, for example, so you'll play the patient's music, but it's the family that will create the playlist. And all of that was gone, but other things were gone as well for staff.

So simple things, like we were only allowed to use hospital toiletries. Now, this seems like quite a small thing, but there's so much you can tell from a patient's toilet bag.

You can tell what aftershave they like. You can tell if they put an aftershave cream on, you can tell if they've got curly hair shampoo, you think, well, they've got curly hair, let's do curls for them. And so there was a complete lack of…well that's just a small thing, but it was that lack of personalisation and your care and that ability to deliver person centred care was completely gone for staff. And you tried to do things with families digitally…we had iPads, we had apps, but there was so much else going on during the pandemic. There was a lack of staff.

Quite often we didn't know what's going to happen day to day. So actually introducing that technology in amongst it all was hard for staff despite the greatest effort. So all of that echoes and also that depersonalisation went both ways, I would say. And it's interested in hearing the patient and family perspective.

Annelieke: What Jo's saying really resonates with me. So it's also what family members talked about…some of the most touching moments to them were when a nurse reached out and said, you know, ‘we're really trying to care for your husband or your child or whoever it was in ICU as a person. Could you send in some photos that we could pin up on their bed? Could you send in their favourite music so that we could play that to them?’

So that kind of work also indicates that the role that staff saw for themselves and took really shifted during the pandemic to incorporate some of those things that were usually done by family members. That was also part of the difficulty, as I understand it, from wanting to do so much and not being able to do all the things at once because of the massive pressures that were they were under.

As well as all the difficulties, what really comes through in the stories are these moments where staff really reached out and did this wonderful thing for them.

Tara: It's really powerful to hear your narrative research and the careful qualitative approach, Annelieke. I'm just wondering, Jo, in your research you very much use mixed methods. I wondered if you could tell us a little bit about what you've been doing to make improvements in critical care and how you've used research to do that.

Jo: My research looked specifically about readmission after critical care. So the first part of it was a meta analysis and we looked at how many people, we think roughly are admitted to critical care and we reckon about 30% of them are re-admitted, unplanned to hospital within 90 days, which has a huge effect on family members and the patients themselves, you know, because there's not only the havoc of going back into hospital, but there's the emotional part of going back into the hospital as well, which we can we completely forget about.

We're going quite often back to the same hospital, to the same accident, emergency, where their patient ended up intensive care and all the quite often trauma that goes around, that readmission, but also the consequences for the healthcare system.

Our healthcare system is under so much pressure and we are saying that one in three of these patients that we think are going home with a good outcome are going to end up back in the hospital. So that's the type of thing that my research is really focused on: how do we do better? How do we actually plan before people go home? How do we link in with community resources, how do we prepare people for going home in a more high-quality way?

And so the previous work I've done, we've integrated health and social care because actually not all of these problems are health related and healthcare can only really scratch the surface of some of the issues that we see. So integrating with social care, with welfare benefits advice, welfare benefits advisory has been hugely important.

But the big thing that my research is still working on, if I'm being honest, is that link with family members. And we know that if we've got – and we know this from other cohorts of families and people – a really strained carer, so if their family member is under tremendous strain and is not coping, that's an indication the patient's going to end up back in the hospital system.

So one of the things were focusing on just now is what do we do to support family members better and how can we do better for them that will ultimately have a benefit for the patient and our healthcare system?

Tara: And have you been doing work, particularly with sepsis survivors?

Jo: So we're actually doing a couple of pieces of work with sepsis survivors and this is a group of patients and people that are very close to my heart. What we've been doing is specifically working with them in pathways of care. And what does good look like for you? Because we quite often will run into programmes of work and pathways of care and integrate new models of care and new roles and sometimes there's really low uptake of them. People don't use these services. So one of the things that we're trying to look at is what does good look like and what do you actually need in this recovery and when do you need it in this recovery process for both patients and carers?

So we've been using the Thiscovery platform through the Institute, which has just been phenomenal to use, and we've worked with over 250 patients, family members and clinicians, and really looking at what does good look like for sepsis survivors.

Tara: That's great, because if there aren't clear guidelines and pathways…I'm just thinking, Debbie, your work's very much about…In a very protocolised world like intensive care, when is it safe or acceptable to not follow very best practice? Do you want to say a little bit about your research?

Debbie: So I've been looking at standardisation and probably from the point of view that there are times when standards can't account for every circumstance that comes through the door.

And we know people describe a difference between work as it might be imagined in policies and procedures, and work as it can actually be achieved as a work as it's actually done. So I've been really interested in trying to understand that more and reconcile some of the differences. And I think just talking about sepsis, maybe, and Jo's point, really, I specifically looked at IV medication, so intravenous medication administration. And in many standards, there's a requirement to create better safety, that nurses have to have two nurses independently checking these medications before they can be administered.

But then, on the other hand, for a patient to have best practice or best care, those antibiotics may need to be administered within an hour. So if you're in a setting where there's good staffing levels, that's very relatively straightforward to achieve.

