

## Remembering Personhood:

*supporting active participation after stroke*

Fiona Jones Reader in Rehabilitation

St George's Faculty of Health and Social Care Sciences Kingston University London

### Life after....

- Psychosocial transition
- Social support has an effect on physical functioning and quality of life
- Predominant theme is social isolation and disconnection from others
- Salter et al, 2009
- Importance of a return to a meaningful life
- Recovery defined in terms of personal values and goals
- Forward progress maintained through hope, preserving energy and control
- Clinical interpretations of little relevance

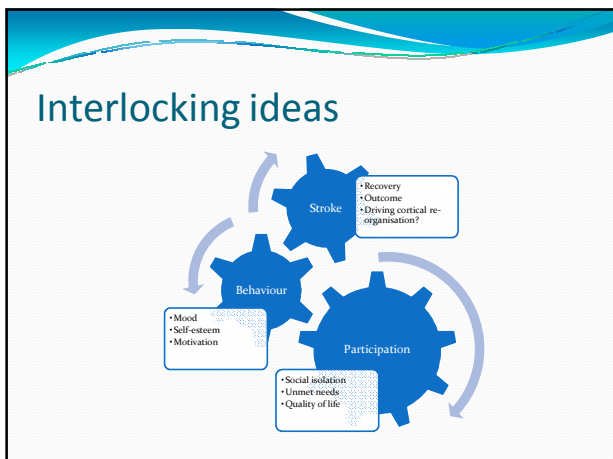
### Life after...

- Social isolation predicts outcome post stroke
- Importance of primary social networks- e.g. leisure, hobbies, companionship, community event, shopping, religious activities
- Friendships prior to stroke may provide mechanism for improved outcome
- Pre-stroke isolation = risk factor for outcomes post stroke

(Boden-Albala,2005)

### 'Stroke Support West Midlands celebrated its 10th anniversary in 2009'

- The club started with four members and has grown to over 70 members from which over 40 attend each week.
- The club is a place to be with friends, who understand and support each other.
- For most people, the most significant activity of the club is the regular Saturday meetings.
- Members consistently express their appreciation of structured exercise sessions at the beginning of the two hour weekly meeting, as well as the time they have to share information and experiences, and enjoy talks from invited speakers.
- The club often arranges activities such as visits to Twycross Zoo and a sports day that caters for all capabilities. The balance of exercise, events, information sharing and mutual support is exactly what members say they want.
- Club members say they feel, **safe, supported and involved**. Survivors help and encourage other survivors; carers reach out to carers. The club pursues its mission of taking the 'dis' out of disability.



### Unmet needs?

- What is meant by long term- 6months-21 years?
- What is a stroke specific long term need?
- Few interventions to support long term need
- Definitions do no incorporate user perceptions of need
- How does need vary according to class , age, ethnicity,gender?

## UK Stroke Survivor Needs Survey

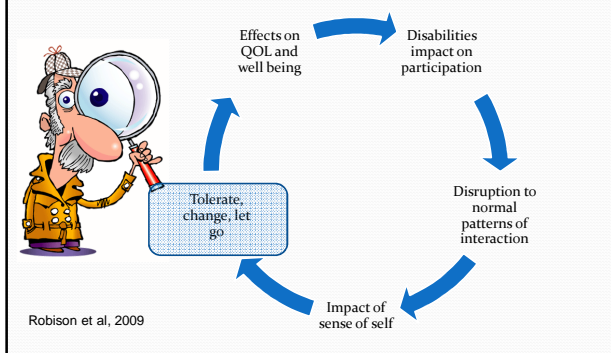
- N=799, 60% response rate
- 49% had one unmet need
- Higher levels of need with Black ethnicity and more severe disability
- 54% need more information
- 1/3rd reported emotional problems
- 1/2 reported fatigue
- 45% problems with concentration, 43% memory, 23% reading (most needs unmet)
- 42% changes in relationships
- 52% changes in work activities
- 67% changes in leisure

## Social effects of stroke

- Evidence of the negative effects of stroke on many aspects of social participation
- Family life
- Unmet financial need
- Deterioration of sexual life

(Daniel et al 2009)

## Longitudinal study of life after stroke

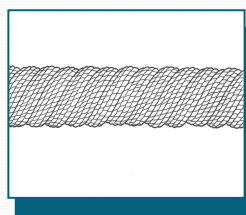


## Life threads

- Limitations of traditional rehabilitation
- Dominance of professional values and practices
- Limited involvement of individual and their families
- Gap between professional and personal realities
- Disability seen as a loss/bereavement

