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2014 Section on Pediatrics Knowledge translation Lecture: Clinicians and researchers on the same path toward facilitating family goals for mobility & participation

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Abstract

BACKGROUND—The Knowledge Translation (KT) Lecture at CSM 2014 was a personal perspective from a researcher who had been a therapist and a longtime clinician, now a Ph.D. candidate.

OBJECTIVE—To better integrate research and clinical care, so KT is a seamless rather than separate process.

KEY POINTS—KT can be enhanced by improved receptivity to evidence, and increasing use of research designs that encourage and even require clinician involvement, from single-subject designs to large-scale pragmatic trials. Clinical practice databases and hiring therapists to provide intervention in research efforts also serve to integrate research and clinical care. Limitations of applying mean group research results to an individual patient were also discussed and suggest an important unanswered topic for future research.

CONCLUSION—We all need to assume responsibility for the researcher-clinician partnership, making our jobs more joyful and fulfilling, and hopefully the biggest beneficiaries will be our current and future patients.

Keywords

cerebral palsy; knowledge translation; lecture; physical therapy; research design

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Introduction

Dr Damiano: Knowledge Translation (KT) is a topic that is especially important for our field and has been in the front of my mind during my research career, having been a practicing therapist who was constantly seeking new information for many years prior to that. Our talk will be focused on strategies for getting physical therapy (PT) clinicians and researchers on the same path toward facilitating child and family goals, functional ability and participation through more effective and efficient knowledge translation. When I was invited to do this it took me about 5 seconds to decide who I was going to ask to join me – Dr. Becky Leonard. I first heard of Dr Leonard in the 1990s when I moved to Virginia and I heard multiple families and physicians talking about her with great respect. This session will not be a strictly didactic presentation but will instead be a more personal informed perspective on this topic based on a core belief that researchers and clinicians have a shared responsibility to provide evidence-based therapy for families. We will discuss major benefits and the barriers to knowledge translation, again from our perspectives, and then strategize about the way forward and what can we be doing together. There are many things that each can do on their own, but what are the models for how we can work together? Some strategies may be more effectively driven by the researchers and some by the clinicians and some will involve a more equal partnership such as doing studies together. The underlying therapeutic context for this discussion will be related to improving mobility and participation in children with cerebral palsy (CP).

Individual Perspectives on Roles of Clinicians and Researchers in Knowledge Translation

Dr. Damiano: Researchers and clinicians, given the different nature of their work as well as other life experiences, understandably may have different perspectives and we will each briefly share ours. I worked as a pediatric physical therapist for more than a decade. The last 20 years I have been a researcher. My motivation for getting a PhD occurred while I was working at the University of North Carolina. I used to go on orthopedic surgery rounds and I always had new ideas of therapeutic activities I wanted to be doing with my patients but at that time, we needed physician approval to alter a prescription for PT. Dr. Walter Greene who was the attending surgeon would say to me “You are welcome to do it – just show me the article that supports it.” I’d go look for the article and discover there was no article. This was 30 years ago and there were basically *no articles that provided scientific evidence for therapy approaches in pediatric therapy!* As an example, I wanted to start doing aerobic training with children with cystic fibrosis and Dr. Greene’s response was again for me to show him the article and once again, no article. It was so frustrating to me that he could go to his orthopedic literature and find some supportive data, but we as physical therapists did not have the same scientific resources. The other unique perspective that I have compared to many academic physical therapists is that I’ve never been on a PT faculty. My entire academic career has been in other clinical departments: orthopedics, neurosurgery, neurology, and now physical medicine and rehabilitation, and in a motion laboratory where I have also worked closely with engineers as well as those from diverse clinical backgrounds.

This more multidisciplinary exposure has reinforced the importance of collaboration for implementing new programs and enforcing positive change.

Dr Leonard: In 2008 while at the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) meeting an acquaintance asked me if I heard that Dr Damiano was coming to the National Institutes of Health (NIH) to direct the Functional and Applied Biomechanics Section. Although my office is only 5 miles from the NIH, I did not consider the opportunity to interact personally with Dr Damiano. But in fact, we have shared several clinical as well as research experiences over the years. I have been a lifelong clinician and it is my foremost love. I have had the privilege of knowing children from infancy to adulthood and to be a small part of the journey with the child and family. I work every day with the most energetic, compassionate, talented and wonderful therapists. Thirteen years ago, I was given the opportunity to teach the pediatric curriculum at Marymount University under the mentorship of Dr. Julie Ries and more recently I have taught the pediatric curriculum at Rocky Mountain University of Health Professions.

