



QUALITY OF LIFE AND FAMILY IMPACT





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NONE



Health-Related Quality of Life

- **Since 1980s ⇒ Health (physical or mental)**
- **Individual level ⇒ Physical and mental health perceptions and their correlates, functional status, social support, and socioeconomic status**
- **Community level ⇒ Resources, conditions, policies, and practices.**
- **CDC: “an individual’s or group’s perceived physical and mental health over time.”**





✓ **Broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life.**

✓ **Health**



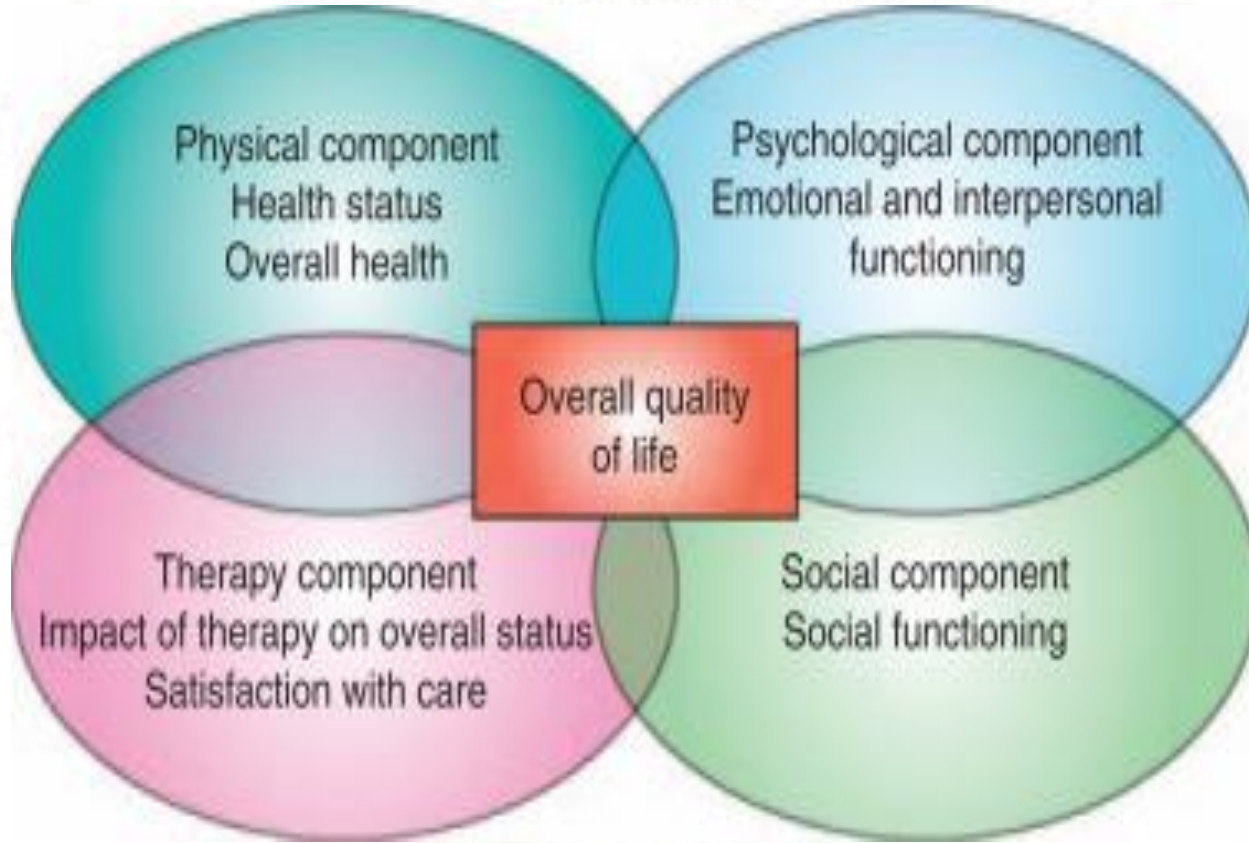
**"Health is a state of complete
physical, mental, and social
well-being, and not merely the
absence of disease or infirmity."**





