

## SCOPING REVIEW

# Outcomes of selective dorsal rhizotomy in ambulatory children and young people with cerebral palsy: A scoping review

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Selective dorsal rhizotomy (SDR) is an irreversible neurosurgical procedure which reduces spasticity in the lower limbs of children and young people with bilateral spastic cerebral palsy (CP).<sup>1,2</sup> Research suggests that SDR combined with intensive physiotherapy can improve gross motor function,

### Abstract

**Aim:** To identify outcomes reported after selective dorsal rhizotomy (SDR) in ambulant children and young people with cerebral palsy in different domains of the International Classification of Functioning, Disability and Health (ICF).

**Method:** A scoping review using the JBI Scoping Review methodology was conducted. Six databases were searched for literature published between 1993 and 2024.

**Results:** A total of 214 published papers met the inclusion criteria. Outcomes under the body function and structure domain were most frequently investigated ( $n = 199$ , 93%), followed by activity ( $n = 123$ , 58%) and participation ( $n = 33$ , 15%) across all studies. Quality of life was reported in 16 (8%) studies, and four (2%) studies mentioned individualized goals for SDR surgery. A combination of validated measures and subjective outcomes was used, with 119 (56%) studies reporting outcomes in two or more domains.

**Interpretation:** Impairment-based outcomes remain the primary focus in SDR research. A small shift in emphasis towards participant-reported outcome measures has been seen in recent years. Few studies reported on the impact of personal and environmental factors. Future SDR studies need to incorporate all domains of the ICF to enhance understanding and capture holistic, meaningful changes in the lives of children and young people with cerebral palsy and their families.

activity, independence, participation, and quality of life.<sup>3,4</sup> However, systematic reviews<sup>5,6</sup> have found limited evidence on the longer-term effectiveness of SDR on functional mobility, self-care activities, and participation, potentially because of low-level evidence and bias in the SDR literature.

**Abbreviations:** ICF, International Classification of Functioning, Disability and Health; SDR, selective dorsal rhizotomy.

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In contrast, some longitudinal observation studies have reported overall gain in gross motor function compared with the natural history of CP.<sup>7,8</sup>

Despite the conflicting evidence, globally there is an increased recognition and uptake of SDR as a permanent surgical intervention for reducing spasticity. Given the irreversible nature of SDR and the uncertainty of longer-term outcomes, decision-making for families can be challenging.<sup>9</sup> A significant knowledge gap remains in understanding which outcomes are most relevant and meaningful for children and families. Identifying the measures used at various stages of follow-up is essential for clarifying the impact of SDR on children and young people with bilateral spastic CP and their families' lives.

The International Classification of Functioning, Disability and Health (ICF)<sup>10</sup> framework has been used in systematic reviews to determine SDR effectiveness.<sup>5,6</sup> The multidimensionality of the SDR outcomes across the ICF lends to a flexible and comprehensive approach to the synthesis of diverse evidence. In this bio-psycho-social model, the impairments of an individual caused by disability are considered in the context of environmental and personal factors. Understanding the relationship between different domains of the ICF 'body functions and structure' (e.g. muscle tone, muscle weakness, joint mobility, deformities), 'activity' (e.g. execution of a task or action, mobility, self-care), and 'participation' (e.g. involvement in a life situation, playing sports, engaging in leisure activities) and contextual factors such as external 'environmental factors' (social, physical, and legislative) and internal 'personal factors' (age, education, social background, motivation, psychological impact) is essential to identify problem areas, tailor management interventions to the individual's needs, and determine the effectiveness of interventions.<sup>11</sup> The ICF provides a common language to describe an individual's health condition and functional abilities, facilitates communication between clinicians and families, allows data comparison across countries, and helps to promote a more holistic understanding of the health-related outcomes and provision of family-centred care.<sup>12</sup>

Healthcare delivery and reporting of outcomes have evolved to emphasize the broader impact of an intervention on quality of life and family experiences.<sup>13</sup> The increasing use of the ICF framework in children and young people with bilateral spastic CP research has shifted the focus towards participation outcomes and the influence of environmental factors.<sup>14</sup> Although various outcomes have been reported to be related to SDR in children and young people with bilateral spastic CP, it remains unclear which ICF domains are most prominent or whether reporting patterns or the choice of outcome measures have changed since the introduction of the ICF in 2001.

