

ARTICLE

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Organisation of services and systems of care in paediatric spinal cord injury rehabilitation in seven countries: a survey with a descriptive cross-sectional design

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STUDY DESIGN: International multicentre cross-sectional study.

OBJECTIVES: To describe the organisation and systems of paediatric spinal cord injury (SCI) rehabilitation services in seven countries and compare them with available recommendations and key features of paediatric SCI.

SETTING: Ten SCI rehabilitation units in seven countries admitting children and adolescents with SCI < 18 years of age. **METHODS:** An online survey reporting data from 2017. Descriptive and qualitative analysis were used to describe the data. **RESULTS:** The units reported large variations in catchment area, paediatric population and referrals, but similar challenges in discharge policy. Nine of the units were publicly funded. Three units had a paediatric SCI unit. The most frequent causes of traumatic injury were motor vehicle accidents, falls, and sports accidents. Unlike the other units, the Chinese units reported acrobatic dancing as a major cause. Mean length of stay in primary rehabilitation ranged between 18 and 203 days. Seven units offered life-long follow-up. There was a notable variation in staffing between the units; some of the teams were not optimal regarding the interdisciplinary and multiprofessional nature of the field. Eight units followed acknowledged standards and recommendations for specialised paediatric SCI rehabilitation and focused on family-centred care and rehabilitation as a dynamic process adapting to the child and the family.

CONCLUSIONS: As anticipated, we found differences in the organisation and administration of rehabilitation services for paediatric SCI in the ten rehabilitation units in seven countries. This might indicate a need for internationally approved, evidence-based guidelines for specialised paediatric SCI rehabilitation.

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INTRODUCTION

Spinal cord injury (SCI) in children and adolescents (paediatric SCI) is a complex and life-changing condition with low prevalence and wide implications for health care [1]. Paediatric SCI includes children and adolescents <18 years of age and refers to both traumatic and atraumatic injuries. This puts a major strain on both the children and their families, regardless of age at injury [2, 3]. SCI affects the physical, psychological and emotional development of the children and the daily life of their families as well as being a challenge for the rehabilitation team and society [4, 5]. The rehabilitation process is complicated by the ongoing physical and emotional development of the child [3]. This makes it important to adapt the rehabilitation process to the children's needs, their ages and developmental stages with continuous involvement of the child's family [6, 7].

The European Association for Children in Hospital (EACH) focuses on the welfare of children in hospitals and declares that children shall only be admitted to hospital if the required care cannot be provided at home or on an outpatient basis. Their

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hospital stay should be as short as possible and rehabilitation should be near their home, family, friends, and school [6, 8]. Furthermore, it states that children should stay in the same unit as other children, if possible not with adults, and the unit should preferably have unique programmes for children regarding education, recovery and psychosocial support [6, 9].

According to the Consumer Guidelines from the American Spinal Injury Association (ASIA) [9], children with SCI should be admitted to paediatric SCI units that admit at least between five and ten new cases of traumatic SCI each year to maintain the necessary skills of the health professionals. Rehabilitation after paediatric SCI is a dynamic process with the child in focus [10]. Three basic principles are recommended: (1) use family-centred care, (2) use a multidisciplinary approach, and (3) view treatment as an ongoing dynamic process that must change as the child grows and develops [11].

The Spinal Cord Injury Rehabilitation Evidence (SCIRE) project defines specialised SCI rehabilitation as "a programme that provides comprehensive, individualised, and patient-focused rehabilitation services, to empower people with SCI and their families to achieve optimal quality of life. Through organised regional referrals, care is delivered through a multidisciplinary team provided by board certified physician specialists and accredited allied health professionals" [12].

To be able to deal with the complicated and variable consequences after a paediatric SCI, a multidisciplinary approach is vital, ensuring that all major issues arising are appropriately managed [9, 13]. The multidisciplinary team should include *at least* a rehabilitation physician, a rehabilitation nurse, physiotherapist, occupational therapist, social worker and preferably a teacher [9].