✓ **Broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life.**

✓ **Health + other domains**

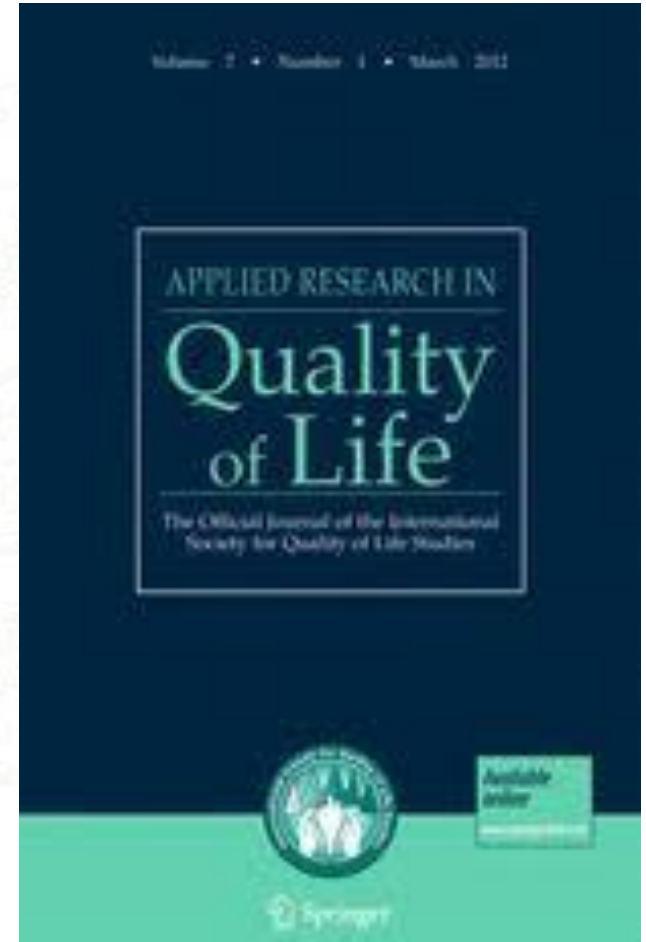


- **No consensus.**
- **Positive emotions and moods + absence of negative emotions + satisfaction with life + fulfillment and positive functioning.**
- **“Judging life positively and feeling good”.**
- **Physical well-being is critical to overall well-being.**

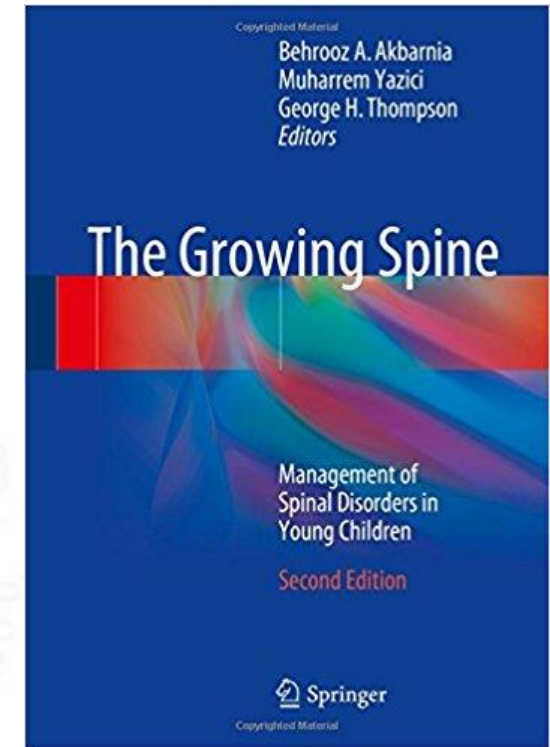
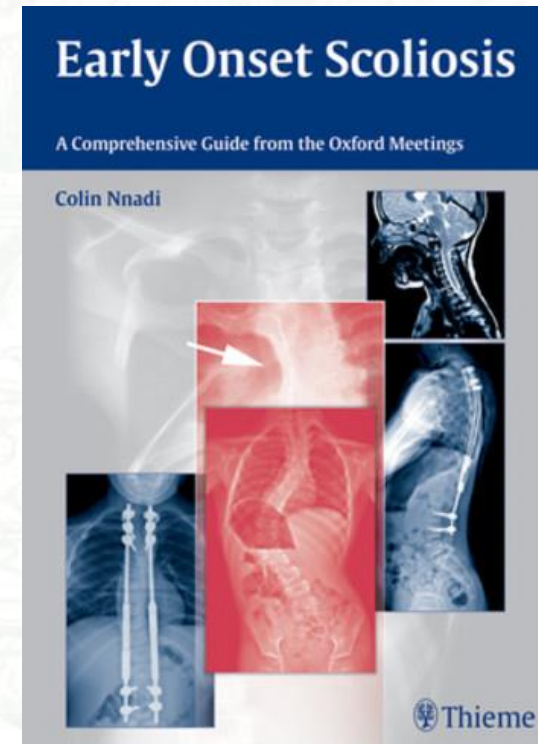