I went back for my Transitional Doctorate in Physical Therapy at Rocky Mountain University of Health Professions under the guidance of Dr. Jane Sweeney, the director of the pediatric program. On completion, she then encouraged me to apply for the advanced doctoral program in pediatric science, which has opened many doors and for which I am very grateful.

Dr Damiano: You can see that Dr Leonard is certainly not your “average” clinician. She is doing her PhD and is currently planning on doing her PhD thesis project in my laboratory at NIH. We will next share how we perceive our roles and what we expect from those in the alternate role. I believe my responsibility as a researcher is to try to design better and more informed treatment options for children and families. That is what drives me every day. I’ve also challenged those who provide therapies that are not supported by a strong scientific rationale or evidence of clinical effectiveness — and are not helpful or in some cases harmful, and the message has not always been pleasantly received. Anytime you are doing something that does not work, instead of doing something that works better, you are doing harm by omission. I feel it is very important that clinicians stop doing the non- or less effective interventions. I also listen very carefully when we have children and families in our studies and often ask them about what would they like us to be researching - what things are interesting and important for them. I freely offer what I know with them when they ask me questions about the latest science. I have participated in many family conferences where we provide information and talk with families to help them understand the evidence. My other responsibility I believe is to make sure I disseminate my findings and synthesize evidence for clinical audiences.

As for the roles of clinicians, I think it is their responsibility to stay abreast of the literature – at least 1 patient at a time. I feel it is unacceptable not to do so. You would not want to go to your physician and ask for treatment for heart disease or cancer and have him or her say: “well I really haven’t read the literature lately”. I think a clinician should always continually re-evaluate and restructure their practice based on the evidence and use validated tests and measures – we have so many great options now – to monitor the achievement of goals or

progress. Finally, I wish there was a better mechanism whereby clinicians could stimulate research based on the questions with which they are confronted and the ideas they come up with on a daily basis.

Dr Leonard: As a clinician I believe my first and foremost responsibility is to advocate and offer every opportunity for a child to reach optimal functional mobility and fitness. The focus of care is a child and family centered approach. As a clinician, I have learned to be diligent in reading the literature and advancing new ideas with attention to synthesizing and sorting the hype from the hope. As a director of a PT practice, I strongly foster a lifelong learning style, not only for myself, but also for the staff and students with whom I work.

The researcher needs to dialogue with clinicians and families as well to create those clinical questions that are pertinent. They should provide evidence on the effectiveness of our short and long-term interventions that is both consumer-friendly and available.

What is Knowledge Translation and How Receptive are We to New Knowledge?

Dr Leonard: Knowledge translation bridges the gap between researchers and clinicians. It can best be described as ensuring that all stakeholders are aware of and use research evidence to inform their own health and healthcare-making decisions. Who are the stakeholders in KT? They are you and I, our children and families, all the health professionals with whom we work, the policy makers, and the entire healthcare industry including the insurance companies.

Simplistically, we have biomedical research evidence which filters into clinical science; and knowledge that then integrates into clinical practice, and policy-making and implementation, but here is a time efficiency problem with translating the research to implementation. As a result of these evidence to practice gaps, the patient fails to benefit from advances in healthcare resulting in a poorer quality of life and loss of productivity at the personal and societal level.

Dr Damiano: I give frequent talks to PT audiences and struggle with how I can better stimulate individual practitioners to change their practice. The ‘neuroscience’ analogy of KT suggests that we each have a wide range of receptivity to new ideas that closely relates to how “hard –wired” or how firmly held our existing ideas or beliefs are. If you think about how you feel about your religion or your political party, your sense of belonging may be so strong that even though you may be interested in other ideas, you are unlikely to change those core beliefs. An example relating to therapy could be neurodevelopmental therapy or NDT training and certification. Many have invested considerable time and expense to receive this training and have been recognized for having done this, which may account in part for the particularly strong allegiance to this therapeutic approach, even when the evidence fails to support its superiority.

