Early Onset Scoliosis

Guidelines for Management in Resource-Limited Settings

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9f Evolution of Experience and Practise in Two Nations

Ujjwal Kanti Debnath,

CONTENTS

INTRODUCTION

Thirty years ago, I was apprenticing under the first scoliosis surgeon in India, Dr. R. N. Mitra in the early 1990s. He was trained by Dr. Walter P. Blount at Milwaukee and later with Dr. John E. Hall in Toronto. He had been treating children with spinal deformity since the 1960s in Kolkata, India. During these 4 years of training under him, I first came across few children between 2–8years of age with scoliosis (infantile or juvenile idiopathic types). I observed that many of these children had resolution of the spinal deformity over a period of time. Since the days of Hippocrates, orthopaedic surgeons were taught that infantile scoliosis worsens with growth [1]. Scott and Morgan [2] noted two patterns of curve behaviour: progressive and resolving. However, when left untreated, the condition can get worse, leading to back pain; impaired cardiorespiratory function; and physical, psychological, and social disability [3,4].

India-born Dr. Mehta had the pioneering idea of casting babies in progressive curves and introduced rib-vertebral angle deformity (RVAD) [5, 6]. I was trained to apply casting on these children followed by bracing. Children with proximal thoracic curves required the use of a Milwaukee Brace, which is usually not well-tolerated (Figure 9f.1) [7–9]. My conscious effort to find a solution for those children with infantile or juvenile scoliosis started building. I scripted the first monograph on scoliosis in India, *Scoliosis – Facts, Figures & Follow-Up for Clinical Research* [7]. This book included contributions from Dr. John Hall, Dr. Alf Nachemson, Dr. John Kostuik, Dr. Robert Winter, and Dr. Yves Cotrel

The concept of early-onset scoliosis (EOS) was just evolving after Prof. Dickson from Leeds coined the term in the early ‘90s [10, 11]. This classification was based on the functional abilities of the child connected with their lung and thorax growth [12]. There is an increase in the alveolar growth and number in the first year of life that reaches its maximum by the age of 8 [13]. The use of growing instrumentation may delay definitive fusion and may help to maintain pulmonary health [14].

Currently, EOS includes all forms of scoliosis in children below the age of 10 who have spinal curvature more than 10° [15]. A higher rate of comorbid disorders is associated with infantile and juvenile scoliosis [16, 17]. In the long

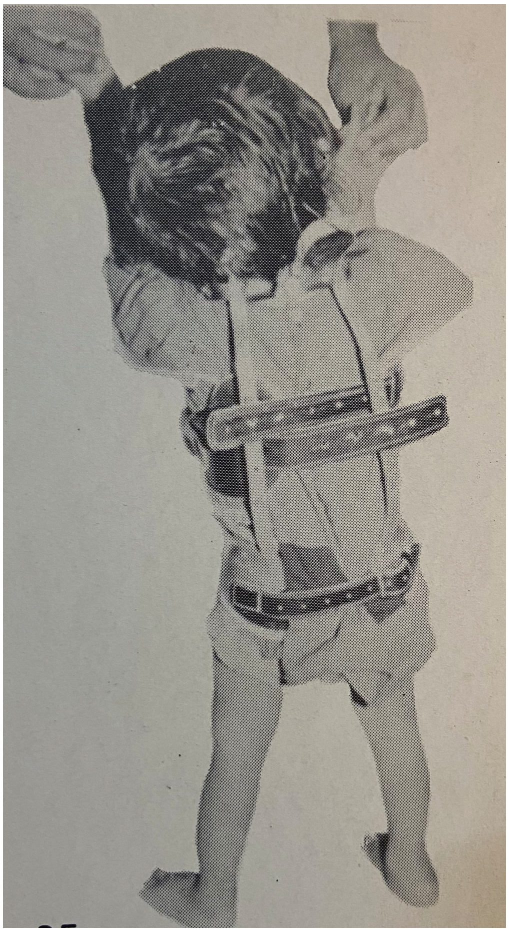


FIGURE 9F.1 Photograph of a 2-year-old girl with EOS treated with Milwaukee bracing in 1972 (from monograph by Mitra and Debnath, 1995).

term, infantile and juvenile scoliosis have high mortality [18].

