Interpreting and implementing stroke self-management support: the importance of context

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“Increasing the capacity, confidence and efficacy of the individual’ for self-management”

(Kennedy et al, 2013)
Self-management support: Key Priority

• **1.2 million stroke survivors in the UK** (Stroke Association, 2016)


• **Key priority for stroke research** (Pollock et al, 2011; Rowat et al, 2016)

• **3rd sector organisations, including Chest, Heart and Stroke Scotland & The Stroke Association**
Self-management support: the evidence

• Self-management programmes may benefit people with stroke living in community settings (Fryer et al, 2016)

• Outcomes:
  – Improved quality of life
  – Enhanced self-efficacy
  – Improved mental well-being
  – Reduced hospital readmission rates

(De Silva, 2011; Taylor et al, 2014; Fryer et al, 2016; Wray et al, 2017)
Core components of self-management support

- Decision making
- Problem solving
- Goal setting
- General rehabilitation/independence
- Quality of life
- Psychosocial impact
- Building confidence and self-efficacy
- Broader wellbeing – ‘living well in the context of a long-term condition’
CARE starts in your heart.
YOU CAN MAKE A DIFFERENCE.

NAME not Condition
#helloynnameis

PLEASE...BE KIND

People may be scared... what can WE do to help + support?

Are you OK that I'm doing this with you?
= dignity respect
People want to be able to stay in their own home
Be cared for in their own home for as long as possible.

Mums + Dads, 'make it better' for us, we need to help make it better for them.

Be the ONE WHO MAKES A DIFFERENCE!!

558 'talks' in 1 day for 2 years
As a carer sometimes I felt: helpless alone scared

"PLEASE DO NOT USE THE WORD 'CHALLENGING'... it's my mom, Joan. NOT "the wee woman with dementia..."

ASK What matters
LISTEN to what matters
DO what matters

People CAN CHANGE lives
What can YOU do?

PLEDGE on 6/6/16

@tommyntour
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The concept of global warming was created by and for the Chinese in order to make U.S. manufacturing non-competitive.
The TALISSMAN project (2012-2014)

Development of self-management intervention

*systematic literature review, stroke survivors (n=20), stroke nurses (two FGs and two telephone interviews, n=11)*

Qualitative evaluation of feasibility and acceptability

*stroke survivors (n=6), stroke nurses (n=5)*

Secondary analysis of qualitative data

*Three FGs & two telephone interviews, Qualified (10-37 years), been in current post (2 months-13 years)*

What is context?

“the set of circumstances or unique factors that surround a particular implementation effort.” (Dramschoder et al, 2009)

“the environment (setting) in which people receive healthcare services or in the context of getting research evidence into practice.” (McCormack et al, 2009)

“includes the factors related to the characteristics of the organisational setting, the individual, his or her role in the organisation and the environment.” (Kaplan et al, 2010)
“Context is one of those words you will encounter again and again without anyone offering anything like a useful definition. It is something of a catch-all word usually used to mean ‘all those things in the situation which are relevant to meaning in some sense but which I haven’t identified.’”

(Bate et al, 2014, Perspectives on Context)
Exploring the role of context

• To understand how perceptions of ‘context’ influence and shape how self-management and self-management support is interpreted and implemented in practice

• Lau et al’s (2016) framework of levels of context: external context, organisation, professionals, intervention
“It is confusing what’s out there though because every political boundary you cross over be it north, south, there will always be this bickering between them and you get better this and that but there’s so much out there that you really don’t know everything that is available and then maybe if a different government comes in they will change the boundaries again and they will change their names. You think you have this knowledge up here [pointing to head] and then you go back to get the telephone number and the contact that you had and they have all changed.” (L1, 2003)
“I think that’s the challenges…we are always trying to find better ways to do things and it’s how that’s all joined up. There’s always people coming up with different ways and ideas to look at things and how does that become joined up in the middle rather than coming from different perspectives.” (L4, phase 1)
“Our follow up is a year post discharge so I tell them what we would like to achieve by the end of that year and then I maybe see them five times in that year. It’s relevant all the way through but I don’t do much at the start. I would be seeing them again three months post discharge and I would say it is quite relevant then. I wouldn’t do it at the start, I find that when patients come out of hospital it takes them a settling in period at home and they are reluctant to receive too much information but you know once they’ve had a couple of months to settle in at home and get established with new patterns of care and then they would be more amenable I think for introducing this.” (H1, phase 1)
“If somebody who’s score was high and they refer to psychology, the psychologists are going to have a fit when they are getting all these referrals, you know what I mean?” (F1, phase 1)
“something that we are doing anyway” (F2, phase 1)

“useful for somebody who is new in the post and maybe didn’t have a lot of experience in the area.” (H1, phase 1)
“We’ve not been used to patients self-managing so we’ve probably put a lot of people in that role [of being dependent] because we have to ‘make it better’. We were programmed to step in there and do everything from the basics to washing, right up to dressings and things and to stand back, it’s difficult. They have to be able to do that [be independent] and [nurses have to] let them go and let them be independent themselves.” (L4, phase 1)

“There just seems to be this element where you are not really allowed to admit that you can’t do things.” (L5, phase 1)
“We have had this one man that wanted to get back and ride a horse or a motorbike and his expectations were that he would be able to do that and give him his due, at the end of it he had an adapted quad bike and things. He raised the level far higher than any therapist would have through that he would have achieved because we err on the side of risk assessment.” (L4, phase 1)

“I would be afraid that people would be more likely to try and overcome a problem themselves and not see their GP and that is not what we promote. Any symptoms could be another TIA or stroke or something…I would be scared that people would try and take care of a health problem when really they should be seeing somebody.” (H1, phase 1)
“What we do ourselves is a lot you know so by the time we have gone over everything that we would like to offer after they have just had a stroke and then having to start this [talking to them about self-management], then yes it’s going to affect [our workload] and the time that we have. It will impact on the length of visits in that we can’t fit as many people in. If it’s something we are going to have to facilitate, you know, it’s going to have an impact on our time.” (H1, phase 1)
Key messages

• Interpretations of self-management and self-management support differ
• Different levels of context
• Context needs to be described and considered in the implementation of interventions
• What next? Empirical testing in a prospective study
Dr Maggie Lawrence, Dr Jo Booth, Dr Anne Rowat, Dr Sian Russell
Mr Campbell Chalmers
Ms Katrina Brennan
Ms Hazel Frazer
Ms Linda Campbell

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Useful references

De Silva (2011) Helping people help themselves: a review of the evidence considering whether it is worthwhile to support self-management London The Health Foundation

Bate et al (2014) Perspectives on Context London The Health Foundation
A community for anyone interested in shaping stroke self-management research and practice

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