For those individuals with less strong allegiances, or for those beliefs that are not so firmly entrenched, receptivity may be far greater. On the other extreme, being too receptive to new

ideas (analogous to a brain that is too “plastic”) is not particularly advantageous because there is no underlying stability in the system. Sometimes we are still gathering information on ideas that are under consideration, or it may also be the case that we have not yet received or retained information about some new strategies. We may accept them in the future or we may not. Interestingly, the science also tells us that most people are in actuality far less receptive to new ideas than they believe themselves to be.

Dr Leonard: I had an interesting experience over 10 years ago that provides clear evidence of the value of being receptive to new information. I was working with a family who had a toddler with congenital hemiplegia. The mother, when researching therapy approaches learned about the University of Alabama’s work with the constraint induced therapy (CIT) program. She told me “I really want this program for my child, but we cannot afford it. Insurance won’t cover it. What can you do to help me?” At the time I was probably not very far along in understanding CIT and we had not developed CIT programs at our office. I approached Marymount University where I knew the students did a 2-year project. I contacted Dr. Julie Ries and asked if it were possible to do a project with CIT. Could the students perform the literature review, analysis, develop a program, and run the intervention with clinician and faculty support? She agreed and mentored the students in this process. It was an interesting and wonderful clinical experience collaborating with students and faculty. The family, who had the idea originally, participated in an effective CIT program created for their child. Dr. Ries published a paper from this experience and she went on to do 3 more CIT projects with this same kind of group dynamics involving students and clinicians.

Self-Evaluation Exercise

So how do you receive knowledge translation on a day-to-day basis? Does your organization offer you opportunities to be rewarded for your innovative thinking? Are you in a more isolated setting or are you at a major medical center where medical research is happening? Do you have time to think? or are you on auto pilot from the beginning of the day to the end of the day? How receptive are you? What are your attitudes, beliefs, and behaviors? How well do you apply clinical guidelines to your patients? Do they fit with your patients and their goals for treatment?

In 2009, Dr. Schreiber¹ piloted a program with 6 pediatric physical therapists to try to evolve a more dynamic evidence-based practice. He found that the therapists were all receptive, but there were barriers: time constraints, difficulty searching for the right literature, time, the receptivity of their environment to new ideas, and challenges with applying a new idea within the day-to-day schedule.

Dr Damiano: A wonderful article has been published recently on evidence-based therapies for children with CP.² Iona Novak, the first author, is a well-respected researcher who is also well versed in KT. What she and her colleagues have used for several years is a green-yellow-red light system to categorize the scientific support for common interventions for children with CP. Basically, this scheme helps summarize what therapies you should definitely use, which you should be doing with a little more caution, and what not to do, using the green, yellow, and red traffic light color scheme in the same respective order. The review was based on the evidence from randomized clinical trials (RCTs) only on

interventions aimed at spasticity and contracture management and improving motor function. Randomized clinical trial data are the best sources of evidence we have in the field. The relative size of the traffic light indicates how strong the evidence is. As an example, the evidence strongly supports the use of botulinum toxin injections to decrease spasticity but not to improve function. Casting is the a PT treatment that emerges as effective for contracture, whereas stretching in PT for a just a few minutes a week is not enough to improve passive range of motion.

For improving motor activities, it is apparent that intense upper limb training paradigms have the biggest and most numerous green lights – it's our big success story. Goal-directed training, bi-manual training, context focused therapy also emerge as showing some effectiveness, but now we see some approaches that may not be worth it or that we should no longer be doing such as NDT or sensory integration but these are therapies that many people across the world still do, and in many cases almost exclusively. Conspicuously absent among the green lights were strategies to enhance mobility in CP, suggesting that more research is needed in this area. Some strategies such as gait training, electrical stimulation and strengthening were included above the “worth it” line, but RCT data were either limited or not consistently positive. This study is in contrast to a review on lower extremity therapy techniques in CP concluding that strengthening had the best evidence for improving and motor function with some support for the other “yellow light” interventions when considering *all* available evidence.³

