

# Caring during ESD – what is it like for the family?



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# ESD is good for....

- *Patients – reduced mortality, dependency, institutionalisation, EADL,*
- *Services – cost effective, patient satisfaction*
- **FAMILY CARERS?**

*1. Fearon P, Langhorne P, Early Supported Discharge Trialists. Services for reducing duration of hospital care for acute stroke patients. Cochrane Database of Systematic Reviews 2012, Issue 9.*



# Our research

- *Not just how stressed but why...*
- *1. Measure*
  - *Work done by carer different tasks (mins)*
  - *Negative Impact of each task on carer*
- *2. Explore relationship with disability*
- *3. Explore experience*

# Developing tool

- *With team: MDT, Carers, Researchers*
- *Interviewer administered questionnaire*
- *ESD staff identified tasks – 14 domains*
- *Tool drafted and edited by team*
- *Carers discussed, piloted and modified tool*
- *Final tool approved by team*

# ESD care burden

- *medication,*
- *speech,*
- *mobility and ex,*
- *memory,*
- *visual tasks,*
- *wash and dress,*
- *toileting,*
- *emotional management,*
- *diet mods,*
- *researching stroke,*
- *health and safety,*
- *completing forms,*
- *interacting HCPs,*
- *new household tasks*

**Time and Impact ‘Yesterday’**

# Tool - example

## 7. Emotional Management

Yesterday, how long do you think you spent in total supporting your friend or family member emotionally?

- Total time spent yesterday was \_\_\_\_\_minutes

Overall how much of an impact did supporting your relative or friend emotionally have on you yesterday?

None

Small

Medium

Large

Very large

# Study

- *Interviewed in week 2*
- *Depth interview 4-8 weeks after ESD*

Variable	Description
<b>Family caregiver gender</b>	13 female 5 male
<b>Family caregiver's relationship to stroke survivor</b>	16 spouse / partner 1 son 1 daughter
<b>Ethnicity</b>	18 White British
<b>Caregiver occupation (n=12)</b>	9 retired 1 waitress 1 teacher 1 chocolatier

	<b>Workload (mins)</b> <b>Median (IQR)</b> <b>Max</b>	<b>Impact</b>
<b>Medication</b>	5 (0.75 – 5) 60	1 (1 -2) 3
<b>Speech</b>	15 (0-30) 360	1.5 (1 – 3) 4
<b>Mobility</b>	52.5 (6.25 – 52.5) 60	1.5 (1 – 3) 5
<b>Memory</b>	10 (0 – 56.25) 120	1.5 (1 – 3) 4
<b>Washing and Dressing</b>	5 (0-23.75) 45	1 (1 – 2) 4
<b>Toileting</b>	1 (0-23.75) 45	1 (1 – 3) 4
<b>Emotional Management</b>	45 (11.35 – 77.5) 960	3 (2 – 4) 5
<b>Diet</b>	5 ( 0-30) 150	1 (1 – 2) 4
<b>Researching Stroke</b>	10 (0 - 60) 120	1.5 (1 – 3.75) 5
<b>Health and Safety</b>	150 (30 – 960) 960	3 (2 – 4) 5
<b>Completing Forms</b>	0 (0 – 12.5) 60	1 (1 – 2) 5
<b>Interacting with health professionals</b>	17.5 (0.25 – 82.5) 480	1 (1 – 3) 5
<b>New household tasks</b>	45 (3.75 – 90) 240	2 (1 -2) 5
<b>Visual tasks</b>	0 (0 – 3.75) 100	1 (1 -1) 4



*Whatever we do I'm aware of the health and safety side of it, it's all the time / taken over the day / constant worry*



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*that's the biggy/ constant reassuring / takes up the most time /Physical stuff more easy / 'it's lonely' / exhausting*

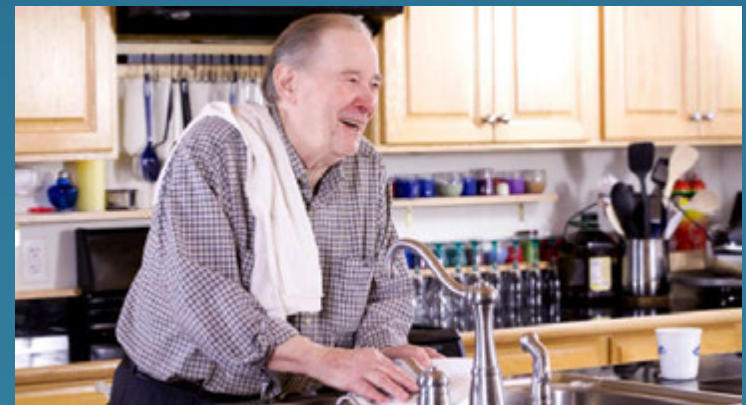
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*time consuming but rewarding/ Loss of independence needs supervising*



