THE LINDA CRANE MEMORIAL LECTURE
The Patient Puzzle: Piecing it Together

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INTRODUCTION

I would like to thank the Cardiovascular & Pulmonary Section, the Pediatric Section, and the Education Section for starting, dedicating, and perpetuating Linda Crane's ideals through this honorary lecture. I would also like thank Nechama Karman, who nominated me for the award, and Gary Brooks and the entire Linda Crane Committee for their commitment to preserve her ideas. It is indeed an honor to present this lecture.

When I thought about this award, I thought, "what am I going to say?" and then I thought, "Wait, before you even think about that, think about who gets these awards..." I realized that all the recipients share something in common: they are all old! As I reflected on this, it made me ask myself, could I really be in that category? So, I took out a picture of me from yesterday (in my very first job) and today (30+ years later). Okay, maybe I am old enough to receive an award, but do I feel old enough to receive one? That's a much more important question, because frankly I feel like this young dancer (pictured during lecture) who is jumping up on one leg and lifting her remaining three limbs into the air to reach out for an adoring throng of gorgeous men. But in reality, I am actually far more likely to exercise this way: reaching out to my family or reaching out for my adorable grandbaby. You know you are old when you have a grandbaby, but you do not care because having a grandchild makes being a parent worth all the suffering.

The Author (right) receiving the Linda Crane Memorial Lecture Award from Ethel Frese, President of the Cardiovascular and Pulmonary Section, APTA.

All right, I am old enough and maybe I feel old enough to give the lecture. But, the most challenging part was, the committee said I could talk about anything that I want. I responded: "No seriously, what should I present?" To which they responded: "Honestly, whatever you want." "You mean I could talk about a peanut butter and jelly sandwich if I wanted?" And they said, "Yes!" Whoa, I thought I better not write this lecture until I discussed this with colleagues that I trust. I talked to Nechama, who had nominated me for the award; to two classmates, Susie Limburg from PT school in 1977 and Marcia Thompson from my doctoral program at Rocky Mountain University; and finally, to my first cardiopulmonary teacher, Donna Frownfelter, who is so much more than my teacher. She is my colleague, my mentor, and my friend. They all had the same advice: "Mary, speak from your passion." That is what I plan to do today.

What did I feel passionate about? I feel passionate about the broader view; I want therapists to look at assessment from a perspective that includes the whole body, looking far beyond the obvious musculoskeletal and neuromuscular systems. I feel passionate about the link; the link between motor deficits such as in musculoskeletal or neuromuscular impairments and the links to the more physiologic based systems, cardiovascular/pulmonary, integument/fascial, and the internal organs systems. And lastly, I feel passionate about the integration of these ideals into every single PT evaluation and treatment.

These passions lead me to the 2020 mission goal of the APTA. We want, and I think we deserve, to be autonomous in our practice and to be the practitioners of choice for consumers. But with that comes responsibility. We need to prove that as professionals we will dig deep to find the real problem for a motor impairment, that we will not take the easy road and simply treat what we see without asking ourselves: "Why do we see it?" That is the one piece of advice that I tell students. Don't just identify that a problem exists. Ask, "Why does it exist?" The second piece of advice? If we want to become autonomous practitioners, demonstrate excellence in differential diagnosis and demonstrate appropriate referrals to other professionals.

THE PUZZLE CASE

So, now I am ready to start. The puzzle that I would like to present to you is in the form of a case. I want you to meet Danny (Figure 1). He is 9 years old. He was referred to me with a diagnosis of thoracic kyphosis, scoliosis, and

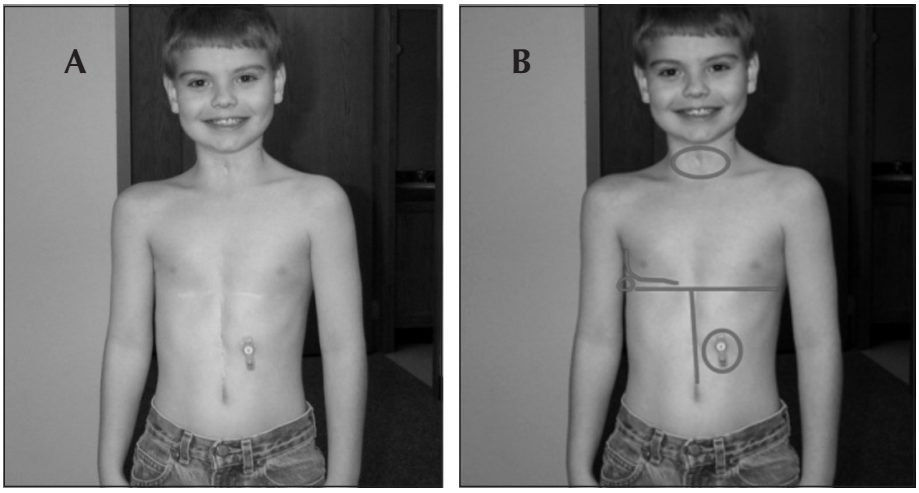


Figure 1. Danny at 9 years old.