Even though research shows that rehabilitation is effective at any age, the literature on the effect of rehabilitation in the paediatric population is scarce [5, 14]. Access to rehabilitation services, the rights of children in health care and the quality of health care for children vary widely in and between countries [1, 15]. Life-long recurring rehabilitation and follow-up services are important to assure that the person with SCI is capable of dealing with the consequences of the SCI throughout life and are often a prerequisite for optimal participation in society [1, 15]. According to New et al. [16], rehabilitation services as well as non-clinical factors may influence the outcomes of rehabilitation, but these are rarely well described. Non-clinical factors include referral, admission, therapy, and follow-up services, and these factors are important parts of the present study as in ongoing research on paediatric SCI internationally [17, 18].

At present, an agreed-on international comprehensive model of care for specialised paediatric SCI rehabilitation is lacking. To have more equitable paediatric SCI rehabilitation in the future, it is essential to study existing systems of care and rehabilitation regarding both clinical and non-clinical factors.

The aim of the present study was to describe the organisation of specialised paediatric SCI rehabilitation in ten rehabilitation units in seven countries (Sweden, Russia, China, Israel, USA, Palestine and Norway) and compare the services in relation to acknowledged standards and recommendations for specialised paediatric SCI rehabilitation and the rights of children in hospitals. A further aim was to use the findings to facilitate the development of improved strategies for specialised paediatric SCI rehabilitation and provide specific information to policy makers, clinicians and young persons with SCI and their families.

METHODS

Design

The present study has a descriptive, multicentre cross-sectional design. The Strengthening the Reporting of Observational Studies in Epidemiology [19, 20] statement was used as a reporting guideline for this article.

Setting and participants

The participating units were part of the Sunnaas International Network in Rehabilitation (SIN) established by Sunnaas Rehabilitation Hospital (SunRH), Norway, in 2000 as a multinational cooperation of research and clinical practice within the field of specialised rehabilitation. In 2016, representatives for paediatric rehabilitation at the SIN-collaborating units were invited to participate in the present research project, the SIN paediatric spinal cord injury (SINpedSCI) project. The contributing units are located in Sweden (three units), China (two units), USA (one unit), Russia (one unit), Israel (one unit), State of Palestine (one unit) and Norway (one unit). An interdisciplinary and multiprofessional project group and a project core team were established at SunRH, consisting of the present head of the research department (JKS), a principal investigator (PI) (KSR) and a study coordinator (SS). A local PI responsible for data collection and contact with the SINpedSCI team in Norway was selected at each unit (Fig. 1).

Data collection

A special customised online survey was used to collect data. A draft version of the survey was developed by the project group based on clinical expertise, literature review and international cooperation [16]. This draft version was reviewed, further developed and refined by the SINpedSCI team during a 2-day workshop (Fig. 1). The final version of the questionnaire, consisting of 100 questions, was available in English as an online questionnaire (web survey) and a paper version. The questionnaire covered six sections: (I) catchment area, organisation of which the paediatric rehabilitation unit was part, funding service, demographics, referral, discharge and length of stay; (II) staffing, therapy intensity, parents, siblings, friends and classmates; (III) ancillary services; (IV) barriers to admission and discharge; (V) prevention regulations and health promotion; (VI) outcome measures and research.

The local PIs were asked to answer the survey referring to hospital data and information for 2017, reported during 2018 and 2019. The survey responses were carefully monitored by the PI and the research coordinator for any discrepancies, missing data and linguistic misunderstandings. Clarification of the responses was done by controlling the numbers and, when necessary, double checking with the local PIs (Fig. 1).

Statistical analysis

Descriptive analysis was used to present length of stay, size of catchment area and therapy intensity with mean and min-max. The proportion of the population aged 0 to 17 years in the catchment areas is presented as a percentage.