Considering that many studies are excluded from systematic reviews because of low-quality evidence, this scoping review expands previous work by examining the full spectrum of outcomes reported for ambulatory children and young people with bilateral spastic CP, in all types of

### What this paper adds

- Impairment-based outcomes continue to be the primary focus of research on selective dorsal rhizotomy (SDR).
- There is inconsistent reporting of contextual factors.
- Highlights the paucity of studies providing children and families perspectives.
- There is a need to include and report individual goals of SDR in clinical practice.
- Developing core clinical and research outcome sets will standardize reporting across the lifespan.

SDR study over the past 30 years—a period during which SDR became a mainstream treatment for lower-limb spasticity. This review does not assess the effectiveness of SDR or the validity of the outcome measures. Instead, by mapping outcomes across ICF domains, it highlights research trends, identifies gaps, and informs selection of key outcomes for clinical practice and future SDR research on children and young people with bilateral spastic CP and their families. The scoping-review research questions were the following. (1) What outcomes are reported in the literature for ambulatory children with bilateral spastic CP at different stages of follow-up after SDR? (2) How do these outcomes map to the domains of body structure and function, activity, participation, and contextual factors in the ICF or in the context of quality of life? (3) Which measurement or evaluation tools are used after SDR to capture these outcomes?

## METHOD

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews, JBI Evidence Synthesis, and Prospero<sup>15</sup> was conducted; no current or ongoing systematic or scoping reviews on the topic were identified. The inclusion criteria for this scoping review were guided by the population, concepts, and context approach.<sup>15</sup> The review protocol was registered in the Open Science Framework register (<https://doi.org/10.17605/OSF.IO/FJXA6>).<sup>16</sup>

## Participants

This review considered all studies that included ambulatory children and young people with a diagnosis of bilateral spastic CP (Gross Motor Function Classification System [GMFCS] levels I, II, and III) who had SDR surgery at some point before 18 years of age. Studies including children and young people with diagnoses other than CP or classified in GMFCS levels IV or V only were excluded.

## Concept

The concept of interest was all outcomes reported after SDR. Only studies reporting outcomes of SDR performed at the lumbosacral level were considered. Any other variants of the surgical procedure or surgical site (e.g. cervical spine) were excluded.

## Context

All SDR outcomes, including adverse events and complications, reported from 1993 to 2024, related to body structure and function, activity, participation, and contextual factors as defined by the ICF.<sup>10</sup> Quality-of-life outcomes, which encompass all components of the ICF, patients' experience, individual goals, and satisfaction with the outcomes of the procedure, were also included.

## Types of evidence source

All study designs such as randomized controlled trials, non-randomized controlled trials, before-and-after studies, prospective and retrospective cohort studies, case-control, case series, and case reports were included. Qualitative studies focusing on the outcomes of SDR were also included. Studies describing the surgical or electrophysiological procedure of SDR, cost-effectiveness, or service delivery were excluded if no outcomes were reported. Abstracts, reviews, opinion papers, and commentaries were also excluded.

## Search strategy

An initial limited search of MEDLINE was undertaken to identify articles on the topic. The text words in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE using OVID platforms. The search strategy, including all identified keywords and index terms, was adapted for each included database. The search strategy was reviewed by a medical librarian according to the guidance in Peer Review of Electronic Search Strategy (PRESS).<sup>17</sup> No restrictions were placed on the publication date or language for the initial search.

## Selection of sources of evidence

Databases searched include Medline and CINAHL Plus with Ovid, Embase with EBSCOhost, Web of Science, Scopus, and Cochrane Database of Systematic Reviews. The key search terms included 'cerebral palsy' AND 'rhizotomy' AND 'child'. Detailed search terms are included in [Appendix S1](#) for all six databases.

## Data extraction and charting

A spreadsheet was developed and piloted to gather information about study type, location, GMFCS level, length of follow-up and outcome domains, measures or tools used, and adverse events and complications ([Appendix S2](#)). Data extraction was completed by two reviewers (DC and GW). The level of evidence was reported using the Oxford Centre for Evidence-based Medicine Scale,<sup>18</sup> which was predominantly used to categorize studies on the basis of the study design. Critical appraisal of studies was not conducted as part of this review.

## Collation and summarizing results

Outcomes were mapped into different domains of ICF body structure and function, activity, participation, and contextual factors on the basis of the ICF definitions.<sup>10</sup> Quality-of-life outcomes, which encompass all components of the ICF, patient experience, individual goals, and patient satisfaction, were categorized separately. Any uncertainty about the categorization of the outcomes was discussed among four researchers (DC, GW, LA, HG), and a consensus reached on the basis of the previous literature and published content validity of the outcome measures. Outcome measures that captured more than one domain of the ICF, such as the Pediatric Evaluation of Disability Inventory<sup>19</sup> and Wee Functional Independence Measure,<sup>20</sup> were included in both the activity and participation domains of the ICF. Similarly, most survey studies captured outcomes across all domains of the ICF and were mapped accordingly. Descriptive analysis, including counts, percentages, and synthesis, was performed in Microsoft Excel version 16.94.