There has been a huge response to the Novak et al article² and it is not all positive. If the intervention you most often use was below the worth-it line or assigned a red light, you are obviously more likely to be less “receptive” to this article. It is interesting that now we have accumulated all this good evidence that we wanted for so long and the authors are doing exactly what we should be doing with it which is putting it together and making treatment recommendations, yet practitioners are now resisting it. Some groups who are among the most critical of the findings, in all fairness, are the orthopedic surgeons because it is arguably more challenging to do RCTs in more invasive procedures such as surgery. There is only 1 RCT on multi-level surgery in children with CP published to date⁴ and it had a positive effect on motor function. But it is only 1 trial. Many are now recognizing that perhaps we need to collect and include different kinds of evidence –such as larger scale comparative effectiveness studies that evaluate treatments head to head within the context of routine clinical care. We also need to consider cost effectiveness compared to benefits, including information on how long each intervention seems to last. For example, the duration of benefit from botulinum toxin is typically much shorter than from surgery. The Novak article did not address these issues, which points out some limitations of evidence summaries. Another weakness is that the recommendations in this article were based on mean group analyses of a very heterogeneous patient population and we should not consider a green light intervention as being universally effective. As an example, we know that rhizotomy reduces spasticity. Does that mean that everyone should get a rhizotomy? Absolutely not. So we clearly need to be cautious in translating these findings to individual patients. But from the positive side, this paper has stimulated our collective thinking about what kind of evidence we are producing and what it means for clinical practice.

To finish up on this issue of receptivity. It is important for each of us when we are trying to talk to our colleagues or our families to assess how receptive someone is likely to be. There is a whole science on how to approach people to increase the receptivity which differs based on the person's opinion at the outset. If you are already agreeing with me on most things, it is not going to be too hard to convince you of something new. If you are neutral or uninterested or if you are uninformed, there is also some leeway there. If you have preformed opinions in opposition to the new ideas, you would not be listening with a very open mind. Finally, context can also influence treatment decisions regardless of evidence, such as settings where some of the more expensive or sophisticated treatment options may not be available, such as in smaller centers or in regions or countries with fewer resources. Conversely if a center had invested in an expensive therapy device, they may be biased towards using it even if the evidence does not support its superiority.

Dr Leonard: Each of us should have some self-awareness of how willing are we to change ourselves within the organization in which we work. Back in the 1960s in the agriculture world, Everett Rogers had developed some concepts about change and acceptance of new ideas within groups. His book called "The Diffusion of Innovations", rewritten in 2003,⁵ presented a very familiar bell curve in which 2.5% of a group is innovators. We have our early adopters at 13.5%, and the vast majority of us (68%) are in the middle where some of us adopt ideas early and others take longer to consider it. Finally the last group of 16% includes the laggards who are stuck in their ways and not accepting any ideas of change. Where do you fit in this curve?

We are now going to direct our attention away from ourselves and our organizations to the individuals we serve, each special patient. We are embarking on the era of personalized medicine which is the ability to determine an individual's unique characteristics and to use those distinctions to move your diagnosis and treatment to a successful outcome. What new types of knowledge do we need for this enhanced level of decision making?

The Way Forward

Dr Damiano: How are we to decide what is the optimal PT treatment plan for each individual patient? I love this quote from the autism community that states: "If you've seen one child with autism, you've seen one child with autism" and I think this holds true for any child with a disability. There is much individual variation in children who are typically developing, but this may even be greater in children with disabilities. The whole basis of evidence-based practice, or EBP, came from Sackett⁶ and is defined as "a conscientious, explicit, and judicious use of current best evidence in making decisions about the *care of individual patients*" (my emphasis). So what are the most effective therapeutic approaches for this patient in front of us?

What we have done in CP over the years is to move beyond looking at CP as a homogeneous population which included anybody who had an early brain injury and a motor disability toward realizing and being more vocal about the fact that this is a group of many different disorders. There has been considerable progress in medical science and in genetics and we are better defining what is and what is not CP. Those who have metabolic

disorders and other genetic syndromes may require different types of treatments, which in some cases may be very effective (e.g. treating dopa-responsive dystonia that can mask as CP). Research inclusion criteria have also gotten more precise such as including only those with unilateral injury or hemiplegia or children who have bilateral injury. But these more well defined groups of children still exhibit tremendous variability when we examine their responses to treatment. So we are doing better but we are still not precise enough for the individual unit of analysis.

