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# Self-management after stroke: an ethnographic study exploring the place of self-management in current rehabilitation practice

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# Self-management after stroke



# Defining self-management

An individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent with living with a chronic condition

(Barlow et al 2002: 366)

# Historical context

- Demographic, epidemiological, policy, economic drives
- Increased predicted numbers of people with one or more long conditions
- Chronic Disease Self-Management Programme (Lorig et al 1999)
- Expert Patient Programme (DH 2001)

- Short term improvements in some patient outcomes but not others (e.g. Foster et al 2009)
- Lack of patient engagement
- Evidence that other self-management approaches work (Health Foundation 2011)

# Common core principles to support self-care (DH 2008)

- Informed choice
- Effective communication
- Facilitate access to information
- Support to develop skills
- Support to use technology
- Advice on accessing support networks and services
- Support risk management and risk taking

- Stroke specific self-management programmes
- Emerging evidence of positive rehabilitation outcomes (Jones and Riazi 2011)
- How do health care professionals provide self-management support to people after stroke?

To investigate what self-management support is currently provided in physiotherapy practice after stroke, to inform the development of an intervention



- Ethnographic approach
- Systematic review and narrative synthesis
- Longitudinal qualitative case studies
- Observations and interviews
- To develop and pilot a self-management intervention

# Research Questions

- What are stroke survivors' and physiotherapists' understandings of self-management after stroke?
- How do physiotherapists work with people after stroke to assist them in developing self-management skills and strategies?
- What contexts promote or hinder self-management at different time points after stroke?

# Recruitment

- 17 stroke patients identified from the South London Stroke Register, admitted to the stroke unit at Guy's and St Thomas' NHS Foundation Trust
- 12 carers
- 19 physiotherapists in acute or community stroke rehabilitation

# Socio-demographic characteristics

## Stroke survivors:

- Age range 53-91 years (mean 71 years)
- 9 men and 8 women
- 10 from White British; 5 Black Caribbean; 2 Black African ethnic backgrounds
- 13 new strokes; 4 recurrent strokes

## Carers:

- 6 spouses/partner; 4 adult children; 1 sibling; 1 neighbour

## Physiotherapists:

- 10 hospital; 9 community; range of experience (band 5-8)