Qualitative analysis

The content of rehabilitation gathered from the survey was described and compared qualitatively against the recommendations for paediatric SCI rehabilitation by the International Spinal Cord Society (ISCOS) [11] and ASIA [9], based on the SCIRE definition of specialised SCI rehabilitation [12] (Fig. 2).

RESULTS

Participating units, referral and discharge processes

Ten units agreed to participate, and all completed the survey. The location of the participating units, catchment area, total and paediatric population in the catchment area, interaction with acute hospitals and referral processes are shown in Table 1. There was a notable variation in the size of the catchment areas varying from 1 to 212 million people (median, 4 million people). The median paediatric population was 1.5 (0.1-48) million. The typical location of patients before admission was in an acute hospital. Referral processes varied among the units; discharge processes were similar (Table 1). The distribution of traumatic and nontraumatic cases in primary rehabilitation and follow-up showed some variation between units. Two units had a few more nontraumatic cases (USA and Israel), while one unit (China/Sichuan) had only traumatic paediatric SCI in primary rehabilitation and for follow-up. Two of the units (Russia, China/Beijing) had more traumatic than non-traumatic paediatric SCI cases for follow-up,

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Fig. 1 Flowchart of survey data collection on paediatric spinal cord injury rehabilitation. The main focus of the process is presented in the boxes, from agreement of the protocol until publication of the final manuscript. The duration of each period and the whole project can be estimated by the given years.

while three other units (Norway, Sweden/Linkoping and Israel) had more non-traumatic cases for follow-up. Two units had the same number for both traumatic and non-traumatic for both primary rehabilitation and follow-up.

Organisation of paediatric SCI rehabilitation

Organisation of paediatric rehabilitation, number of beds, number of patients in the last 12 and 36 months and length of stay (LoS) are shown in Table 2. All units except two had a paediatric rehabilitation unit; three units had a paediatric SCI rehabilitation unit. The total number of paediatric patients with SCI in the last 12 months varied between 0 and 93 and between 1 and 278 in the last 36 months. LoS in primary rehabilitation varied between 18 and 203 days (median, 34 days) and between 20 and 180 days (median, 65 days) for follow-up stays (8 of 10 units). For four of the units that offered follow-up, the LoS for the follow-up was longer than for the primary rehabilitation.

Regarding problems with barriers to discharge, five units reported moderate problems after paediatric SCI rehabilitation. The main factors that contributed to barriers for discharge were home modifications, suitable accommodation and funding of equipment.

Most frequent causes of injury

The three most frequent causes of injury were reported only for traumatic cases, not for non-traumatic cases in the present study. Motor vehicle accidents were rated as the most frequent or the second most frequent cause of injury by all reporting units. Sport accidents were reported as the most frequent cause by Sweden/Stockholm and Israel; gunshots were reported as the most frequent cause in the USA and were third most frequent in Palestine and Israel. Unlike all the other units, both Chinese units reported that forced hyperextension during acrobatic dancing was the most frequent (China/Beijing) or second most frequent (China/Sichuan) cause of injury.

Staff and therapy

All units had a rehabilitation physician and rehabilitation nurses. However, not all recommended allied health professionals were represented in all units. Most of the units had physical therapists (eight of ten), occupational therapists (eight of ten), psychologists (five of ten) and social workers (six of ten). School staff were available in six of ten units; two units shared school staff with other wards.



Fig. 2 The main principles in paediatric spinal cord injury rehabilitation are shown here. The participating units were considered according to these principles, described by ISCoS (International Spinal Cord Society) [11], ASIA (American Spinal Injury Association) [9] and SCIRE (Spinal Cord Injury Research Evidence) [12].

All units provided therapy to patients 5–6 days/week. The number of sessions led by therapists varied between 1.5 to 6 h/ day (median, 4 h/day) and accessibility for self-training was between 0 and 12 h/day (median, 7 h/day) (Table 3).