I will refer you to an article I wrote and which was recently published focusing on the topic of personalized neurorehabilitation for individuals with CP⁷ and will only briefly summarize here. As our knowledge of genetic differences has increased, we have started to recognize that these differences may go far in helping explain why people may respond differently to medications,⁸ or even to interventions such as exercise.⁹ If we perform clinical trials where some patients get far better, some do not change, and some get worse, how can we really justify using the mean result for everyone we treat? Many trial reports do not include each individual's data, but when we started examining the individual results of our intervention studies as well as data from other training studies in CP that were reported, this same diverse change pattern kept emerging. Attempts to explain this variability with more obvious characteristics such as age of the child, severity of involvement or compliance with training have failed to account for this, suggesting other as yet unknown factors are involved. Research designs that explore the relationship of individual characteristics to outcomes are therefore warranted. These can range from single subject designs (n-of-1 studies) to large databases that link detailed patient characteristics to better and worse outcomes across interventions. These types of designs are ideally suited to greater clinician involvement in research. Therapists could perform n-of-1 studies on every patient. If they regularly used objective assessments, outcomes could be tracked during the course of care, and if they wanted to demonstrate that a specific intervention alone was responsible for the change, the intervention could be temporarily withdrawn and the patient reassessed. A growing push in medicine is to conduct pragmatic clinical trials within the context of clinical care, and feed information directly back to the clinicians for implementation, which provides direct and far more expeditious knowledge translation. These trials have already been done successfully for spinal cord, stroke, and more recently traumatic brain injury rehabilitation,¹⁰ and are ideally suited to a heterogeneous population with high response variability such as CP. What they have found not to be effective for patients in acute stages of brain injury is to be working on lower level activities like bed mobility or trying to articulate sounds. What they found to be effective were higher level activities. Get patients up standing and stepping, even if they are still semi-comatose; have them work on functional skills, functional language. So therapy progression is totally flipped around. Before, we were trying to progress patients along a sequence from simple to more complex activities, but this was shown not to be effective. Centers that participated in these studies have actually started to implement these findings and are tracking outcomes prospectively in their patients to see if they are different. What this approach involves for therapists is point-of-care documentation since we do not have sufficient data about what is done in therapy in an electronic medical record. It might be possible to do this alternately by utilizing more specific billing categories, e.g. do not just state that we did "general exercise", but instead document exactly

what we did in the therapy session. In her studies, Dr. Susan Horn¹¹ has used a separate form that was designed by the therapists participating in the research that is point of care documentation listing all possible types of exercises that would be done with this patient group, and the time spent in each relevant category. The form takes less than 30 seconds to fill out and then it can be scanned and fed directly into a database. As an example, you would check off gait training or strengthening and fill in how much time spent in each. Ultimately each of those activities would be associated with better or worse outcomes. Everybody who comes into your clinic is enrolled. Everybody is measured and tracked over time. You put in what you did. Every other assessment or procedure that was done to them is also documented from the clinic note and other medical records and then the data are analyzed. And then since the clinicians are all part of the process, they can readily understand the feedback from the data which is often in the form of direct clinical recommendations (e.g. do more X, do not do Y) and then they can implement this almost seamlessly. You can see how much faster that information gets into clinical practice, as compared to the traditional process of researchers collecting and publishing data that somehow filters down into the clinical realm – or not. Collecting data within the context of clinical care is a process that would best be accomplished through collaboration between researchers or clinicians. Researchers can design the study but they do not generate the data. They are not running the clinics; they are not seeing the patients. A great example is Dr Leonard who was trying to design a clinical database all on her own and trying to figure out what kind of data she needed to collect. Partnering with or having Just a few conversations with people who do this every day can help guide the process of identifying what you want to measure and which are the most effective, efficient and appropriate outcomes to use. Working together more could be so powerful for our profession. Clinicians would have data to show that their clinic has excellent patient outcomes and these data could further be used as justification to consumers and to insurance companies to support our interventions.

Dr Leonard: For those of you who were at the research forum at CSM 2014, Amy Bailes and Laura Prosser both presented the critical value of the electronic medical records. Our office wanted to improve our electronic medical record to be thorough yet efficient. Our practice purchased a system with a pediatric template in it. The template did not work for us. The need to develop our own algorithms became apparent and we are now doing just that. Our goal is to build algorithms based on the Guide for Physical Therapist Practice¹² and be inclusive of the International Classification of Functioning, Disability and Health (ICF).¹³ This effort has spanned over a year with the entire staff and continues as an on-going project. Developing a thorough electronic record must allow for accurate collection of data in a timely manner. We are challenged to create a database which provides sufficient information for insurance mandates, education for families, as well as the ability to be used for case studies, retrospective studies and comparative effectiveness studies.