My pursuit for further knowledge and skill to understand the disease led me to the British Isles. I spent a few years in Ireland, where I had tried to set up a school screening programme to detect children with EOS in a county hospital, but this failed due to lack of funding. Later, I passed the Fellowship of the Royal Colleges of Surgeons exam (FRCS) and went to the United Kingdom.

NOTTINGHAM, 1999

In the first few months at Queens Medical Centre (QMC), Nottingham, it was difficult to keep pace with the scoliosis world. Dr. John Webb, legendary spine surgeon, had enormous experience in treating difficult spinal problems. It was difficult in those days to be in his surgical theatre because there was a significantly high number of surgeons converging to train here from around the world. I spent most of my time in the clinic seeing as many patients with spinal deformity. This improved my knowledge about the different indications for surgery in each patient, and I kept my notes for my future reference. I observed many postoperative follow up patients who had unilateral growth arrest, segmental posterior instrumentation without fusion (Luque Trolley with or without convex epiphysiodesis) [19]. Convex epiphysiodesis alone did not prevent deformity progression and the addition of instrumentation could slow progression but did not reverse it [20]. The initial results of treatment of progressive EOS with Luque Trolley alone at this centre were disappointing, so an apical convex epiphysiodesis was added. I realised that convex epiphysiodesis has a tethering effect on growth phenomenon and should be avoided when growth guided instrumentation is used.

In Luque Trolley, initially called 'L' rods, were used with the straight ends being left long to allow for spinal growth. The 'L' portion is secured to the laminae of the end-vertebrae (Figure 9f.2). Subsequently, 'U' rods were used (Figure 9f.3a & b). The Luque Trolley acts as a brace for the spine against curve progression. The curve correction by this method was predicted by two factors, i.e. less upper end vertebral tilt and concave rib droop [21]. The results of Klemme et al. [22] suggest that progressive scoliosis can be controlled in many children while allowing normalised growth of instrumented spinal segments. The progressive structural changes alter the curve response to incremental distraction. These changes determine the treatment duration and ultimate gain in spinal length.

I had met many spinal Fellows at Nottingham from around the world who remain great friends; most notable was Dr. J. R. McConnell from Allentown, Pennsylvania. My interaction with them had updated my knowledge on surgical management of EOS. Subsequently, I joined

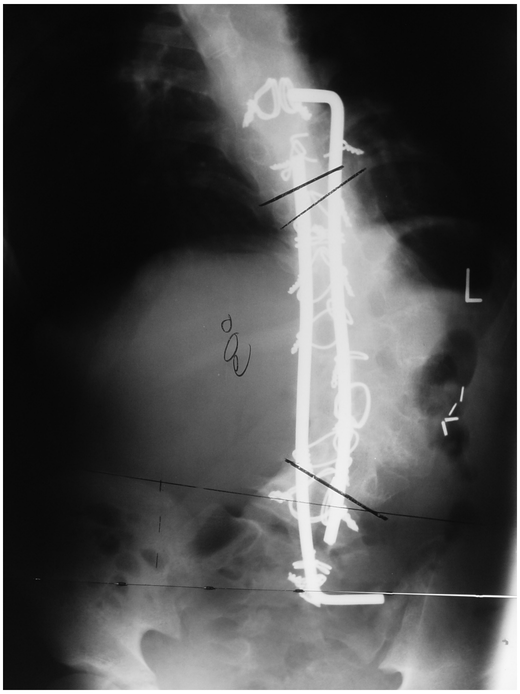
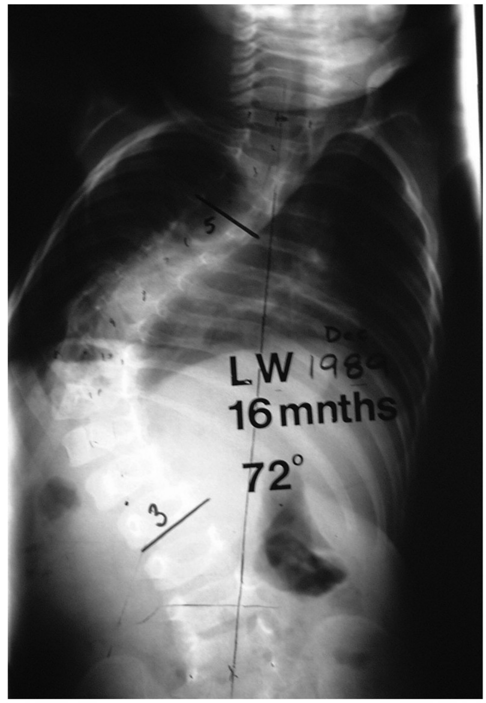


FIGURE 9F.2 Postoperative AP view x-rays of a 9-year-old boy with EOS and Luque Trolley in 'L' configuration.