A. Diagnoses
1. **Current Dx: Thoracic kyphosis, thoracic scoliosis, chestwall deformity**
2. **Pertinent Past Medical Dx: Tracheoesophageal fistula, subglottal stenosis, esophageal atresia**

B. Pertinent Scars (from top):
1. **scar from multiple reconstructive surgeries on his trachea**
2. **right thoracotomy scar**
3. **right chest tube scar**
4. **horizontal lower chest scar (harvesting of bilateral costal cartilage for tracheal reconstruction)**
5. **vertical abdominal scar from multiple abdominal surgeries**
6. **scar from gastrostomy tube (G-tube)**

a chestwall deformity. Of course, that obviously makes him a musculoskeletal patient, right? Oh and by the way, he has a history of tracheoesophageal fistula, subglottal stenosis, and esophageal atresia.

His primary complaint at that time was immobility of his trunk and spine. All I needed to do was a few mobilizations, stretches, strengthening, and a home exercise program and send him home, right? Yes, you may have noted a little sarcasm in my voice.

At age 7½ years old, Danny has a bit of a thoracic kyphosis that you can see in this picture (Figure 2a) in spite of being in a prone on extended arm position. If you look at his head and neck, he has more cervical extension via his eyeballs than he has in his actual cervical spine. Treating Danny's musculoskeletal may make him feel good, but will that single system focus really find the problem and solution to his immobility? The more important question is: "Why does a young 7-year-old boy have a kyphosis, a scoliosis and something funky going on with his neck?"

Come back to the *Guide to Physical Therapist Practice*, which identifies 4 body systems to evaluate for motor impairments: musculoskeletal, neuromuscular, cardiovascular/pulmonary, integument/fascial.[1] I will add the one they forgot to put in the book: the internal organs, which have mechanical properties as well as physiologic properties. I will talk about this case, using these 5 body systems and not 4 (Figure 3).

If we look at these body systems in relationship to postural control, looking at Danny at age 9 (Figure 1), the obvious systems of impairment would be in the musculoskeletal and neuromuscular systems, and the less obvious systems would be the cardiovascular/pulmonary, integument/fascial, and the internal organ systems. I would like to draw a more distinct division. Musculoskeletal and neuromuscular deficits are often associated with activities that we would describe as being related to the idea of *thriving*. When the impairments are in the other 3 systems, it is very often associated with the idea of *surviving*. I tease my orthopedic colleagues when they tell me that they do not do treat cardiopulmonary impairments. I respond by saying: "that is my point." Everyone moves first from a *survival* standpoint. As an organism, we are programmed first and foremost to *survive*. If we cannot meet our physiologic *survival* needs, we cannot focus on *thriving*. Let's go back and look at Danny: was he *thriving* or was he stuck in *surviving*?

Soda Pop Can Model of Postural Control

In order to understand the relationship between *surviving* and *thriving*, I am going to present a model of postural control that I developed in graduate school, called the "Soda Pop Can Model of Postural Control."[2,3] A soda pop can is strong only when it's closed. The closed can allows internal pressures to stabilize its weak aluminum shell, much like our weak skeletal frame. That is the link that I

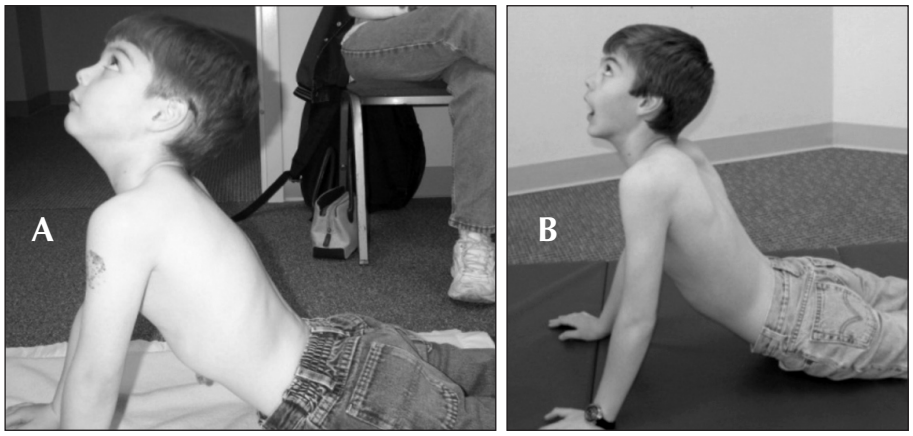


Figure 2. Danny in prone extension position.

A. Danny: Age 7 ½ years old. In spite of being prone on extended arms, Danny demonstrates a thoracic kyphosis and limited cervical lordosis.

B. Danny: Age 12 ½ years old post anterior abdominal Z-plasty scar revision. Note increased lumbar lordosis and a slight reduction in thoracic kyphosis.

- Musculoskeletal (MS)
- Neuromuscular (NM)
- Cardiovascular/pulmonary (CP)
- Integumentary/fascial (INT)
- Internal organs (IO)

Figure 3. Body systems associated with motor impairments.

see across with all motor impairments; the ability to generate, to maintain, and to regulate pressures within the trunk (our aluminum shell) to allow the limbs to move efficiently and effectively off of that core stability.

