Introduction: People’s experiences and perceptions of stroke have been researched quite extensively, in particular the effect of stroke on the self and self-concept, but how much upper limb dysfunction contributes to this is not known. This study explores the impact that upper limb dysfunction specifically could have on people’s lives after stroke.

Method: A phenomenological study with a series of 4 semi-structured interviews at 2, 6, 12, and 18 months post stroke with 13 participants recruited from a stroke rehabilitation unit. Data were analysed using thematic analysis and modified framework analysis.

Results: 3 main themes emerged from the data: Incompetent Adult; Disrupted life and altered self-concept. Findings indicated that upper limb dysfunction after stroke can lead to a lack of competency and capability in self-care, valued activities and life roles, resulting in profound changes and loss in many areas of a person’s life. This in turn can affect a person’s self-concept, leaving them with low self-esteem, and an altered self-image and identity.

Discussion: Upper limb dysfunction appears to be a significant factor in the changes that people encounter in self-concept after stroke. Interventions for the upper limb should therefore be considered as vital and important a part of rehabilitation as other aspects such as mobility.