
Managing uncertainty in life after stroke: a qualitative study of the experiences of informal carers

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Presentation aims

- Who are informal carers?
 - Background research.
 - Our study – methods and findings with quotes from carers.
 - Conclusions and possible implications.
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Who are informal carers?

- ‘A carer is someone who, without payment, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability.’ (Princess Royal Trust for Carers)
 - *“I am a husband, a parent, a nurse, a chauffeur, a receptionist, a translator, a counsellor, a mediator; I never did realise I was a carer until someone told me I was.”*
 - It is estimated that carers in general save the economy £87 billion annually (Carers UK, 2007).
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Some stroke carer facts

- There are no figures specifically for informal carers of stroke survivors.
 - In England there are more than 900,000 stroke survivors and about half of these are dependent on others for everyday activities (DH, 2005).
 - Caring for stroke survivors often has an adverse impact on informal carers.
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Stroke carer research background

- Research with carers of stroke survivors has increased considerably over the last decade.
 - Inadequate descriptions of carers and under-recognition of their diversity make it very difficult to predict the impact of caring.
 - Quantitative studies tend to focus on the negative impact of caring such as 'burden', reduced quality of life, and poorer psychological health (e.g. anxiety and depression) (Greenwood et al, 2008).
 - Qualitative studies also identify negative consequences but are more likely to describe positive outcomes for carers (Greenwood et al, 2008).
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Our study

- Using a series of 3 in-depth interviews we explored the evolution of informal carers' experiences of caring for stroke survivors:
 - 1st interview - close to discharge
 - 2nd interview - 1 month post discharge
 - 3rd interview - 3 months post discharge.
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Study sample and design

- Carers were recruited from the stroke unit at St George's and from the Wolfson.
 - A purposive sample of informal carers looking after stroke survivors in their own or the survivors' homes.
 - Interviews were open-ended and led by participants.
 - Interviews were audio-taped and later transcribed verbatim.
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The interviews

- 31 carers were interviewed.
 - 23 were interviewed three times, four twice and four once.
 - 81 interviews in total.
 - Most first interviews were in side rooms at St George's or the Wolfson whereas the majority of the second and third interviews were in carers' and survivors' homes.
 - Interviews ranged in length from 30-90 minutes.
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Carer demographics

- Carers were fairly typical of those described in other stroke research.
 - 71% were female.
 - 52% were spouses/partners.
 - 71% were living with the survivors.
 - 77% were aged 66 years or older (and retired) most of the remainder were aged between 40-65 years.
 - 58% were White British. All carers spoke English although it was not always their first language.
 - The majority of survivors were moderately or severely dependent (using Barthel scores).
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Data analysis and identifying themes

- Data analysis was ongoing, starting during data collection.
 - Emerging themes were discussed amongst the team helping to identify patterns.
 - Themes were followed up at subsequent interviews focusing ideas and also validating participants' accounts.
 - 'Deviant' cases were noted and used to help understand carers' experiences.
 - Data collection continued until 'saturation' of the themes.
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Themes

- A number of interconnected themes were identified with a central, linking theme of uncertainty.
 - Associated themes included strategies for managing uncertainty, identification of positives and thinking about the future.
 - These themes can all be related to what was happening in the carers' lives following stroke and to their management of uncertainty.
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‘New’ and ‘established’ carers

- Early on, we identified some striking differences between participants who had already been carers prior to this stroke (‘established carers’) and those new to the role.
 - This distinction became an important part of the data analysis.
 - In later interviews, differences between new and established carers were less pronounced.
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Uncertainty

- Expressions of uncertainty varied over time but remained a central, recurring theme.
 - Initially it centred on survivors' prognosis:
'I would say the constant thing that he would have another stroke even though they say that he won't... that he will fall, break a leg, break a hip.' **Wife, new carer**
 - Once home, uncertainty continued about survivors' longer-term disability and the unreliability of formal support.
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Uncertainty and new carers

- Uncertainty was most striking in new carers.
- It was often related to difficulty in visualizing what to expect in terms of their caring role, their ability to cope, eligibility for formal support and potential changes to living arrangements.