## Study selection

The search was performed in May 2022 and updated in July 2024. The primary reviewer (DC) ran the initial searches and uploaded all citations into EndNote X9.3.3/2020 (Clarivate Analytics, PA, USA). After removing duplicates, all citations were imported into the Rayyan literature review tool (Rayyan Systems, Cambridge, MA, USA).<sup>21</sup> Titles and abstracts were screened by two independent reviewers (DC, GW) for eligibility against the inclusion criteria. The full text of potentially relevant studies ( $n=310$ ) was assessed in detail against the inclusion criteria by two independent reviewers (DC and GW), who were blinded to each other's screening decisions. Reasons for excluding studies that did not meet the inclusion criteria were recorded in the Rayyan online software and are provided in [Table S1](#). Any disagreements between the reviewers at each stage of the selection process were resolved through discussion or with an additional reviewer (HG). The search results and study inclusion process are presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram<sup>22</sup> ([Figure S1](#)).

## RESULTS

### Characteristics of studies included

This review included 214 studies (Table S2). Seven studies reported outcomes using randomized controlled trial designs.<sup>23–29</sup> Longitudinal observational studies were the most common study design ( $n=94$ , 44%), and retrospective cohort studies ( $n=91$ , 43%), followed by surveys ( $n=12$ , 6%),<sup>30–41</sup> case reports ( $n=6$ , 3%),<sup>42–47</sup> and two qualitative studies<sup>48,49</sup> reporting parental and children's experiences after SDR. The level of evidence of studies was primarily graded as level IV ( $n=178$ , observational studies), followed by level III ( $n=21$ , with a control group), level V ( $n=6$ , case reports), and level II ( $n=7$ , randomized controlled trials). Most studies were conducted in North America (50%), European countries (24%), the Western Pacific region (18%), and Africa (6%) (Appendix S3). Sample sizes ranged from 1 to 785 (median 33, interquartile range 19–75). Participants' ages typically ranged from 3 years to 28 years. All study and participants' characteristics are presented in Table 1. While the primary focus was on ambulant children and young people with bilateral spastic CP, classified in GMFCS levels I to III, several studies also included participants in GMFCS levels IV and V. The GMFCS levels and topological classifications presented in Table 1 reflect the overall composition of the study samples.

### Distribution of outcomes across the ICF domains

Ninety-one (43%) studies reported outcomes in a single domain of the ICF, 90 (42%) included two domains, 30 (14%) reported outcomes in more than two domains, and two studies<sup>50,51</sup> focused on quality of life. Across all studies, the body function and structure domain was most reported ( $n=199$ , 93%), followed by activity ( $n=123$ , 58%) and participation ( $n=33$ , 15%). Quality of life was reported in 16 (8%) studies, and four (2%) studies<sup>50,52–54</sup> mentioned individualized goals for SDR surgery (Appendix S3). The trends in distribution of outcomes over time showed a slight increase in participation-based outcomes as well as the introduction of health-related quality-of-life outcomes in the past decade (Figure 1). Outcomes in body function and structure are still most widely reported; however, the relative proportion is reducing. Two qualitative studies<sup>48,49</sup> explored parental perspectives and children's experiences on the outcomes of SDR (Appendix S3). Studies with survey designs included questions across all domains of the ICF except one survey study<sup>41</sup> focusing on the caregivers' burden.

### Outcome measurement tools

A variety of outcome measurement tools ( $n=113$ ) were used across all ICF domains but some consistency and

trends in outcomes were noted. The most frequently used outcome measures were the Modified Ashworth Scale<sup>55</sup> or its variants ( $n=91$ , 43%), joint range of movement ( $n=66$ , 31%), instrumented gait analysis ( $n=52$ , 24%), Gross Motor Function Measure<sup>56</sup> ( $n=60$ , 28%) in the activity domain, and Pediatric Evaluation of Disability Inventory<sup>19,57</sup> ( $n=13$ , 6%) in the activity and participation domains (Figure 2). The distribution of identified outcomes and the measures used are mapped across the ICF domains (Appendix S4).

