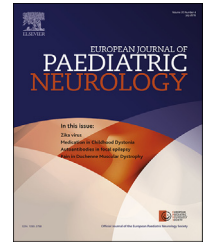




ELSEVIER

Official Journal of the European Paediatric Neurology Society



Original article

Self-reported needs after pediatric stroke

Anne L. Gordon^{a,b,*}, Loan Nguyen^b, Anna Pantou^{a,c}, Andrew A. Mallick^d,
Vijeya Ganesan^e, Elizabeth Wraige^a, Christopher McKevitt^b^a Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust, UK^b King's College London, UK^c The Stroke Association, UK^d Bristol Royal Hospital for Children, UK^e University College London, Great Ormond Street Institute of Child Health, UK

ARTICLE INFO

Article history:

Received 12 October 2017

Received in revised form

11 June 2018

Accepted 12 June 2018

keywords:

Stroke

Caregivers

Rehabilitation

Health care utilization

Child

ABSTRACT

Background: Pediatric stroke has the potential for long term impact on the lives of children and their families. Child-centred intervention depends on understanding of needs from diagnosis onwards. However, little is known about the health and care support self-reported needs of this population.

Aims: This study aimed to describe the nature and extent of needs (met and unmet) of pediatric stroke patients and their families and compare these with previously reported adult stroke needs.

Methods: The questionnaire, adapted from a previously published adult stroke study, was conducted with parents of children who had an ischemic or haemorrhagic stroke between birth – 18 years, and young people with stroke now aged between 12 and 18 years. Participants were recruited from three tertiary pediatric stroke clinics in England. Levels and type of needs, and self-reported neurological impairment were captured. Comparisons of needs was reported descriptively and explored using Chi-square test.

Results: Of 44 participants (39 parents, 5 young people), over two thirds reported at least one unmet need. Over half had difficulties in school-related activities, and over one-third in leisure activities and social relationships. Participants reported similar nature and extent of need when compared to previously reported adult stroke needs. Higher severity of neurological impairment was associated with higher number of needs.

Conclusions: Children and young people and their parents have high levels of unmet need across a range of health domains in the months and years after pediatric stroke. This information supports the importance of a needs-based approach to maximising health and well-being.

© 2018 European Paediatric Neurology Society. Published by Elsevier Ltd. All rights reserved.

* Corresponding author. Paediatric Neuroscience Evelina London Children's Hospital SE1 7EH, UK.

E-mail address: anne.gordon@gstt.nhs.uk (A.L. Gordon).

@Anne8G (A.L. Gordon)

<https://doi.org/10.1016/j.ejpn.2018.06.003>

1090-3798/© 2018 European Paediatric Neurology Society. Published by Elsevier Ltd. All rights reserved.

1. Introduction

Pediatric stroke has been recognized as a serious health condition often associated with life-long morbidity.^{1–7} The long-term functional consequences can include participation restrictions in education, self-care, social relationships and leisure activities.^{3,4,9,18} Studies have also reported reduced quality of life.^{10,11} Given the long-term morbidity experienced by this population it is important to know if perceived health needs are unmet. Previous studies of children with chronic health conditions have shown a mis-match between clinically identified health impairments and receipt of healthcare to meet their needs.^{5,12,13} In the United Kingdom (UK) children typically receive acute care in tertiary level paediatric neuroscience centres. Beyond discharge there is no established pathway, and services are delivered by community based universal healthcare providers, social care and education systems.¹⁴ Provision of rehabilitation and other forms of support beyond discharge is patchy. Our clinical experience is that self-reported needs after stroke evolve and change over time as a child grows and develops and may relate to aspects of health not typically measured in a clinical setting including social and economic factors. No research has documented the level and type of self-reported need nor provision of care from the perspective of children and families.

