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DOI:

[10.1016/j.ejpn.2018.06.003](https://doi.org/10.1016/j.ejpn.2018.06.003)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Gordon, A. L., Nguyen, L., Panton, A., Mallick, A. A., Ganesan, V., Wraige, E., & McKeivitt, C. J. (2018). Self-Reported Needs After Pediatric Stroke. *European Journal of Paediatric Neurology*. Advance online publication. <https://doi.org/10.1016/j.ejpn.2018.06.003>

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Self-Reported Needs After Pediatric Stroke

Anne L Gordon^{1,2} PhD, Loan Nguyen² MPH, Anna Panton^{1,3} MSc, Andrew A Mallick⁴ PhD, Vijeya Ganesan⁵ MD, Elizabeth Wraige¹MBBS, Christopher McKeivitt² PhD

1. Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust, UK
2. King's College London, UK
3. The Stroke Association, UK
4. Bristol Royal Hospital for Children, UK
5. University College London, Great Ormond Street Institute of Child Health, UK

Corresponding Author:

Dr Anne Gordon
Paediatric Neuroscience
Evelina London Children's Hospital
London SE1 7EH
Email: anne.gordon@gstt.nhs.uk
[Twitter: @Anne8G](https://twitter.com/Anne8G)
Tel: 020 7188 7188

Cover title: Self-Reported Needs After Pediatric Stroke

Indexing Terms (MeSH compliant)

Stroke
Caregivers
Rehabilitation
Health care utilization
Child

Word count: 4048

Table:

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Supplementary Tables: included in separate pdf

Word count: 251

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 - 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 need-based approach to maximising health and well-being.

Introduction

Pediatric stroke has been recognized as a serious health condition often associated with life-long morbidity¹⁻⁷. The long-term functional consequences can include participation restrictions in education, self-care, social relationships and leisure activities^{3, 4, 9, 19}. 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 systems¹⁴. 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 survivors¹⁵⁻¹⁷. 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, 18, 19, 20}. Clinically defined outcomes may have only limited use is

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. .

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. This included ~~including~~ exploration of the relationship between sociodemographic and impairment factors with level of need population¹⁷.

Methods

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 to 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 diagnosed beyond the neonatal period, and premature infants (<36 weeks gestation).

Survey Instrument

The survey instrument was adapted from a previously published stroke survivor long-term needs survey¹⁷, 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.

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' (~~ie~~i.e. 'good outcome') and > 0.5 as 'moderate or severe impairment ('poor outcome')^{21, 22}.

Administration of the Survey and RRQ

In the absence of a national register or database for this population participants were identified and recruited by clinicians at each of three sites in England where child stroke specialist clinics were established. This was a sample of convenience based on who could be

contacted and consented. Written consent was obtained, or in the case of young people at 12-18 years of age, assent combined with written consent of parents. The Recovery and Recurrence Questionnaire (RRQ) was completed by parents over the telephone or in written form with the support of the research team or a clinician who was familiar with the patient.

Data analysis

Frequencies and proportions were used to summarise levels and type of need. The median of the total number of unmet self-report needs was calculated according to sociodemographic group and good vs poor outcome on the RRQ. Comparisons were made between socio-demographic groups and RRQ characteristics using Chi-squared test dividing total needs as met, partially met or unmet.

Socio-demographic data included age at diagnosis and age at the time of the study, self-reported ethnicity, gender and time since stroke diagnosis, and postcode. Postcode data were used to identify respondents living in the 20% most and 20% least deprived areas of England using the Index of Multiple Deprivation 2015²³. Data from the questionnaires were analysed using SPSS version 22.

Results

Respondents

The response rate was 54% (44 out of 82 questionnaires returned). More than half of the respondents were from Evelina London Children's Hospital (64%) reflecting the presence of both neonatal and childhood stroke services at that site. Out of 44 respondents, 39 were parents or primary carers of patients, and 5 were young people.

Over a third (39%) of the children/young people were aged between 1- 5 years (preschool age) at the time of the study, 59% were 5 – 18 years old, and only 1 child was less than a year old. Twenty-seven (60%) were male. Nearly a quarter (23%) were neonates at the time of diagnosis, 41% were pre-schoolers and over a third (36%) were aged 5 years or above. Over half (61%) had been diagnosed between 6 – 24 months prior to completing the survey. Only 2 (5%) respondents lived in a postcode area described within the 20% most deprived area. Over three-quarters of the children/young people (n=36, 80%) were white, 4 (9%) black and 5(11%) were Asian. The following results combine the responses of both young people and parents/carers as only five young people completed the questionnaire.

