Title: CHANGING LIFESTYLE AFTER STROKE- THE ROLE AND PERSPECTIVES OF INFORMAL CARERS

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Text: Purpose: to explore and gain insight into ways in which Portuguese informal carers perceive the stroke causes and their role for prevention of stroke recurrence.

Relevance: Secondary prevention can reduce the risk of recurrent stroke by approximately 90% if lifestyle changes, like smoking cessation, were implemented early (Spence, 2010). However, recent trials, evaluating secondary prevention programmes with multiple risk factor intervention, demonstrate little changes on lifestyle habits (Ebrahim, 2006). Suggestions to implement active strategies, involving patients and carers, are made (Smith et al., 2009; Slark, 2010), but little is known about how carers can effectively be involved. Considering the experience of informal carers, this study focused on their perceived role on lifestyle change, and how they can contribute to help physiotherapists define active and effective strategies for stroke secondary prevention.

Participants: Six informal carers (50% female; mean age of 45 years and SD: 19.5), five of them are relatives of a person who suffered a stroke and one caregiver, were invited to integrate a theoretical sample (Flick, 2006) in 3 Portuguese Health Institutions. Each participant was the person who spent more time with the individual after stroke, as a minimum of one day per week.

Methods: One-to-one interviews following a semi-structured guide where taken with the participants. Informal carers were asked to give their perspectives about the perceived causes of stroke occurred, the life after stroke and their perceived role for changing behaviours.

Analysis: Interviews were audio recording and transcribed verbatim. Analyses of transcriptions and field notes were conducted by thematic analyses (Flick, 2006).

Results: Two main themes emerged from the data. The theme: “Stroke- why did it happened?”, representing the meanings given to the factors related to stroke causes. The participants identified some risk factors for a stroke (as hypertension, diabetes and smoking), but, generally, they didn’t establish a casual relationship between them and its relevance for the occurrence of stroke relative’s. Considering: “Reasons to change”, participants believed that they have a crucial role in helping their relatives to adopt a healthy lifestyle and control risk factors for recurrence. They valued the fact that their own behaviours influenced the behaviours changing of their relatives. However, the major motivation has to be intrinsic, believing that their support is mainly psychological.

Conclusions: Informal carers’ perceptions emphasized the importance of subjective risk perception for changing behaviours. They can have a relevant role on reducing risk of stroke if they improve their risk perception about stroke, because information per se seems not to be sufficient. Further research is important to understand the impact of different strategies on subjective risk perception.

Implications: In rehabilitation programmes after stroke, and to improve stroke secondary prevention, physiotherapists should evaluate and understand the subjective risk perception from individuals after stroke and their informal carers, involving them during all the process.

Key-Words: 1. secondary prevention  
2. stroke carers  
3. lifestyle

Ethics approval: Ethical approval was obtained from Hospital S. Bernardo and Hospital Prof. Dr. Fernando Fonseca. All participants signed an informed consent.