

Health and life priorities for paediatric SCI from the perspective of young individuals with SCI and their parents/caregivers in the UK: final analysis of the UK arm of the PEPSCI Collaboration

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INTRODUCTION

Although spinal cord injury (SCI) under the age of 15 years of age is relatively rare, the injury entails important physiological and psychological consequences [1]. The annual incidence of paediatric SCI has recently been estimated between 3.3 and 13.2% [2], with a higher number in male teenagers [3]. Limited focus has been made to explore the research priorities for the paediatric SCI population using service user surveys. For the first time, the UK arm of the Pan-European Paediatric Spinal Cord Injury (PEPSCI) Collaboration has analysed research priorities rated by young people with SCI as well as parents/caregivers.

METHODS

Study design

Cross-sectional, quantitative, multi-centre, national survey.

Methodology

Community-residing participants (aged 8-25 years) with paediatric onset of SCI (i.e. injury before the age of 18 years) and with a SCI evolution of ≥ 6 months were identified at 5 UK SCI rehabilitation centres and invited to take part in the survey along with parents/caregivers. Following assent/consent, age-specific surveys, that were designed based on reports of Simpson and colleagues on health and life priorities of adults with SCI [4], were completed by the eligible participants online or on paper. Ratings of research priorities were made using a 5-point Likert Scale (1 - Very unimportant, 2 - Unimportant, 3 - Neither important nor unimportant, 4 - Important, 5 - Very important). Neurological information was obtained from the healthcare professional following permission of participants.

RESULTS AND DISCUSSION

Participant demographics

The sample group included 34 individuals with pSCI (mean age=17.1 years, n=10 for 8-12 years, n=24 for 13-25 years), predominantly White-British male (Table 1) with AIS grade A and a neurological level between C1-L2. In addition 43 parents and caregivers also provided research priority data. The mean time since injury was 8.8 years, ranging from 1 to 23 years (Table 2).

Table 1: Characteristics of individuals with SCI

Characteristics of individuals with SCI	N	%
Age		
8-12	10	28.6
13-17	8	22.9
18-25	16	45.7
Gender		
Male	17	48.6
Female	16	45.7
Not stated	1	2.9
Ethnicity		
White-British	24	68.6
White: Irish	1	2.9
White: Any other White background	3	8.6
Mixed: White and Black Caribbean	1	2.9
Asian or Asian British: Indian	1	2.9
Asian or Asian British: Any other Asian background	1	2.9
Black or Black British: African	1	2.9
Not stated	2	5.7

Table 2: Details of SCI

Details of SCI	N	%
Cause of injury		
Motor vehicle/pedestrian accident	7	20.0
Sports	1	2.9
Fall	1	2.9
Other accident	2	5.7
Tumour	2	5.7
Inflammation/Infection	3	8.6
Transverse myelitis	3	8.6
Surgical complication	3	8.6
Congenital	2	5.7
Other	7	20.0
Not known	1	2.9
Not stated	2	5.7
AIS grade		
A	15	42.9
B	3	8.6
C/D	10	28.6
E	2	5.7
Not stated	4	11.4
Injury type		
Tetraplegia	16	45.7
Paraplegia	17	48.6
Cauda equina	1	2.9
Time since injury		
<1 year ago	0	0.0
1-3 years ago	7	20.0
4-10 years ago	15	42.9
11-20 years ago	9	25.7
>20 years ago	2	5.7
Not stated	1	2.9

Study setting

Five hospitals in the UK, namely Stoke Mandeville Hospital, Royal National Orthopaedic Hospital, James Cook University Hospital, Sheffield Teaching Hospitals and the Robert Jones and Agnes Hunt Orthopaedic Hospital, as part of the PEPSCI Collaboration.

Ranked participant reported research priorities

% Very Important Score (5)	Research Priority	% Important - Very Important Scores (4 & 5)	Median Score (1-5) IQR
80	Experience at school	90	5 (5-5)
70	Physical feeling (health)	70	5 (3.5-5)
56	Ability to take care (selfcare)	89	5 (4-5)
50	Relationship with others	90	4.5 (4-5)
40	Emotional feeling	90	4 (4-5)
40	Ability to get around places	50	3.5 (3-5)
20	Participation in activities	50	3.5 (3-4)

Individuals with SCI aged 8-12 (n=10)

% Very Important Score (5)	Research Priority	% Important - Very Important Scores (4 & 5)	Median Score (1-5) IQR
59	Presence of pain	91	5 (4-5)
59	Emptying bladder	86	5 (4-5)
57	Emptying bowel	86	5 (4-5)
55	Presence of spasms	96	5 (4-5)
52	Presence of skin sores	91	5 (4-5)
50	Ability to move arms/hands	77	4.5 (4-5)
46	Physical health	75	4.0 (3.75-5)
46	Ability to walk/wheel/move	82	4 (4-5)
46	Ability to move leg and feet	73	4 (3.25-5)
44	Ability to eat and drink	70	4 (3-5)

Individuals with SCI aged 13-25 (n=24)

% Very Important Score (5)	Research Priority	% Important - Very Important Scores (4 & 5)	Median Score (1-5) IQR
74	Emptying bladder	83	5 (4.25-5)
74	Emptying bowel	83	5 (4.25-5)
74	Ability to walk/wheel/move	82	5 (4.3-5)
70	Ability to move leg and feet	80	5 (4-5)
63	Presence of pain	85	5 (4-5)
63	Presence of spasms	85	5 (4-5)
63	Presence of skin sores	83	5 (4-5)
61	Physical health	87	5 (4-5)
61	Ability to breath and cough	79	5 (4-5)
59	Access to healthcare	80	5 (4-5)

Parents and caregivers (n=43)

- Younger individuals (aged 8-12 years) report research priorities for schooling, physical health, selfcare, psychological wellbeing, relationships and mobility.
- Older individuals (aged 13-25 years) report research priorities for secondary SCI complications, upper limb function, physical health, mobility, lower limb function and eating & drinking.
- Parents and caregivers highlight research priorities for bladder and bowel, mobility, lower limb function, physical health, breathing, and access to healthcare.

CONCLUSION AND SIGNIFICANCE

For the first time research priorities have been identified for the UK paediatric SCI population following integration of views of young individuals with SCI and their parents and caregivers. The outcomes of this survey will help to guide research into paediatric disability after SCI by scoping future research topics rated highly by stakeholders. Moreover, knowledge of the specific health and life domains identified through this survey will also assist health service organisations to target relevant clinical and social issues for future service developments related to paediatric SCI management.

References

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