

Focus on carers: challenges and satisfactions

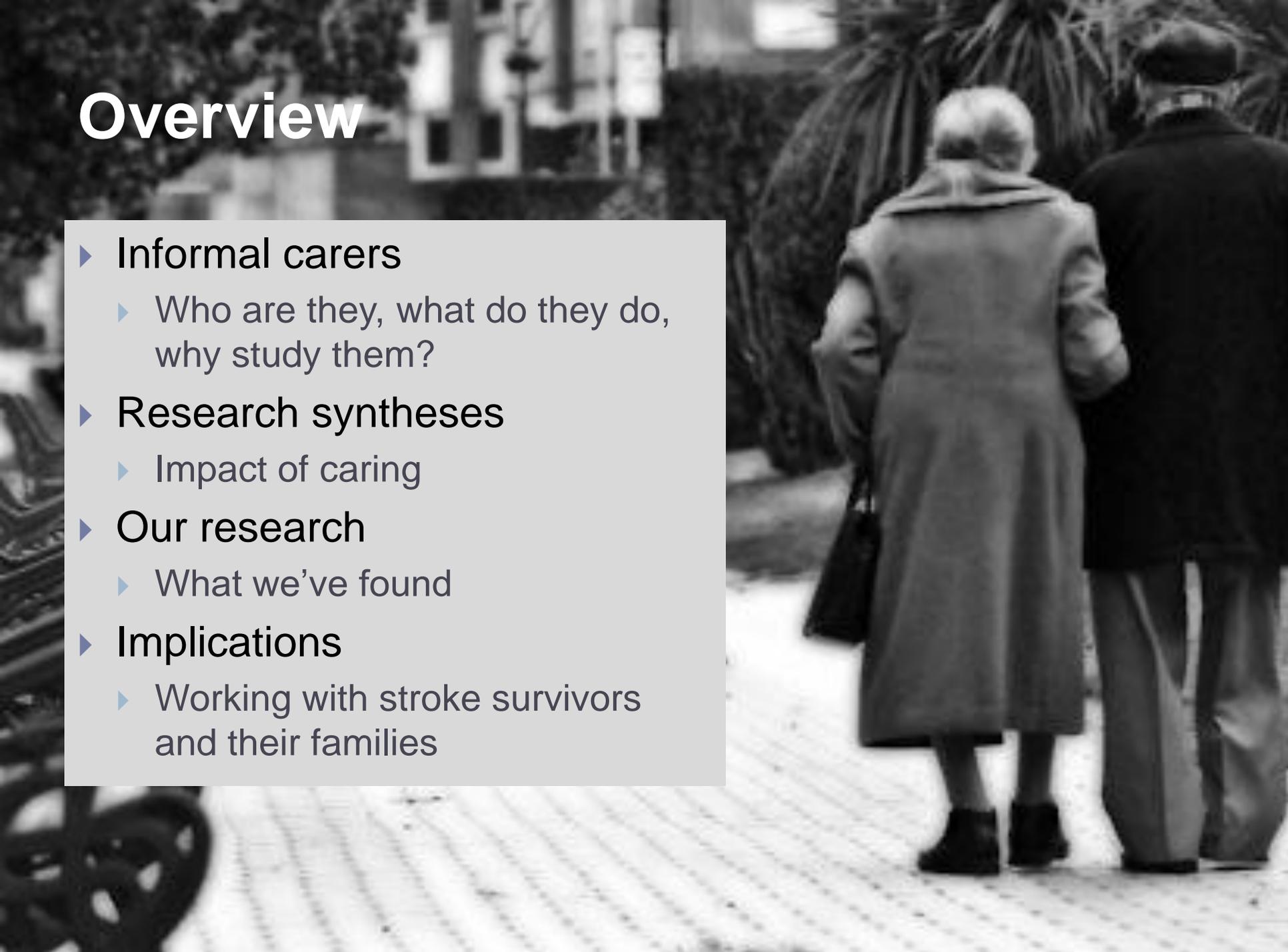
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Overview



- ▶ **Informal carers**
 - ▶ Who are they, what do they do, why study them?
- ▶ **Research syntheses**
 - ▶ Impact of caring
- ▶ **Our research**
 - ▶ What we've found
- ▶ **Implications**
 - ▶ Working with stroke survivors and their families

Informal carers and what they do

... someone who, without payment, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help.' (Princess Royal Trust for Carers, 2009)

- Approx **6 million** people in England and Wales are carers
- **3/5** of us will be carers at some point
- **1.25** million people care for more than 50 hours per week
- Caring activities include a wide range of things....