- **HRQOL vs. well-being. Synonymous?**
- **HRQOL ⇒ patient outcomes ⇒ deficits in functioning.**
- **Well-being ⇒ functioning, including positive emotions and psychological resources.**
- **Well-being ⇒ presence of high levels of positive functioning—primarily in the mental health domain (inclusive of social health).**



- **Children with EOS \Rightarrow $\uparrow\uparrow$ mortality at 40 years of age.**
- **Significantly impaired HRQOL (physical function and caregiver burden).**



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- **Treatment can adversely affect QoL: hospital appointments, restricted activities and general worry.**
- **With life-threatening conditions ⇒ significant changes in QoL.**
- **In palliative care, the sole purpose of therapy may be to improve QoL.**





MIXTURE. HETEROGENEOUS

Classification of Early Onset Scoliosis (C-EOS)

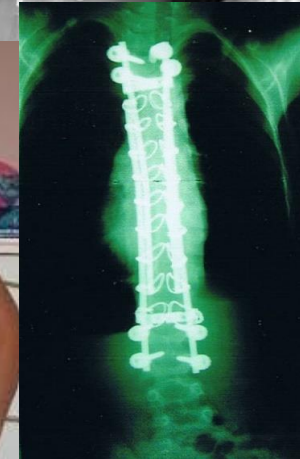
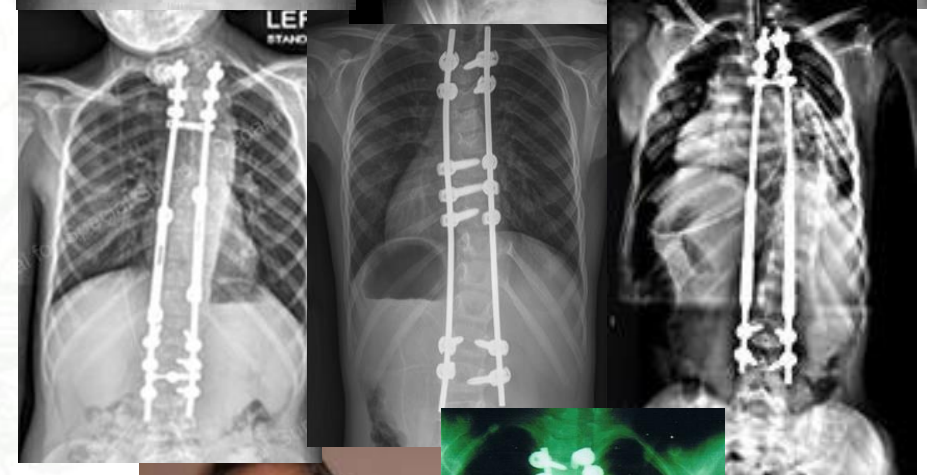
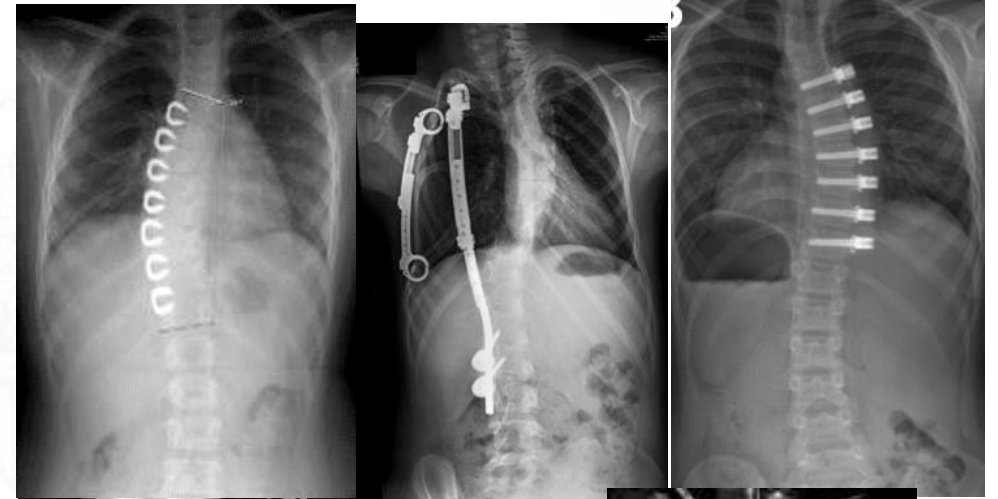
Age	Etiology	Major Curve Angle	Kyphosis	APR Modifier
Continuous Prefix	Congenital/Structural	1: <20°	(-): <20°	P ⁰ : <10°/yr
	neuroMuscular	2: 20-50°	N: 20-50°	P ¹ : 10-20°/yr
	Syndromic	3: 51-90°	(+): >50°	P ² : >20°/yr
	Idiopathic	4: >90°		