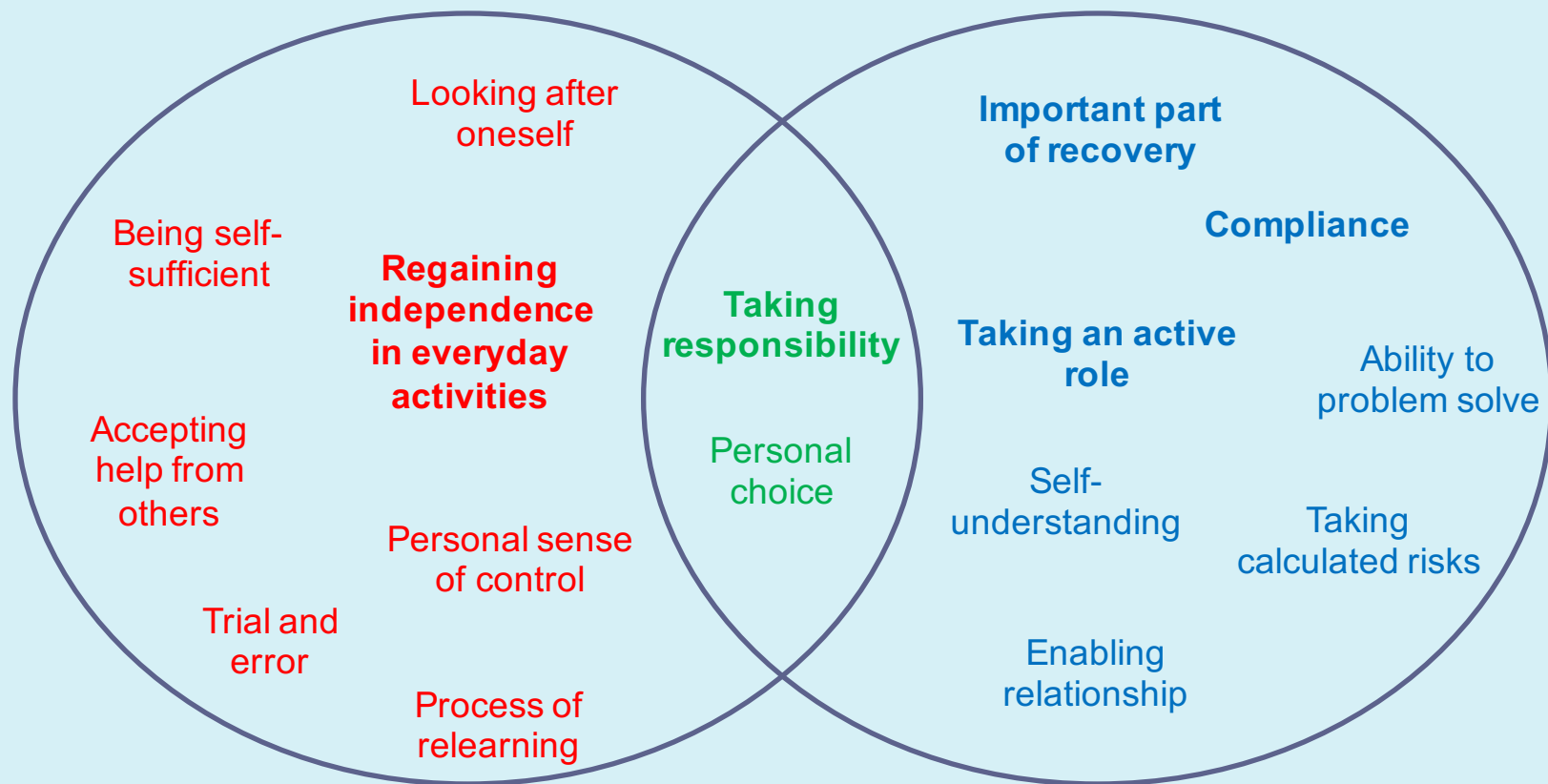
# Data collection

- 170 hours of observations
- 13 initial interviews with stroke survivors
- 8 joint and 2 separate interviews with carers
- 13 interviews with physiotherapists
- 10 follow-up interviews

# What is self-management?

## Stroke Survivors

## Physiotherapists



Self-management is about **looking after yourself**...Well it's no good sitting feeling sorry for yourself all the time is it? That's what it boils down to with me I think. It doesn't get you anywhere does it to sit and mope.  
*(Participant 12, female, aged 80)*

Self-management to me, it means that you **do things for yourself, you manage yourself**, like you set yourself things...It can refer to a lot of things, really, what you do, what you're doing, you know, but I mean this is the first time **I've had a stroke so basically I'm a learner as well, I'm beginning** as well, so certain things that I do I'm learning at the same time and then I use that to help myself for the next time. *(Participant 5, male, aged 53)*



Self-management, I suppose it's, in terms of a patient, **taking an active role in their own rehab**, not just in terms of participating in our sessions, but also outside our sessions, **taking on board what advice we're giving**, if we're giving them any exercises on top or any sort of additional programme to work through. And being able to continue with that and doing those sort of exercise programmes, **taking a bit more of a role in their recovery and their rehabilitation.** (*Hospital physiotherapist*)

Self-management, it's about **providing the patient with the tools to achieve what they want to achieve**. So it's getting through with them what are their targets, what are their objectives, **what do they want to gain from us and then how do they feel they're going to get there**. Then it's providing them, **if they want**, with the information, with the **tools** that they need to do that and **encouraging** them as best as possible to, how best to utilise those tools.  
*(Community physiotherapist)*