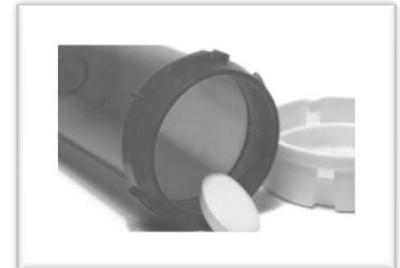
Personal care



Emotional support



Practical support



Carers in Ireland



- **4.8%** of the population 15+ years are carers
- **62%** are women
- Carers provide an average of **24 hrs** care per week
- Carers over 65 years average **36 hrs**
- In total **600,000+** hours of care per week are provided by carers 65+ years *(The Carers Association, 2006)*

Why investigate carers' experiences?

Carers save economies huge amounts of money

£119 billion (UK)

€2.5 billion (Ireland)

Stroke carers

£2.5 billion (UK)

Carers want this role

Carers influence survivor outcomes

Becoming a carer

'... Suddenly not only are you responsible for yourself, but for somebody else and for everything.'

'I don't sleep through the night. Mike can't get out of bed and go to the toilet, so I have to go to push, sit him up and then come round and take him to the loo... Sometimes it can be eight times a night and other times two or three.'

'And all of a sudden nobody wants to know you. So all the friends you've had disappear. So from going out and meeting people, suddenly I am indoors all the time and I don't see anybody.'

'I would love to go out but because I know he would love to go out too, I can't. I feel guilty...'

Literature reviews of carers' experiences

Our research team has undertaken four systematic reviews

- One quantitative
- Two qualitative
- One mixed methods



Review findings overall

- Research has increased consistently from the 1990's
- European studies dominate with most of the remainder coming from N. America and the Far East
- Research tends to focus on the first year after discharge (acute or rehabilitation)
- The majority of studies are cross-sectional with relatively few longitudinal ones

Participants in the research studies

Carer participants are largely

- Female
- Spouses i.e. usually wives
- Average age 50 to 60 years
- Ethnicity seldom reported

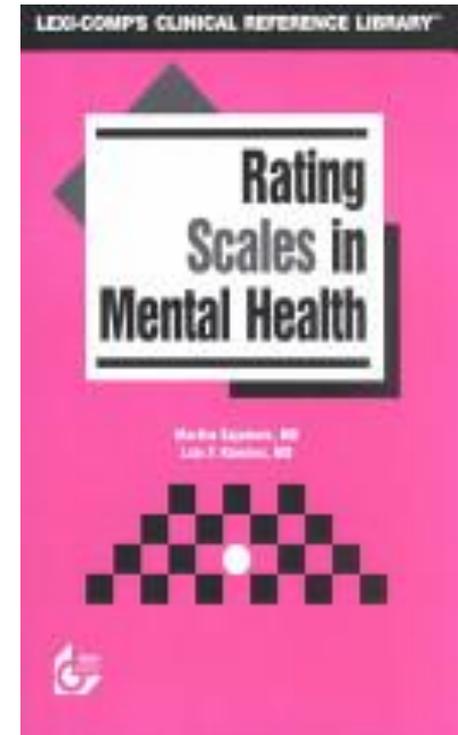
Stroke survivors are more often

- Male
- Slightly older
- Usually not severely disabled



Quantitative review: Outcomes

- Quantitative research generally uses validated outcome measures, often self-completion questionnaires
- The most frequently measured outcomes relate to carer emotional health (depression or anxiety)
- Other common outcomes include burden, quality of life, physical health, stress and strain



Relationships between carer outcomes and carer characteristics

Is it possible to predict which carers are most likely to have adverse outcomes?

- Carer outcomes are often *associated* with carer psychological characteristics e.g. Self-efficacy and self-esteem
- E.g. carers with greater sense of self-efficacy and higher self-esteem tend to experience fewer emotional difficulties, less burden etc.
- There was little clear evidence for associations with gender or age

Relationships between carer outcomes and survivor characteristics

Can we say anything about the impact of stroke survivor characteristics on carers?