But I've been looking at this standard across different hospital contexts where that is not the reality. And so nurses are having to weigh up the benefits and the risks all of the time. Is it safer to wait for a double check because I'm not that familiar with this medication, or there's something about the patient that makes me concerned, or is it safer actually for me to say, I'm going to park that standard because this patient needs the medication? So my work's been really looking at striking the right balance between standards and moving away, when it's safe to move away.

Tara: It's really interesting because were talking earlier about critical care tends to be quite a high ratio of staff and so on. And I guess there are different kinds of safety issues. I've heard about ‘alarm fatigue’, say, in critical care. Do you want to tell us a bit, Debbie, about, you know, some of the safety issues and things like alarm fatigue?

Debbie: Because patients in this kind of setting can be very unwell. It is not uncommon for some of the alarm parameters that would be suitable for a patient on a standard ward wouldn't suit a patient being cared for intensive care.

But that doesn't mean that they don't need very close monitoring and perhaps the even close. Well, certainly more close monitoring, but it's adapted very much to the individual. So what might be considered very irregular in a ward might be a little bit more normal within critical care, because it's a very individualised approach.

So I suppose that touches on some other interests I've got, is that transition point from wards to intensive care and back again, and actually how we're making patients and their families really feel safe around that process. I don't know, Jo, whether you've done any work in that area, but it's often a time of anxiety, really, when a patient's had a nurse virtually with them all of the time, and suddenly they're moving to something that feels quite frightening and risky.

Jo: Absolutely. And I think…it's a hard one because I actually think this is intensive care’s responsibility, because we don't prepare patients and family members enough so they almost…they can get information at any point, 24 hours a day. And that's appropriate for when patients are sick, when patients becoming increasingly unwell, it's important that they have that contact.

But actually, people going to the wards and having less intensive staff is a good sign. It means they're getting better. But quite often we don't get that message across particularly well. And so it can be a huge jump for family members especially those who are used to coming in and being able to have really knowledgeable staff, multidisciplinary staff, there on tap, to give them that information.

And I think the other thing – and we do this at every point in our healthcare system – it’s not just about the transition from ICU to home. We don't move patients around a system particularly well at any point in the hospital system, do we? It's just an ongoing issue.

If you look at intensive care, sometimes we have different information systems. We have different paperwork and then they go downstream and it's like a different risk assessment. In intensive care, we'll start medicines and they’ll not follow up the medicines downstream. We'll stop them, we'll start them, we'll increase them, we'll decrease them, we'll do all sorts and turn them in their head. And actually we're really bad at communicating that.

I think it's a global problem across the healthcare system. They're just fracture points as we move patients about the hospital or move patients around different services. And I'd love to think that the movement to digitalised healthcare records is a way forward. I'm not completely convinced that's going to solve problems, but I think it will be a step in the right direction.

Tara: Annelieke, did your research cover much about transitions and step downs?

Annelieke: Yes, lots actually. So it really resonates. Family members described the contrast between intensive care and the wards, which had to do with staffing levels. Indeed, they said there was always a nurse there and then I was on the ward it was very hard to get somebody's attention. Family members described calling in and finding it much harder to get to staff.

And I think for staff, for family members, it was particularly difficult sometimes to understand this at a distance. So I think that's a contrast between having been a family member to a patient in the pandemic and at other times where you can go in and you can see what's going on.

So for family members at a distance, it was quite difficult to build these relationships and then when they had them, that transition really meant that they then lost them and had to reinvest. Not understanding in what context they were doing that because they couldn't see or witness that was difficult.

But then again, it was also so that patients did sometimes recognise that this is a step forward…I am recovering and closer to getting home. And having said that, I think the biggest transition for patients was perhaps the one from hospital to home.

So for family members who had up until that point almost literally been on the sidelines and then became full time carers to patients who are really still quite sick or dependent, at least when they came home from intensive care.

That was a massive transition for people, which was very difficult. And because in the pandemic the infrastructure for care, particularly for COVID patients, hadn't been set up yet in the early months…many experienced that as a drop off a cliff. You had a designated ICU team, spent some time on the ward where you still had people who looked after you…and then you went home.

And there were very much a lot of insecurity and uncertainties about what to do or how to handle that whilst being physically really quite ill, and all that emotional labour that family members and patients did. So it’s definitely recognisable. And I think going forward, one of the things to flag up, is that despite us having – as a society – having moved largely beyond COVID in the discussion of it and the rhetoric about it, I think it's really important to keep track of the ripple effects of the pandemic, how it's still impacting many people in many way, be that in work burnout or PTSD or prolonged grief.

There's all these things that still extend their tentacles into this time. There is a past COVID, but there's also still a COVID that pops up in different forms. And I think that's something to be aware of.

Debbie: I was just thinking…it's probably rewinding a little bit, Annelieke, but about patient diaries. Sometimes we use patient diaries within critical care to document the patient's journey in a way that they can understand when they go home, so the family members can read it and contribute.

And I was just thinking when patients’ families weren't able to be there and see what their loved one had gone through and then they're expected to support them, to live independently at home, there's quite a big gap, isn't there? I just wondered whether that came out in your narratives and the work that you did.