# Self-management support



# Observation 1 (FN 12, stroke unit, 28/02/2012)

The physiotherapist (PT) lowers the bed with the remote control and suggests to the man, who is wearing orange pyjamas, to sit up over the edge of the bed. **'Now remember what I told you M [first name]'** she says. The PT **stands** on the right side of his bed. **He attempts to turn onto his weaker right side to hold the bed lever with his left hand.** **'That's it. Good'** encourages the PT. He struggles to bring his weaker right leg over the edge of the bed and the PT assists him. **Once sitting over the bed the PT again praises the man 'Well done!'**, encouraging him to place his feet on the floor. She then suggests a plan for the therapy session **'I thought we could do some walking in the corridor with your frame.'** 'Yes' says the man in a quiet tone of voice. The PT reaches for the blue handling belt lying at the bottom of the bed and starts to put it around the man's waist. **'Can you fasten it up yourself, M?'** He holds on to the plastic buckle of the belt with both hands and eventually manages to click it together. 'Good' encourages the PT, further adjusting the belt so that it lies symmetrically around his waist. She then retrieves a pair of blue slippers next to the man's bedside locker, placing these near his feet. Kneeling down, she encourages the man to lift his left leg off the floor and places his foot in the slipper. She then asks him to lift his weaker right leg off the ground but he struggles to do this, so she assists him by supporting his foot and lower leg, placing the slightly swollen foot into the slipper for him. **'So now we are going to get in the wheelchair'** she continues. The PT **stands** in front of the man **'After three we are going to sit in the chair'**. **Ok '1-2-3' Now lean forwards and reach for the arm of the wheelchair' instructs the PT.** Whilst standing in front of him she blocks his weaker right knee with her knees. She supports him around the straps of the handling belt and assists him to pivot around into the wheelchair. He manages to transfer relatively well. **'Well done. That was really good. Now shuffle back in the chair'**. she encourages him whilst supporting his weaker right leg. In the wheelchair the PT brings the wheelchair foot rests around. **'Lift your left leg. Now your right leg'** she instructs. The man struggles again to lift his weaker right leg onto the foot rest and the PT assists him.....

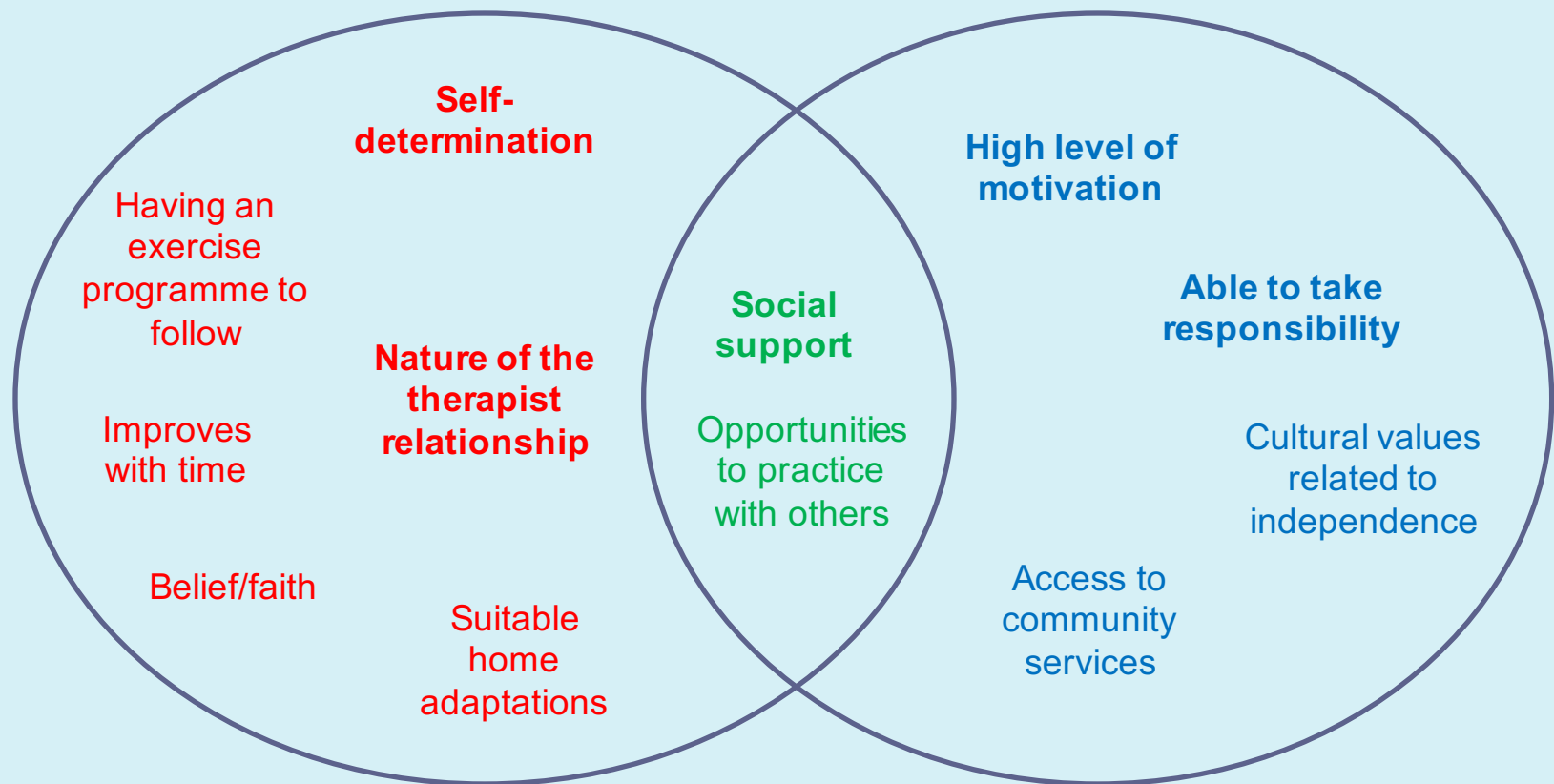
# Observation 2 (FN 63, patient's home, 17/07/2012)