Look at the can like our trunk (Figure 4). The diaphragm sits in the middle of the can. The diaphragm is not a respiratory muscle; it is a pressure regulator. It is the most important pressure regulator in the whole body. To call it only a respiratory muscle is to ignore its many important functions. The diaphragm's job is to completely divide the thoracic cavity from the abdominal cavity, thus its movement simultaneously changes pressures in both cavities. What we do with that pressure is up to us! Of course, respiration is a nice thing to do with that pressure, but there are many other functions of the diaphragm.

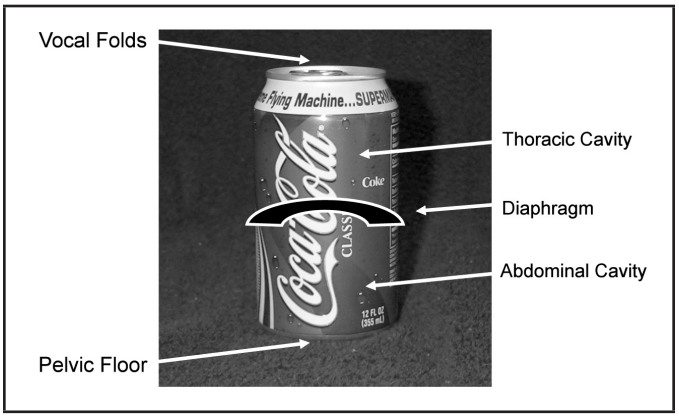


Figure 4. A Postural Control Model Using a Soda-Pop Can

Today, we will just discuss one additional role of the diaphragm; its role as a postural muscle. The body's core is not just in the abdominal cavity. It reaches from the pelvic floor on the bottom, up to the vocal folds on the top. If any portion of that can is opened (breached), whether it is opened via a tracheotomy on top, stress incontinence on the bottom, or weak abdominal, diaphragm or chest muscles in the middle, the entire can is not functional! I do not care how many Pilates classes you go to, the abdominal muscles alone cannot provide core stability.

The soda-pop can model is our link to understanding motor impairments across diagnoses. We must look inside the can. The lungs obviously need internal pressures to be regulated, as does the heart and vascular structures. Those of you who work with patients with spinal cord injuries know what I am talking about. Their blood pressure is normal until they have a spinal cord injury when they are suddenly extremely hypotensive. Without internal pressure support in the can, they cannot maintain pressure throughout the entire vascular system resulting in low blood pressure. The same is true for the other internal structures such as the gastrointestinal (GI) tract and the lymphatic system that are fluid- or air-based systems.

Find the Problem! Danny's Birth History

Where was Danny's true problem? Was it in the obvious musculoskeletal (MS) system, or were his MS impairments simply the consequence of other underlying pathologies? I need to take a step back and to explain his diagnoses. If you are not in pediatrics, these terms may sound foreign indeed. A tracheoesophageal fistula is an incomplete differentiation of the trachea and the esophagus in-utero.[4] In other words, it is a patent opening between the 2 tubes, a life threatening condition. On top of that, Danny had a severe subglottal stenosis, which is narrowing of the trachea inferior to the vocal folds.[5,6] Just underneath the vocal folds, his trachea failed to completely differentiate, resulting in just a residual pinhole of an airway. In other words, his airway was almost completely closed. And lastly, he had esophageal atresia. Danny's esophagus ended in a blind sac. It did not connect to the stomach. Any one of these conditions is very serious and life-threatening. Danny had all three (Figure 5).

Danny's major diagnoses at birth
- Tracheoesophageal fistula (hole between the trachea and esophagus)
- Severe subglottal stenosis (almost a completely closed upper airway)
- Esophageal atresia (esophagus ended in a blind pouch and did not connect to the stomach)
- Intra-uterine growth retardation (IGR)

Secondary diagnoses in the perinatal period
- Benign hypotonia
- Failure to thrive
- The potential for musculoskeletal and integumentary impairments

Figure 5. Danny's Early Life Problems

Meet Danny at birth (Figure 6). He was born at 34 weeks gestation (6 weeks premature), which nowadays carries a good prognosis. He weighed less than 4 pounds, demonstrating intrauterine growth retardation (IGR). He had immediate and severe acute respiratory distress and his Apgar scores were 1/10. He was not breathing. Unaware of his multiple birth defects, the doctors tried to intubate, but they could not get a tube through his pinhole-sized airway. They used an Ambu bag (an air-filled bag that is squeezed manually to push air into lungs). It must have seemed odd to the physicians to see air inflating the lungs because they were unsuccessful at intubating him. However, in spite of their heroic efforts, his carbon-dioxide levels continued to rise. He was rushed to surgery. At 2:00 am he was trached and put on a mechanical ventilator.