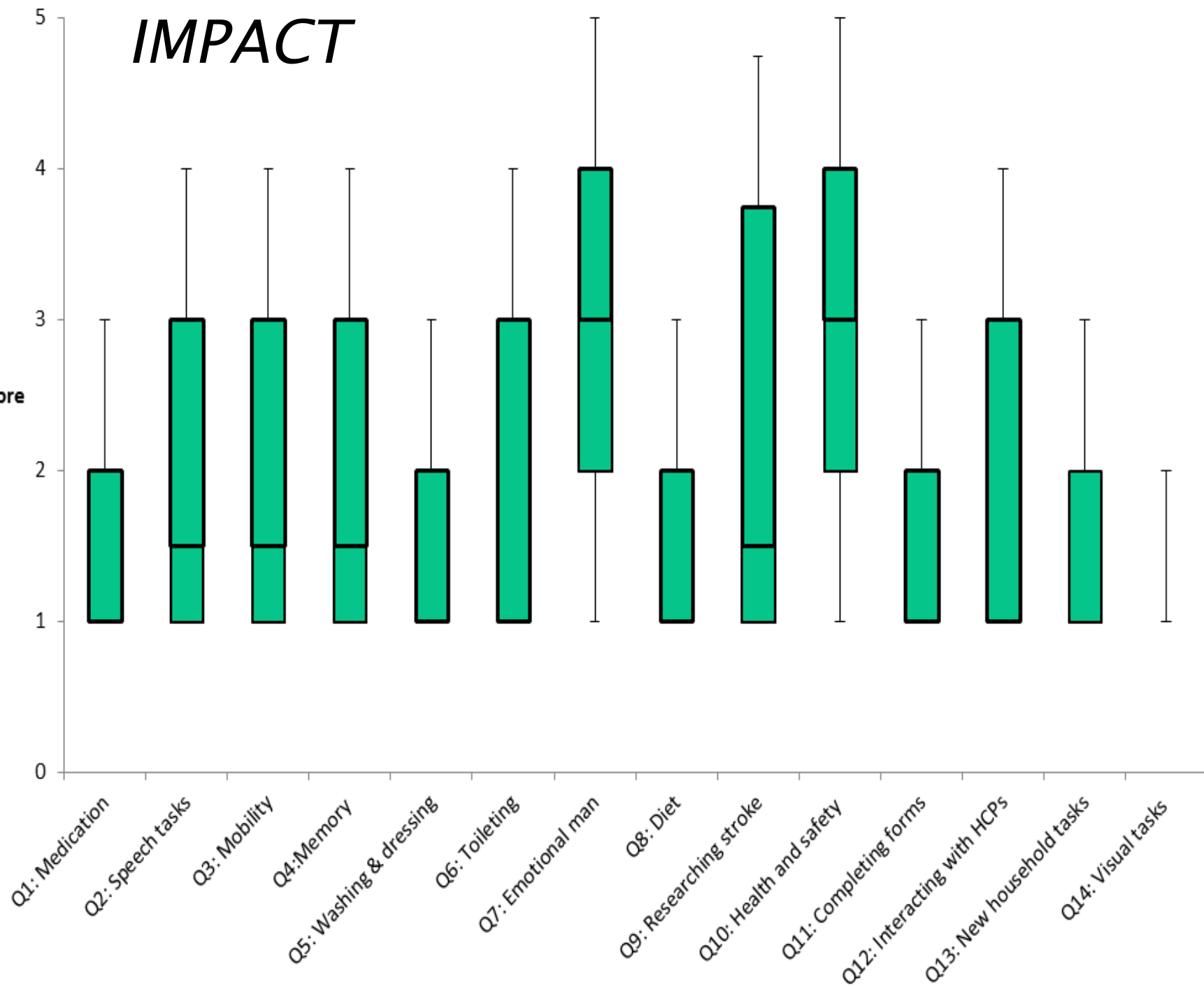
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*Everything wife used to do was probably taken for granted; only now do I realise how much she did in a day*