### Length of follow-up

The length of follow-up after SDR varied from immediate postoperative outcomes to long-term follow-up into adulthood. Most studies ( $n=120$ , 56%) reported short-term outcomes up to 2 years after SDR, with fewer undertaking longitudinal follow-up up to 5 years ( $n=29$ , 14%). Some followed patients up to 18 years ( $n=47$ , 23%), or over longer terms into adulthood ( $n=16$ , 8%). In two studies,<sup>58,59</sup> the length of follow-up was not clear.

### Quality of life

Sixteen studies reported quality of life using validated questionnaires, including the Diener Satisfaction with Life Scale ( $n=5$ ),<sup>32,34,35,60,61</sup> Cerebral Palsy Quality of Life questionnaire<sup>50,51,62–64</sup> ( $n=5$ ), 36-Item Short Form Health Survey<sup>40,65,66</sup> ( $n=3$ ), Abbreviated WHO Quality of Life assessment<sup>60,61</sup> ( $n=2$ ), and opinions of patients and caregivers about aspects of their quality of life after surgery.<sup>67</sup>

### Goal setting and satisfaction

Four studies reported individualized goals of SDR,<sup>50,52–54</sup> with the Canadian Occupational Performance Measure<sup>68</sup> used in three.<sup>50,53,54</sup> Two studies described and provided examples of individualized goals in the areas of self-care, leisure, and productivity,<sup>50</sup> and personal care, functional mobility, community management, work, household management, and recreation.<sup>53</sup> One study reported on the achievement of main goal areas, including improvement in comfort, orthopaedic risks, and improvements in sitting, standing, and visceral functions.<sup>52</sup> Seventeen studies reported parents' or participants' satisfaction with the SDR procedure<sup>30–32,34,35,38,39,66,69–72</sup> using a subjective question.

### Other outcomes

Six studies reported changes in bladder function before and after SDR.<sup>53,54,73–76</sup> Some studies reported other outcomes often described as 'suprasegmental' effects of SDR. These

**TABLE 1** Characteristics of included studies ( $n=214$ ) and participants' characteristics ( $n=13\,530$ ).

Characteristics of included studies ( $n=214$ )		
Study characteristics	<i>n</i>	%
Year of publication		
1993–2002	73	34.1
2003–2012	55	25.7
2013–2024	86	40.2
World Health Organization regions		
North America	107	50
Europe	52	24.3
Western Pacific	38	17.8
Africa	12	5.6
South America	3	1.4
Eastern Mediterranean	1	0.5
Study design		
Randomized controlled trials	7	3.3
Longitudinal observational	94	43.9
Retrospective cohort	91	42.5
Surveys	12	5.6
Case reports	6	2.8
Qualitative	2	0.9
Sample sizes		
0–10	16	7.5
11–30	75	35
31–50	49	22.9
51–100	38	17.8
101–200	27	12.6
201–500	7	3.3
501–800	2	0.9
Participants' characteristics ( $n=13\,530$ )		
Age <sup>a</sup> ( $n=143$ studies, 66.8%)		
Average age 6 years 6 months; range 3 years to 28 years	9346	69.1
Sex ( $n=169$ studies, 79%) ( $n=9815$ participants, 72.5%)		
Male	6031	61.4
Female	3784	38.6
GMFCS level ( $n=110$ studies, 51.4%) ( $n=5454$ participants, 40.3%)		
I	342	6.3
II	777	14.2
III	890	16.3
IV	319	5.9
V	49	0.9
Combined levels (I–III)	856	15.6
Combined levels (I–V)	2221	40.7
Cerebral palsy subtype <sup>b</sup> ( $n=8491$ , 62.8%)		
( $n=150$ studies, 72.9%)		
Spastic diplegia	4382	51.6
Spastic quadriplegia	1159	13.6
Triplegia	216	2.5

**TABLE 1** (Continued)

Characteristics of included studies ( $n=214$ )		
Study characteristics	<i>n</i>	%
Hemiplegia	329	3.9
Other (upper limb, monoplegia)	46	0.5
Combined diplegia, quadriplegia, triplegia, hemiplegia	629	7.4
Bilateral spastic	1097	12.9
Unilateral spastic	10	0.1
Spastic cerebral palsy (not specified)	2760	32.5
( $n=12$ studies, 5.6%)		
Ambulatory	619	
Non-ambulatory	80	
Follow-up duration		
$n=120$ studies	Up to 2 years	6694 49.5
$n=29$	Up to 5 years	2048 15.1
$n=47$	Up to 18 years	4169 30.8
$n=16$	Into adulthood	567 4.2
$n=2$	Not clear	52 0.4