- Survivor disability, impairment and dependency are features most commonly associated with negative carer outcomes
- Survivor disability is associated with carer emotional well-being, burden, quality of life, stress and strain
- However conclusions about these associations are limited:
 - Associations are often not strong
 - Averages are reported
 - Research only measures limited outcomes

Qualitative review

- Most qualitative research uses open-ended interviews and focus groups
- Sample sizes are much smaller than in quantitative research
- Thematic analysis of transcripts is frequently used to identify recurring themes in carers' experiences



Qualitative findings

- Qualitative research also identifies difficulties for carers e.g. emotional responses, information and training needs
- But they also focus more on e.g. role and relationship changes, uncertainty, coping strategies and satisfactions in caring

Review of satisfactions in stroke caring

There are a range of positive experiences

- Progress in rehabilitation is the most common source of satisfaction
- Other satisfactions include: Preventing deterioration, feeling appreciated, strengthened and improved relationships with the care recipient and other family members, increased self-esteem and increased meaning and purpose to life
- Carers reporting positive experiences appeared more likely to describe successful coping strategies with possible implications for supporting carers

Criticisms of the research overall

- Lack of focus on individual differences
- Too much emphasis on the time immediately post discharge
- Too few longitudinal studies
- Too little context – e.g. availability of support
- Too much emphasis on the negative aspects (e.g. stress) of carers' experiences
- Too much reliance on well-used outcome measures with lack of clarity of the concepts (e.g. burden)
- Lack of theory

Our qualitative research

- Aims: investigating carer experiences and identifying differences
- 31 carers interviewed three times
- 81 interviews
- Recruited from acute and rehabilitation wards
- Interviews at discharge, one month and three months
- Interviews were audio-taped and transcribed
- Two-thirds of participants were female and most were White British

Themes: Uncertainty, reduced autonomy and interconnected themes

- Uncertainty and reduced autonomy were central themes
- Additional interconnected themes were e.g.
 - Practical strategies (e.g. routines) and emotional strategies (e.g. laughter) used to manage uncertainty and to increase autonomy
 - ‘Absolute’ and ‘relative’ positives of caring
- ‘New’ and ‘experienced’ carers often described different experiences and coping strategies

Uncertainty: typical comments

- *'They just don't know — that is what is quite scary, it is the unknown. You just don't know what it is going to be like in a year's time . . . because . . . everybody is just so different.'* (Daughter, new carer, 1st interview)
- *'I find it (the future) a bit frightening, you know. It is not so much in six months; it is in two or three years time, what we are going to be doing? But we can't plan that far in the future, can we?'* (Wife, new carer, 3rd interview)

Other comments

- *'I still get up at night and ... make sure he is breathing ... Well it makes you suddenly aware of just how old you are and what might have been.'*
(Wife, new carer, 1st interview)

At the 3rd interview the same carer said:

- *'I think that every time we get a little bit further away, it makes us more secure. It is like dangerous waters and we are gradually sailing out of them.'*

