

The Hopkins Centre

Research for Rehabilitation and Resilience

A Multi-Disciplinary Service Model for Hypertonicity Management Post Brain Injury: Experience and Perceptions of Service-Users in Queensland

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Bold ideas. Better solutions.



Metro South Health

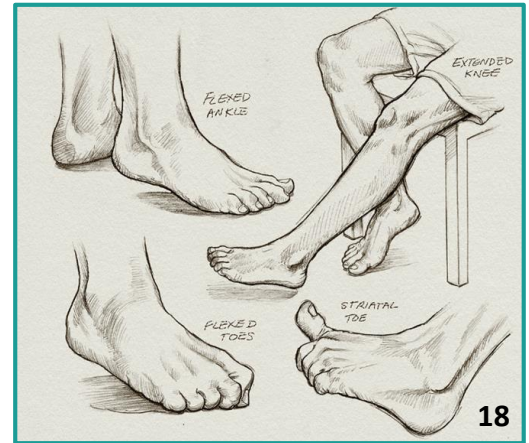
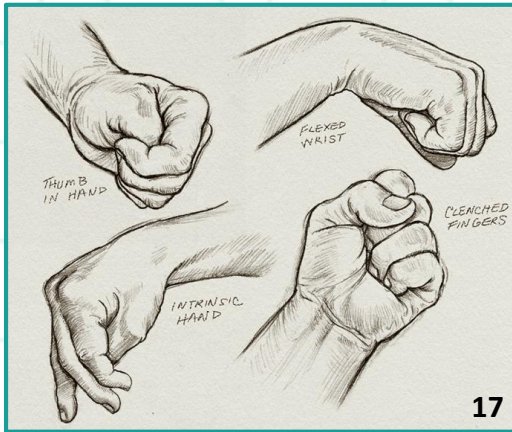


Queensland
Government

A joint initiative of the
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Background - Hypertonicity



4X Health
Care Costs⁶

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30%
Stroke
patients¹⁻³



75%
Severe TBI
patients⁴



Background - Hypertonicity



**Botulinum
Toxin
injection^{4,8}**



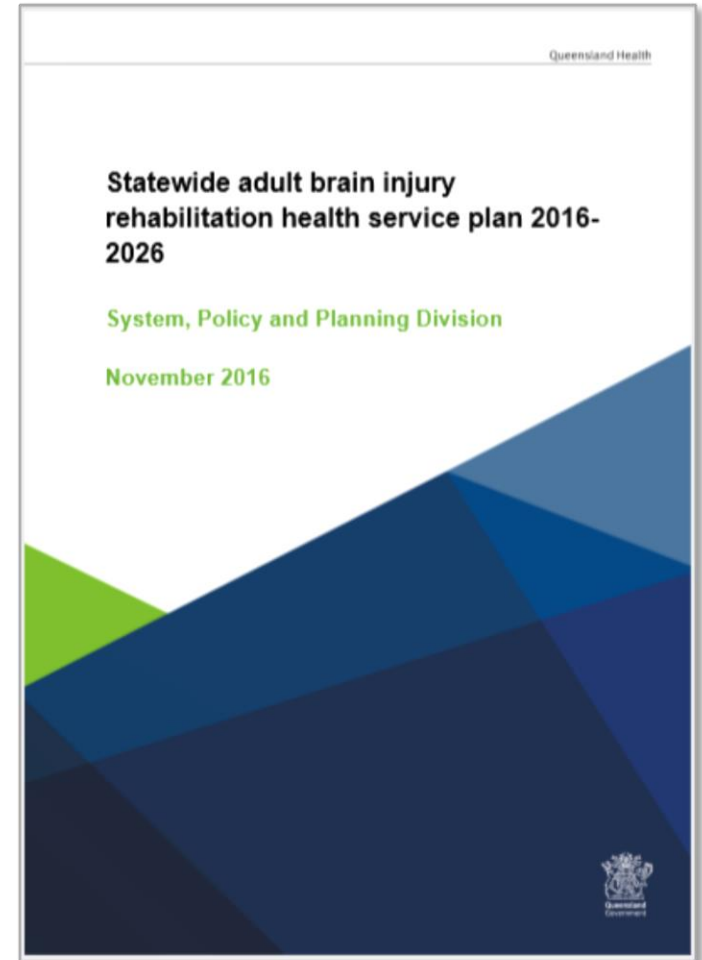
**Multi-
disciplinary
Management⁹**

Rehabilitation⁷



Background - Hypertonicity Service

- Princess Alexandra Hospital
Statewide Multi-disciplinary
Hypertonicity Service (PAHTS)



Aims

1. To explore patient and carer experience and perceptions of PAHTS
2. To characterise patient and carer satisfaction with PAHTS delivery
3. To identify areas for improvement in the service model

Method

- **Design:** Qualitative
- **Sample and Recruitment:** Purposive sampling, phone recruitment PAHTS patients & carers
- **Data Collection:** Audio-recorded focus groups, guided by open-ended questions¹¹
- **Data Analysis:** Thematic analysis¹²
- Institutional and ethical approvals, and participant consent was obtained.