Ellis-Hill et al 2008

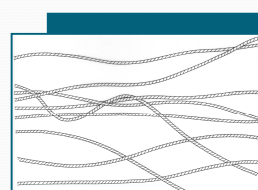
## Life threads



- Variety of stories we can tell about ourselves
- Helps create a sense of identity, situation, past present and future

Ellis-Hill et al 2008

## Parallel life threads



- Stories created between two people
- Identity and sense of self are not fixed but created and constantly received
- Continuity is essential for psychological well being
- Creating links between past which is known and future which is unknown

Ellis-Hill et al 2008

## Therapeutic relationship..... on equal terms?

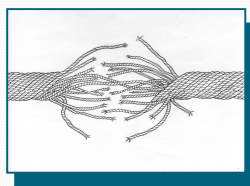
- Non-tragedy/affirmation model of disability
- Empowerment/partnership/user involvement- just words?
- Models of disability are not models of professional intervention

## Non-tragedy

- Be yourself
- Don't presume disabled people desire normality
- Recognise disabled people's expertise
- Maintain integrity
- Actively listen
- Relinquish power

Swain and French (2008)

## Life threads frayed - stroke



- Predictability of life is lost
- Biographical disruption
- 'Loss of me' distanced from their new selves
- Personhood has strangeness and unfamiliarity

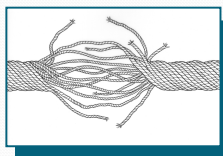
Ellis-Hill et al 2008

## Sudden life change

*'Its a very severe thing to happen to anyone its not like getting a -you know - having a broken arm or something like that which incapacitates you for a couple of months Put your arm in plaster and normally just take the plaster off and get back to where you were before 1364/1*

*... you lead a normal life one day and within a matter of minutes, overnight it all comes to an end ' 1387/1*

## Life threads joined

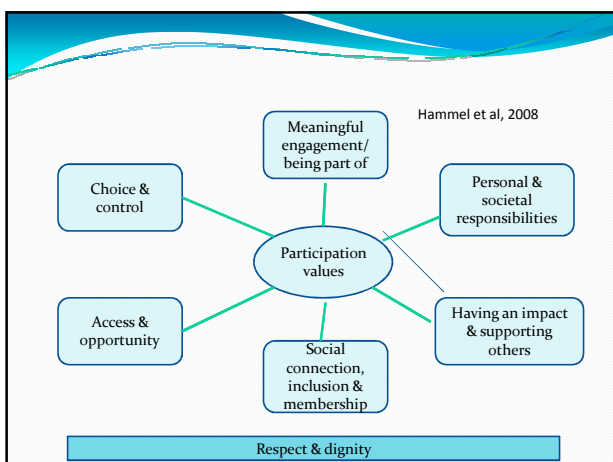


- Managing the new me
- Finding out the rules
- Actively making sense of what's happened

Ellis-Hill et al 2008

## Participation- can it be defined?

- Qualitative multi-centred study (n=63) people with diverse disabilities
- No gold standard, no definitions of what is ideal or optimal
- Individual should be free to define and pursue participation on their terms, rather than predetermined societal norms
- Participation doesn't happen in a vacuum,
- Environment dynamically influences participation



- Perenboom & Chorus (2003) define participation to include the **fulfilment of personal goals and societal roles and being autonomous to some extent or being able to control your own life**
- Fulfilment of personal goals and societal roles, together with actual performance should be the key indicator (Perenboom & Chorus, 2003)

### Problems with the ICF

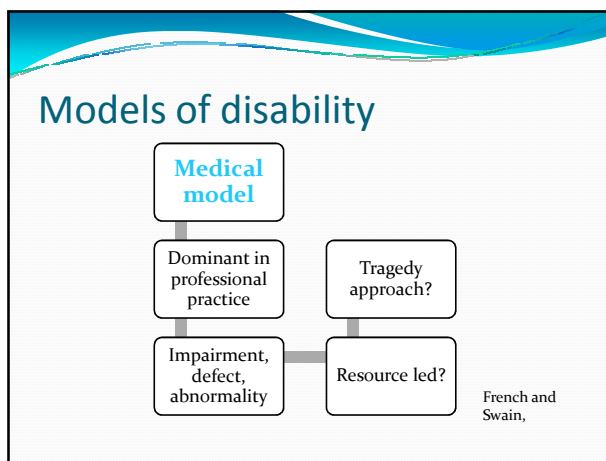
- *'...the ICIDH-2 will continue to be used to count, classify and control disabled people all over the world rather than to ensure their emancipation because it remains based upon the twin pillars of methodological individualism and investigatory foundationalism.'*  
Oliver 2009, page 113