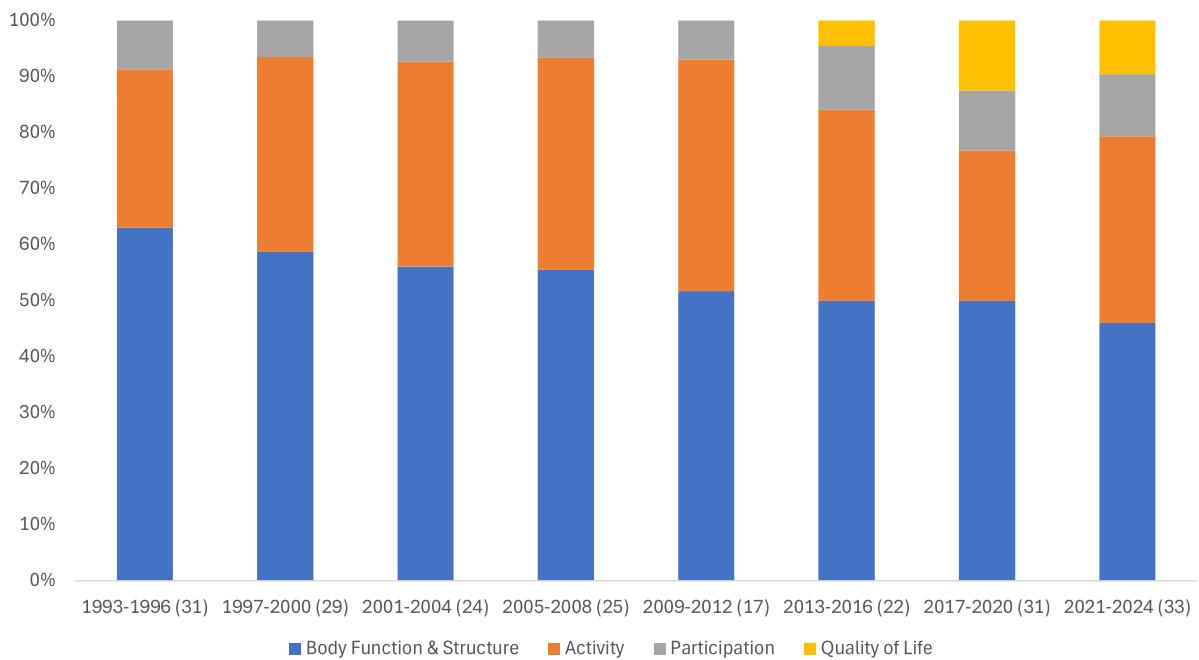
<sup>a</sup>Where the mean age and corresponding range were provided.<sup>b</sup>As reported by the original study.

Abbreviation: GMFCS, Gross Motor Function Classification System.

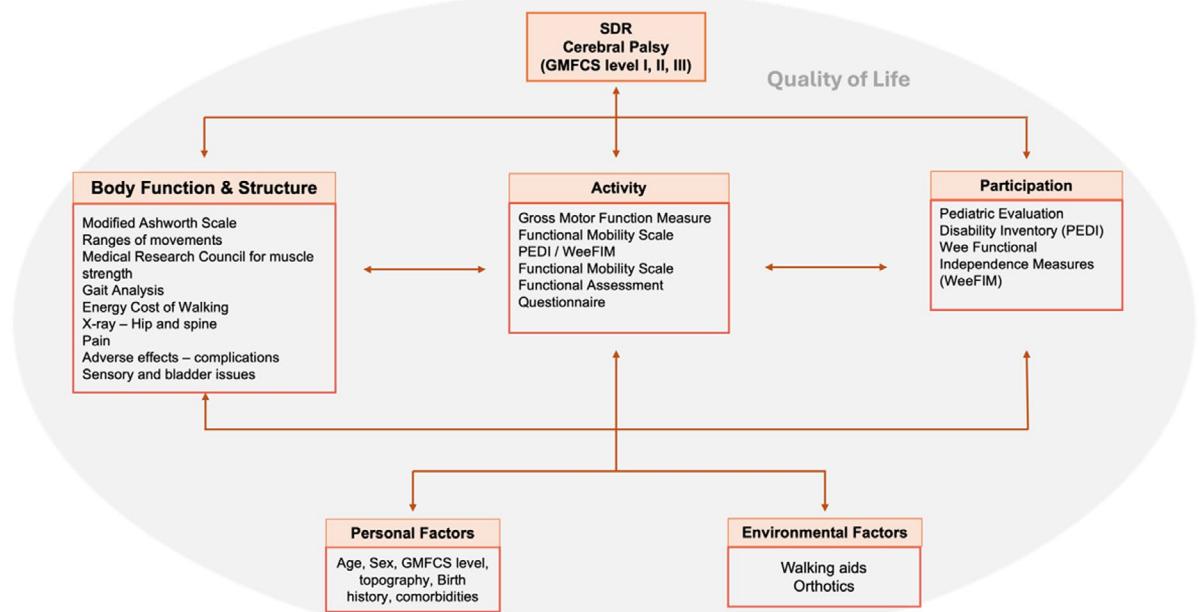
included outcomes not directly related to the sectioning of the lumbosacral dorsal nerve root sections. Thirteen studies reported effects on upper limbs, including changes in muscle tone ( $n=2$ ),<sup>77,78</sup> movement pattern, hand function, and fine motor skills ( $n=10$ ) and self-reported current manual ability using MACS<sup>32,34,35</sup> in survey studies. The outcome measures used to assess upper limb function included the Quality of Upper Extremity Skills Test ( $n=3$ )<sup>79</sup> and the fine motor domain of Peabody Developmental Motor Scales ( $n=3$ ).<sup>80</sup> Changes in eye movements,<sup>43,81</sup> cognitive performance,<sup>82</sup> and speech<sup>81</sup> were also reported.