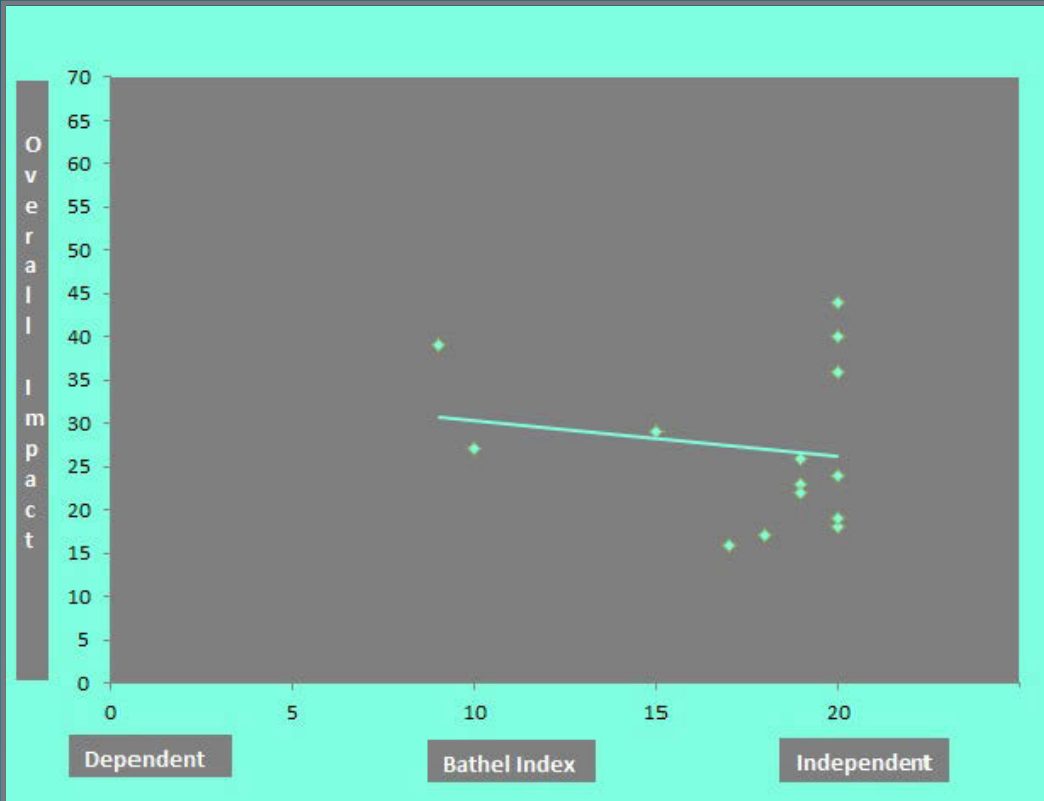


# IMPACT

Impact Score



# Carer impact and disability



- *No relationship between severity of care impact and patient disability*
- *NB relatively high Barthel scores*

# Unprepared for hospital discharge

Surprised by early discharge

Worried it was too soon

Little or no consultation about if and when

Little warning of imminent D/C

Inadequate time to prepare

Inadequate consideration of other circumstances  
(carers health, work, other care responsibilities)

Lack/delayed NHS equipment provision

Inflexible care packages

# Rehabilitation support

ESD support is valued

ESD provides respite

ESD develops knowledge/skills

Excellent support for physical rehab

Inadequate support for communication,  
cognitive or emotional issues

Carers not always involved enough

# When ESD ends

ESD too short

Lack of continuity with other services

Lack of therapy hinders recovery

Not in system – lack of follow-up

Still adjusting



# Feeling responsible and anxious

Concerns about safety and falls

Unwilling to leave them alone

Anxiety about further strokes

Coping with memory loss and disorientation

Managing communication

Unable navigate care and health systems

Lack of sleep – physical care and worry

# Changed relationship

Doing intimate care is distressing

Seeing loved one frail

Coping with changed personality

“Nagging” about rehab causes arguments

Difficult to balance risk and patient

independence

# Carers needs not addressed

Lack of emotional support for carer

New household tasks – extra work but unskilled

Being unwell and trying to care

Cant add this to other care responsibilities

Working (a needed break but not considered)

Loss of leisure and social life

Protecting the rest of the family

Added costs

# Discussion



- *Set expectations of ESD*
- *Understand home and carer situation*
- *Practical support – equipment, advice*
- *Discuss realistic risk management with patient and family*

# Discussion

- *Find out how much involvement carers want in ESD sessions and rehab*
- *Reaching carers who aren't available*
- *Emotional management and support for patients and carers*

