

The Hidden Aspects of Stroke



Katy Rothwell

(Knowledge Transfer Associate, NIHR CLAHRC for Greater Manchester)

Overview

- What are the ‘hidden aspects’ of stroke?
- Why are they important?
- Why long-term post stroke?
- Evidence-base: needs survey, 6/12 reviews & care homes
- Implications

Hidden aspects of stroke

- Recently become a frequently used term.
- Often placed in two brackets:

Mood-related problems

Frustration
Loss of confidence
Low mood
Anxiety
Emotionalism
Fatigue

Cognition-related problems

Dementia
Memory
Attention, concentration & distraction
Information processing
Personality changes

What do we mean by hidden?



Hidden from the
general public

What do we mean by hidden?



Hidden from
**health/social care
professionals**

Hidden from
Carer/Family

What do we mean by hidden?



Hidden from the **stroke survivor** themselves

Hidden aspects of stroke

- Tend to be problems encountered in the longer-term.
- **Why?**

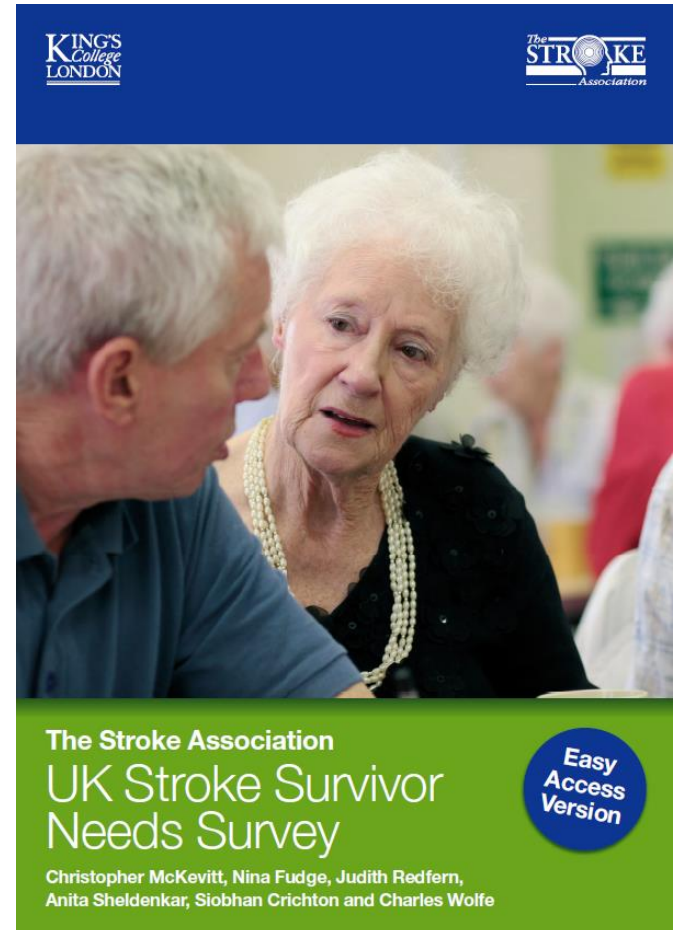


Stroke Needs Survey

- Survey of stroke survivors 1-5 years post-stroke.
- Aimed to obtain information about:
 - The long-term needs of people with stroke
 - The number of people with each different need
 - The proportion of the needs that are NOT met
- 799 participants; Self-reported
- Results published in 2011 (*McKevitt et al- Stroke*)

Stroke Needs Survey

- Of those reporting unmet needs, the median number of unmet needs was 3 (range 1-13)



Stroke Needs Survey

	No. Reporting a Problem (Weighted %)	Proportion Reporting Need Unmet (Weighted %)	Proportion Reporting Need Met to Some Extent (Weighted %)	Proportion Reporting Need Met (Weighted %)
Mobility problems	321 (58.4)	25	43	32
Falls	265 (43.9)	21	47	32
Incontinence problems	217 (37.2)	21	40	39
Pain	249 (39.5)	15	34	51
Fatigue problems	301 (51.7)	43	36	21
Emotional problems	244 (38.4)	39	34	27
Concentration problems	260 (44.7)	43	41	16
Memory problems	260 (42.8)	59	25	16
Speaking difficulties	194 (34.3)	28	39	33
Reading difficulties	148 (23.2)	34	43	23
Sight problems	212 (37.2)	26	35	39

Six Month Reviews

- Pilot established in 2010 in collaboration with The Stroke Association.
- Between July and August 2010 15 Information, Advice and Support coordinators completed between 6 and 11 reviews each.
- All service users have been discharged approximately 6 months prior to the review.
- All reviews were delivered in the home setting using GM-SAT.

Six Month Reviews

	Number (n) of unmet needs identified	Percentage (%) of individuals presenting with unmet need
Medication management	4	3
Medication compliance	18	13
Secondary prevention (non lifestyle)	30	22
Alcohol	7	5
Diet	9	7
Smoking	10	7
Exercise	18	13
Vision	8	6
Hearing	8	6
Communication	13	9
Swallowing	7	5
Nutrition	6	4
Weight management	8	6
Pain	12	9
Headaches/ Migraines	9	7
Seizures	0	0
Continence	13	9
Activities of daily living	13	9
Mobility	9	7

	Number (n) of unmet needs identified	Percentage (%) of individuals presenting with unmet need
Falls	10	7
Depression	26	19
Anxiety	20	15
Emotionalism	4	3
Personality changes	16	12
Sexual health	4	3
Fatigue	47	34
Sleep pattern	11	8
Memory, concentration and attention	35	26
Driving	13	9
Transport and travel	7	5
Activities and hobbies	11	8
Employment	9	7
Benefits and finances	25	18
House and home	10	7
Carer/ Supporter needs	11	8
Other	3	2
TOTAL	464	

It was good to be able to discuss the effects that the stroke has had on my everyday life with someone impartial and willing to give me help and advice regarding things that were bothering me. The best thing about the review was being able to talk about anything I wished to and be believed. Most people tend to think that everything is just ok.