Managing uncertainty: Routines

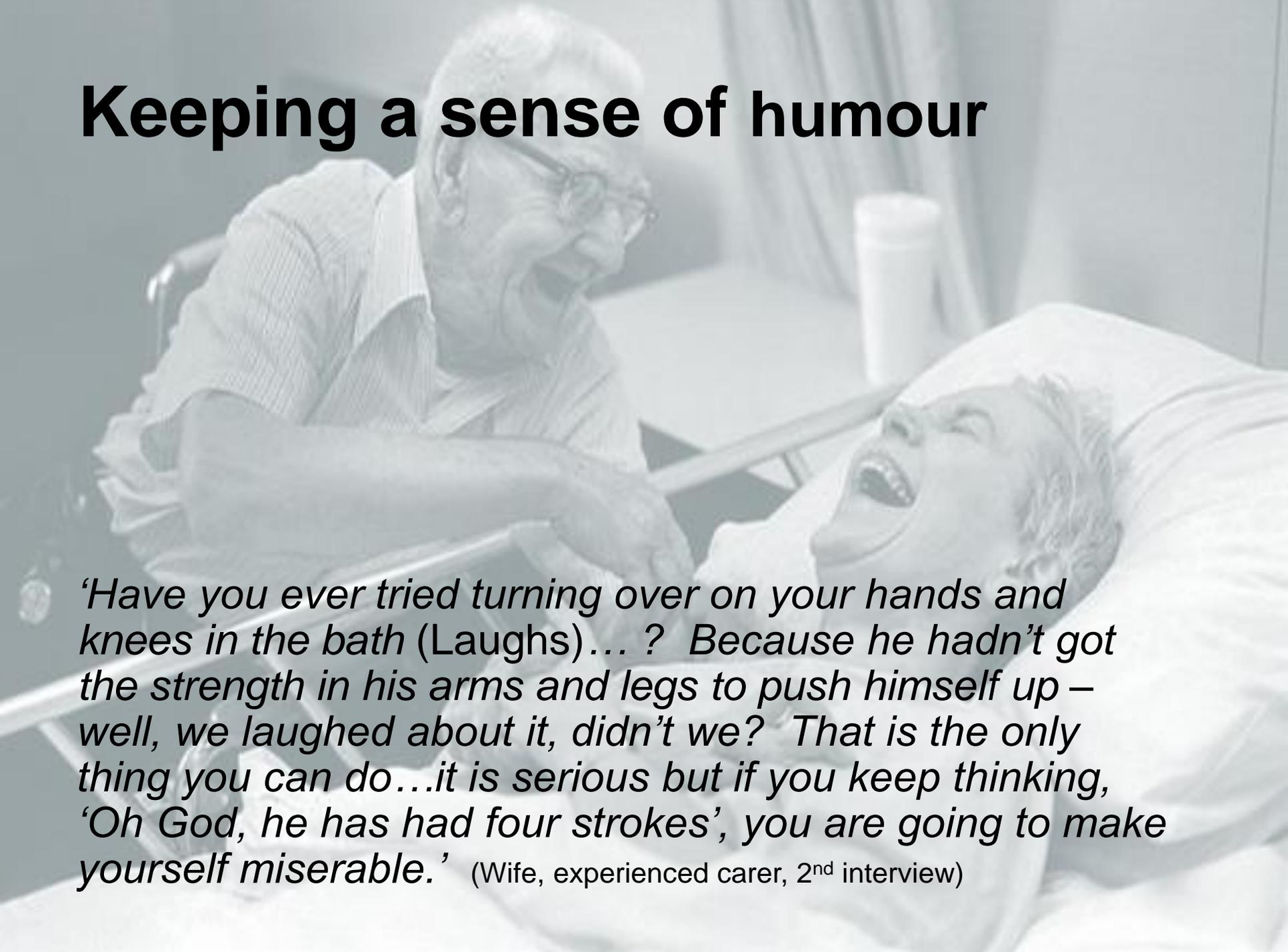
Once home, establishing routines was one way of reducing uncertainty.

- *‘There is a routine there and it is working and so from that point of view, we can relax a little bit.’*
(Daughter, new carer, 3rd interview)
- *‘That routine is established now – meals... washing... cleaning... so I don’t think about it now until she goes off the menu that I have set and that becomes a bit of a... and then she will want to do extra washing or come shopping... or want to do some other stuff and change it a bit so that becomes aggravating.’* (Husband, new carer, 3rd interview)

Living day-by-day

- 'Taking one day at a time' and 'living day-by-day' were mentioned repeatedly
- Focusing on the present allowed carers to enjoy everyday things
- *'If they're going to have one (stroke), they'll have one, you know, you can't sit there for six weeks or three months thinking 'Oh God, is it going to happen today. If it's going to happen, it'll happen and when it happens then you cope with it...you can't live on what's going to happen... You'd be a nervous wreck.'* (Sister, experienced carer, 2nd interview)
- Changed values, (e.g. less emphasis on material things), enjoying what they had and accepting their situation were often mentioned

Keeping a sense of humour



‘Have you ever tried turning over on your hands and knees in the bath (Laughs)... ? Because he hadn’t got the strength in his arms and legs to push himself up – well, we laughed about it, didn’t we? That is the only thing you can do...it is serious but if you keep thinking, ‘Oh God, he has had four strokes’, you are going to make yourself miserable.’ (Wife, experienced carer, 2nd interview)