Several studies have evaluated the long term self-reported needs of adult stroke survivors.^{15–17} These studies have aimed to capture aspects of health and care need that include support, information and social factors. The needs of adults following stroke cannot however be extrapolated to children and young people given the differences in developmental stage at onset. Stroke in children has been shown to impact the lives of children and young people, and parent health.^{3,6,8,11,18} Clinically defined outcomes may have only limited use in assessing long-term needs and targeting services to meet needs. Understanding of the expressed needs, met and unmet, of children after stroke and their parents is important in informing the development of patient-centred services.

2. Aims

We conducted an exploratory study to investigate self-reported needs of pediatric stroke patients and their parents or carers to inform the development of appropriate patient and family centred services. Further, to explore similarities and differences with adult stroke patients, we interpreted our findings in the context of previously published data from an adult stroke population. This included exploration of the relationship between sociodemographic and impairment factors with level of need.¹⁷

3. Methods

3.1. Study population

Participants were recruited from three tertiary level children's hospitals in England that provide paediatric stroke outpatient

clinics: Evelina London Children's Hospital (Guy's and St Thomas' Hospital NHS Foundation Trust), Great Ormond Street Hospital for Children NHS Foundation Trust, and University Hospitals Bristol NHS Foundation Trust. Ethical approval for the study was obtained by London–Chelsea Research Ethics Committee (Ref: 14/LO/0070). Eligible participants were parents or carers of children or young people diagnosed with ischemic or haemorrhagic stroke from day one of life to 18 years of age, or young people who had been diagnosed with a stroke any time from day 1 of life, and who were aged 12–18 years old at the time of the study. Co-morbidity was not an exclusion criterion. Exclusion criteria included patients diagnosed with presumed perinatal stroke beyond the neonatal period, and premature infants (<36 weeks gestation).

3.2. Survey instrument

The survey instrument was adapted from a previously published stroke survivor long-term needs survey,¹⁷ quantifying levels of unmet need in adults one to five years after stroke. The key content was retained and consistent with the adult version with some domains adapted for the pediatric population by an experienced paediatric stroke clinician (AG). Two versions were developed, one for parents and one for young people. Both versions included demographic information, and closed questions with response categories to identify presence and level of need across the following five domains – 1. health after stroke 2. everyday life 3. education and work 4. family, friends, leisure and use of support groups and 5. finance. The parent version consisted of 49 closed questions, and included questions about the impact of the child's stroke on the parent's life. The young people's version included 33 questions and included all parent version questions apart from those on finance and impact on parent's life. Feedback regarding the questionnaire was sought from service users prior to distribution.

In categorising level of unmet need, participants were asked to choose from five response categories in relation to support received. For example, 'In the past 12 months have you had enough help with fatigue (feeling tired a lot of the time)?' - Yes definitely; Yes to some extent; No, I have not had enough; I did not want any; I have not had any difficulties with fatigue.

3.3. Recovery & Recurrence Questionnaire (RRQ)

To assess levels of neurological impairment, the survey included the RRQ, a carer reported version of the clinically-administered Paediatric Stroke Outcome Measure (PSOM).³ Total RRQ scores and total PSOM scores have been shown to have good agreement. The RRQ has 5 sub-sections (sensorimotor function left and right, language comprehension and production, and cognition/behaviour) with an ordinal 4-point severity rate (0 = no deficit, 0.5 = mild deficit, 1 = moderate deficit and 2 = severe deficit). Total RRQ scores range from 0 to 10 (0 = no impairments and 10 = severe impairments). RRQ scores were converted into two groups based on the severity level of neurological impairments in each sub-section and overall. Scores from 0 to 0.5 were classified as 'no impairment or mild impairment' (i.e. 'good outcome') and >0.5 as 'moderate or severe impairment' ('poor outcome').^{19,20}

Download English Version:

<https://daneshyari.com/en/article/10215388>

Download Persian Version:

<https://daneshyari.com/article/10215388>

[Daneshyari.com](https://daneshyari.com)