A

FIGURE 9F.3A AP view x-ray of a 16-month-old girl with EOS.

as a specialist trainee in orthopaedics in Cardiff in 2002.

CARDIFF, 2005

During my training in Cardiff, I had developed the first web-based scoliosis registry and database for the spinal unit at University Hospital of Wales (UHW) with help from Dr. John Howes, Consultant Spine Surgeon. He had invited Dr. Robert Campbell from the United States who had developed VEPTR (vertical expandable titanium prosthetic rods). He demonstrated the technique of application in children with thoracic insufficiency syndrome [23, 24] [Figure 9f.4]. This technique indirectly fixes scoliosis without fusion. VEPTR treatment has demonstrated continued spinal growth with serial expansion improving the coronal curves [25]. Over the next few years, a hybrid technique using growing rods with VEPTR was introduced to reduce the complications. The hybrid technique incorporates the VEPTR concept by using ribs as proximal anchor sites but also uses pedicle screws for distal anchors [26, 27].

NOTTINGHAM, 2007

I returned to QMC, Nottingham, to do my spinal fellowship programme. I now had the opportunity to do surgeries alongside Dr. J. K. Webb, Dr. S. M. H. Mehdian, Dr. M. P. Grevitt, and Dr. B. J. C. Freeman. I was exposed to these surgeons who had wide clinical and surgical acumen. The most notable experience was with Dr. Webb, who I consider my mentor in spine surgery (spine guru) (Figure 9f.5). I had done many complex surgeries independently with his guidance with or without him. I devoted most of my time on spinal clinics, surgery, and research in the unit. I was reviewing the EOS cases performed here. The growth-rod concept had evolved in Nottingham, like elsewhere, in the last 5 years. The idea behind growth rods in treating EOS is to correct spinal curvature and permit skeletal growth. Luque Trolley was abandoned due to high incidence of complications, spontaneous fusion, and inadequate spinal growth. This technique was replaced by dual growth rods and sublaminar wiring

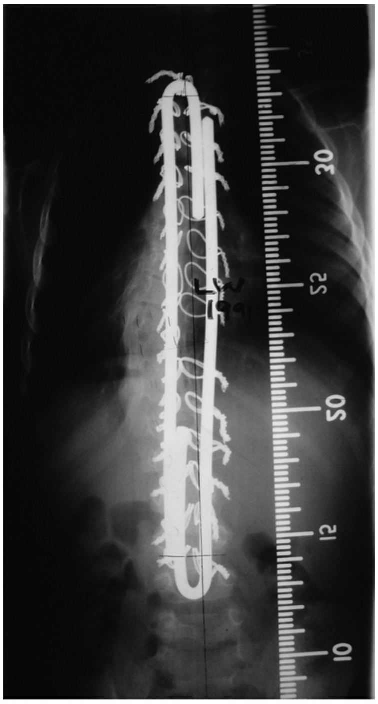


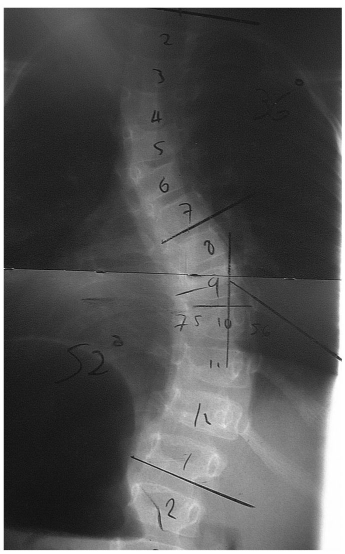
FIGURE 9F.3B 5 years postoperative AP view x-ray at 7 years of age with Luque Trolley in 'U' configuration.