Paediatric SCI rehabilitation in the participating units according to key features

Details of paediatric SCI rehabilitation in the participating units according to key features of paediatric SCI rehabilitation described by ISCoS [11], ASIA [9], based on the definition of specialised SCI rehabilitation by SCIRE [12] are shown in Table 4. Nine of ten units reported using a multidisciplinary approach. Four units (Sweden/Stockholm, Sweden/Gothenburg, China/Sichuan, Russia/Petrozavodsk) did not have five to ten new cases of paediatric SCI in the year of study (2017). All units indicated having parental accommodation, but only three units integrated siblings in the rehabilitation process. All units reported a dynamic treatment process that is comprehensive, individualised and focuses on the child and their family.

Follow-up

All units offered some form of long-term follow-up activities after discharge. The frequency and content of the follow-up varied in the different units. Some units did not meet the patients in person for follow-up stays, but instead offered information booklets, telephone calls or video consultations, either to the parents or to adolescents or took calls from the families if necessary. Seven units reported a life-long follow-up programme. Four units had mobile follow-up teams. After the age of 18 years, most adolescents were referred to an adult unit for follow-up.

SCI prevention activities

Three units (Palestine, Russia/Petrozavodsk, China/Beijing) reported they were engaged in paediatric SCI prevention actions. The engagement varied from awareness sessions at schools to integration of children with disabilities in schools (Palestine), publication of articles and brochures, speeches for parents in kindergarten and schools to popular science books (Russia/ Petrozavodsk) to TV programmes to make people aware of the danger of spine extension in dancing (China/Beijing). Five units reported that use of safety belts and child seats in cars is mandatory in their catchment area (Israel, Sweden's three centres and Norway). The units in China and Palestine stated that awareness of child protection in traffic was inadequate.

DISCUSSION

This study is, to our knowledge, the first international multicentre study to describe the organisation of rehabilitation services and systems of care for paediatric SCI and to compare the services in relation to acknowledged standards and recommendations for specialised paediatric SCI rehabilitation and the rights of children in hospitals. Our results highlight the need for improvement where these services are currently inadequate or not available. Only three of the ten units had a paediatric SCI unit and there was a notable variation in staffing among the units. The mean LoS in primary rehabilitation ranged between 18 and 203 days and seven units offered life-long follow-up. Eight units followed acknowl-edged standards and recommendations for specialised paediatric SCI rehabilitation and the rights of children in hospitals, features used as a framework in the present study.

Table 1.	Rehabilitation units, (catchment area, total	l and paediatric po	opulation in the ca	tchment area, inte	action with acu	te hospitals and re	ferral processes.		
Variable	Norway	Sweden Linköping	Sweden Stockholm	Sweden Gothenburg	USA	Palestine	Israel	Russia	China Beijing	China Sichuan
City	Oslo	Linköping	Stockholm	Gothenburg	New York	Bethlehem	Tel Hashomer	Petrozavodsk	Beijing	Sichuan
Catchment area (CA)	Regional ^a	Regional ^a	Regional ^a	Regional	Regional	Whole country	Whole country	Regional ^a	City and some provinces	Regional
Population i CA (million)	in 3.0	1.0	2.3	1.95	20.0	4.8	8.0	0.6	212.0	83.0
Population 0–17 years i CA (million)	n (%)	0.2 (20.0)	0.5 (22.0)	0.3 (17.0)	4.2 (21.0)	2.2 (45.0)	3 (37.5)	0.1 (16.0)	48.0 (22.6)	28.0 (33.7)
Funding so	urce Public/government	Public/government	Public/government	Public/government	Public/government; private insurance	Public/ government; private insurance/ funding	Public/government; medical tourism	Compulsory Medical Insurance Fund	Public/ government; private insurance ^b	Public/government
Direct links acute SCI ur	to Yes hit	Yes	Yes	Yes	No	Yes	Yes	No	No	No
Referral pro to unit	cess Acute hospital ^c	Neurosurgical or orthopaedic units in same hospital	Acute hospital	Acute hospital	Physiatry, orthopaedic surgeons and neurology	Admission readiness assessed by MD	Medical report from referral team acute hospital	Acute hospital	Recommendation from the MD responsible at acute hospital to parents	When stable patier is transferred to rehabilitation centr
Readiness decision for discharge	Rehabilitation team	Rehabilitation team	Rehabilitation team	Rehabilitation team	Rehabilitation team	Rehabilitation team; funding limitations	Rehabilitation team	Rehabilitation team	Rehabilitation team; third party constraints; funding limitations	Rehabilitation team
								- - - -		