WHERE YOU CAN SEE THE DIFFERENT COMPONENTS OF THE MIXTURE.



Variability of Expert Opinion in Treatment of Early-onset Scoliosis

Michael G. Vitale MD, MPH, Jaime A. Gomez MD,
Hiroko Matsumoto MA, David P. Roye Jr MD;
members of Chest Wall and Spine Deformity Study Group





Anesthetic Effects on the Developing Nervous System

If You Aren't Concerned, You Haven't Been Paying Attention

Psychological Dysfunction in Children Who Require Repetitive Surgery for Early Onset Scoliosis

John M. Flynn, MD,* Hiroko Matsumoto, MA,† Frances Torres, PhD,‡ Norman Ramirez, MD,*
and Michael G. Vitale, MD, MPH§

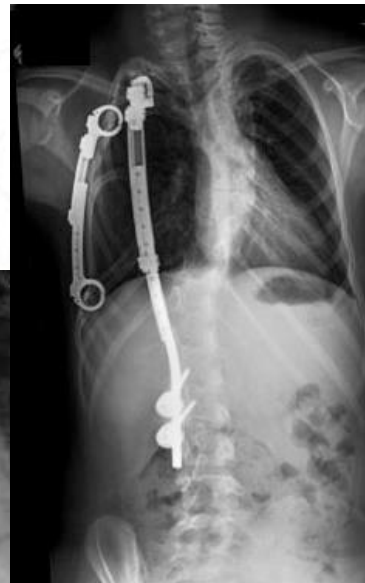
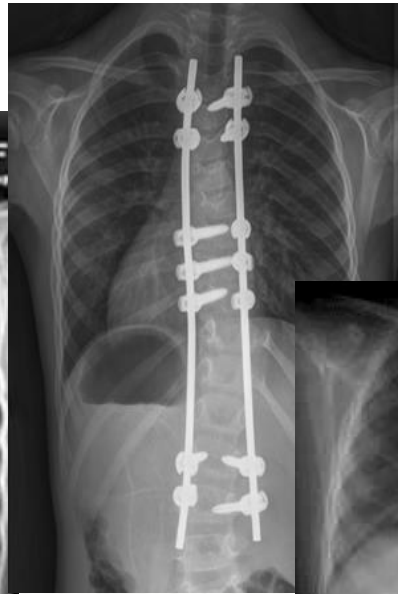
SPINE Volume 35, Number 25, pp 2193-2204
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Complications of Growth-Sparing Surgery in Early Onset Scoliosis

Behrooz A. Akbarnia, MD,*† and John B. Emans, MD‡

- **Frequent surgeries.**
- **Frequent complications.**
- **Frequent non-spinal procedures.**





- ✓ **“Better” treatments**
- ✓ **Improving QoL?**

There is no point in assessing QoL if we are unable to change it.