FIGURE 9F.4 AP view x-ray of a 6-year-old boy with EOS and thoracic insufficiency syndrome treated with VEPTR.

(Figure 9f.6a–b). We used proximal (hooks or screws) and distal pedicle screws as anchors. The two titanium rods placed side by side anchored with sublaminar wires. In our experience, proximal fixation was obtained over three levels with at least five fixation points. We performed lengthening every 6 to 12 months, depending on the age. It has been shown that frequent lengthening (≤6 months) may have greater curve correction and overall increased spinal growth [28, 29]. Ouellet et al. [30] published five patients treated with a modern Luque Trolley technique in which the proximal and distal ends of the construct were instrumented and fused. I worked with Dr. Mehdian, an innovative surgeon with whom I have published many papers. He showed me the use of an H bar construct (Figure 9f.7) for EOS neuromuscular scoliosis (spinal muscular atrophy, Duchenne muscular atrophy, and cerebral palsy) [31, 32].

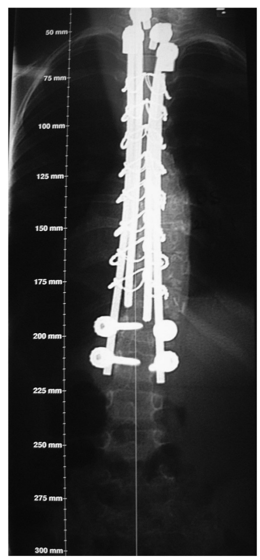
In the flurry of surgeries and my ongoing thesis work on lumbar spondylolysis, I was studying the timing of definitive fusion for these EOS children who had grown as adolescents (the research question that had intrigued me 7 years ago). I presented a paper to a Scoliosis Research Society (SRS) meeting at Salt Lake City, Utah [33]. During this meeting, I learnt a lot through presentations by many surgeons who were engaged in different types of research with EOS. Most surgeons were discussing the distraction-based strategies, and only a few spoke on growth-guided strategies for the treatment of EOS (Figure 9f.8). Notable papers did imprint an image of the various kinds of EOS treatment based on multiple surgical experiences, e.g. Dr. Flynn on VEPTR [34], Dr. Akbarnia on congenital scoliosis (posterior resection and growing rods) [35] and SHILLA procedure by Dr. McCarthy. McCarthy et al. [36] developed the SHILLA growth guidance system (SGGS), which included short segment posterior fixation and fusion at the apex of the deformity. The rods

FIGURE 9F.5 Dr. John Webb (spine guru) and Dr. U. K. Debnath at QMC, Nottingham, 2007.



A

FIGURE 9F.6A AP view x-ray of a 7-year-old boy with EOS.



B

FIGURE 9F.6B Postoperative AP view x-ray showing posterior hybrid Luque fixation in the in the same boy.

can slide across the proximal and distal anchor points. The complications of rod breakage were reported up to 30% of patients [36].

Tsuji et al. [37]from Nagoya, Japan, presented a casting technique to reinforce conservative treatment in EOS until growing rod surgery could be performed [37]. The need for repeated surgeries under general anaesthesia is a major drawback in growth-rod surgery. High incidence of anaesthetic and wound complications were reported [38, 39]. Patients who were younger at the time of initial surgery had higher complication rates, as I observed in a 10-year-old boy who had multiple surgical debridements

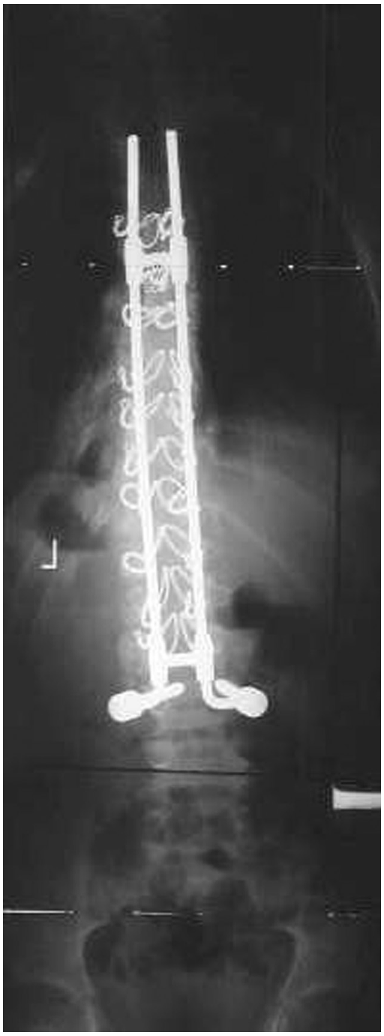


FIGURE 9F.7 AP view x-ray of 9-year-old boy with neuromuscular EOS treated with Luque Trolley with H bar.

for ongoing infection following growth rods at 6 years of age.