Participating rehabilitation units: Unit for Children and Adolescents, Sunnaas Rehabilitation Hospital, Oslo, Norway (SRH); Rehab Station Stockholm Spinalis, Stockholm, Sweden; HRH Crown Princess Victoria's Children's and Youth Hospital, Linköping Hospital, Linköping, Sweden; Institute of Neuroscience and Physiology Rehabilitation Medicine, Sahlgrenska University Hospital, Gothenburg, Sweden; Rusk Rehabilitation Institute, New York, USA; Department of Pediatric Rehabilitation, The Edmond & Lity Safra Children's Hospital, The Chaim Sheba Medical Center, Tel Hashomer, Israel; China Rehabilitation and Research Center, Beying, PR China; Bayi Rehabilitation Center, Chengdu, PR China; Rehabilitation Center, Children's City Hospital, Petrozavodsk, Karelian Republic, Russian Federation; Bethlehem Arabic Society Rehabilitation, The Protectorate of Palestine. SCI spinal cord injury.

^aAdditionally, paediatric SCIs from the whole country are included.

^oDepends on the cause; car accidents are funded privately, falls from a height are funded by public/government. Referral from an acute hospital and then early assessment by an ambulatory rehabilitation team from Sunnaas.

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Table 2. Organisation of paedia	tric spinal cord	injury rehabilitati	on in participating	g rehabilitation units	, number of beds, n	umber of patie	nts in the last 1.	2 and 36 mon	iths and lengt	n of stay.
Variable	Norway	Sweden Linköping	Sweden Stockholm	Sweden Gothenburg	USA	Palestine	Israel	Russia	China Beijing	China Sichuan
Paediatric rehabilitation unit	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes
No. of beds	5-7	1 ^a	0	0	16	15	20	30	36	60
Paediatric SCI rehabilitation unit	Yes	Yes	No	No	No	Yes	No	No	No	No
No. of beds	2–3 ^a	1 ^a	0 ^a	0 ^a	0 ^a	1–3 ^a	0 ^a	0 ^a	0 ^a	0 ^a
Total no. of paediatric SCIs in the last 12 months ^b	œ	20	-	0	12	12	18	m	93	4
Total no. of paediatric SCIs in the last 36 months ^b	24	20	80	-	40	19	32	7	278	Q
Length of stay (days) in primary rehabilitation, mean (range)	66 (29–136)	NA	52 (40–69)	NA	21–30 (5–60)	40 (30–120)	203 (60–365)	18 (15–21)	20 (12–28)	28 (66–120)
Length of stay (days) for follow- up, mean (range)	3 (3–5)	NA	(06-06) 06	NA	90–120 (15–life- long)	40 (30–120)	120 (120–120)	20 (15–24)	180 (30–360)	26 (14–43)
Primary rehabilitation, first-time re. SCI spinal cord injury, NA not availa ^a Number of beds is on demand. ^b Total number of paediatric patien	habilitation after able. its with any neur	sustaining SCI. ological impairme	nt due to spinal co	rd injury of any durat	ion.					