### Disability – societies problem?

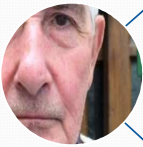
- There is no single *right* way to look at disability, but there is a wrong way. The wrong way is to mistake one's own disciplinary training as the only approach to understanding disability (Groce, 1999 p 291)

### Able to make you able...

- .....the point about disability of course is that the individual has a permanent impairment and consequently the central issue is environmental and social restriction; making the physical and social world accessible to us....*making people able is a medical goal*
- Vic Finkelstein



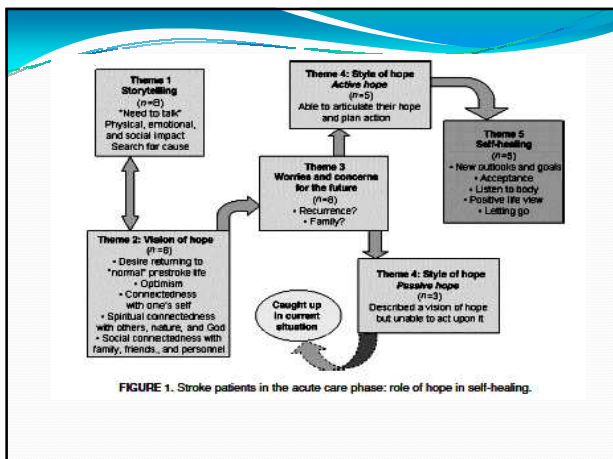
## Behaviour change



- Emotional difficulties
  - Stress coping model
  - CBT
- Confidence and self-belief
  - Social Cognition model
  - Barriers, social influences and knowledge
- Readiness to change
  - Stages of change model
  - Motivational interviewing

- Story telling
- Vision of hope
- Worries and concerns for the future

Arnaert, 2006



### Passive Hope

Main source of hope is external – health professionals  
Could we have disproportional affect here?

### Active Hope

What can I do to help myself?

*health beliefs  
self-efficacy  
empowerment*

## How often do we find the time to really hear patient stories?

What role do stories have in the therapeutic and rehabilitation process?

How often do our policies, processes and professionalism run the risk of stifling hope?

'...it is possible for stroke survivors to understand the full importance and implications of the illness and still maintain a positive outlook.'

Arnaert et al 2006

- central and critical role in individual assessment and creative redirection:
  - Identifying internal and external hope
  - Fostering strategies such as connectedness with self and others

### A new definition of rehabilitation?

*‘Through rehabilitation, involving engagement in physical, psychological and social processes, people can learn how to live a life that is not dominated by their disability.’*

Ellis- Hills et al 2008

French and Swain, 2008

### Personal reflexivity

- What is your personal understanding of disability
- How much time do you spend focusing on improving a physical body
- How often do you listen-wholly listen...
- Who has the power?
- What is your professional agenda

### Skills checklist

- Knowing a persons story
- What are their motivations
- Self-discovery and problem solving together
- Do you know what the community can offer
- Participation focus early-involve family and friends
- Finding new ways to do things
- Ensuring continuity with past life

### On being a person...

- ‘a standing or status bestowed upon one human being by others, in the context of relationship and social being. It implies recognition and respect and trust’.

Kitwood, 1997

### Key References

- Salter, B, Hellings C, Foley N, and R Teasell. The experience of living with stroke: a qualitative meta-synthesis. J Rehabil Med 2008; 40: 595-602
- Boden-albala, B, et al., Social isolation and outcomes post stroke. Neurology 2005;64:1888-1892
- Daniel et al., What Are the Social Consequences of Stroke for Working-Aged Adults?: A Systematic Review. Stroke 2009;40:e431-e440;
- Robison et al., Resuming previously valued activities post-stroke: who or what helps? Disability and Rehabilitation, 2009; 31(19): 1555-1566
- Ellis-Hill et al., Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability Disability and Rehabilitation, 2008; 30(2): 150 - 159
- Swain, J and French, S.(2008) Disability on Equal Terms. London: Sage
- Hammell et al., What does participation mean? An insider perspective from people with disabilities Disability and Rehabilitation, 2008; 30(19): 1445-1460
- Arnaert, A., Filteau, N. and Sourial, R. (2006) Stroke Patients in the Acute Care Phase: Role of Hope in Self-healing. Holistic Nursing Practice 20(3) 137-146
- Kitwood, T (1997) Dementia Reconsidered: the person comes first Open University Press