The subglottal stenosis could have killed him. What saved him ironically was having a hole between his trachea and his esophagus. When they Ambu-bagged him, the air went into his esophagus and then through the hole in the trachea beneath his subglottal stenosis and finally into his lungs. It did get air to his lungs, but because of the

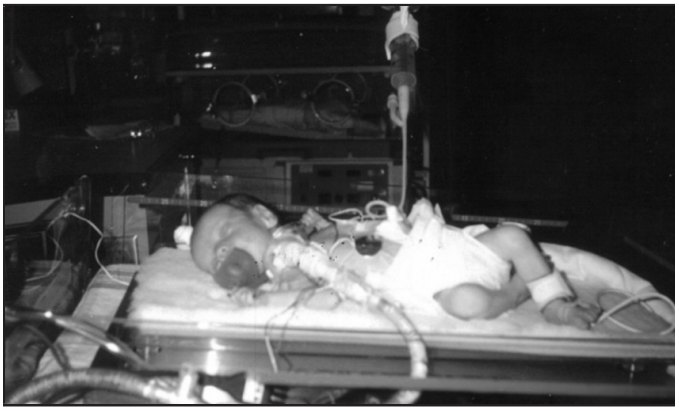


Figure 6. Danny in the NICU.

air's crooked path, his expired CO_2 had a very difficult time finding its way out causing his CO_2 to rise to dangerously high levels. The success of the Ambu bag bought the medical team enough time to get him to surgery to perform a tracheostomy (trach) and to successfully get him on a ventilator. Ironically, his esophageal atresia saved his life. If his esophagus was connected to his stomach, the air forced into his body through the Ambu bag would have followed the path of least resistance and wound up in his stomach rather than taking the more convoluted route to his lungs.

About a week later, the doctors surgically repaired the tracheoesophageal fistula via a right thoracotomy incision. They also repaired the esophageal atresia, hooking up the esophagus to the stomach. He also had a gastrostomy tube (G-tube) placed at that point. He was discharged at a month old with the trach and a G-tube. So, he was fine, right?

Progression of Medical Problems in the NICU

Let's look at our puzzle at this point (Figure 7A). The problem started very acutely in his cardiovascular/pulmonary (CP) system, followed very closely by deficits in his internal organs (IO). His priorities had to be to breathe first, eat second. If you cannot breathe, you cannot worry about eating. Nearly a tie, but breathing and living (*surviving*) comes first and *thriving* comes second.

A. Progression of problems as an infant in the NICU.

CP → IO → NM → MS → INT

B. Priorities of PT interventions at 9 years old. Focus of treatment has changed significantly from NICU period.

INT → MS → NM → IO → CP

Legend:
CP = cardiovascular/pulmonary
IO = internal organs
NM = neuromuscular
MS = musculoskeletal
INT = integumentary/fascial

Figure 7. Danny's Medical Problems by Body Systems

What was his muscle tone? This is a very, very sick baby. Did he have nice flexion tone? No. So, his secondary diagnosis was benign hypotonia. In other words, he had extremely low muscle tone because he had no energy to move! That made his neuromuscular (NM) system his third system of impairment. He could not move, allowing gravity to freely act upon his weakened system, making his musculoskeletal (MS) system the next potential system of impairment. Combine this with the effects from his multiple surgeries, and you could clearly see why he might have developed a problem with his integument/fascial (INT) system. Luckily, integument impairments were not a problem for Danny as an infant.

Danny forgot to die. In spite of the unbelievable obstacles, he survived. I met Danny for the first time around age 2½. The physical therapy focus was still on supporting his physiologic state with interventions such as airway clearance.

If we listed Danny's medical problems during the NICU period, we could identify that his most pressing and life threatening impairment started in cardiopulmonary system with a severe subglottal stenosis and a tracheoesophageal fistula. It progressed quickly to problems in the internal organs due to the tracheoesophageal fistula and the esophageal atresia which resulted in IGR, then failure to thrive outside the womb, and after the atresia repair, gastroesophageal reflux disease (GERD).[7] The sequelae continued with consequential benign hypotonia, and numerous aspiration pneumonias.[8]

Because his GI system ended in a blind sac, there was no lower esophageal sphincter, which guarantees he will reflux the rest of his life. The latest research on the diaphragm shows that it actually accounts for 40% of the reason you do not reflux.[9,10] The lower esophageal sphincter cannot prevent reflux on its own.

Therefore, if I identified his progression of impairments as a neonate; they started in his physiologically based systems, cardiopulmonary and internal organs, which in turn adversely influenced the neuromuscular system creating low tone, and they had the potential to adversely affect his musculoskeletal and integument/fascial systems. However, if I listed his NICU problems as a PT, his primary problem was hypotonia (NM). The musculoskeletal problems were not there yet, important words, not yet.

I want you to think about how Danny moved. He had severe reflux every day of his life until he had a Nissen fundoplication at age 3 (surgical procedure wrapping the fundus of the stomach around lower esophagus thereby strengthening the role of the lower esophageal sphincter). His movement patterns were in response to the noxious stimulus of reflux, so he moved in extension to move away from his painful gut. Everything about Danny was extension: eyes up, head up, shoulders up, legs straight. These kids are very often misdiagnosed with a neurologic impairment such as cerebral palsy or dystonia, when in fact it is not a neurologic impairment at all.[11-13] It is a neuromotor presentation as a response to a noxious stimulus, much like a sliver in your foot. The sliver would cause you to limp and could eventually cause knee pain, but the knee pain

would have been ultimately caused by the sliver. Danny showed avoidance of flexion activities. He had a survival breathing strategy. In other words, at all costs he was focused on meeting his breathing needs. Postural control needs be damned! His motor presentation was not due to a neurologic insult.