Table 3. Therapy ir	ntensity, group and	individual and	d accessibility of training	\mathfrak{g} facilities in the \mathfrak{p}	articipating	units.				
Variable	Norway	Sweden Linköping	Sweden Stockholm	Sweden Gothenburg	NSA	Palestine	Israel	Russia	China Beijing	China Sichuan
Therapy/week (days)	Ŋ	S	9	Ŋ	5-6	S	6	5	5.5	6
Therapy/day (h)										
Led by therapists	4	£	9	m	4	6	4	3.5-6	1.5	6
Led by nurses or other ward personnel	-	As needed	S	F	7	NA	m	2–3		7
Self-training and/ or training together with/assisted by parents, peers, volunteers	-	As needed	7	-	-	7	m	2-3	2.5	1.5
Accessibility of training facilities (self-training), (hours/day)	10-12	0.4	6	m	7	ω	Up to 10	4	Missing	-
Group therapy sessions	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Q	Yes
Group therapy session content	Climbing, arts and crafts, physical activity, gaming, cooking		Wheelchair skills	Group exercise, gardening	Cooking	Upper limb, transfer and mobility, cooking, group exercise, art therarov sessions	Cooking, socialising, functional groups and learning	Respiratory gymnastics, exercises for spine, classes on music, speech therapy, with psychologist, dog assisted therapy, art theraby, addotive fitness		Transfer and mobility and group exercise

Table 4. Paediatric SCI rehabilitation in the based on SCIRE (Spinal Cord Injury Research	participating h Evidence)	g units according to l [12].	key features described	by ISCoS (Internationa	l Spinal C	ord Society)	[11], ASIA	(Americar	n Spinal Injury A	.ssociation) [9],
Features	Norway	Sweden Linköping	Sweden Stockholm	Sweden Gothenburg	USA	Palestine	Israel	Russia	China Beijing	China Sichuan
I. Multidisciplinary approacha										
Multidisciplinary team	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
II. Family-centred care										
Unit near home (regional)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Parental accommodation	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Siblings integrated	Yes	Yes	Yes	Partly	Partly	Partly	Partly	Partly	Partly	Partly
III. Treatment as an ongoing dynamic process										
Comprehensive, individualised, patient focused	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Organised referrals ^b	Yes	Yes	Yes	Yes	Partly	Partly	Partly	No	Partly	Partly
IV. Paediatric patient programmes										
Separate paediatric unit	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes
5-10 new paediatric SCIs/year	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	No
Located with children with other traumatic injuries	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Minimum 3 h therapy/day	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Supplemental therapyc	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
^a Rehabilitation physician, rehabilitation nurses, ^b Referral time should be short, organised and	, physical the by an establ	rapists, occupational th ished process. The ans	nerapists, psychologist, wers indicated in the t	social worker, teacher. :able are based on answ	ers on refe	errals and link	s to an ac	ute hospit:	al (Table 1). Partl	y refers to little
structure/continuity in the referral process. ^c Definition: group therapy, self-training, trainin	ig with family									

Organisation of paediatric SCI rehabilitation

Not surprisingly, there was a notable variation between the units regarding both the total population in the catchment areas and the paediatric population. To develop and maintain the necessary and updated skills to manage paediatric SCI rehabilitation, it is recommended that a paediatric SCI unit has a minimum of five to ten new patients every year [9]. This prerequisite may not be present in all participating units. It is assumed that hospitals that see few paediatric patients often lack the necessary expertise and knowledge to care optimally for these children [21]. Dhillon et al. [21] suggest that care should be organised in regional centres to optimise care and improve outcomes. This is especially important when the incidence is low. Only three of the units had a paediatric SCI unit. According to recommendations (ASIA [9], EACH [6]), children with SCI should preferably be located with other children with the same (or similar) diagnosis to optimise outcomes of rehabilitation. Children have better outcomes and recovery after traumatic injuries when treated at paediatric units or units with extra resources for children [21-23]. The psychological benefits are also a reason to enable rehabilitation for children together with other children and adolescents [24] because the peer effect is important. Children/adolescents with SCI need to meet persons of all ages with SCI to get a perspective of the future as well.