Neurological Impairment

Thirty-six (86%) of respondents had an overall RRQ rating of ‘good’ neurological outcome with the remaining 14% having a ‘poor’ outcome (i.e. moderate or severe neurological impairments) (median total score 1, range 0-4). The median RRQ subdomain score was 0 across domains apart from the cognitive/behaviour domain where over a third (40%) of the children were rated as having moderate or severe impairments (median 1). Moderate to severe neurological impairment was evident in right sensorimotor (28%) left sensorimotor (18%), language production (14%) and language comprehension (3%) domains.

Needs

Almost all respondents (98%) reported they had at least one health problem following the stroke across all domains. Thirty-two (73%) respondents reported at least one unmet need (median 1, range 1-9) across a range of domains. Needs are presented according to the categories of the survey.

Information About Stroke

The majority of the respondents (87%) reported wanting more information about their/their child's stroke and half wanted more information about stroke in general. Almost all (95%) respondents reported having seen a pediatrician or ~~paediatric~~ pediatric neurologist within the previous year, and less than 5% of respondents reported an unmet need in terms of accessing a medical practitioner.

Health After Stroke

Thirty-four respondents (77%) reported they/their child had not completely recovered from the stroke. Table 1 reports level of problems and level of unmet need across domains. The highest level of reported problems were in physical function, while unmet needs were highest in mobility, pain and vision.

Table 1 here

In all domains (except memory and emotional health) the proportion of those with unmet/partially met needs was greater than those with met needs. There were no significant correlations between RRQ scores (good vs poor) and unmet/partially met vs met needs for any of the domains assessed. A higher proportion of those with good total or domain RRQ scores reported no needs, although this did not reach statistical significance in univariate analysis.

Everyday Life

This domain included questions regarding activities of daily living, environmental adaptations and use of transport. Over a third of respondents reported problems in this domain with 24 % of respondents having unmet needs and 65% partially met needs. Less

than 20% reported needing adaptations within or outside the home. A high proportion (86%) reported transport difficulties in the past year due to the stroke.

There was no significant difference between those reporting good vs poor RRQ and proportions of met or unmet/partially met needs ($p = 0.93$). There was not a statistically significant relationship between good/poor RRQ scores and presence of needs or meet/unmet needs.

Education and Work

More than thirty percent of the respondents reported problems in this domain including school activities, learning, writing and computer use. The highest proportion of unmet needs were in school activities and learning. Over half of the respondents (55%) reported a problem in school activities, compared with learning (48%), writing (43%) and computer use (34%). Of these areas, the highest proportion of unmet need was in school activities (25%) and learning difficulties (24%). In the univariate analysis, poor RRQ score associated with higher proportion of unmet needs, reaching statistical significance in writing ($p = 0.021$) and computer use ($p = 0.012$).

Family, friends, leisure and support groups

Thirteen (30%) respondents reported experiencing problems with friendships; 15 (34%) in participating in leisure activities alone and 16 (36%) in participating in leisure activities with friends. Of these 30% reported receiving all the help they needed in friendships; 27% in leisure activities alone; and 38% in leisure activities with friends.

Twenty-four (60%) respondents reported that the stroke had impacted the relationship between the child/young person and parents to some degree. Twenty-five (57%) and 20 (45%) described impact on relationships within and outside the family respectively. Poor RRQ scores were associated with higher proportion of unmet/partially met need when compared with no need ($p = 0.02$).

From a parent/carer perspective, 68% reported adverse impact on their relationship with other family members; 73% on their health; 63% on social and leisure time and 59% on income. Almost all parents (96%) received enough support. Sources of support identified included their partner (76%), parents or close family (74%), children (13%), friends (68%), charitable bodies (37%), doctors (45%), therapists (47%) and 32% from other sources. Over two-thirds (71%) reported not having the opportunity to meet other families affected by stroke, despite wanting this opportunity.

Finances

Over half (57%) of parent respondents received benefits to support the family income. A small number of parents (11%) wanted more information about benefits to support their family income.

Adult and pediatric stroke needs compared

Figures 1-2 illustrate the proportion of problems and unmet needs previously reported in the adult stroke population¹⁷ with the findings of this study. Of the child stroke respondents at least 40% reported unmet or partially met needs across all domains. Proportionally the presence of self-reported need was similar between the adult and child groups across all domains. In exploring those with unmet or partially met needs, there was more variation. The child stroke population were more likely to report unmet/partially met needs in vision, pain

and mobility and the adult stroke population in fatigue, cognitive and emotional domains. Given the differences in sample sizes it was not possible to statistically compare these two populations.

Figures 1 & 2 here

Discussion

This study identifies self-reported unmet needs of the pediatric stroke population predominantly 6-24 months post-incident stroke. Almost three-quarters of respondents reported at least one unmet need. This prevalence is consistent with previous studies in families and children with other chronic health conditions²⁴⁻²⁷. The adverse impact of stroke on parents in terms of family relationships, finances and health reported in this study confirms previous findings in the small number of studies available³.