The man is sitting over the edge of his bed and the physiotherapist (PT) is sitting in a white plastic chair next to him. He is wearing a white T-shirt and grey towelling shorts. She asks him **'What would you like to do today S [first name]?'.** **'Anything you want me to do regarding exercises'** he replies. **'You're the boss!'** The physiotherapist smiles and says **'I can definitely guide you with the exercises, but it's your choice'**. 'With that in mind' she continues, producing from her bag a number of individual A4 sheets of paper of black-and-white photos of a man pictured performing various seated arm exercises, and large text instructions by each photograph. 'Shall we go through the exercises for your arm then?' suggests the PT. 'Okay' the man replies. The PT, **sitting next to the man on his bed**, first asks him to demonstrate how much movement he has in his left weaker arm. He lifts the arm up to about 70° and complains that he cannot lift it up any higher due to pain in the front of the shoulder. The PT asks him to relax his arm on his lap. She then **palpates the front of the shoulder joint** before asking him to relax his arm as she takes the weight of it to assess the movement. The PT passively moves the arm several times forwards and out to the side, encouraging the man to relax the weight of his arm, before placing his hand back down on his lap. The PT then goes through a series of arm exercises the man can do under the supervision of his wife. **As she goes through the exercises with him she intermittently corrects his technique, with his wife present, standing observing.** After going through the exercises, **the PT asks how he is getting on with his walking.** He replies that he can walk inside the flat with his wife close by. **The PT asks him what he would like to achieve this week 'I want to go to the toilet without asking my wife's help' he says in a rather embarrassed tone. 'That sounds like a good plan' replies the PT,** who then proceeds to ask him **where he would like to walk to today?** He replies that he would like to walk, but has some concerns walking onto the balcony with people around. The PT suggests that he could try walking on the balcony and **reassures** him that there are likely to be few people around at this time....