**YOU CAN'T
IMPROVE WHAT
YOU DON'T
MEASURE.**



✓ **Challenging to measure**

✓ **Everyone can define it differently**

✓ **Culture, values, spirituality, etc.**



**Nothing's beautiful from
every point of view.**

Horace

- **Developing field of research.**
- **Well established in adults.**
- **Important marker of health outcome for children for those with chronic or life-threatening conditions.**

- **Children and adolescents are able to report on the state of their own health.**
- **Methods suitable for young children may not be applicable to adolescents.**
- **Children may lack the cognitive ability to evaluate their health using abstract concepts.**
- **Young children may lack the required linguistic skills to answer questions designed for self-completion by older children.**

- **Changes with the child's age \Rightarrow age-specific instruments.**
- **Some for use exclusively in children and adolescents**
- **Some existing adult-specific methods modified.**
- **Children and adolescents preferences may be different.**
- **Dimensions included may not cover all dimensions of health relevant to children and adolescents.**



- **Age-sensitivity.**
- **The meaning of QoL changes with age and developmental level.**
- **Issues of central concern for children of different ages.**
- **Narrow age ranges are inadequate in situations, such as clinical trials, where the aim is to assess changes in QoL over time.**

- **Generic methods: measure HRQoL in children and adolescents for a range of conditions, both chronic and acute.**
- **Disease-specific methods measure HRQoL with reference to a particular condition.**
- **Disease-specific: More sensitive to small changes in the condition of the patient in question.
May describe the functioning of a patient with greater clarity.
Lack comparability across different diseases.**

- **Parents most useful. Anxiety?**
- **Clinicians' knowledge is useful. Less contact?**
- **Teachers? Evaluate a child's emotional and physical functioning.**
- **Parent-child agreement is normally greater for sick compared with healthy children.**
- **Parents' reports appear to be more reliable for observable behaviours, such as physical symptoms and function, but less reliable for cognitive and emotional attributes.**

Measuring Quality of Life in Children With Early Onset Scoliosis: Development and Initial Validation of the Early Onset Scoliosis Questionnaire

Jacqueline Corona, MD,† Hiroko Matsumoto, MA,*†
David P. Roye, Jr, MD,*† and Michael G. Vitale, MD, MPH*†*

Conclusions: The EOSQ reflects QOL and caregiver burden in the EOS population. The EOSQ will expand options for outcome assessment in this unique population.



...can analyze and ...
...the mix of activities
...performed in terms of the
... **knowledge** ...
... knowledge ...
... peers as a ...
... understanding ...

Functional and Radiographic Outcomes Following Growth-Sparing Management of Early-Onset Scoliosis

Charles E. Johnston, MD, Dong-Phuong Tran, MS, and Anna McClung, BSN, RN

Investigation performed at the Texas Scottish Rite Hospital, Dallas, Texas

Conclusions: A realistic long-term goal for the management of early-onset scoliosis appears to be spine elongation and maintenance of pulmonary function at a level that is no less than the percentage of normal at initial presentation. Functional testing and patient-reported outcomes at a mean of 3 years from the last surgery suggest that activity levels were generally equal to those of controls but required greater physiologic demand. General health and physical function outcomes revealed continued impairment in these domains.



Health-Related Quality of Life in Children With Thoracic Insufficiency Syndrome

Michael G. Vitale, MD, MPH,†‡ Hiroko Matsumoto, MA,*†‡ David P. Roye Jr, MD,*†
Jaime A. Gomez, MD,*† Randal R. Betz, MD,§ John B. Emans, MD,|| David L. Skaggs, MD,¶
John T. Smith, MD,# Kit M. Song, MD,** and Robert M. Campbell Jr, MD††*

Conclusions: The children with TIS had lower physical scores and higher caregiver burden scores than healthy children. However, the scores in psychosocial domains were similar to those in healthy children. Our study demonstrated that QOL of children and burden of care in their parents remained the same after VEPTR instrumentation. Children's QOL seemed to be not affected by whether they had VEPTR-related complications or not.