During this period of my fellowship, I had learnt significantly through interactions with a multidisciplinary team that included a spinal clinical nurse specialist, clinical psychologist, paediatrician, radiologists, anaesthetists, physiotherapists, and of course the theatre staff. The tertiary care UK hospitals have a well-tuned multidisciplinary team for delivering children's spine surgery. This group of clinicians meets to review the proposed benefit and risk of spinal surgery for the child. The parent and families are provided with all the necessary information at their preoperative visit by the nurse who comprehensively reinforces the procedure and plan. Clinical photography forms an essential part of the management. As part of the team, we all were responsible for providing compassionate, high-quality, safe care whilst working in an acute fast-paced environment.

I successfully performed many operations to correct the spinal deformities in children and my 1-year fellowship ran out before I realised it. During this time, I was supported by all my cofellows, who were incidentally neurosurgeons, and became great friends for life.

OPERATION STRAIGHT SPINE (OSS), KOLKATA

'Operation Straight Spine', a transatlantic collaboration between the two surgeons for treating spinal problems in the underprivileged children in India, was taking shape. In November 2006, Dr J. R. McConnell, a consultant spine surgeon and I embarked on this journey with a team to perform a spinal surgical workshop at a charitable teaching hospital in Kolkata (Figure 9f.9). This required a tireless, organised effort in an uncharted sea. Following the success of the first surgical workshop in 2006, I was travelling between India and UK to establish this annual programme doing at least 10 spinal operations. At this time, we treated few children with EOS. Many of them underwent simple traditional dual growing rods (TGR) with dominos in which the rod slides.

KOLKATA, 2011

I relocated from London to Kolkata in 2011 and started to practise spine surgery at a private hospital. But my engagement with spinal patients of OSS continued in a more organised fashion in the charitable sector. The annual workshops continued to support the cause. EOS cases were evaluated in a weekly clinic. Our work was gradually recognised by SRS who endorsed the programme as the first global outreach programme (GOP) for spinal surgery site in India. We were honored at an SRS meeting at Anchorage, Alaska, in September 2014 for 'Operation Straight Spine'.

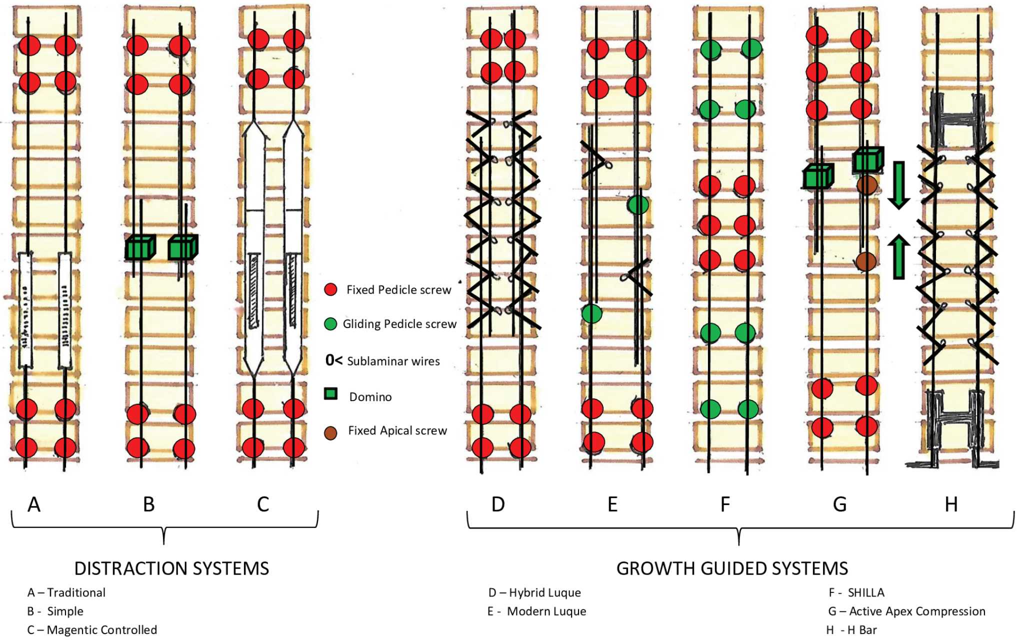


FIGURE 9F.8 Schematic diagram of growing rod techniques.