Care Home Stroke Population

- 122 stroke survivors
- BI ≤ 10 and no primary dementia diagnosis
- Assessment 3, 6 & 12 months
- Depression: HADS > 7

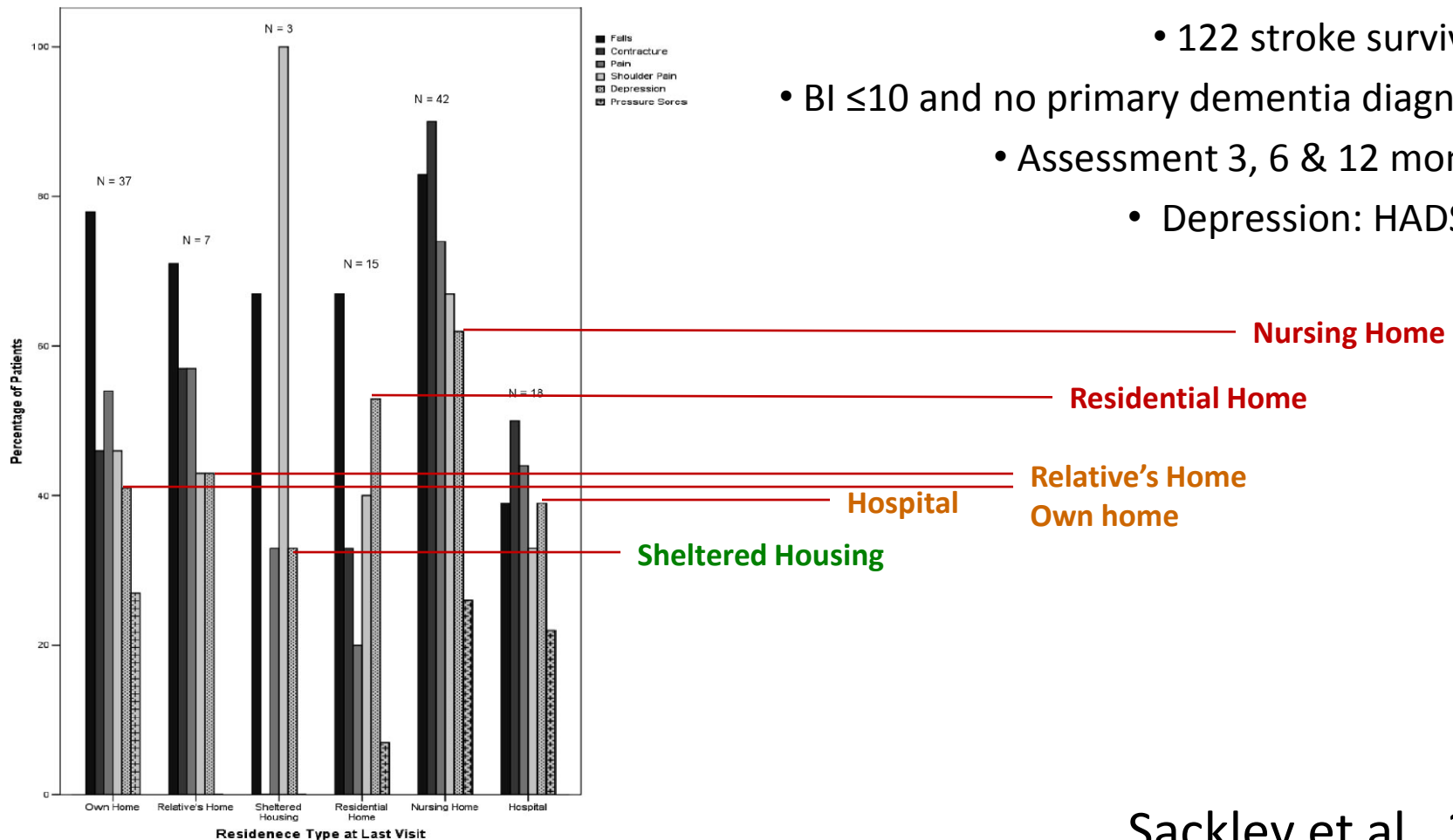


Figure 2. Histogram showing the percentage of participants experiencing each complication in the first 12 months poststroke as a fraction of the number of participants in each place of residence at their final assessment (n=122).

Sackley et al., 2008

Implications

- Real need to support stroke survivors in the long-term
- Benefit of a (traditionally frowned upon) 'checklist approach'
- Awareness raising
- Training needs
- How do we measure the benefits of long-term reviews and support?



Implications

Domain 2 Enhancing quality of life for people with long-term conditions

- Joint health and social care plans on discharge
- Psychological support for mood, behaviour and cognitive disturbance by 6/12 after stroke
- **Reviewed by 6/12 after leaving hospital**
- Supported by stroke skilled early supported discharge team (ESD)

A (very) personal account...

Can't help it but brain goes on strike
Something happened when I was doing alright
The outside's ok but the inside's not right
I was the lucky one but still parts took flight
Into a world that's covered with fright
Few people care and fewer can see
Just what this stroke has done to me
Life is a front now, it has to be
A smile, a kiss and a chirpy old me
It's only what they've expected of me
The struggle annoyingly won't go away
The face goes on for another day
If they only knew, instead they only see
Just how bad this (stroke) is for me.



Google 'stroke poetry'