'We just want to know what is the next step – what we are going to do when he gets home and what sort of help we are going to get?' Son, new carer

Uncertainty and established carers

This woman's comments were at one end of the spectrum. She was a full-time informal carer for another relative. Before discharge she was very positive about also looking after the stroke survivor:

'... it's just run of the mill. (Laughs) It sounds very throw away but it's just ... Yes...it's a stroke...it's nothing really.'

Uncertainty and clinicians

- A common theme was the sense unpredictability of stroke outcomes that carers had gained from clinicians.
- This uncertainty often allows carers to remain hopeful but also makes thinking about the future difficult.
- Some carers compared stroke unfavourably to heart attacks or cancer which to them seemed more predictable.

'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

Uncertainty and fears for the future

- Initially fear of further strokes was mentioned frequently.

'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.'

- But with time this fear lessened:

'Yes I mean 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.' Wife, new carer

Strategies for coping with uncertainty

- Established carers tended to describe coping strategies sooner than new carers.
 - Despite the diversity of their situations, some coping strategies were mentioned repeatedly.
 - Common strategies included:
 - Establishing routines
 - Living day-by-day
 - Keeping a sense of humour.
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Routines

- Routines were a common way of reducing uncertainty and increasing control.

'It was hard to start with but now it is sort of getting in a routine so unless suddenly something goes wrong... everyone has some sort of job.' Son, new carer

Disruption to routines

- Ironically sometimes carers described how they had settled into a routine but this was disrupted as their survivors improved.

‘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

Living day-by-day

- Focusing on the present reduced uncertainty and 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, established carer

Sense of humour

- Keeping a sense of humour came up repeatedly. Again it seems to be useful because it focuses on the present. This wife described how she had to telephone for help to get her husband out of the bath:

‘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, established carer**

The rewards of caring - relative positives

- Comparison with others:
'There is one lady that had a stroke before Mum and she hasn't gained any physical movement at all, you know and I think with Mum well I think she has improved a lot anyway.' Daughter, new carer
- Healthier life styles 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
- Re-evaluation was common:
'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

The rewards of caring - absolute positives

'... and 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, established carer

'I suppose we have come together more because we have had to cope with difficult situations.' Son, new carer



An uncertain future

- Carers often found it difficult to talk about the future only referring to it in later interviews:

‘But it is the constant... you wake up and it is still there. And it don’t go away, does it? ... but I wonder about this time next year ... I mean how do we plan for a holiday?... Everything is better than it was, definitely, definitely but ...how long is this going to go on?’ Husband, new carer

Life has changed permanently

'I don't sort of talk to him like I might have done in the old days. I certainly wouldn't dream of having words with him and sort of going out and leaving it in the air just in case something happens because you would never forgive yourself. Certainly... it is very much in the forefront of my mind.' Wife, new carer

Implications

- Whilst outcomes from stroke are difficult to predict, clinicians may inadvertently add to carers' uncertainty by emphasising individual differences and describing a 'spectrum of recovery'. This leaves survivors and carers to interpret this for themselves.
 - Uncertainty is double edged - it allows carers to hang onto hope but at the same time it can leave them in limbo.
 - Stressing unpredictability in stroke recovery may reinforce avoiding thinking about the future.
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Implications continued

- Uncertainty when caring for stroke survivors is unlikely to go completely but encouraging carers to acknowledge it and talk openly about it, may make their lives easier.
 - Changes in carers' needs and experiences over time have implications for assessment and support provision.
 - Clinicians should take into account possible differences between carers with previous caring experience and those new to the role.
 - Carers' support needs sometimes grew over time as they attempted to return to other responsibilities, again with implications for assessment.
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Conclusions

- Uncertainty was an important, recurrent theme amongst these carers.
 - Other themes including coping strategies, identifying positives and questioning the future could be seen to both influence and be influenced by uncertainty.
 - In general, compared with new carers, established carers identified coping strategies and positives much earlier.
 - Finally it should not be forgotten that being a carer of a stroke survivor is not always a completely negative experience. Some people derive considerable satisfactions and rewards from caring.
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Reference:

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Managing uncertainty in life after stroke: a qualitative study of the experiences of established and new informal carers in the first three months after discharge. *International Journal of Nursing Studies*, 46, 1122-1133.