We noted that there were differences in referral processes, whereas discharge routines were quite similar, but some units reported some challenges with discharge, such as home modifications and funding of equipment. Home modifications often take longer than the planned rehabilitation stay, but all countries, even with different economic situations, had similar challenges. Some barriers to access to health services for individuals with SCI include availability (i.e. delivery of services requires a resource; this is often centralised and limited in rural areas) and accessibility (often reported as difficulty with access to health services and assistive devices) [1].

In all but four units, the LoS for follow-up was longer than or equal to the LoS for primary rehabilitation. Guidelines recommend that children should stay in hospital only for short periods of time, and the goal should be to establish rehabilitation at home, near home, or in close collaboration with the child's local care providers [6, 9]. Continuous contact with family, friends, and school are found to be important factors for the physical and psychological development of the young person with SCI [9]. Therefore, hospitals should focus on establishing good routines for well-planned and organised discharge with continuous close collaboration between the child and family, the local care providers and the SCI unit.

It is likely that differences in services and systems of care between units and countries can influence patient outcomes from rehabilitation, but this remains to be studied. It is important to learn more about paediatric SCI to be able to achieve advances in the specialised rehabilitation of children with SCI. Both EACH [6] and ASIA [9] have published guidelines about children's rights and how they should be treated in hospital, but to our knowledge, there are no internationally approved, evidence-based guidelines for specialised paediatric SCI rehabilitation, and the literature about specialised paediatric SCI rehabilitation is limited. The perspective of the children themselves and their families are essential in the planning of rehabilitation interventions and follow-up. Thus, there is a need to explore these issues using a qualitative research approach.

Staff and therapy

There was a notable variation in staffing between the units, which indicated that for some units it might have been more difficult to achieve an interdisciplinary and multi-professional rehabilitation. It is internationally accepted that a multidisciplinary team approach is one of the prerequisites for successful rehabilitation outcomes [14, 25]. Multidisciplinary paediatric teams are characterised by

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several disciplines working together with the child and the parents towards the child's goals [5, 9, 11, 13], and the literature confirms the need for certified and accredited health professionals as important resources [9, 12]. The participating units did not have the recommended professions in a multidisciplinary paediatric SCI team, and one unit indicated that it did not apply a multidisciplinary approach. Both Chinese units and Russia/Petrozavodsk reported that the family contributes a lot to the active rehabilitation process and the daily training of the patients. In paediatric rehabilitation, the whole family is important and should be considered in the treatment [11]. The literature is clear about the necessity of having the family around the injured child [9], and even though the key features for paediatric SCI rehabilitation (Table 4) were mostly met by all the units, these are topics to be investigated further as important steps towards approved common guidelines for paediatric SCI rehabilitation.

Follow-up

Regular clinical follow-up is essential for patients with neurological deficits, either innate or acquired [26]. In line with recommendations [12, 27], all units offered follow-up during the first year after injury, however, some units only had outpatient follow-up. Clinical experience indicates that especially children and adolescents with SCI need regular follow-up to avoid or minimise development of complications such as pressure ulcers, scoliosis and so forth, to avoid obstacles to reintegration [5]. It is important that the young person with SCI resumes life with friends, school, and activities and participates together with their peers [28]. By following up children regularly, health professionals can contribute to this and provide children with the tools to participate in a good social life.

Causes of injury and injury prevention

The number of traumatic versus non-traumatic cases of paediatric SCI showed some variation between the participating units. As expected, the most frequent causes of traumatic injury reported in this study were well-known and highly preventable causes such as motor vehicle accidents, falls and sports [29-31]. Motor vehicle accidents are shown to be the primary cause, accounting for 50% to 81% worldwide [1]. Failure to secure the child adequately in the car is a common cause of these injuries [29, 32]. Three units reported lack of awareness of child safety in traffic, both as passengers and as other road users. In contrast to the other units, both Chinese units reported that hyperextension, mostly in combination with acrobatic dancing among girls, was overrepresented as a cause of paediatric SCI. Tong et al. [33] found that extreme dorsal extension caused spinal cord ischaemia, which was most likely the reason for SCI. In other countries, falls and sport accidents were reported as common causes for paediatric SCI, and often the cervical spine is damaged [29, 30].