While the majority of participants had seen a paediatrician in the preceding year, a high proportion cited unmet needs in terms of information about their child's stroke/their stroke. Our clinical experience suggests parents and young people's questions frequently centre on aetiology, recurrence risk, and long-term trajectory. While the knowledge base in these areas is increasing²⁸⁻³¹ research is needed to understand how best to provide individualised information to patients and families. Parent/carer and young person engagement undertaken

in developing the recently published UK Childhood Stroke Guidelines also highlighted these domains of concern in informing consensus level family information and support guidance¹⁴.

Children with a higher level of neurological impairments were reported as having a higher number of unmet needs in domains including patients and parents' health, daily living, family and social relationships. Previous studies have explored the relationship between the extent of neurological impairment and functional outcome using clinical measures^{3,4,9,10,11,18}. This study found an association between self-reported needs and severity of neurological impairment. Although this sample had a relatively good neurological outcome overall (by RRQ), there were higher than previously reported impairments in the cognitive/behavioural sub-domain^{32,33}. Despite this a high proportion of unmet need was reported.

The child stroke population is small compared to adult stroke, however the sample size described is consistent with many studies of pediatric stroke. Further the racial distribution is similar to that described² and the response rate was adequate for this type of study. Few young people participated, and therefore the data represent predominantly parent proxy rating rather than the direct view of the individuals themselves. In a study of this size it was only possible to perform univariate analysis and not to identify possible predictors of needs. A previous adult stroke study has reported that level of disability and ethnicity were independent predictors of total number of unmet needs¹⁷.

This is the first time the self-reported needs of adult and pediatric stroke populations have been compared. The presence of problems and extent to which needs were met were broadly similar between the two groups. Given the high levels of unmet need, these findings challenge the existing assumptions that children recover better than adults after stroke⁴. In

the UK the pathways for supporting the breadth of needs from diagnosis onwards through to adulthood have not been well defined. The recent publication of national clinical guidelines for childhood stroke¹⁴ recommend integrated management across health, social care and education services. The adoption of these guidelines provides the opportunity to evaluate impact in terms of meeting the needs of patients and families but requires a flexible long-term approach to meet evolving needs. Evaluation of services requires evidence of the nature, extent and prevalence of needs beyond those typically defined in a clinical setting.

Health and care services working with this population need to consider in evaluating health and needs the importance of taking an active role in eliciting the concerns and priorities of children and families. This can be used in targeting resources towards specific needs. Only then can we maximize the impact of our intervention to improve health and wellbeing for this population of children, young people and their families.

Acknowledgements

Sincere thanks to the young people and parents/carers who participated in this study.

Source of funding

The project coordinator (AP) was supported by the ICAP-funded Stroke Association Child Stroke Project.

Disclosures: None

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Table 1. Proportions of respondents reporting stroke- related health problems and the extent to which need met

	No. Reporting a Problem N (%)	Proportion Reporting Need Unmet/ Partially met (%)	Proportion Reporting Need Met (%)
Mobility	31(70.5)	93.5	6.5
Hand movement	30(68.2)	70.0	30.0
Communication	20(45.5)	70.0	30.0
Pain	14(31.8)	92.9	7.1
Fatigue	19(43.2)	57.9	42.1
Emotional	20(45.5)	40.0	60.0
Concentration	21(47.7)	61.9	38.1
Memory	15(34.1)	40.0	60.0
Vision	14(31.8)	92.9	7.1