Psychological Dysfunction in Children Who Require Repetitive Surgery for Early Onset Scoliosis

John M. Flynn, MD, Hiroko Matsumoto, MA,† Frances Torres, PhD,‡ Norman Ramirez, MD,* and Michael G. Vitale, MD, MPH§*

Conclusions: Clinicians caring for children with EOS should have a heightened awareness for possible adverse psychological outcomes in this population and consider early referral for appropriate psychological assessment and care. Additional studies are necessary to further qualify and quantify the psychological effects of multiple anesthesia surgeries in EOS patients.

Conclusion: A higher prevalence of depressive and anxiety symptoms was observed in patients with EOS along with dysfunctional areas of daily life. Other comorbidities may also contribute to dysfunction and difficulties. Determination of the aspects of EOS treatment that have a negative impact on psychosocial functioning may allow for more competent help for these patients.

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**Spine
Deformity**

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Spine Deformity 5 (2017) 334–341

Psychological Profile of Children Who Require Repetitive Surgical Procedures for Early Onset Scoliosis: Is a Poorer Quality of Life the Cost of a Straighter Spine?

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Orthopediatrica
ORTOPEDIA PEDIÁTRICA AVANZADA

Psychosocial Effects of Repetitive Surgeries in Children With Early-Onset Scoliosis: Are We Putting Them at Risk?

Hiroko Matsumoto, MA, Brendan A. Williams, BA,* Jacqueline Corona, MD,†
Jonathan S. Comer, PhD,‡ Prudence W. Fisher, PhD,§ Yuval Neria, PhD,§
Benjamin D. Roye, MD, MPH,*|| David P. Roye I, MD,*|| and Michael G. Vitale, MD, MPH*||*

Conclusions: Our findings showed a higher prevalence of Abnormal psychosocial scores in multiple domains in multi-operated EOS patients as compared with national norms. Our findings suggest that EOS patients with abnormal psychosocial scores were younger at the time of their initial scoliosis surgery. The number of repetitive surgeries also correlated positively with 3 behavioral problem scores. Although healthier scores were seen in 1 positive behavioral domain in more operated children suggesting the potential for “posttraumatic growth,” the other findings of this study are concerning given the increasing use of this treatment modality and indicate a need for ongoing screening and mental health care in this high-risk population.

251. Spinal Muscular Atrophy; Growing Spinal Instrumentation Preserves Lung Volume and Maintains Quality of Life

Nicholas Feinberg; Hiroko Matsumoto, PhDc; Zachary Bloom; John M. Flynn, MD; Peter F. Sturm, MD, MBA; Sumeet Garg, MD; David Price Roye Jr., MD; Michael G. Vitale, MD, MPH; Children's Spine Study Group; Growing Spine Study Group

Conclusion

Surgery for SMA maintains lung volume, and improves scores in multiple EOSQ-24 subdomains.

Paper #28

Quality of Life and Burden of Care in Patients with EOS Undergoing Casting



*Emily Auran, Hiroko Matsumoto, David P. Roye, Michael G. Vitale,
Peter F. Sturm, James O. Sanders, Matthew Oetgen, Sumeet Garg,
Children's Spine Study Group Growing Spine Study Group*

Conclusions: Idiopathic EOS patients' HRQoL begins within a normal range but declines while in cast, and remains lower after the treatment. While non-idiopathic patients begin with lower HRQoL, their decline in-cast is relatively small, and recovers post-casting. An explanation is that before casting, idiopathic patients have a comparatively higher HRQoL and are thus more negatively impacted by the restrictive casting intervention.



Paper #27

Improvement of Pulmonary Function Measured by Patient-Reported Outcomes in Patients with Spinal Muscular Atrophy After VEPTR Surgery



Michael G. Vitale, Hiroko Matsumoto, John D. Mueller, Patrick J. Cahill, Peter F. Sturm, David P. Roye, John T. Smith

Conclusions: Pulmonary function in SMA patients measured by patient-reported outcomes demonstrated significant improvement after VEPTR surgery. Although it is difficult to objectively measure pulmonary function, quality of life may be a good indicator for well-being and satisfaction toward pulmonary function.