## Adverse events

Ninety-four studies (44%) mentioned SDR adverse events or complications, with 21 explicitly stating no complications. The most commonly reported complications were abnormal sensations in the first 6 weeks after the surgery ( $n=34$ ), followed by urinary complications ( $n=35$ ), postoperative back and leg pain ( $n=18$ ), and long-term back and leg pain ( $n=12$ ), postoperative hypotonia or weakness ( $n=11$ ), constipation ( $n=10$ ), pulmonary complications ( $n=10$ ), long-term sensory issues ( $n=9$ ), wound healing ( $n=11$ ), cerebrospinal fluid leak ( $n=11$ ), postoperative infections ( $n=7$ ), and headaches ( $n=6$ ). Two case-report studies reported incidences of sudden falls<sup>45</sup> and spinal cord tethering.<sup>42</sup>



**FIGURE 1** Percentage distribution of International Classification for Functioning, Disability and Health (ICF) outcomes over the years. Number of publications in each 4-year period included in parentheses.



**FIGURE 2** Commonly used outcome measures mapped across the International Classification for Functioning, Disability and Health (ICF). Abbreviations: GMFCS, Gross Motor Function Classification System; PEDI, Pediatric Evaluation of Disability Inventory; WeeFIM, Wee Functional Independence Measure.

## Additional interventions after SDR

Several studies ( $n=54$ , 25%) reported on orthopaedic interventions required after SDR. The incidence of spinal deformities and hip migration after SDR was reported in 30 (14%) and 16 (6%) studies respectively.

## Contextual factors

Personal and environmental factors were not reported consistently. Most studies provided basic characteristics of preoperative patients (age, sex, baseline ambulatory status), with some ( $n=30$ ) providing additional demographic

characteristics of the participants, such as birth history, comorbidities, and cognitive level. Studies in the adult population who had undergone SDR in childhood presented information on employment status ( $n=8$ ), socioeconomic status ( $n=7$ ), education level ( $n=6$ ), living situation ( $n=5$ ), and marital status ( $n=4$ ). Only eight studies reported on the use of orthotics and assistive devices.

## DISCUSSION

This scoping review identified 214 studies on SDR outcomes over the past three decades. SDR is now an established treatment for managing spasticity in children and young people with bilateral spastic CP and is available in more than 27 countries, with the number of publications reporting SDR outcomes increasing in recent years. Since the introduction of the ICF more than 20 years ago, there has been a gradual shift in CP research towards understanding the effect of interventions across all domains, including activity and participation.<sup>10,83</sup> However, the emphasis of SDR outcome research remains on impairment-based outcomes in the body function and structure domain. Despite growing recognition of the importance of capturing the participation and quality-of-life outcomes, these are still inconsistently measured or reported in the SDR literature.

