E-Poster
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Mapping the Journey and Experience of People Living With Post-Stroke Spasticity

Topic: Complications/Sequelae (ie Spasticity, Immobilization and Frailty)

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BACKGROUND

There is limited understanding of the experiences of people living with post-stroke spasticity (PSS), which is needed to inform provision of post-stroke care and rehabilitation services. Patient experience mapping is a comprehensive approach to consolidation of the lived experiences of patients leading to actionable insights. We aimed to develop a patient experience journey map (PEJM) to capture the experiences of people navigating the PSS care pathway in Europe.

METHODS

The PSS-PEJM was developed using qualitative methods, involving: (1) collation of patient experiences; (2) PEJM creation, insights generation and iterative validation by a multi-stakeholder working group including 11 members from the Stroke Alliance for Europe (SAFE) from nine countries (Belgium, Bulgaria, Cyprus, Estonia, North Macedonia, Norway, Portugal, Slovenia and Ukraine); and (3) external validation by an independent panel (people living with PSS, a caregiver, patient organization representatives and healthcare professionals; n = 23).

RESULTS

The PEJM revealed a complex and fragmented PSS care pathway. Following a stroke, the route to PSS diagnosis is heterogeneous, with no specific medical team assigned to look for PSS symptoms. People report feelings of shock and grief, with concerns more about the stroke itself than about PSS. Upon PSS diagnosis, there are no formalized referral and assessment processes, leading to difficulties and delays in receiving rehabilitation and treatment. People experience relief and hope at diagnosis but can feel overwhelmed with information. They worry about the impact of PSS on their independence and the need for lifelong physiotherapy. Some but not all have the opportunity to discuss treatment and rehabilitation goals with healthcare professionals. Long-term monitoring, care and rehabilitation support in the community can be limited, and people would benefit from clearer instructions and cooperation between the medical and social systems. Loneliness and depression are common, but a person's experience of the health system and support networks influences the emotions they experience. People learn to cope with their symptoms and hope for effective treatment that can improve their quality of life.

CONCLUSION

For people with PSS, the lack of an optimized care pathway causes delays in receiving a diagnosis, treatment, rehabilitation and long-term support, contributing to the 'emotional rollercoaster' many experience. This PEJM provides actionable insights, goals and steps to improve stroke survivors' lives and supports the Stroke Action Plan for Europe.

Statement of Disclosures

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