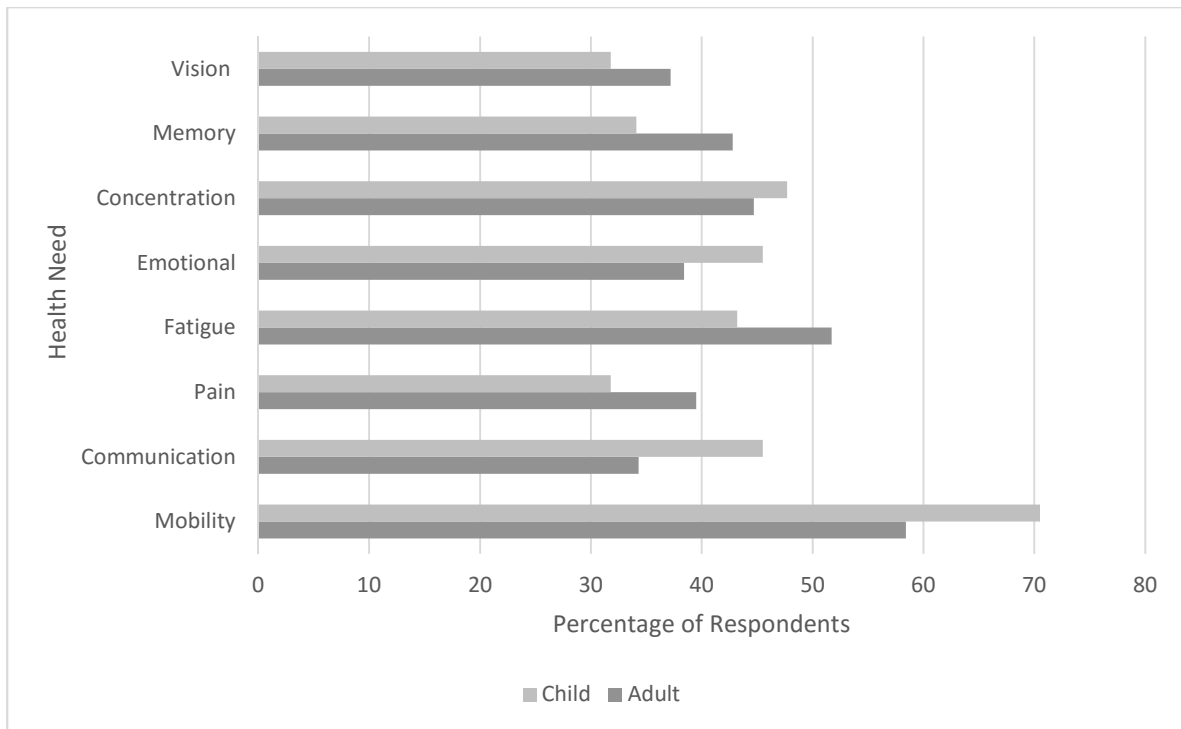


Figure 1. Proportion of Participants Reporting a Problem (%)

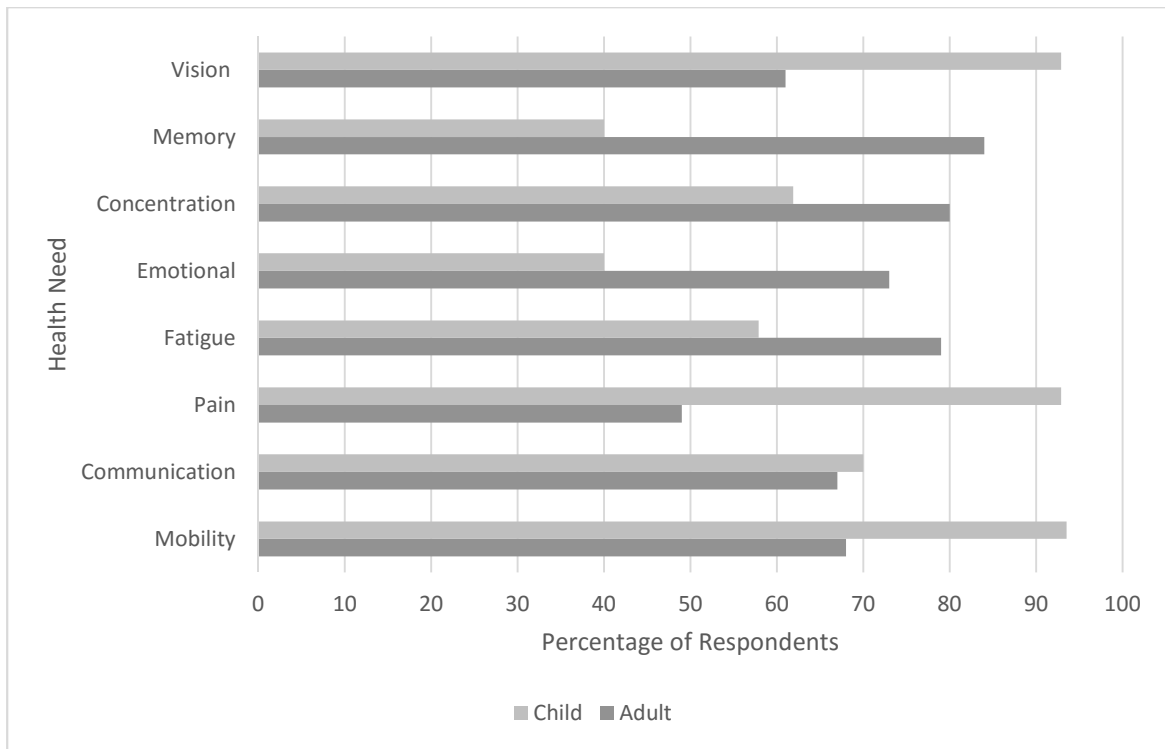


Figure 2. Proportion of Participants Reporting Need Unmet/Partially Met (%)