Although SDR is an invasive surgical procedure that reduces spasticity, children, young people, and families often have broader goals around function, participation, and improving family life.<sup>50</sup> The relationship between spasticity and functional outcomes is complex and influenced by multiple factors, such as age at surgery, baseline gross motor ability, muscle strength, voluntary motor control, and the child's motivation and interests.<sup>84,85</sup> Importantly, a reduction in spasticity after SDR does not inherently result in improved function or participation. Therefore, it is essential for health-care professionals to communicate these complexities to families, ensuring that families' expectations and goals for SDR are aligned with anticipated outcomes for each individual child, thereby supporting informed and shared decision-making. Capturing and reporting such measures along with the other domains of the ICF<sup>86</sup> is valuable, yet a significant knowledge gap persists about patient-specific goals for SDR. Participation-based goals and outcomes may not be achieved through spasticity reduction alone. It is likely that achieving such goals may require a targeted participation-based approach addressing other barriers to participation.<sup>87</sup> Including these outcomes can help determine how SDR and rehabilitation affect the ability of children and young people with bilateral spastic CP to engage in real-world situations at home, school, and in the community.

We identified 113 different measures and tools used in the SDR literature across the body function and structure, activity, and participation domains. Although some quality-of-life measures, such as the Cerebral Palsy Quality of Life,<sup>88</sup>

include aspects related to the environment, none of the outcome measures used were intended to assess the influence of environmental factors specifically. The diversity in the range of outcome measures used is probably multifactorial, from the availability of standardized outcomes, feasibility (time and resources), and clinical use. Participation and contextual factors are reported less frequently, possibly because of the lack of availability of standardized outcome measures that are meaningful to families and clinicians and are sensitive enough to capture changes over time. In recent decades, there has been an increased focus on determining the effect of interventions on quality of life<sup>89</sup> and identifying environmental barriers and facilitators to participation.<sup>90</sup> Measures such as Participant and Environment Measure for Children and Youth<sup>91</sup> and European Child Environment Questionnaire<sup>92</sup> could help systematically capture the influence of environmental factors on daily activities, participation, and quality of life. Outcome measures such as the Canadian Occupational Performance Measure,<sup>68</sup> Goal Attainment Scale,<sup>93</sup> or Gait Outcome Assessment List<sup>94</sup> can be helpful in identifying parents' and children's goals for SDR<sup>50</sup> as used in other neurosurgical techniques such as deep brain stimulation and intrathecal baclofen.<sup>95,96</sup>

Collecting outcomes longitudinally is vital for understanding changes in the functional trajectory in children and young people with bilateral spastic CP who undergo SDR in childhood. However, selecting and capturing relevant outcomes across the lifespan can be challenging owing to the lack of validated measures for adults with CP. Benner et al. highlighted the differences in the outcome measures used in children and young people and adults with CP.<sup>97</sup> While impairment-based measures (e.g. tone, range of motion, strength, gait analysis) extend into adulthood, there are no comparable standardized measures across the other ICF domains (activity, participation, environmental factors). Although the items in the outcome measures commonly used in childhood, for example the Gross Motor Function Measure, may still be relevant in capturing abilities, they are not appropriate or meaningful owing to the changing functional needs of children as they transition into their adolescent years and adulthood. Schiariti et al. developed a toolbox of standardized measures aligned with the ICF core sets for children and young people with bilateral spastic CP up to 18 years of age.<sup>98</sup> However, key intervention-specific outcomes such as pain, spasticity, or gait outcomes are not included. This mismatch between clinical and patient-centred outcomes emphasizes the need for a core outcome set in SDR studies similar to that developed for lower-limb orthopaedic surgery for children and young people with bilateral spastic CP.<sup>99</sup> Establishing such a set would standardize assessments across centres, facilitate data pooling, and strengthen the evidence base on SDR outcomes. It could also aid decision-making preoperatively for families and clinicians by providing more relevant information for selecting appropriate candidates for SDR intervention.

The research methodologies and study designs used in the SDR literature are predominantly quantitative observational studies, providing only one perspective, which limits

a broader holistic understanding of the impact of SDR. This focus probably reflects the nature of the intervention and follow-ups being conducted in clinical settings where the emphasis is on clinical decision-making, which may differ from what is meaningful to children and young people with bilateral spastic CP and their families. Only two studies explored parental and children and young people perspectives on SDR outcomes.<sup>48,100</sup> Including these perspectives and evaluating the psychological impact can offer deeper insights into families' expectations and support decision-making.<sup>9,49</sup> Clinicians should use evidence-based measures to inform treatment decisions, monitor progress, and enable comparisons across centres and patient populations. Clear documentation of ICF personal and environmental factors can reveal patterns despite the heterogeneity in children and young people with bilateral spastic CP. Moreover, integrating participation outcomes, goal-setting practices, or frameworks such as the F-words can enhance communication and better align SDR intervention goals with families' priorities.<sup>101</sup> Such integration, alongside clinical assessments, enables a more holistic evaluation and can help clinicians and families plan future interventions to maximize function.

