Supporting well-being after stroke: The problem of the pace of stroke care in New Zealand



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Background

Well-being is important for living well after stroke; people with stroke and clinicians agree it is not adequately addressed in services.

Study aim: To identify how clinicians support well-being, and how their practice is influenced by the context in which they work.

Methods

Methodology: Institutional Ethnography

Data gathering: Interviews with 34 stroke service providers from all disciplines and across the continuum of care

Data analysis: Applied Tensions Analysis

Findings

Stroke services are underpinned by a pace of care which starts from when people enter in ED to when they are discharged from services. This is influenced by multiple factors. Amidst the drive to give people the 'best chance' of [physical] recovery and to discharge in a timely manner, there is little space to slow the pace of care to identify and respond to people's well-being needs. It is assumed these will naturally improve, or other services will support well-being - yet few services exist. The pace of care - and support - comes to a halt.



Rapid, time-constrained hyperacute care

Hyperacute care is fast, as teams seek to make accurate diagnoses and commence appropriate treatments.

It's so hyper acute, everything is happening in there, definitely psychosocial care is missed out. That's where we as CNS's come in. We talk to the patients, we talk with the family members who are there because we'll have a little bit more time than the medical team that are organising the transfer. But we try and spend as much time or give as much time as we can. (CNS)

Early MDT intervention centred on diagnosis, identification of impairments, prevention of secondary complications, secondary stroke prevention. This sets up what follows.



The pressure to 'keep people moving' through and out of services

Inpatient services are under occupancy pressures, leading to a focus on people being medically stable and safe to discharge.

Goal setting can unfortunately lend itself to thinking about safety at home and what's the bare minimum you need to be able to do to get home (OT)

Community services are often time-limited (up to ~12 weeks); few have psychologists or social workers. This shapes what is a 'legitimate goal': commonly shorter-term goals focused on physical, occupational or communicative function.

Prioritising disciplinary-based physical care and recovery

Disciplinary interventions commonly focus on people's physical, cognitive and communicative needs. There is a drive to give people the "best chance" to improve their impairments.

I do feel we then move to impairment-based stuff quite quickly, yeah. ... I think we're aware that there isn't much out there so it's almost like a rush to give them the best chance and by that chance we're prioritising impairment-based. (SLT)

Time pressures, prioritisation of physical function, perceptions of what is in one's professional scope, and what clinicians enjoy and feel competent to do all contributes to how well-being needs are (and are not) prioritised.

People feel pressured to get their session done and move on or do something that day in relation to your role and so ... no-one takes hold of that emotional well-being side of things and that just pulls away because the patient's doing physio, SLT and OT, but not other things (SLT)



Assumptions that well-being can wait, and will naturally improve as physical well-being improves

Long-term well-being is seen as something that can be addressed later. This reflects particular views about what is in and out of scope for services, and what areas of life are prioritised at particular times.

[The time] to address well-being is once all the practicalities [toileting, arm function, mobility] have been addressed, your head's above water and then you've got a bit of space to think, okay what else now ..So, I think that is the place that [well-being] sort of naturally happens (Physio)

Impacts of the current pace of care on practice and people

- Clinicians provide 'in-the-moment' wellbeing support - sitting with people, listening, giving reassurance and information, involving family.
- Clinicians know well-being is important, but time spent supporting well-being can be seen as time taken away from their areas of expertise.
- The pressure to focus on physical needs and moving people through services, knowing there are other unmet needs, can contribute to moral injury for staff.
- Many clinicians struggle to articulate what they do to support well-being, meaning well-being work is often invisible - to them and to others.
- Clinicians report little training or support to address well-being.
- There is little space to attend to things that support long-term well-being.

You're expected to go through all your rehab and be looking forward and being brave and doing all this adaptation but you're still actually grieving, so you're not ready for most of it in a way. And it's all too quick and too soon, and then you're washed out the other end.

(Community advisor)

Discussion

The existing pace and focus of services orients clinicians toward particular aspects of care.

There is limited space and support for people to provide comprehensive well-being support in existing service models in Aotearoa.

If we are to change practices, to better align with the needs and priorities of people with stroke, and to support longterm well-being, these changes need to be supported and enabled by the culture and structures of stroke care.



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