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Stroke survivors experience of quality of life, participation and resilience

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BACKGROUND: Within a Swedish context, the lived experience of stroke in the acute phase has been documented in a number of studies using a biopsychosocial perspective. However less is known about the challenges in the chronic long-term phase. **OBJECTIVE:** In this study we wanted to explore the lived experience from stroke survivors in Sweden about their resilience and participation, and the relationship between these two constructs and quality of life. **MATERIALS AND METHOD:** Kumla is a medium-sized municipality in Sweden in which 330 people living with stroke were identified at the 31st December 2019. A purposive sample of 19 informants were selected based on age, gender, occupation and severity of stroke. Semi-structured telephone interviews were conducted with 10 male and 9 females. The informants were aged between 44-89 years and had lived with their stroke between 1 and 19 years. The interviews were transcribed verbatim and analyzed using qualitative content analysis. **RESULTS:** The informants described how the stroke had affected their lives and that they had to 'adapt life' due to their stroke. They described their experience as while having found ways to cope with life after stroke, they did not accept the situation. This was captured in the material with an overarching theme; *Life with stroke has been adapted to but not accepted*. However the lack of acceptance was explained by some as a resignation, that their lives had changed for good and it has to be accommodated, while others' experience was one of still working to overcome many of the limitations that they faced. The overarching theme was linked to five subthemes: 1) Adapting and adjusting to life, 2) Meaningful values in life, 3) Inner resources, 4) Support and treatment from social relations, and 5) Support and treatment from external resources. **CONCLUSION:** Informants explored a tension between adapting to the circumstances and accepting life after stroke. Factors associated with adaptation in life included meaningful values, the informants' own strategies for adaptation and also support from relationship and society. Resilience strategies were useful, and the contribution of individual, social and societal resources for recovery was important. Quality of life was enhanced both directly and through increased participation.

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