Other outcomes, such as adverse effects of SDR, have been inconsistently reported across studies. These events range from immediate peri- or postoperative surgical complications such as infection, cerebrospinal fluid leak, bladder dysfunction, and dysesthesias to orthopaedic outcomes such as hip migration and further orthopaedic surgeries. Inconsistent language and varied descriptions across studies made synthesis challenging. Mishra et al.<sup>102</sup> recently categorized SDR-related complications as structural (e.g. hip migration, spinal deformities) and non-structural. However, because hip dysplasia and scoliosis frequently occur in children and young people with bilateral spastic CP, irrespective of SDR, attributing these directly to SDR may be inappropriate. There is a need for further consensus and standardization in reporting adverse events.

Research on SDR outcomes has increased over time, and the reporting of research findings has evolved over the years. The findings of this scoping review should be interpreted considering the publication guidelines at the time, which may have resulted in a potential bias with favourable reporting of some outcomes. Additionally, most research comes from North America and European countries, with limited evidence from low- to middle-income countries. This raises questions about the worldwide accessibility of this procedure and the choice of outcome measures. Variations in health-care provision<sup>103</sup> and treatment protocols between and within countries,<sup>3,4</sup> such as the timing of SDR intervention, access to and frequency of rehabilitation, and support in the community, further highlight the need to consider contextual factors when interpreting SDR outcomes.

There are some other limitations to this review. Multiple publications from the same centre may have falsely

overestimated the frequency of some measures used. Although some studies referred to their previous or concurrent publications, this was not consistent across the SDR literature. Reviews, commentaries, and abstracts were excluded to reduce duplication. The reference lists of previous systematic reviews were hand-searched, but the grey literature was not searched. This could have resulted in some omission of outcome measures reported in this scoping review. The focus was on the types of outcome and measures used rather than quality of evidence or psychometric properties of these measures. Categorizing and mapping some measures to the ICF required frequent discussions, particularly for concepts not clearly defined or coded in the ICF, such as adverse events, measures of participation, life satisfaction, and quality of life.

In conclusion, this scoping review offers a comprehensive summary of outcomes reported in the SDR literature over the past three decades. Most studies focused on outcomes in the ICF domain of body function and structure, commonly using measures such as the Modified Ashworth Scale, joint range assessments, and gait analysis across various follow-up periods. In the activity domain, the Gross Motor Function Measure remains the most frequently used outcome measure. A smaller number of studies, particularly those with longer-term follow-up into adulthood or survey-based designs, have reported contextual factors and outcomes related to participation and quality of life. The review highlights several gaps that have implications for both clinical practice and future research. Greater consistency in language and systematic reporting of contextual factors and adverse events will improve cross-study comparisons and enhance generalizability. To capture meaningful outcomes across the lifespan, future research should use broader study designs, such as qualitative, mixed-methods, or participatory approaches, incorporating perspectives from children, young people, and families. The development of a core outcome set, informed by all stakeholders, would support greater consistency in SDR research and clinical practice.

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## CONFLICT OF INTEREST STATEMENT

The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

## DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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## SUPPORTING INFORMATION

The following additional material may be found online:

**Appendix S1:** Search terms and search strategy for all six databases.

**Appendix S2:** Data extraction instrument.

**Appendix S3:** Visual representation of data.

**Appendix S4:** Outcome domains and outcome measures used in the literature and ICF coding.

**Table S1:** Excluded articles.

**Table S2:** Included studies.

**Figure S1:** PRISMA flow diagram.

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### Distance Learning Unit 2 Neonatal Neurology complements and expands upon the BPNA Neonatal Neurology Assessment and Treatment Education (NeoNATE) courses.

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The BPNA paediatric neurology Distance Learning course complements both our NeoNATE courses and clinical training. It is delivered completely online & is available to doctors throughout the world.

#### Distance Learning Unit 02 Neonatal Neurology

This unit covers the biological processes involved in brain development then goes on to see how environmental and genetic disorders may have an adverse effect on that process. We will study perinatal brain injury and causes of this in both the preterm and the term born baby, neonatal encephalopathy, and assessment, differential diagnosis and treatment options in the floppy and "stiff" baby. The unit will also address different aspects of neonatal neurological examination, neurophysiology, and neonatal imaging

Study Hours: 61.0 CPD Points 61

If you have any questions, please email [shortcourses@bpna.org.uk](mailto:shortcourses@bpna.org.uk)  
 +44 (0)1204 526002