Annelieke: Thank you for that question. It’s a really interesting one. So commonly in ICU it is the practice to keep some diary of treatments. Perhaps Jo can say a bit more about this.

The diary…it can be really important for patients to then retrospectively make sense of what happened to them in the time when they were unconscious or had really horrendous dreams – often experienced as nightmares that are really real to people. So many patients found hard to differentiate between what really happened and what happened in these hallucinations. And that's where the diaries can be really important for people to make that distinction.

And as well as the practice, too, once people have been discharged from hospital it’s important that at some point they can come back to ICU to see what the environment was like.

And those two things…sometimes ICU units managed that in the pandemic. And when they did, from what I've heard, patients found this really helpful to do exactly that, to piece together that time when they don't remember.

But unfortunately, because there was such high pressures on staff, it wasn't really possible to keep these diaries. Some patients got clinical notes so that really jumbled copies of things, and some people didn't get anything. Some people got them a month later. So I think that was something that really came up and that then was a challenge for patients.

How do you reconstruct that time when that diary doesn't exist? Sometimes they could use their family who called in and got information and kept notes, but not all families kept those notes.

And some patients, I also have to say, were radically distancing themselves from the idea that they had to know exactly. And they said that's something that my body almost…has chosen not to remember and therefore I won't dig into it.

So, very different ways there of dealing with it, but very much the centrality of the diary was, through its absence, proven to be really vital.

Tara: And I think you mentioned Annelieke before the lasting effects of the pandemic. As we wind up our conversation, I wonder what you all think about the learning from the pandemic, good and bad, going forward, and what it means for critical care and quality and safety of critical care.

Jo: in terms of the learning from critical care I think what it's brought out in terms of the quality and delivery, is the need for staff to have critical care skills across the hospital. And that was something that we were challenged with during the pandemic is that, when we needed staff to know how to run a dialysis machine or support somebody in a ventilator. But fundamental critical care skills were often lacking across all disciplines.

It wasn't just nursing or just medicine, it was across all disciplines. So I think there's that upskilling of staff around delivery of critical care services. I think, for me, the biggest learning in the hospital has been about healthcare inequalities. I actually think that's opened our eyes more widely, not just in critical care, but across how we deliver healthcare services, how we do research as well, I have to say.

 Jo: And I think there's now a real focus in EDI, and I think there's a real focus in healthcare disparities, which I'm not convinced was necessarily there in everything we did before the pandemic. And I think that can only be a good thing.

So I want to turn that into a silver lining. I think there's things that have came out of the pandemic that have opened our eyes about how people access healthcare, how we deliver healthcare and how we can do better. And I think that has resulted in a focus in certain things that we should have been focusing on a long time ago, but perhaps have got a laser focus in now.

Debbie: I'm interested in adaptation and really improving safety and thinking about that. And I read – I think it was like a viewpoint paper just after the pandemic – where they'd had bedside learning coordinators in the Nightingale Hospitals to try and really rapidly change things that weren't working effectively, because it was a period of great innovation as well.

I know when Jo and I have spoken previously, there were lots of things happening very quickly that were probably beneficial. So I think what would be really nice is to continue to build on those ways we found to adapt safely and build upon that as we go forward.

Tara: That's fascinating. There's a bit of me too that says, I wonder if there's ever any evaluation of these bedside nursing coordinators. And it's fantastic that…a thousand flowers bloom, but it would also be good to know which were assessed.

Debbie: What stood out for me just when I was reading that paper was how nice to have someone there to fix the things that don't work day to day. Because during the ethnographic work I've been doing, they are the things that make healthcare professionals feel like they're stuck in the mud sometimes they can't get forward. And it was just nice to see that there was interested in resolving those fundamental problems sometimes.

Tara: Great, thank you. And Annelieke.

Annelieke: I want to echo also what Jo said; this sustained attention to inequalities and how they come about also through healthcare practice.

But perhaps to add another point; as an anthropologist, I'm going to say the relationships that make care possible, that extend beyond the clinical encounter and clinical setting.

And I guess the lesson there is there's got to be more in place next time to provide that care for patients, but also very much for staff members. I think what the pandemic really brought home is that staff members are professionals, but they're also people with all their vulnerabilities and the care that they require. And we haven't really touched upon it, but staff members who became patients themselves. That really made that abundantly clear.

So I think that these vulnerabilities and the relationships to keep a good eye on those and support those wherever possible.

Tara: Well, what fantastic lessons about inequalities and particularly what you were saying about the family support, Jo…but also socioeconomic and other inequalities that affect patients’ experience and whether or not in fact they end up coming back to hospital.

The innovation that Debbie talks about that we saw, and hopefully we've evaluated some of that in terms of moving forward.

And then Annelieke's point that relationships matter and the relational work that goes on in critical care to make patients and families thrive. So thank you all very much. Big thank you to the guests who joined us today, Jo McPeake, Debbie Clark and Annelieke Driessen. I've been your host, Tara Lamont, and I hope you've enjoyed Listen to THIS.

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