Paper #20

Health-Related Quality Of Life In Early-Onset Scoliosis Patients Treated Surgically: EOSQ Scores In Traditional Growing Rod Vs. Magnetically-Controlled Growing Rods

Muharrem Yazici, H. Gokhan Demirkiran, Z. Deniz Olgun, Gizem Irem Kinikli, Senol Bekmez, Mehmet Berktas

Conclusions: HQRL data obtained from MCGR and TGR reveal superior outcomes in the financial burden and patient satisfaction, and possibly physical activity when controlled for number of lengthenings, for MCGR. However, in all other domains, both techniques score similarly, indicating that the TGR is far from being obsolete at this time.

Paper #4

Pulmonary function evaluation in children affected by neuromuscular scoliosis treated for the spine deformity with Magnetically Controlled Growing Rods

Luca Fabio Coloumbo, Miriam Gotti, Chiara Bersanini, Francesco Motta, Francesca Izzo, Valentina Caretti

Conclusions: With MCGR we reduced morbidity and complications due to surgery. We found a better pulmonary function in children after MCGR compared to control group

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- **Condition that either interferes, or is likely to interfere with an individual's daily functioning for at least three months of a year, or a condition that will require hospitalization for more than one month in a year.**
- **Prolonged in their duration, they do not resolve spontaneously, and they are rarely cured completely.**



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- **Improvements in the delivery of specialized care ⇒ increasing survival rates for pediatric patients.**
- **Not only living longer, but dealing with more aggressive treatments ⇒ impacts their quality of life.**





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- **More than simply the physical disease**
- **Effects on individuals' and families' lives.**
- **Profound impact on the welfare of each family member.**





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- **Being diagnosed with a chronic disease can be a major upheaval in families' lives and often leads to many stressors and worries.**
- **Families with chronically ill children are fundamentally normal families forced to cope with extraordinary circumstances.**



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- **Strain in all areas of life: financial, physical, emotional, social, behavioral, and personal domains.**

Financially: Huge amounts of strain when medical bills pile up.

Physically: Not enough sleep or not have their normal routine.

Emotionally: Stress and uncertainty about the future, an upcoming procedure, or extensive worry about the ill child.

Socially: Isolation or overburdened.

Behaviorally: Different directions than normally expected.



- **Childhood chronic illness often results in worry, stress, disruptions in routine, change, financial constraints and more; these types of effects notably manifest themselves in the physical, social, financial, emotional spheres.**
- **A childhood illness in the family can cause tremendous amounts of stress for all members. It often results in changes in family roles, relationships, and disrupts family normalcy.**

- **Structure is important in early childhood development.**
- **Routine and structure ⇒ Sense of security, develop self-discipline and boundaries, leads to clear and foreseeable expectations, creates a sense of mastery over their own lives, and ultimately allows them to handle change.**
- **Well siblings of children with chronic illnesses ⇒ ↑ risk for negative psychological effects (depressive thinking, sadness, anxiety and uneasiness).**

- **Being diagnosed with a chronic illness places enormous demands (medical or otherwise) on children and their families, and can become the basic organizing principle of family life.**
- **Researchers and clinicians agree that childhood chronic illness produces substantial amounts of stress on families.**

- **It is largely accepted that families facing serious pediatric illness are fundamentally ordinary families that face extraordinary stressors and are forced to cope with unique circumstances.**
- **The experience of chronic illness is a unique family *and* individual experience resulting in changes in a variety of spheres.**

Compas et al. note that, “parents serve as resources to support and scaffold children’s coping. Parents who are ineffective in coping with the stress of their child’s illness may contribute to increased distress in their children”.

Parents also may demonstrate increased levels of anxiety and overprotectiveness; they may have lower expectations for their ill child and his or her siblings; and they may fail to provide boundaries or consistent discipline for their children.

Each disease has great “variability in its clinical expression, chronicity, severity, and the associated hardships imposed on individual families”.



VS





AMA Journal of Ethics®

Illuminating the art of medicine

Physician Responsibility for Patients' Quality of Life

Philip M. Rosoff, MD

One of the tasks of modern medicine is to endeavor to ensure that patients' quality of life is, at least, no worse when they leave our care than when they entered, and, at best, that it is better, according to recognized index quality indicators. To be sure, doctors who treat patients with life-threatening conditions focus quite rightly on instituting therapeutic measures to preserve life, and often they are not able to address the impact of medical care on quality of life until after the life-saving intervention.





**MUCHAS
GRACIAS**

