How do carers of stroke survivors experience the stepped care model of post-stroke support?

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Individuals who experience stroke face a number of difficulties including problems with mobility, fatigue, speech and partaking in social activities as well as problems with emotional well-being (McKevitt et al., 2011).

Informal carers are a valuable resource, providing both emotional and practical support to stroke survivors in the community (Anderson, Linto & Stewart Wynne, 1995).
A carer can have a major effect on the on-going wellbeing of the stroke survivor, particularly on the stroke progress and psychological wellbeing (Anderson, Linto & Stewart Wynne, 1995).

Taking this into account, McCullagh, Brigstocke, Donaldson and Kalra (2005) suggested that services should adopt an approach centred on both the stroke survivor and the carer and provide appropriate support in order for them to fulfil their caring role.
A local Community Stroke Clinical Psychology service aims to provide support not only for stroke survivors, but also for their informal carers.

The service uses an MDT approach and sees both stroke survivors and family members, seeing them as having individual needs.
The service applies a psychology-led stepped care model, which provides different levels of support at steps one, two and three and includes both indirect and direct work with stroke survivors and their families.

It aims to provide psychological support in a hierarchical manner which offers simpler interventions first, with more complex interventions being offered later if necessary.
This study aimed to explore what aspects of the service carers found to be helpful and aimed to identify if there were any gaps in the service provided.

More specifically, this study aimed to understand whether carers were aware of different professionals working together to provide their support and what may have helped with their adjustment and coping.
This study used qualitative methodology and semi-structured interviews were conducted to obtain information about participants’ experiences of the stepped care model.

All participants had accessed step three of the stepped care model and therefore had received direct input from psychology.

The interview schedule was developed in consultation with the project supervisors and the service user consultant.

The data were analysed using thematic analysis, following the steps outlined by Braun and Clarke (2006).
Results

* All of the carers in this study were partners or spouses of the stroke survivor so the results summarise partners’ experience of stroke and the community service.

* The carers talked about their partners needs as well as their own so the themes are intertwined with both their experiences.

* One participant described having a negative experience of the service as a whole and his experiences were often in contrast to the other four participants.
Results

* Themes
* Context
  * ‘impact of stroke’
* Three further themes
  * ‘experiences of integrative team working’
  * ‘practical and tailored support’
  * ‘emotional care – the role of the psychologist’.
‘Impact of stroke’

* Understanding the impact that the stroke had on both the individual and their carer is important, as this is the context in which the stepped care model was received.

* Carers experienced significant emotional reactions to their partners having a stroke, often reporting this as the biggest impact.

* “The biggest impact was, I won’t say doing the work and caring, I think for me it was more emotional.”
‘Experience of integrative team working’

* This theme describes the way in which the team worked together providing support in a co-ordinated and organised manner and highlights that they were always there when the service users needed them.

* Subthemes
  * always there and contactable’
  * ‘communication within the team’. 
‘Experience of integrative team working’

‘Always there and contactable’

This first subtheme was described by three of the participants and highlights how they felt the team were always there when needed and could contact them whenever.

“I know they’ve said, even though they’ve discharged him, if you feel you’ve got any concerns, just get in touch, it’s not a problem.”
‘Communication with the team’

Three of the participants were aware of the different professionals within the team working together to provide holistic support and they described the experience of concerns being passed on as helpful.

“So the fact that they all know each other and they all work together, yes it’s a big help.”
‘Practical and tailored support’

- This theme describes how participants’ receiving practical support, information and tailored care felt this was important in aiding their ability to cope with their caring role.

- Two subthemes
  - ‘Practical information and advice’
  - ‘Tailored support’.
‘Practical and tailored support’

‘Practical information and advice’

This subtheme outlines the help that participants received from the service to deal with practical issues, including getting time away for themselves, arrangements being made for them, and involvement of the Stroke Association.

“And, erm, she got in touch with social services to get them involved, got it sorted out, got a crisis meeting for me arranged and everything.”
‘Practical and tailored support’

‘Tailored support’

- This subtheme highlighted that participants often felt that both they and their partner were given the right amount of support and that it fitted with their ongoing needs and was tailored to them.

- “when it was really difficult, she was coming every week, and then as I proved I was dealing with things better, then it was every three weeks.”
The final theme that was identified describes what participants perceived to be support for their psychological and emotional difficulties, which they predominantly viewed as being provided by the psychologist.

Four of the participants said that they felt they received support for their psychological and emotional difficulties once they had involvement with the psychologist.

“I’m, like I say, a phone call from [the psychologist] and she’s here and she’d sort everything herself for us. She’s a star. She really is. I’d be lost without her.”
One participant had a negative experience of the psychologist and described feeling like he was being told he was doing everything wrong.

“I find it quite upsetting for me because the way they term it as if I’m hindering [partner’s name]’s rehabilitation. Because I’m caring, and I’m doing things, I’m not letting her do things for herself.”
* Four of the participants had a positive experience of most aspects of the service.

* However, one participant felt that the support they received through the service did not meet their needs and in fact produced negative outcomes for the carer.

* Difficult to draw conclusions from five participants.
Four participants outlined how the team worked together effectively and this way of working facilitated communication and understanding within the team.

The reports from the participants identified the importance of practical support and information and advice as well as support with their emotional and psychological difficulties.

Most significantly, participants acknowledged the important role of the psychologist in leading and shaping the psychological aspect of the service and outlined that the input from the psychologist was invaluable.
Reflections

* Participants
* Planning ahead
* Allowing time for everything!
* Good luck!

