

Therapy for the upper limb after stroke: a longitudinal, phenomenological study of the experiences and perceptions of stroke survivors.

Dr Judy Purton [1][2]

Dr Sue Hunter [2], Professor Julius Sim [2]

[1]York St John University, [2] Keele University

j.purton@yorks.ac.uk

Background

- 70% of people after stroke have upper limb (UL) dysfunction
- 40% persistent lack of function in UL
- Experiences of stroke in general are well researched, but ...
- Specific impact of UL dysfunction and **people's experiences and perceptions of therapy for UL not explored.**

Aim and Methodology

- To explore people's experiences and perceptions of therapy for the upper limb during the first 18 months after stroke.
- Phenomenological study
- Semi-structured interviews at 2, 6, 12 and 18 months post stroke.
- Audio recorded and transcribed
- Thematic and modified framework analysis.

Participants

- 13 people with stroke
- Recruited from a stroke unit
- 8 female, 5 male, ≥ 62 years
- 10 left upper limb dysfunction, 3 right upper limb dysfunction
- 12 with right hand dominance
- 3 with dominant arm affected

Findings

- The experience of recovery
 - Changing priorities
 - Experiences of therapy
 - Lack of information and advice
 - Patients as active partners

Changing Priorities

- Focus on regaining or improving walking (2 months)

‘Being able to walk out and go wherever I want.’

- Focus moves to UL at 6 months and beyond
 - Full impact on self-care, valued activities, roles now being recognised

‘Get this hand going ... I think it’s coming home and trying to do things here and I can’t.’

‘Need two hands to get on with my life’

Changing Priorities

- Walking, in itself, is not enough to regain full independence and participation.

‘Well if I could only use my arm I’d be able to do a lot more for myself ... dress myself, have a shower on my own. I’d be able to walk down the street and get on a bus, play with my granddaughter.’ (12 months)

‘Sometimes i just wish I could save myself with this hand...It would help if I could walk like I do [stick in unaffected hand] and I could use my hand for something.’ (12 months)

- Two handedness
- Balance, gait

Experiences of Therapy

- Lower limb prioritised by therapists to facilitate hospital discharge (2 months)
‘They just get you out of there.’
 - In line with patients’ priorities
- Dissatisfaction with short term therapy in community, still focused on lower limb
 - not in line with patients’ priorities (6 months)
‘But then they ask you “what would you rather have – your hand or your walking”’
‘OT came weekly and took me for walks ... but other than that they didn’t do a lot.’

Experiences of Therapy

- Abandoned - therapy services discontinued by 6 months post-stroke, left with dysfunctional UL
 - ‘Well they’ve got rid of me ... I’m on my own’*
 - ‘I feel cut off’*
- Referral on to local gyms, but not specific to UL needs
 - ‘I reckon a bit more physio on this [hand] and I’d be able to use it a bit more. I feel gutted, they came for 3 months and suddenly stopped.’*
 - Support, dexterity, two handedness

Lack of Information and Advice

- Limited information about UL recovery
- Mis-interpretation, (filling the information gap)
 - ‘I mean, naive me thought it would come back automatically. My walking was coming on and this would follow.’* (12 months)
 - ‘I thought I’d get home and start doing all the things I did before.’* (12 months)
- Health professionals disregard for the arm, avoiding questions
 - ‘How long is a piece of string?’* (2 months)
 - ‘He [consultant] hasn’t said anything about my arm yet.’* (6 months)
 - ‘The doctors [GPs], they never mention it [the arm].’* (12 months)

Lack of information and advice

- Lack of engagement with people's attempts to 'treat' their UL

'Well you feel you've been left out in the cold. All the time seems to be taken up with what they want to do.' (12 months)

- Purchasing muscle stimulator for arm
- Using UL hand cycle
- Devising their own exercises

'I try different things but I don't know if I'm doing right or wrong' (12 months)

Personal responsibility – active partners

- Recognition of role and responsibility in recovery
- Not passive recipients of therapy
 - Motivation, attitude
 - ‘Well it’s me that’s got to make these things work.’* (6 months)
- People with stroke recognise services cannot be continuous in long term
- Different models of service to provide support
 - Self-management, peer support
 - ‘I think group therapy would be better. You can see how well other people are doing and they can see how well you are doing.’* (6 months)

Personal Responsibility – active partners

- Access back into services for review and guidance
 - ‘You just need that little bit of pushing behind you, for someone to say “yes you’ve done that right, yes it is getting better”.’* (12 months)
 - ‘I slosh it about in water like I was told to do in hospital ... Just somebody to talk to about it now and again.’* (18 months)
 - ‘Well if somebody gave me instructions I could do them at home’* (12 months)
- Wasted opportunities for people to be less dependent on services in long term
- Wasted potential for more recovery
 - ‘Well there’ll be a lot of people like me around and they should see it as wasting assets.’* (6 months)

Conclusions and Implications

- There is a lot to learn from people with stroke about the UL
- UL vital for independence and participation
 - Two handedness
 - UL role in balance and walking
- Attention to UL in early rehab
 - Change in therapists and patients priorities
- UL rehab should continue into community
 - Capitalise on active partners to look at creative ways to extend access to review, information
 - peer support, self-management