Regarding his cardiopulmonary system, he had recurring aspiration pneumonias. His respiratory rate on a good day was 60-70 breaths/minute. He had very low tolerance to physical activity but his heart was stable for now. In his integumentary system, he had surgical scars but no restrictions right now. In his internal organs, he showed severe reflux, failure to thrive, oral aversions, and severe ear infections. Reflux can backup all the way to the eustachian tubes and can cause hearing loss. Armed with this information, I would prioritize the cardiopulmonary system as my primary focus. The internal organs would be close behind. By helping infant Danny meet his survival needs first, it would allow me to more appropriately later focus on his neuromuscular system and to anticipate the need for musculoskeletal and integumentary interventions if they became a problem later on.

Danny: 9 years old

But what about now? Nine years old and 34 surgeries later, he comes to you with thoracic kyphosis and chestwall deformities and oh yeah, that complicated history. Where is he now? At this point, his integument and his internal organs are his greatest impairment to motor performance. It is not musculoskeletal first. That is simply the expression of the "sliver." His integument restrictions secondary to his surgical scarring have caused musculoskeletal restrictions of his ribcage and his spine that worsened as he grew. Unfortunately for Danny, he never met a scar that he could not make adhere. He was genetically inclined to deep scar tissue. The fascial restrictions in turn restricted his chestwall movements thus impairing his cardiopulmonary system. His lung growth was stunted by the restrictive lung condition. His chestwall, in particular on the right side where his ribs fused secondary to the thoracotomy, did not grow and develop normally, creating a permanent atelectasis in his right middle lobe.

His neuromotor movement strategies perpetuated the conflict between his breathing mechanics which were survival oriented, and postural control/balance strategies which are thriving oriented. Unfortunately, for Danny, PTs are drawn to the thriving oriented tasks like gait and balance and play. "Come on, Danny, we will have fun, join in!" However, Danny was sitting there at rest, breathing 60 breaths/minute, thinking; "You go ahead and have fun. I will join you later." This all eventually caused cardiac restrictions due to the internal scarring and the chestwall immobility which caused mechanical compression of his heart's mitral valve.

Integument/Fascia

Take a fresh look at Danny and his scars (Figure 1b). He had multiple surgeries through his anterior neck to repair his airway. The surgeons said he had no skin left to pull together to close the tracheostomy incision. Remember the photo of Danny in prone on elbows (Figure 2a)? He showed more cervical extension via his eye gaze than his actual spine. The skin on his anterior neck is so limited that the only way he can move into extension is to open his mouth and pull his eyes upward (Figure 2b).

The scars from his thoracotomy and chest drainage tubes on his right lateral chestwall caused fusion of ribs 5 and 6, which eventually led to a thoracic scoliosis and to hypoplasia and a permanent atelectasis under that restriction.

He had 2 surgeries that combined to make one long horizontal scar just beneath his pectoral muscles around rib 6. The surgeons used some of Danny's anterior costal cartilage to rebuild his trachea. These scars actually healed well and did not cause restrictions as significantly as other scars did.

Moving down to his abdomen, he had several vertical abdominal incisions including a Nissen fundoplication. The surgeons repeatedly tried to get Danny's severe reflux under control. And lastly, he had a gastrostomy tube (G-tube) placed which he used for a mighty, mighty long time.

Think about what all of these scars did to Danny and what they can do to all of our patients, particularly our pediatric patients who must mature around these restrictions. The patients need these surgeries. Danny would not have lived without them. But how can we pretend for a single minute that integumentary restrictions will not potentially cause severe and profound motor and health problems in the long run.

Internal Organs

His reflux and the mechanical compromises of his GI system led to nutritional deficits, poor weight gain, and long-term damage to the esophagus as well as chronic ear infections that led to permanent hearing loss. The irritation to the airways caused hyper-reactive airways, not true asthma, but extremely hyper-reactive airways and chronic obstructive lung disease because of the multiple aspirations and infections. He now had both obstructive and restrictive lung disease.

Neuromuscular

Danny has demonstrated a preference for extension strategies, likely leftover from his early painful responses to trunk flexion movement. However, his spine and chestwall musculoskeletal restrictions limited his spinal extension. This in turn may have caused an overflow response to his lower extremities and may explain his continued preference for lower extremity extension patterns. The connection between reflux and aversion-extension strategies may make you re-think the cause for his gait deviation. Danny was a toe-walker with excessive functional hip external rotation, tight calves, and incredibly tight hamstrings! Connect the dots: the pain of reflux drove his earliest motor plans from toe-walking on the bottom to eyes-up posturing and hearing loss at the top.

Now re-think your PT program. If you treat Danny's toe walking by simply telling him to practice putting his heels

down, you may not correct his gait. Instead, you will have to look at his reflux and what happens to his gut when he puts his heel down or when he looks down. In other words, to improve his gait, you will have to address his GI system. Of course long term, the consequences of his atypical neuromotor plan for gait can cause pain. And, in fact, he does have right hip pain.