# Factors facilitating self-management

## Stroke Survivors

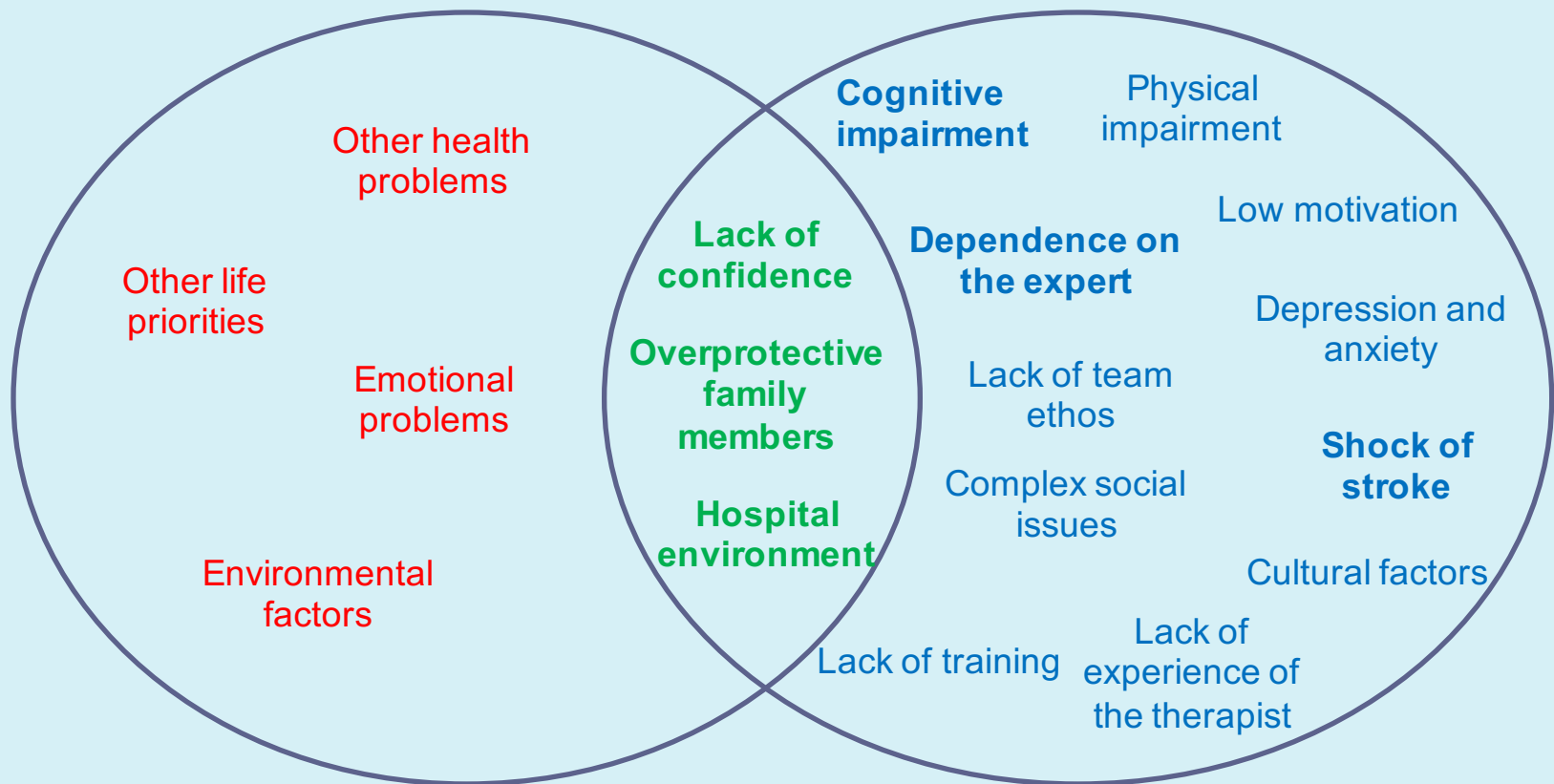
## Physiotherapists



# Barriers to self-management

## Stroke Survivors

## Physiotherapists



Well in the beginning, I do think many patients, even though they need to be perhaps aware of what their condition is about, let's say if somebody has just been diagnosed with having had a stroke, in the beginning people are just really **low in confidence, they're like shell shocked**, they don't know what to do and when we set goals with patients, they often say '**oh well, you're the professional, you tell me what to do**', so **they're not ready to self manage or to take responsibility** themselves yet. Very rarely I see people who say 'right, I've had a stroke, this is where I am, this is what I want to achieve', because they don't really know where they are, what has happened to them and they very much **look at the health care professional to guide them** (*Community physiotherapist*)



# Conclusions

- Differences in stroke survivors' and health professionals' understandings of self-management
- Physiotherapists focused mainly on cognitive and technical aspects
- Nature of therapist/patient relationship important for stroke survivors
- Self-management seeded early on, but a challenge
- Tension between 'dependence' on the expert and assuming responsibility for one's own recovery
- How best to address this in stroke rehabilitation?