The Role of Families in Their Child's Outcomes

Dr Leonard: Dr Damiano discussed patient factors that modify outcomes; however, there are many other external factors that shape outcomes. As a clinician one of the first modifiers that comes to my mind is our families. As stated so eloquently by Dr. Peter Rosenbaum at the AACPD meeting this fall, "the family is the single most important environment in

which the child lives. In the context of working with children with disability, we have to pay attention first and foremost to the family". I ask each of you to think about a family that you remember as being truly remarkable how they balanced their life and helped their child achieve an optimal functional mobility despite the disability. Or think about a family who, no matter how hard they tried, faced too many barriers to help their child to an optimal level. I am sure each of you has stories that we could all share enthusiastically as learning points. Families are critical for our treatment successes. I have selected some quotes from our practice that speak to the challenges the families have:

"When I come to therapy I get great ideas; when I go home life happens."

"My niece always makes gains in her 3 weeks of intensive PT, but when she goes home the carryover is minimal and she does not keep those gains."

"My personality has always been FedEx – I like things done really quickly. When my son was born with a disability, life got very hard because everything slowed down so much."

"When our son was first diagnosed I remember how overwhelmed we felt. We had wonderful therapists. Each one filled a notebook with 20 minutes of activities. It felt that dire consequences would follow if we did not do every homework assignment. I tried very hard. I remember how exhausted I was."

Family dynamics are complex. Think about those families that did extraordinarily well or those who had barriers. Raina and colleagues¹⁴ have described caretaking with influences affecting the ability to be fully competent and informed. She discusses the following categories: the background of the family; the socioeconomic level; the educational level; 1 parent working; 2 parents working; single parent. They all have their context. What about the child's disability? These authors identified that the child with the most severe physical disability or the most severe behavior placed the greatest stress on the family in terms of management. All of our parents and caretakers come with unique personas and temperaments that affect their response to having a child with a disability, which we need to take into account. We also need to consider the caring/supportive factors around our families. What kind of nuclear family support do they have? What about the extended family and the influences? Does the medical community, educational community and community at large help or hinder them? When we think of evidence-based work and moving our children forward, we must remember the triad of best practice with the patient values and expectations and what each family is capable of doing. From contemporary motor learning theory, we recognize that practice is essential but do we understand the effect of this for families? We need to find ways to help the family give practice and opportunity to their child.

Bartlett and Palisano¹⁵ conducted interviews with therapists to identify factors that were most important for motor outcomes. One of those factors was families and family attributes. The authors noted that no research evidence existed regarding the role of family attributes on the acquisition of motor abilities of children with CP. But as clinicians we know how important family attributes are. In a more recent article Almasari, O'Neill and Palisano¹⁶

presented a pediatric rehabilitation model that emphasized the shared responsibility and family empowerment.

We may wonder sometimes how effectively we teach our families; what are our perceptions of the family success in achieving effective home programs? At Cincinnati Children's, they assessed their torticollis home programs and they completed a small research study to explore using motivational interviewing techniques for improved home program outcomes (personal communication). They explored how therapy affected the parental perception of services and also the number of treatment services to reach independence in the home therapy program. They used a transactional model of learning and teaching, and trained a group of therapists to use motivational interviewing techniques, using open-ended questions avoiding the yes-no questions. Techniques were developed for interacting with and coaching parents. They compared a group of therapists and parents who provided their typical standard of care versus the therapists and parents who used the motivational interviewing techniques. In the small pilot project they assessed the parental perception of family centered care. They found no statistical difference in the Respectful and Supportive Care scale between the groups, but a significant difference in the Enabling and Partnership scale was found favoring those who had received instructions by therapists trained in the motivational interviewing and coaching. As a final point of learning, Cincinnati Childrens' documented the family home program success by evaluating the families: Are they able to do the home program? Are they independent or progressing toward the skills that were needed? More qualitative research is needed to understand the dynamics of family-therapist interaction and to measure how effective it is.