Cardiovascular/Pulmonary

Cardiac stress develops secondary to chronic pulmonary dysfunction. Danny developed cor pulmonale (enlargement of the right ventricle of the heart due to disease of the lungs or of the pulmonary blood vessels), which has led to a high-energy cost of survival. It is a physical challenge for Danny to eat with the mechanical compromises of his reconstructed esophagus and airway, but now add an increased metabolic burden from his cardiac and pulmonary system. It is almost impossible for Danny to consume enough calories to support survival and growth, but remarkably with his effort and his wonderful family's support, he has done incredibly well. With a concerted effort, at age 15, he is 5 foot 2 and 91 pounds; huge by Danny's standards. All of these survival consequences have resulted in poor endurance and limited participation.

PT Priorities Change as Danny Ages

Go back to age 9 years old when he was referred to PT with a diagnosis of "scoliosis" and "tight hamstrings." Do you still believe this is just a musculoskeletal problem?

So, what's the new priority for me as his PT (Figure 7B)? At age 9, I would look at his integument/fascial restrictions first. I have to do whatever I can to release the scars or refer him to another professional either within my field or to a doctor to see what we can do about these restrictions. He is not done growing yet. Then I would look at the musculoskeletal and posture alignment. I need enough skin to be able to do anything with the spine and the other joints. Then when I have better alignment, I can focus on what is going on with the neuromotor control, all of which I hope will improve his gastrointestinal system. The work on these systems will then hopefully lead to an improvement in his cardiopulmonary/vascular system. In other words, at age 9, Danny's treatment priorities are in reversed order from his infantile stage, but his treatment is still planned around an assessment of all 5 systems.

Integument/Fascial Restrictions

As I told you, Danny was an expert at creating scars. (He said if his capacity to scar was a school grade, he would get an A+.) His abdominal scar was so tight that it caused the thoracic kyphosis! He did not have any congenital anomalies of the spine. As Danny grew, his stomach wall did not grow with him, causing his thoracic spine to "grow over" the restriction with a kyphosis. Mobilizing his spine without mobilizing his fascia first would not produce the best results. He needed more "skin" in order to free the underlying spinal and chestwall restrictions.

Unfortunately, traditional fascial releases did not work, and believe me, we tried everything. His entire team of therapists, doctors, and family worked with Danny using herbal treatments to manual myofascial releases to hanging him upside down (facetious)--whatever it took to try to get the abdominal scar to release. In the end, Danny was referred to a plastic surgeon who did a Z-plasty (surgical procedure using a Z-shaped incision) to increase the functional length of the scar and reduce fascial restrictions. They literally revised the scar like a zipper in order to give him a little more abdominal length.

His G tube was removed at 10 years old. He had a persistent pinhole opening, much like a long standing hole from a pierced ear, thus later requiring a surgical closing.

His deep, long midline abdominal scar should make you wonder about the integrity of the underlying viscera. And what about the viscera under the G tube scar? His tracheal scar limited his cervical range of motion and unfortunately, because of his multiple airway reconstructions and the delicate nature of the skin on the neck, he did not have enough skin to do any kind of revision according to the plastic surgeon. Danny will not be able to gain significant cervical motion secondary to his tracheal scar. His functional cervical extension is achieved primarily with his capital neck extensors or as Danny would tell you, with an open mouth and upward eye gaze.

His cervical spine lacks a normal lordosis and his thoracic spine is kyphotic. That should make you suspect that his lumbar spine would present with a compensatory excessive lordosis, but as you see in his prone on elbows photo (Figure 2a), he lacks even a full normal lumbar lordosis. Postabdominal Z-plasty, you see an increase in lumbar extension and a reduction in his thoracic kyphosis (Figure 2b). His tight hamstrings may have significantly contributed to the flattening of his lumbar lordosis. With plastic surgery, his family and PT (he sees his primary PT 1 to 4 times per month, he sees me quarterly), we have a fighting chance to prepare his body for that pubescent period of growth.

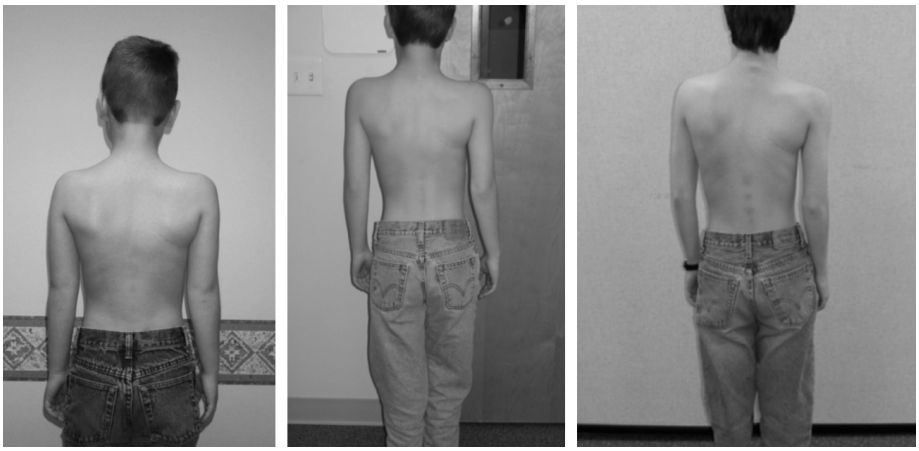
Scoliosis

His thoracotomy was at 6 days old. The surgeons had to save his life, but unfortunately those ribs are so teeny-tiny that right ribs 5 and 6 fused postsurgery.[14-16] It is often the chest tubes that are the most vile when it comes to post-surgical ribcage restrictions in infants. That caused his high thoracic scoliosis that progressed very slowly until puberty. We explored every angle for intervention. We did fascial work from here to the moon to try to hypermobilize the ribs above and below the restriction. A TLSO (thoracic lumbar sacral orthosis) or body jacket as it is more commonly called, was not appropriate for Danny because of his reduced pulmonary capacity.[8,17] If we restricted his thoracic spine enough to try to manage the scoliosis, it would have prevented Danny from using the limited breathing strategies he had. We were more likely to wind up with more severe pulmonary complications.