Identifying positive aspects of carers' experiences

- We termed these '**relative positives**' and '**absolute positives**'
- **Relative positives** were more likely to be described by carers new to caring and **absolute positives** were more likely to be described by experienced carers later in their caring role

Relative positives

- Comparing yourself with others worse off:
‘There is one lady that had a stroke before Mum and she hasn’t gained any physical movement at all well I think Mum has improved a lot anyway.’ (Daughter, new carer, 2nd interview)
- Healthier, improved lifestyles were also mentioned:
‘... well she has quit smoking... I think that is a good thing. And we have to take life at a much easier pace and stop rushing...’ (Husband, new carer, 3rd interview)
- Appreciation of what you do have:
‘It means it does make you appreciate what you have got... and also makes you look at other people and think ‘My God, I am lucky!’ ...we are a hell of a lot luckier than some people...’ (Wife, new carer, 3rd interview)

Absolute positives

‘Absolute positives’ did not involve comparisons:

‘Because of the stroke we have both given up work and we have ended up getting a nice little place. We are seeing two grandchildren growing up which we would never have seen.’ (Wife, experienced carer, 2nd interview)

‘We have come together more because we have had to cope with difficult situations.’ (Son, new carer, 3rd interview)

Implications of uncertainty

- Uncertainty changes over time – initially it may be about prognosis but later about whether a holiday is possible
- Uncertainty is double edged - it allows carers to hope things will improve but it can leave them in limbo unable to plan ahead
- When professionals stress the unpredictability in recovery after stroke, they may reinforce uncertainty and not thinking about the future
- Uncertainty when caring for stroke survivors is unlikely to go completely but encouraging carers to acknowledge it, talk openly about it and realise that this is a common experience may make their lives easier

Reduced autonomy

- Reductions in autonomy have been identified in stroke survivors but little attention has been given to reduced autonomy in carers
- Carers in our research described reduced autonomy, choices and dependence on others which they often found difficult
- Unpredictable services led to a feeling of reduced control
- They often could no longer choose what they did and when
- Carers often had to rely on both formal and informal support and had to ask for help

Reduced choice and control

‘ . . . They (the district nurses) can come at any time . . . The more time you wait, the more Mary is waiting and myself, we get a little bit – a little bit of anxiety . . . It is just knowing, are you going to come, or aren’t you going to come ...?’ (Husband, new carer, 3rd interview)

‘Because he don’t like to stay in the house all by himself - I can’t leave him at all . . . I have tried to talk to him. I said ‘Look, if you don’t come to the temple with me, I can’t see anybody unless the children come over here.’
(Wife, new carer, 3rd interview)

Managing reduced autonomy

Over the course of the interviews, carers described efforts to increase control over their situations. Strategies included selection, optimisation, negotiation and asking for and accepting help

- **Selection** – carers selected activities that were manageable or changed how they did them
- **Optimisation** – Carers talked about to *‘taking time’* over activities, and ensuring that survivors had plenty of rest. Journeys or shopping trips were often planned in great detail
- **Negotiation and asking for help** – some carers became expert at negotiating help

Implications of research with carers

- Caring is dynamic - changes in carers' needs and experiences over time have implications for their assessment and provision of support. E.g. improvement in the survivor's condition can make things more difficult

'She wants to go shopping now and it will be a little bit of a battle about what we need and what we don't need. Not a battle but before I could nip down there – I know I shouldn't do it – and leave her in bed and I could be down to the supermarket from here and back before she had got dressed or in the car or ... but no, now she wants to come.' (Husband, new carer, 3rd interview)

- Carers' support needs may grow over time as they return to other responsibilities (e.g. paid work)

Implications cont

- Professionals should take into account possible differences between experienced and new carers
- Carers may need help to increase their autonomy
- It should not be assumed that caring is only about burden and stress. Helping carers identify satisfactions in caring may improve both carers' lives and those they care for
- Amongst carers of people with dementia, those using emotion-focused strategies such as humour and positive re-framing reported less anxiety than those who used problem-focused coping

Conclusions



- Carers are important
 - in themselves
 - for the support and well-being of stroke survivors
 - for the economy
- Carers are not passive but respond actively often with novel strategies
- Professionals need to actively engage with carers and recognise their expertise and contribution to recovery

Acknowledgements and references

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