Research and Clinical Outcome Assessment on a Patient-by-Patient Basis

Dr Damiano: Earlier we discussed the need for clinical databases and large-scale comparative effectiveness studies. Another important clinical research approach on the other end of the spectrum as far as sample size which is single subject design. Dr. Susan Harris had championed this methodology in PT practice for many years, but few seemed to be listening to her. But she was right. Methodologies and statistical analysis techniques for single subject design can be very sophisticated and rigorous. For those of us who like to assess mean groups effects and are concerned about the generalizability or external validity of results, these are still possible using n-of-1 designs with sufficient replication of cases. The value though is that we can also very clearly see what happens at the individual level. From a research standpoint, when you see a clear effect after you administer a treatment that was not present in the baseline or in the periods when the treatment was not administered, the internal validity is incredibly strong. If I were to return to PT practice, I would basically want to evaluate each of my patients using a single subject design. I would want to use the most appropriate assessment prior to starting treatment to measure progress on patient-identified therapy goals and follow them over time so I would know whether the treatment plan was effective or if and when it required modifications. If this type of practice were common, we would have data on every single one of our patients. It is also very motivating to patients to track progress. "You've been coming here for x-many months, and this is how much you have improved"; how powerful is that?

Dr. Laura Prosser designed a single subject early intervention study when she was a post-doctoral fellow with me at the NIH. We developed a novel intervention approach using an over ground harness system that we were not at all certain toddlers would be willing to tolerate, so we first tested feasibility as well as preliminary effectiveness on a case-by-case basis, with replication. The mobility training program was designed to simulate how infants without a motor disability acquire motor skills and addresses the overarching context for this talk which is enhancing mobility in the lower extremities. Infants developing typically use a trial and error approach when attempting new skills and often experience many failures (e.g. falls) before they achieve consistent success. No one has to teach them these skills; their learning is all self-initiated, given the proper environment. The harness simply unweighted them so that anti-gravity movements were easier and then self-initiated movements were encouraged within an environment of toys and other equipment that encouraged motor exploration during the treatment session. We enrolled 5 toddlers, all of whom had CP and at least a 4-month motor delay and we tracked their rate of motor development through multiple assessments during a baseline, an intervention phase and a follow-up period. The results are published¹⁷; but what is most relevant for the discussion here was how useful this design was to evaluate the treatment effect not just within but also across individuals. Four of the 5 children had a measurable increase in developmental rate in the intervention phase compared to a same length baseline and follow-up phases, with only the most-mildly affected child not showing this because she started taking independent steps for the first time in the baseline period, so she made her greatest gains then. This design could easily be implemented in a clinical setting. If you are doing periodic assessments of patient progress, you could add new interventions into your program for short periods and see if these alter the child's trajectory. You can try on- and off-periods to see if the effects vary with and without the intervention. At the very least, you will be able to closely monitor outcomes in your own practice, and if an intervention seems to be particularly promising, you could submit a case report or team up with some researchers in your area to study this further.

In summary, future directions in CP research that are likely to influence the effectiveness of our intervention aimed at improving mobility are the efforts to increase diagnostic precision and early detection of CP. Recent data suggest that we should incorporate into any clinical trial or comparative effectiveness study that may be conducted genetic data that may provide insights into individual patient response variability. We clearly need to be making far greater efforts together to start collecting data in the process of everyday clinical care with those who are providing that care. As a researcher I should be spending more time mentoring clinicians and doing active collaboration with them.

A final recommended strategy that I have used successfully in the past is to hire practicing physical therapists to deliver the intervention. The idea is not novel, because I participated in several studies when I was a clinician, but this strategy is not used as much as it could be. I did this for a strengthening study, which worked extremely well and was very motivating to the therapists to try a new intervention that was not something they would typically do and to see if it was effective (it was!) Reimbursing therapists for their time to participate in research seems like a win-win situation for researchers and clinicians, but also could be a win for the patients and families as well. This would also help solve one of our persistent problems of patient enrollment. We struggled to enroll 30 children with CP over several

years to participate in 1 of my studies but when you visit Dr Leonard's PT practice, appropriate participants seem to be everywhere. This is the key message here. We need to find ways to forge this partnership. It is all of our responsibilities and could make all of our jobs more joyful and more fulfilling if we work together, and hopefully the biggest beneficiaries will be our current and future patients.

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