FIGURE 9F.9 Dr J. R. McConnell (Allentown, Pennsylvania) and sister Marian Barry (London) with Dr U. K. Debnath during OSS 2010 at surgery in Kolkata, India.

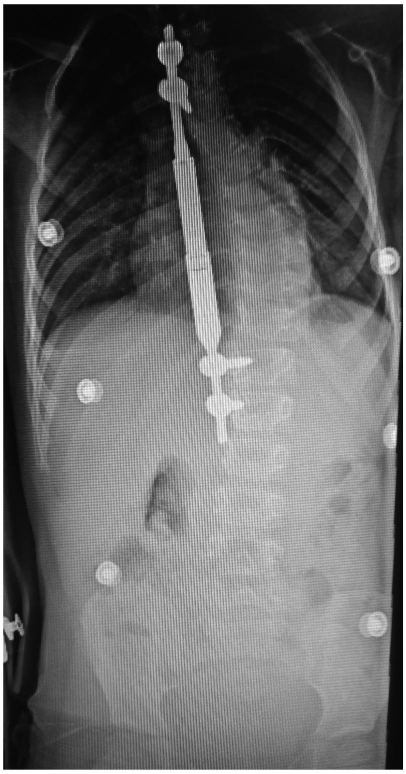
LONDON, 2015

I returned to the UK for a short fellowship at Great Ormond Street Hospital, London. I reviewed many children with EOS who were idiopathic, congenital, neuromuscular, or syndromic. I was introduced to magnetically controlled growing rods (MCGRs) here, and I did many implantation, removal, exchanges, and revisions for EOS children. The MCGR procedure can be safely and effectively used in outpatient settings minimising psychological distress and improved quality of life [40, 41].

I was part of an audit on 46 EOS patients treated in past 3 years who had undergone MCGR. The mean age was 6.8 ± 1.9 years at the time of primary surgery. The major coronal curve magnitude improved from a mean Cobb angle of 70° (preoperative) to 34° (postoperative) in primary cases. Device failure occurred in 16 children (28%), leading to a decision for operative revision in 14 cases. It was observed that four patients developed a superficial wound infection. In the dual rod group, two patients had pull-out of proximal hook and another had prominent metalwork. Six patients had a rod breakage.

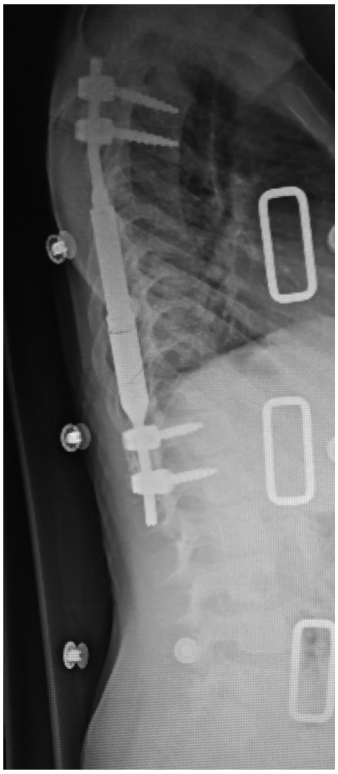
The MCGR consists of a titanium spinal distractible rod with an enlarged midportion containing a rotating mechanism (thickened actuator portion that houses the magnet) (Figure 9f.10a and b). Dual rods have been shown to produce increased distraction forces and to allow for differential correction [41]. The maximum length distractible is 4.8 cm. During outpatient distraction visits, patients were positioned prone, and a skin marker was used to mark the internal magnet. A hand-held magnetic external remote controller (ERC) was placed on the patient's back. Once the magnetic field was applied, the rod lengthens thus distracting the spine. Although MCGR has reduced the number of planned surgeries for distraction, there are incidences of unplanned visits to the operation theatre [42]. A skill well learnt could not be transferred to the patients in my practice due to the enormous costs [43].