Participant demographics (n=12)

Gender: female	6
Age: mean years (SD)	46 (19)
Diagnosis:	
- Stroke	6
- TBI	2
Time since diagnosis: Mean years (SD)	4.5 (2.9)
HT Service attendance type:	
- Outpatient	2
- Inpatient & Outpatient	6
Service attendances: Mean (SD)	9 (2.7)
Diagnosis to initial HT Service assessment : median months	5.5
Botulinum toxin received	
- Upper & lower limb injections	4
- Upper limb injections	4
Botulinum toxin cycles: mean (SD)	2.75 (0.89)

Findings - Thematic Framework

	Theme	Description
1	Accessing the service 1.1 Gaining access initially 1.2 Continuing access	For those who the service is designed to benefit, access presented challenges over the continuum of rehabilitation.
2	Evolving service expectations 2.1 Expectations before 2.2 Expectations during 2.3 Expectations after	Users' understanding of the service and its purpose was variable and dynamic over the rehabilitation trajectory, as their knowledge of their own potential and the capacity of the service developed in parallel.
3	Generating value 3.1 Tailoring the service for users 3.2 Co-creating the future with users	The service was adapted to individuals' needs, enabling them to actively engage in and optimise their rehabilitation journey.
4	Attaining patient outcomes 4.1 Connecting with personal potential 4.2 Connecting with other rehabilitation services 4.3 Connecting with peers	The service supported users to close the gaps between what they desired and what they could change in activities of daily living and activity participation.

Theme 1: Accessing the service

1.1 Gaining access initially

I wouldn't have known; it's not out there. The doctors, your local GP doesn't know a thing about this sort of thing. We want to know about it, and you're lucky that you are here. At least for the doctor to refer a patient...the doctor never even bothered to pull the arm out and see, to see whether there was any tightness or mobility (3:C3).

Users depend on health professionals' awareness and understanding of the service, and on their readiness to provide a referral.

Theme 2: Evolving expectations

2.1 Expectations before service participation

You just don't know what to expect. You get your hopes built up, and you don't want to have them built up because you don't want failure. For us, it was mixed emotions (3:C4).

I somehow imagined it would make everything faster and quicker and easier, so I had very high expectations (2:P3).

We came from an inpatient referral, so...we kind of knew that they were reviewing for Botox injections (1:C1).

Early expectations of the service were shaped by different levels of uncertainty.

Theme 2: Evolving expectations

2.2 Expectations during service participation

Staff were telling me ‘don’t get your hopes up too high’, ‘it’s not going to do everything’.... but I really hoped it would (2:P3).

I’m always just like, I hope this works properly (3:P8).

While I was in hospital, the registrar in the rehab unit did explain the process very well to me...I found it really quite an exciting process because I had had so much information about how it works (2:P4).

Patients’ expectations of the service were being shaped by their levels of discovery.

Theme 2: Evolving expectations

2.3 Expectations after service participation

It enabled me to work on my therapy, so I can now do things without Botox that I could only do with Botox before (2:P3).

The only thing that I find a little bit disappointing is that it's not long-term. It's as long as the Botox lasts, and as long as you keep doing the exercise... it's a forever job (3:C3).

I really noticed no difference... if we go down this road again, I'll be intrigued to see how we go (2:C2).

Ongoing expectations were shaped by levels of hope regarding service opportunity and recovery potential.

Theme 3: Generating value

3.1 Tailoring the service for users

They did listen to me and were willing to change [the treatment plan]. It's flexible and not "this is how it is in the book" (3:C3).

[The physiotherapist and occupational therapist] explained what's good and what's bad. You know...concentrate on that part first...when we see that is improved, we would go up another step (3:P7).

Goal setting is hard....Your goals from a Hypertonicity perspective are more set by your therapists. [They] tell me which things I need to do first to get the most amount of use (1:C1).

Coordinated and integrated care supported person-centred goal setting and treatment planning.

Theme 3: Generating value

3.2 Co-creating the future with users

I think it's...an interplay of post Hypertonicity Clinic, what services you're accessing to make the most of that period where the Botox is effective (1:C1).

It's what you want, to have that goal that you can achieve...We put a bit of work in and you put a bit of work in (2:P5).

In a therapeutic alliance, service users became active members of the team within and across services.

Theme 4: Attaining patient outcomes

4.1 Connecting with personal potential

The expectation was that I'd be in a nursing home but...they were able to get me to a stage where I could go home and think about having a normal life (2:P4).

