



Talking-past-each-other:  
Health professional and  
family perspectives on  
accessing post-stroke  
information



# Co-authors

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# Our study

## Aim:

To ascertain information and education needs of families post-stroke through identifying current practice and resources, and the appropriateness, accessibility, method of delivery, timeliness and gaps in education and information giving.



# Background

- The global burden of stroke is increasing<sup>1</sup>
- Stroke can have negative consequences on the health, wellbeing and quality of life of both the stroke survivor and their extended family<sup>2</sup>
- The importance of information and education provision, alongside the right support, for stroke survivors and their families is well documented<sup>3</sup>
- While there is evidence that the provision of information is beneficial “the best way to provide information is still not clear”<sup>4</sup>

<sup>1</sup>Feigin, V. L., et al. (2014). *Lancet*, 383(9913), 245-254.

<sup>2</sup>Ellis, C., et al. (2013). *Journal of Stroke and Cerebrovascular Diseases* 22(4), 309-317; Yu, Y., et al. (2013). *Journal of Clinical Nursing*, 22(15-16), 2160-2171.

<sup>3</sup>Cameron, J. I., & Gignac, M. A. M. (2008). *Patient Education & Counseling*, 70(3), 305-314; Cameron, J. I., et al. (2013). *Disability & Rehabilitation*, 35(4), 315-324.

<sup>4</sup>Forster, A., et al. (2012). *Cochrane Database of Systematic Reviews* 11, CD001919; Forster, A., et al. (2001). *Cochrane Database of Systematic Reviews* (3), Cd001919; Smith, J., et al. (2009). *Clinical Rehabilitation*, 23(3), 195-206.



# Research questions

- What information and resources were provided to/received by families across the care continuum?
- How information was delivered?
- What preferences did families have for the way information was provided?
- What, if any, were the barriers and gaps in information provision?



# Methods

- Design: Mixed methods descriptive survey
- Ethics: Northern X Regional Ethics Committee (NTX/10/EXP/071)
- Inclusion criteria - Family members:
  - being a family member of someone who had experienced stroke in the previous two years
  - adequate spoken English to complete consent and the questionnaire
- Inclusion criteria - Health professionals:
  - currently working with people post-stroke

# Participants: Family members

	Family member (n=19)	Stroke survivor (n=13)
Mean age	53 years	63.7 years
Age range	14-77 years	42-84 years
Gender		
Male	4	2
Female	15	11
Ethnicity		
NZ European/Pakeha	18	2
Other	1	11
Average time since stroke	1.6 years	1.6 years
Time since stroke range	0.4-4.11 years	0.4-4.11 years
Relationship to stroke survivor	Wife (n=7) Husband (n=2) Partner (n=1) Son or daughter (n=7) Brother (n=1) Mother-in-law (n=1)	

# Participants: Health professionals

Profession	Number	Workplace
Registered nurse	5	Hospital - rehabilitation ward
Enrolled nurse	1	Hospital - rehabilitation ward
Occupational therapist	3	Hospital - rehabilitation ward
Stroke physician	1	Hospital - older adult services
Physiotherapist	2	Hospital - rehabilitation clinic
Speech language therapist	2	Hospital - rehabilitation clinic
Therapy assistant	2	Hospital - rehabilitation clinic
Community stroke advisor	5	Stroke Foundation - community
Other	2	Stroke Foundation - office
<b>Total</b>	<b>23</b>	



# Participants: Health professionals (cont.)

Health professionals (n=23)	Number
Work experience in stroke services (no. of years)	
Mean	11.25
Range	1.5-35
Stroke-specific skills/education	
Yes	19
No	4
Clients with stroke (% of workload)	
Mean	52
Range	5-100
Time-point on stroke continuum where working with stroke families (multiple responses possible)	
Acute	11
Rehabilitation	11
Community	11



# Data collection and analysis

- Two questionnaires developed
  - Family members
  - Health professionals
- Quantitative and qualitative data
- Administered via face to face interviews (n=40)
- Electronic/postal versions (n=2)
- Quantitative data - descriptive statistics
- Qualitative data - thematic content analysis



# Findings - Health professionals

- Information development and preparation
- Teaching strategies
- Effectiveness of available information
- Effective methods for delivery
- Health literacy assessment
- Changes to make a difference
- Information delivery and content
- Barriers in provision
- Timing of information giving
- Knowledge gaps
- Web-based information
- Gaps/omissions in information provision



# Findings - Families

## Information provision at the time of stroke

- Living with a stroke survivor
- Information about stroke

## Information provision post-discharge

- Little of it
- Now is when we need it



# Findings - Families (cont.)

What families would have liked:

- More about the impact of personality changes
- More information about the demands of caring for the stroke survivor
- How time consuming caring was
- Availability of community services
- Whole family to be involved in MDT-family meetings



## Findings - Families (cont.)

“Demand information or get someone to ask for you”

“Get as much information as you can”

“Seek advice from a professional rather than hearsay”

“The Stroke Foundation has the best advice”

“Talk to other people who have been through it, because it’s hard to know unless you've been there”

“Nothing can prepare you for it, it’s very sudden and takes time to get through”

“Family support in those times is very important, get ready for the long haul”



# Key points

- Information provision is important and valued
- Access to information was variable in both quality and timeliness
  - Unmet needs
  - Limitations in resources - time, funding, quality of resources
- Health literacy not often assessed
- Limitations in digital literacy
- Timing it right (or wrong)
- Not family focused



# Conclusions

- Access to appropriate information post-stroke was problematic for most families and their specific needs were often overlooked
- Families may have complex needs that are different to the stroke survivor's needs
- Health professionals recognised the limitations of resources, time and funding alongside the need for timely, quality information provision post-stroke, however, a gap was identified between their theoretical understanding of best practice and their actual practice
- To provide best practice for stroke survivors and their families, post-stroke education should be based on assessment of health literacy and changing needs across the post-stroke continuum





# Questions?