We even explored the VEPTR surgical procedure (Vertical Expansion Project Titanium Ribs), otherwise known as the titanium rib project, to see if this new surgical procedure could safely manage his scoliosis and increase his chestwall mobility. The surgeons control the scoliosis and the rib spacing by implanting a vertical expanding bar on the rib cage, similar to braces on your teeth. Every 6

months or so, they go back in surgically and crank the bar apart so the scoliosis and rib cage can be manage throughout several growth periods.[18,19] Unfortunately, the surgical team felt that Danny was too old at age 7½. Because of his delicate airway, they felt that the surgery was more of a risk for Danny's health than the potential orthopedic benefit.

Danny's scoliosis progressed from 10° at age 9, to 33° at age 15. The photo shows that the progression was significant (Figure 8). We were unable to prevent the progression, but not for a lack of trying.



Age 9, < 10° **Age 13, 13°** **Age 15, 33°**

Figure 8. Progressions of Danny's high right-sided thoracic scoliosis.

Anterior chestwall scars

The costal cartilage from his lower anterior ribs were harvested to rebuild his trachea and larynx. Finally, manual fascial releases worked. Danny was thrilled that one area of his body out of the 34 surgeries responded to any kind of fascial intervention.

At age 13 as he laterally side bends to his left (Figure 9a), you see a flattening of his upper right chest around the area of the high right-sided scoliosis. I was ecstatic because that was the most open his right chest had ever been. When he side bends to the right (Figure 9b), his chestwall restriction is noticeably lower because of the G-tube site restriction.

Danny's left anterior chest actually looks pretty good. His right side is a little bit depressed. That's not a true pectus excavatum (concave lower sternum, a.k.a. "funnel chest"). That was probably the least deforming and impairing of all of his deformities. Once we addressed his fascial restrictions as best as we could for the moment, it was finally time to do the musculoskeletal interventions of mobilizations, stretches, and a home exercise program.

Neuromotor retraining

Can we strengthen now? Almost. He needs neuromuscular retraining first or else he will just strengthen his old *survival* oriented motor plans. We have to look at his breathing and postural control strategies in tandem because they are the same muscles, so I cannot work on breathing retraining without recognizing that I am simultaneously working on postural control strategies and vice versa. Danny's movement strategies were atypical but they were necessary for his *survival* as a baby. The most common pattern that you see in kids with breathing difficulties is overuse of the trapezius for everything: shoulder flexion, breathing, trunk control, etc. Why? Because when they were infants that muscle was one of the only muscles they could recruit for breathing besides the diaphragm. That motor plan becomes very well solidified.

We needed to reroute his distal control strategies to more proximal control so that he could better regulate his soda pop can's internal pressures. He used what I call, the "interstate bypass route." Those of you who live in a big city know what I am talking about. You take the bypass around the city to avoid traffic jams. Similarly, these kids recruit "distal" muscles such as their trapezius, biceps, and hip flexors to stabilize their core rather than going "through the city," which would require the recruitment of their proximal muscles such as the diaphragm and abdominals.

Danny developed excessive pronation of both feet, requiring orthotic support. He also had tight hamstrings. He used both strategies to maximize trunk extension and decrease gastric reflux forces. It was important to recognize why these postural control strategies developed in the first place before we try to redirect them. From there, we can work on the complicated applications of postural control aspects of balance and gait while continuing to recognize that breathing and postural control muscles are the same muscles.