The National Health Services' (NHS) machinery of a multidisciplinary team was more established in this hospital. The surgical team (nurse in-charge, scrub nurses, and scrub technicians) prepared the environment and the necessary instruments and equipment in readiness for an anaesthetic, surgery, or recovery of patients. Patient safety and good practice depends on an effective surgical team working along with a highly skilled surgeon. The whole team enhances the performance of the team and



A

FIGURE 9F.10A Postoperative AP view x-rays of a 6-year-old with single MAGEC rod.



B

FIGURE 9F.10B Postoperative lat view x-ray of the same boy.

results in good patient outcomes. This organised facility was lacking in my practice in India.

SRS GOLDEN JUBILEE MEETING, MINNEAPOLIS, MINNESOTA, 2015

The SRS committee awarded me with a scholarship to attend the 50th annual meeting in Minneapolis, Minnesota, in October 2015. I attended the precourse meeting on EOS, which updated my ongoing learning. There was still no consensus on ideal age, threshold Cobb angle, and lengthening interval

Instrumentation for EOS is based on either distraction, guided-growth, or compression-based strategies (Figure 9f.8). Most surgeons were using distraction-based growth rods (submuscular insertion) for EOS between 4–10 years of age with a curve over 70° [44]. Dr. Akbarnia reported 46% complications (mostly implant failures and infection) and a spinal growth of 1.8 cm/yr [28]. Compression-based techniques have gained attention with the development of anterior vertebral body tethering, e.g. stapling [45]. SGGS had fewer surgeries (2.8) compared with growth rods (7.4) but had high rates of complication [46]. The TGR group had more surgeries, but SGGS patients had more unplanned procedures [47].

KOLKATA 2016–20

I continued to deliver the OSS programme supported by the team from the United States and UK. We had a good team of paediatric anaesthetist and nurses led by Dr. Neena Gupta and Dr. Caroline Davies from St. Thomas' hospital, London, who has always provided support for all the scoliosis patients on which we have operated. We continued doing the TGRs with dominos. The phenomenon of decreasing gains in spinal lengthening was reported [48]. This 'law of diminishing returns' was observed in our patients as well.

Although MCGR was advantageous in many respects, e.g. noninvasive outpatient lengthening, reduced risk of infection, avoiding multiple surgeries, and improved patient satisfaction, the disadvantages were complications and technical issues [49,50]. After gaining knowledge on distraction-based systems, my inclination toward growth-guided techniques were influenced recently by a new classification of EOS [51]. This was deemed valid and demonstrated its potential use in guiding decision-making [52].

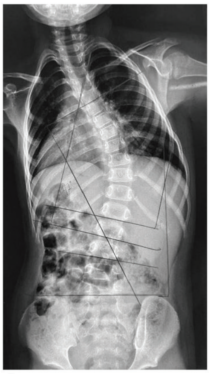
I had organised the OSS '20 programme recently. We had successfully treated eight scoliosis patients. This time Dr. Alaaeldin Ahmad, a paediatric spine surgeon from Palestine, joined us for the workshop on my invitation. He was discussing his new technique of guided-growth implantation, called Active Apex Correction (APC) technique. There were few unique aspects to this construct [53,54]. In this modified technique, the most wedged vertebra was selected followed by insertion of pedicle screws in the convex side of the vertebrae above and below the wedged one. Instead of apical fusion, apex compression was applied at the wedged vertebra (Figure 9f.8g). The procedure was more economical (using two screws instead of six at the apex of the curve) for underprivileged patients globally [53].

During this programme, Dr. Ahmad performed the APC technique in three children with EOS with my assistance (Figure 9f.11). One 13-year-old girl had surgery on four previous occasions. Now, the girl has grown tall, but there was a progressive curve decompensating at L2/L3 vertebral disc on radiographs. Due to a lack of surgeries for growth modulation for last 3 years, she developed a crankshaft phenomenon. She underwent APC technique of dual growing rods (Figure 9f.12a–g).

