









Invisible threads can make the strongest of ties: how to do successful self-management support

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- Evidence, theory, and core components of successful self-management – route to impact
- How a system level change can impact on the experience, confidence of patients, as well as the satisfaction, well-being of staff, and the efficiency of the service
- How to integrate and sustain supported self-management as a practitioner, as a whole team and through a stroke pathway-
- How it feels to be supported and work in this way as a patient and as a staff member personal reflections from a stroke survivor and stroke practitioner





What does it feel like to face life after a stroke?

I thought of it like a journey by car [...] you have everything planned and all of a sudden, the car grinds to a halt. And you had checked the car but everything just seems be going wrong and you end up wondering "what's going on here?"

(Participant NROL July 2021

https://www.ucl.ac.uk/ion/research/ourdepartments/clinical-and-movementneurosciences/people/ward-lab/neurorehab-online-0)

7 reviews, 130 studies

We have reached saturation!



- 1. Stroke has a devastating effect on self-image
- 2. Individuals have varying selfmanagement needs across the recovery trajectory
- 3. There is a need for longer term psychological and emotional support particularly when physical recovery slows
- 4. Information needs are considerable but variable
- 5. Need- good person-centered communication, peer support, supported goal setting and planning

Studies such as these help inform self-management programmes



Original Article

CLINICAL REHABILITATION

Is independence enough? Rehabilitation should include autonomy and social engagement to achieve quality of life Clinical Rehabilitation
2021, Vol. 35(1) 3–12

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John McClure 10 and Caspian Leah

Question...How can self-management support align with the long-term goal of rehabilitation?

Problems with the term self-management..



Boger EJ, Demain SH, Latter SM. Stroke self-management: a focus group study to identify the factors influencing self-management following stroke. Int J Nurs Stud. 2015 Jan;52(1):175-87. doi: 10.1016/j.ijnurstu.2014.05.006. Epub 2014 May 24. PMID: 24917370.

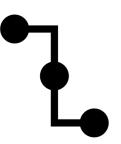
Cochrane review 2016... and the evidence base is building



'Self-management programmes do improve the quality of life after stroke. People with stroke reported improvements in their ability to live the way they wanted and that they felt more empowered to take charge of their lives, rather than be dependent on other people for their happiness and satisfaction with life'

***53 stroke self-management clinical trials currently on ISTCRN database

Evidence from other long-term conditions



'Self-Management Support can lead to significant improvements, in...



knowledge



experience

But what is the secret ingredient?



service use and costs



health behaviours and outcomes

Reynolds, R., Dennis, S., Hasan, I. *et al.* A systematic review of chronic disease management interventions in primary care. *BMC Fam Pract* **19,** 11 (2018). https://doi.org/10.1186/s12875-017-0692-3

Why is this relevant?

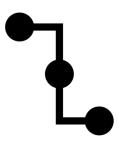
- ✓ Self-efficacy positively associated with mobility, activities of daily living, and quality of life and negatively associated with depression
- ✓ Self-efficacy can mediate self-management skills such as problem solving and goal setting
- ✓ Evidence that changing self-efficacy can influence independence and self-management

National Clinical Guidelines for Stroke 2016 2.13 Self-Management https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx

Bandura A. Self- Efficacy: The Exercise of Control. W.H. Freeman, New York, 1997.

Making the connections: Houston, we need a theory....





- ✓ Social Cognitive Theory most commonly theoretical base for self-management programmes
- ✓ Self-efficacy is 'An individual's belief in their own capability to produce a change in a specific behaviour '
- ✓ Self-efficacy is critical to the success of self-management

Making a change ..with one small step

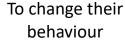








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• The feeling of success= the most powerful source of self-efficacy

Using past skills and experiences – <u>focusing on</u> <u>assets</u> not only deficits





What does 'integrated' self-management support feel like?

'The very first session was what do you hope to achieve? She asked me "what do I want to get out of therapy?" '

'As I was saying to [Physiotherapist] the other day, when are you people off? And she said when you feel like you don't need us anymore'

'I would see it (finishing therapy) as a challenge you see. And if I feel something is a challenge, I will try to see if I can overcome that problem'

Jones F, McKevitt C, Riazi A, et al

How is rehabilitation with and without an integrated self-management approach perceived by UK community-dwelling stroke survivors? A qualitative process evaluation to explore implementation and contextual variations

BMJ Open 2017;7:e014109. doi: 10.1136/bmjopen-2016-014109

The All Wales Project

. . . .

Phases 1&2

- Awareness raising in 10 stroke units
- Masterclasses for teams already trained held in January

Phases 3 &4

- 2 stage introductory team training across 4 health boards
- Support for implementation

Phases 5&6

- Masterclasses
- Evaluation-
- Dissemination events
- Report







https://www.bridgesselfmanagement.org.uk/project/bridges-wales-stroke-self-management-project/

The People 1st Project — integrating self-management support in stroke services across East of England



- A mixed-method evaluation led by UEA (Dr Nicola Hancock)
- 550 healthcare practitioners, across 24 NHS Trusts in the East of England,
- Explored how practitioners assimilated and enacted learning from Bridges in their practice, both on an individual and collective basis.
- Results showed increase in staff confidence and skill around supported self-management,
- Transformations to practice including changes to the structure of, and language used, in patient interactions to place them at the centre of rehabilitation







Question 1

What is the scope to initiate self-management support?

 "I think everything's very prescriptive in the hospital, people do this, do that, your meal comes to you, but there's no choice in things that they do, so I think we, I think on a cognitive level, patients aren't thinking for themselves, everything's done to you" (Penny- Wales project) Q2are you already doing it already?...

• Now I see that it's everything, it's not just allowing them time to wash themselves, it's basically putting the ball in their court for them to choose what goals they wanna do, and supporting them more than dictating to them. So I'd probably say the challenges I faced prior was a lack of understanding really as to what SM truly was, so since then I don't see any challenges, I'm much more aware, it's opened my eyes." (Joan-Wales project)

•

Q3- could working in this way feel easier you?

 "You know sometimes you do feel under pressure that you have to give a yes or a no to a patient or a professional or a consultant...It [Bridges] did feel like it gave us permission to be a bit more pragmatic and a bit more open ended...because of course people do sometimes end up surprising you and going back to activities that you didn't think they would be capable of." (Tash – Wales project)



Is self-management support about dose?

- 400 people within 16 weeks of stroke
- Randomised to a single 'Take Charge' session
- Talking therapy
- Focused on autonomy, purpose, mastery, connectedness
- Significant effect on HRQOL and independence

Fu V, Weatherall M, McPherson K, et al. Taking Charge after Stroke: A randomized controlled trial of a personcentered, self-directed rehabilitation intervention. *International Journal of Stroke*. 2020;15(9):954-964. doi:10.1177/1747493020915144

Is it about context?









The replicability problem:



It takes effort and creativity to adopt in a new setting because it is context specific



The soil is the context, and the sapling is the complex intervention.

What is it about the soil that makes the intervention thrive, or not?



Final thoughts from Estonia...

- "Mina ei anna teraapiale suunda, vaid rohkem patsient annab mulle ja mina toetan teda, see on muutunud."
- "It is not me giving the direction for the therapy, but it is the patient who does this, and I support them, this is what has changed".







Thank you for listening...



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