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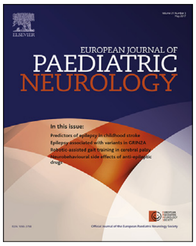

Original article

Lived experience of having a child with stroke: A qualitative study

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ABSTRACT

Objective: To assess the lived experience of parents whose child has suffered a stroke.

Methods: A qualitative study model was chosen, comprising in-depth interviews with parents separately or altogether. A semi-structured interview guide was used. Interviews were audio-recorded, transcribed verbatim and analysed using constant comparison and content analysis. Participant checking was performed. Thirteen families of children aged 1 month to 17 years, having suffered ischaemic or haemorrhagic arterial stroke within one to five years, were recruited. Interviews were conducted within home setting.

Results: After fourteen interviews, data saturation was met and six main narrative themes were identified, underlining a common path of stroke lived experience: brutality of diagnosis, lack of information regarding disease condition, feeling of abandonment after discharge from hospital, focus on functional recovery, late awareness of cognitive disorders, and need for psychological support and family adaptation.

Conclusion: This is the first qualitative study reporting lived experience of childhood stroke caregivers. In line with other qualitative studies exploring the feelings of parents coping with severe neurological conditions of childhood, our results advocate the need for evaluation of family centred health interventions.

Abbreviations: CNIL, Comité National Informatique et Liberté; AIS, arterial ischaemic stroke; AHS, arterial haemorrhagic stroke; TIA, transient ischaemic stroke; PVA, post-varicella arteriopathy; TCA, transient cerebral arteriopathy; HUS, haemolytic and uraemic syndrome; AVM, arterio-venous malformation; SAMU, Service d'Aide Médicale Urgente; MRI, magnetic resonance imaging; IQ, intellectual quotient; EMDR, eye-movement desensitization and reprocessing.

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1. Introduction

Paediatric stroke is one of the leading causes of death among children in high income countries.[1] With an estimated incidence of 1–3 cases per 100.000 children per year, it is a rare event, but its functional and social burden represents a major public health concern.[2,3] Indeed, physical, cognitive and behavioural consequences might be lifelong in 50–75% of children suffering a stroke.[2,4–6]

Relatives of a stroke adult patient often have an impaired health status compared to controls.[7] Furthermore, one month after discharge, relatives of a patient having suffered a stroke are often prone to complex and contradictory feelings: having to adapt to the new situation, to a relative that is “not the same anymore”, feeling a loss of freedom and independence, but with a growing hope as days go by.[7,8]

Within a family of a child that has experienced stroke, important disruption might occur.[2] Bemister et al. have recently shown in a case-control study that mothers of a child with perinatal stroke often present with more depression symptoms, less marital satisfaction, decreased quality of life and altered family functioning compared to controls, especially if children suffer with moderate to severe disabilities.[9] Furthermore, there is some evidence that parents having a child with arterial ischaemic stroke (AIS) would prefer research to focus on physical impairments rather than on cognitive/behavioural or social issues.[10]

The first aim of this work was to report the lived experience of parents whose child had experienced a stroke (thus excluding the perinatal period). The second aim was to focus on their awareness of stroke related cognitive/behavioural disorders, with the hypothesis that they came underestimated during the first phase of rehabilitation.

2. Material and methods

2.1. Research team

This research was conducted by S.S, MSc. and S.D, MSc, MD.

Ms. S.S is a trained occupational therapist and researcher that has conducted in-depth interviews in past studies. She was the main investigator of the present work with the aim to graduate for a master in cognitive sciences. Her time was dedicated to investigations and theoretical courses. Her interests in this research were both intellectual and for career opportunities.

M. S.D is a trained paediatric neurologist and stroke researcher. In 2012, and prior to study, he passed the “4 days of Qualitative Research in Health Care”, the main European course on medical qualitative research, in Antwerp, Belgium. At time of study, he was mainly involved in clinics, but had some nonpaid dedicated time for research (one day per week). His interests in this research were mainly for career reasons, as this work was part of a larger PhD project.

2.2. Participant selection

A multi-centre qualitative study was conducted during the year 2013 in the Rhone-Alpes region, France. Eligible cases were selected using the computer databases of the Saint-Etienne and Lyon hospitals and rehabilitation clinics, France (International Classification of Diseases 11th version, codes I61, I62, I63, I64). Families were included using a purposive sampling approach.[11] Parents or legal representatives of a child (between 1 month and 17 years old) having survived an ischaemic or haemorrhagic arterial stroke within 1–5 years were chosen. Family members had to speak French fairly enough to participate in interviews, and written consent was necessary. Participants were furthermore chosen from various socio-demographic backgrounds (age, occupation, educational level…) so that different life perspectives could be explored.

Families of children with perinatal stroke or suffering cognitive/behavioural disorders not linked to stroke were excluded.

2.3. Method of approach

Twenty-one families were approached through regular mail. With this letter, they were warned that they would be contacted within 2 weeks and proposed to participate in the study, and that they had the right to decline by replying back (via regular, electronic mail or phone). We further contacted the families that had not replied using phone calls/mails or during their physician's office visit.

2.4. Setting and data collection

Parents who agreed to participate were interviewed by investigators within their home setting (see semi-structured questionnaire in Fig. 1).[12] Investigators were not involved in the clinical care of interviewed families except for patient 1, 2 and 3.

Audio-records and field notes were gathered using appropriate material. Relatives were left the choice of being interviewed separately or altogether. All interviews were conducted with no child present.

For each patient, the following clinical data was recorded: age, sex, age at stroke, cause of stroke, stroke severity

- Could you tell me what happened ?
- How was your child doing before stroke ?
- What did you feel during his stroke ?
- What happened when you turned back home ?
- What happened when your child turned back to school ?
- How do you live now ?
- Did stroke change him ?
- How do you manage with this change ?
- How do you see the future ?

Fig. 1 – Semi-structured interview guide.