I'm very passionate about cooking...[and have been able to] hold onto a cabbage and cut it (2:P4).

We've found his friends... were distant... but the more he's been able to move better and not look so... cramped up... they see him more as able. It's like it has given him old friendships back again (3:C4).

The service expanded users' awareness of what was possible to achieve.

Theme 4: Attaining patient outcomes

4.2 Connecting with other rehabilitation services

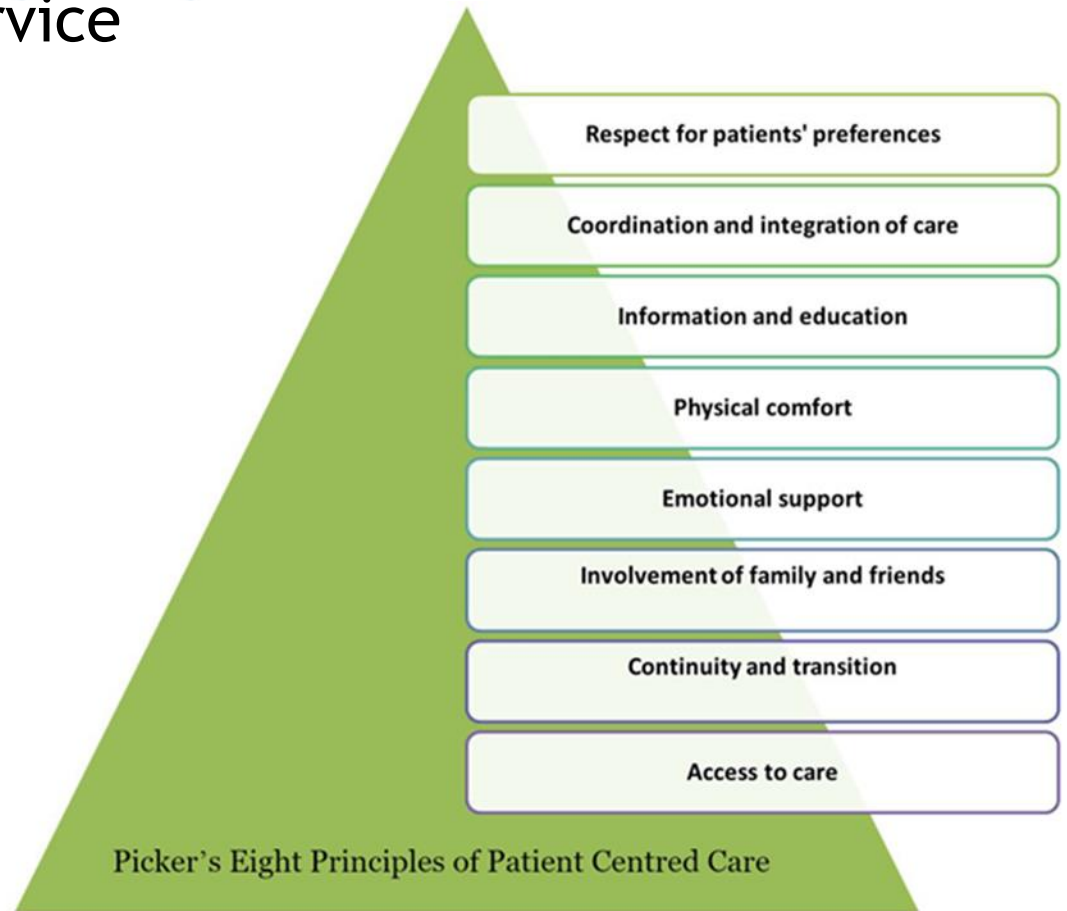
It is not so much about the HTS itself and the service it specifically offers, it is about integrating other services into the follow up from there. Because, at the end of the day, you are putting toxins in your body, so you want to maximise that period of effectiveness (1:C1).

Post-Botox, I would go to Sporting Wheelies [gym] to get the repetition. I got access to an accredited Exercise Physiologist [who] can take [the HTS's] tips and tricks and work with me outside of the HTS (1:P2).

The HTC provided crucial linkages and transition to follow-up services for ongoing care.

Discussion

- This is the first study to explore, in depth, patients experience and perceptions of a multi-disciplinary brain injury hypertonicity service
- Patient centred care¹³
- Therapeutic alliance¹⁴
- Service Access^{15,16}



Limitations

- One small study.
- One health service.
- Participant characteristics.

Implications

- Service improvement initiatives
- Education of patients, carers and health professionals
- Highly specialised service - postgrad education within disciplines
- Need further qualitative research to explore themes

Conclusions

- Service-users made a valuable contribution to service evaluation and this will lead to service improvement initiatives across QLD
- Further qualitative research necessary to understand the lived experience of hypertonicity post brain injury to facilitate delivery of patient centred care

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