

Do the understanding, knowledge and fears of the caregivers of first time stroke survivors accurately reflect the difficulties faced after discharge from hospital?

Background: Stroke survivors are often supported by informal caregivers after discharge from hospital. Caregivers may be unprepared for new roles which require assimilation of a variety of skills and information. This study sought to understand the experiences of informal caregivers of stroke survivors during the hospital discharge period to determine whether their understanding, knowledge and fears before discharge were appropriate when considered three months after discharge.

Method: A Qualitative research design developed within a phenomenological paradigm was used to explore the lived experiences of people caring for stroke survivors at home. Four purposively sampled carers were interviewed at two time points; two weeks before planned hospital discharge and three months after discharge from hospital. Subjects were recruited from two rehabilitation sites within Aneurin Bevan Health Board during a three month period in 2011.

Semi-structured interviews enabled the collection of data specific to the research subject with sufficient depth to allow meaningful analysis. Ethical approval was obtained from the South Wales Local Research Ethics Committee.

Data Analysis: Data was categorized into broad themes and then coded. Each subjects' responses at interview one and two were analyzed and compared with all responses. The themes were then considered and discussed against the published literature. Data was triangulated using respondent validation and a reflective diary for the researcher. Use of these methods of triangulation allowed the researcher to stay in touch with the raw data and simplified data analysis. Silverman 2010

Quote 1.

"..it's going to be non stop you know: coal face, 24/7, seven days a week, fifty two weeks a year 'til whatever time it is.." R3I1

Quote 2.

"..until dad comes home and we know what he's capable of and what he isn't around the house I don't think we can go any further with that [care planning].." R1I1

Quote 3.

"..they haven't said what level she'll get to. They haven't said: 'we're expecting S2 to walk tidy or things like that, we haven't had that communication..' R2I1

Quote 4.

"..I've found it hard you know; manipulating joints and it does take its toll on me yeah.." R1I2

Results: All carers demonstrated a clear understanding that stroke would lead to significant changes in lifestyle (quote 1) and expressed concern that they lacked knowledge about stroke and how to care for a person with stroke. Carers 1 and 3 were also concerned that they lacked the technical skill to support their stroke survivor. All carers had received and read the generic information supplied by the Stroke Association and had found it useful. However carers 1,2 and 3 found that this information raised more questions than it answered leading them to want information specific to their unique set of circumstances (quote 2,3). There was disparity in expectation of the impact of behavioral and personality changes in all carers. Spousal carers anticipated greater levels of personality and behavioral changes in their stroke survivors than they encountered; however the daughter-carers failed to anticipate behavioral changes and found this aspect of caring one of the more challenging things to deal with. This finding is supported by Murray et al (2006). Three carers found supporting exercise routines a burden both physically and emotionally in addition to all the other carer tasks (quote 4,5). The carers expressed feelings of guilt at not being able to support exercises effectively and three carers expressed a wish for increased intensity of physiotherapy input (quote 6). The carers with stroke survivors with the greatest impairment expressed feelings of confinement and loneliness (Quote 7,8).

Quote 5.

"..if it wasn't for me I don't think he'd be as advanced as he is because he only has physio twice a week... and nothing through the rest of the week" R1I2

Quote 6.

"..every day she's going backwards now because she's not having any physio at all other than what we're doing and like as you know yourself when you've got to do it for your family, you don't do it.." R2I2

Quote 7.

"..myself I feel a bit isolated in a way, I need someone to talk to even, doesn't matter if I know them, to be able to talk through a number of issues. Nothing too critical but I do find at times that these things build up.." R3I2

Quote 8.

"..you can't sit there and say 'we'll have a conversation' because there's nothing she's doing, we're doing the same things 'cos we're with her constantly, there's no conversation, we're just sat there like dummies.." R2I2

Conclusion: The experiences, challenges and concerns of the informal caregivers of stroke survivors vary but there are some common themes which could shape the support offered to this group of people during the discharge period. Work could be done to improve specificity of communication, tailoring it to individual's particular needs.

Areas for future research:

1. The perceived burden of exercise practice and ways to reduce this.
2. Methods of information giving in preparation for hospital discharge.
3. Carer preparation for behavioural and personality change in stroke survivors.

References:

- Silverman D (2010) Doing Qualitative Research (3rd Edition) Los Angeles. Sage Publications.
- Murray J, Young J (2006) Feasibility study of a primary care based model for stroke aftercare. British Journal of General Practice 10 775-780