'Children diagnosed with EOS can lead healthy active lives if detected early and advised treatment in right direction' [55]. This dictum holds true for many of my patients. One 14-year-old boy with EOS had simple growing rods (with dominoes) when he was just 6 years old. He had good correction achieved through the previous lengthening procedures. The growth rods were removed this year. This gives me the utmost satisfaction when such children say 'my scoliosis surgery changed me and my life for the better, because my back is now straighter and I don't have any physical restrictions'. However, recent evidence indicates that the removal of implants without fusion is an unacceptable treatment strategy that leads to poor outcomes [56, 57].

In my experience, patients with repeated surgery in EOS demonstrated some psychosocial

FIGURE 9F.11 Dr. Alaaeldin Ahmad (Palestine), Dr U. K. Debnath (Kolkata, India), Dr. Shah Alam (Dacca, Bangladesh) and spinal fellows at surgery during OSS ‘20 at Institute of Post-Graduate Medical Education and Research,Kolkata.



A

B

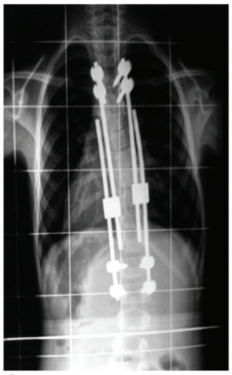
FIGURE 9F.12A AP view x-rays of a 5-year-old girl with EOS treated during OSS 2012.

FIGURE 9F.12B 2 months postoperative photograph of the 5-year-old girl with EOS treated with simple growing rods.

issues. The children are anxious and depressed when they introspect on the multiple invasive procedures. It has been reported that in EOS children, there is abnormal psychosocial scores with a positive correlation between behavioural problems and the number of repeat surgeries [58].

There is no multidisciplinary team to discuss regarding the patient’s surgical and emotional needs in India. There are major gaps and healthcare inefficiencies and inequalities in India.

The surgeon, for his own interest, builds up a dedicated team for a successful campaign for children’s spine surgery. Above all, the burden of caregiving, decision-making, parent counselling, surgery, and postoperative follow-up is handled singularly by the surgeon. A dedicated team of spinal surgical nurses and scrub technicians have been shown to improve surgical outcomes [59]. Constant surveillance and continuous improvement of the quality and safety



C

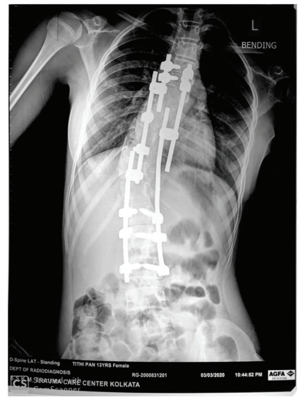
FIGURE 9F.12C AP view x-rays of the same girl with EOS showing dual growing rods.

D

FIGURE 9F.12D Photograph of the same girl at 13 years old showing curve progression.

E

FIGURE 9F.12E AP view x-rays of the same girl showing decompensation at L1 vertebrae.



F

FIGURE 9F.12F AP x-rays of the same girl showing active apex compression (APC) technique of growth rods.

G

FIGURE 9F.12G Postoperative photograph of the same girl showing curve correction during OSS 2020.

of spine treatments is imperative in modern healthcare where the responsibility needs to be shared [60].

CONCLUSION

Although there are various cultural and social differences that exist between the UK and India, the UK's NHS presents an excellent working environment in which aspiring surgeons from India or other nations are able to significantly progress their careers. The broad training and experiences from numerous excellent centres under many legends, enabled me to give my EOS patients and their parents a decision, a treatment plan, and a prognostic idea. In India, surgeons constantly adjust treatment based not on accepted 'best' treatment modalities, but on what is 'appropriate' for a particular individual. In fact, decisions regarding management are based on how much a patient or their families can afford.

The wide experience of two nations has certainly made me wiser. Multiple treatment options for EOS are available to us, and each has its advantages and disadvantages. 'Choosing wisely' enables us to provide the best care [61]. Therefore, I choose techniques that are tailored to the individual patient's needs to achieve the best long-term functional outcome. Amongst all these differences, practising in India is much more satisfying because most patients are still inordinately grateful. It is a little more gratifying to apply the skill and knowledge gained from training in the NHS in treating such complex spinal problems.

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