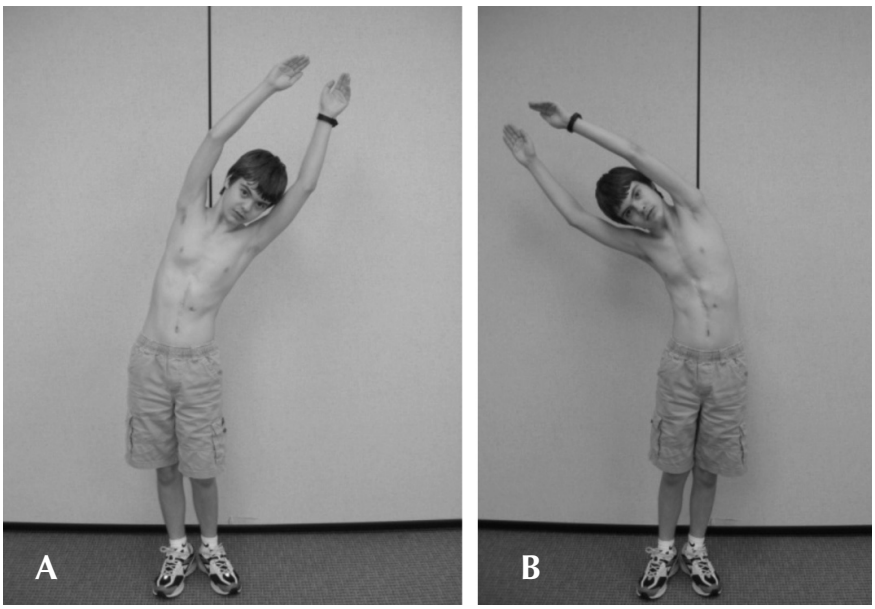


Figure 9. Danny's chest wall mobility in lateral sidebending.
A. Lateral side bend to left shows decreased upper right thoracic cage mobility secondary to right scoliosis
B. Lateral side bend to right shows decreased lower left thoracic cage mobility secondary to abdominal G-tube scar restriction

Internal organs

He is stable at this point. My question to you is, is it good enough? I referred him to this fabulous pediatric GI feeding team and they are continuing to work with him very aggressively using both western and eastern medicine approaches. I plan on doing more visceral manipulation with Danny as soon as I have better skill in this area. He is slowly gaining weight. His food gets stuck in his esophagus, but at this point, he has learned compensatory strategies that effectively get the food through to his stomach. Very surprisingly, he has normal bowel and bladder function. In the long term, I continue to be concerned about the integrity of his abdominal viscera secondary to the esophageal atresia repair and the multiple surgical adhesions.

Cardiovascular/Pulmonary

For many, many years the focus of Danny's program was on *survival*, particularly of his pulmonary system. His airway clearance program has changed with his age and his lung condition. We tried ventilatory muscle training (series of resistive devices aimed at strengthening both the inspiratory and expiratory muscles). Right now, it is still a little too hard for him. He winds up using too much energy becoming fatigued and unable to focus on school. Therapy and life is always a balance. Realistically, you know it is going to be his lungs, and secondarily it will be his heart, that will be his primary limitations to physical activities. I worked very closely with his pediatric pulmonologist to determine when to push Danny and when to back off. Danny also sees a cardiologist annually.

SUMMARY

Time precludes me from going into more detail. I used Danny's case to illustrate the fact that motor impairments are never "just" a musculoskeletal problem or "just" a neuromotor problem, etc. We were not born with a single system. We were born with systems that interact to give us the control that we need for health and for participation. If Danny's motor deficits and the immobility of his trunk was treated from a single system perspective, would he be as healthy and functional as he is today?

After 34 surgeries and 15 years, Danny's story is nothing short of a miracle. The doctors never, ever, thought he would be decannulated (trach tube removed) because his airway kept rejecting all the reconstruction efforts by the surgeons, but eventually he was successful; a miracle. The fact that he ever got his G-tube removed and that he can eat by mouth is even more of a miracle. The fact that he can walk and talk and chew gum, be a normal high school freshman and go to a big public high school, I think is another miracle as well.

But what about tomorrow? Look at Danny's journey. He has come so far in 15 years and if you were a teacher or a PT in his high school, you would not be able to tell that he is not just another normal boy with baggy pants that fall off his hips. But watch out, because I will soon be turning him over to you for therapy as an adult. He will still need to be assessed and treated from a multisystem perspective. He will never be a single system patient. In fact, I would challenge you to find me any patient that is a single system patient.

I challenge all of you to find the problem. I used the concept of a puzzle because I wanted you to see the body's multiple systems as interlocked. Find the problem! Ask, "Why do I see that motor presentation?" Don't simply identify that someone has a shoulder problem or other motor impairment, but ask why is the shoulder problem there? Find the real impairment to the motor performance needed for participation and health. Learn to identify all the body systems, to look at their interactions and to look at which ones are contributing to the problem or the solution. As an infant, Danny's musculoskeletal and integumentary systems played a very minor role, thus, because you looked at all 5 systems, you could overtly rule out the need to treat those systems at the moment. Determine which body system is the primary limitation to motor performance initially and which one is the problem now.

I want you to think about *surviving* and *thriving*. I am in pediatrics, but think about the application to patients in acute care. Most of you can tell me the day that "Mr. Jones" changed from *surviving* to *thriving*. It is usually the day that he laughed at your joke, or that he told you a joke. It is when they are no longer worried about their physiologic state and they can safely allow themselves to think about *thriving.*

Prioritize your interventions. Integrate a multisystem perspective into your daily practice for all motor dysfunctions, low back pain, shoulder problems, spinal cord injuries, stroke...

What is in the future? I think we can do even a better job at differential diagnoses and referrals for every "Danny." We need to recognize not only where the problem is, but when it is beyond our scope. When should we refer to that plastic surgeon? When should we call in the pediatric GI doctor or when should we call in one of our colleagues who has more expertise in a specialty area than us?

I would like to challenge every PT in this room to become a better problem solver, a better puzzle solver en route to becoming that autonomous practitioner. I believe that when we are good at that, the consumers will see us as the practitioners of choice. We will not need to tell them. If we are effective as diagnosticians, we will be better able to plan correct interventions. Thank you.

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