These accidents often happen at home, in sport situations or in traffic and highlight the importance of informing and educating society for promoting safety at home, in sports and in traffic.

In the present study, the question about the most common causes of paediatric SCI was formulated asking for traumatic injury, hence, causes of non-traumatic injury were not specifically reported. Non-traumatic causes are not preventable to the same degree as traumatic injuries and can be caused by a variety of conditions like tumours, infections and bleedings. Although the number of traumatic and non-traumatic cases reported by the units coincided, the number of reported cases indicates that both groups where reached by rehabilitation efforts. The need for rehabilitation and follow-up of non-traumatic SCI patients should not be forgotten in the research of paediatric SCI.

Strengths and limitations

This is the first international multicentre study to describe the organisation of rehabilitation services and systems of care for paediatric patients with SCI and to compare the services in

relation to acknowledged standards and recommendations for specialised paediatric SCI rehabilitation and the rights of children in hospitals. The participating units had a large variation in size, number of citizens, topography, culture and development, with great variability in economic, politics and sociodemographic conditions. One strength is that most of the participating units were leading rehabilitation units in their respective countries. Also, the survey was designed in cooperation with the participating units and their PIs could influence the wording in the questionnaire. In addition, we provided a list with terms and definitions to clarify interpretation and the research team undertook a thorough follow-up of the answers.

A limitation of the study was that the participating units were a selected cohort cooperating within SIN, and not selected in a random manner, hampering the transferability. However, because the inclusion criteria required participation in SIN, the results served as a useful benchmark for description and comparison of units within the network. Also, our results identified services and systems of care that can be implemented where not currently available and therefore highlight opportunities for improvements in the different units. Another limitation was that the cause of non-traumatic injury unfortunately was not asked for in the questionnaire.

This survey was based on self-report. Collecting data via survey has the advantage that the informants can complete it in their natural setting and when it suits them. They had the possibility to validate their answers with others, which increases the validity of the study. There can be recall bias, because we asked about numbers from the last 24 and 36 months. On the other hand, those numbers most certainly were archived in the organisation's system and can therefore be trusted.

CONCLUSIONS

This study aimed to broaden the body of knowledge on paediatric SCI internationally, thus enabling discussion and development of organisational models and quality of care in specialised rehabilitation for children and adolescents with SCI. Results showed that there were similarities in the organisation and administration of rehabilitation services in the ten units, but also notable differences, probably based on economic, political, sociodemographic and cultural diversity between countries and regions. For some units the study showed a gap between the organisation and administration of the paediatric SCI rehabilitation services and available recommendations for specialised paediatric SCI rehabilitation by ISCoS [11], ASIA [9] and the EACH recommendations for children's rights in hospitals [6]. This may indicate a need for internationally approved, evidence-based guidelines for specialised paediatric SCI. Further research with a prospective study design including clinical variables is needed to shed further light on this topic.

DATA AVAILABILITY

The questionnaire used in the study is available as supplementary material. The data generated and analysed during the current study are available from the corresponding author upon reasonable request, after ethical considerations.

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AUTHOR CONTRIBUTIONS

KSR, SS, VJ and JKS substantially contributed to the conception of the study. KSR, SS, VJ, WH, MA and JKS contributed to development of the study design. All authors critically revised the data collection instrument. KSR and SS led the data collection. WH and KSR prepared the manuscript and led the data analysis. WH, KSR, SS, VJ, MA and JKS substantially contributed to data interpretation and manuscript revision. All authors participated in critically revising the manuscript and have read and approved the final manuscript.

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COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

Ethical approval was obtained from local ethical committees for all the participating clinics and from the Regional Ethics Committee of Health South-East Norway (2017/ 1867; 21. December 2017, 3. April 2019, 26. May 2020) for this project. The study is registered in ClinGovTrials.gov, 12 June 2018, NCT04117854.

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