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# CLINICAL DECISION-MAKING IN TRANSITION TO CONSULTATIVE PHYSICAL THERAPY SERVICES FOR A NINE-YEAR-OLD GIRL WITH SPASTIC HEMIPLEGIC CEREBRAL PALSY: A CASE REPORT

Ву

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### **CAPSTONE**

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#### Abstract

**Title** Clinical decision-making in transition to consultative physical therapy services for a nine-year-old girl with spastic hemiplegic cerebral palsy: A case report.

**Background** Although many pediatric patients with non-progression conditions utilize rehabilitation services, clear pathways towards transitioning away from direct service aren't adequately addressed in the literature. A number of established frameworks for clinical and ethical decision making can be utilized.

**Purpose** The purpose of this case report is to illustrate the application of established frameworks in the literature to a particular case of a nine-year-old female patient with mild spastic hemiplegic cerebral palsy receiving weekly home-based physical therapy services, in which the ultimate decision was to reduce services, highlighting the utility and limitations of such an application.

**Case Description** This case is a nine-year-old Caucasian female with mild spastic hemiplegic cerebral palsy receiving weekly physical therapy services in her home.

**Outcomes** The clinical decision-making process based on the literature and employed in the study was considered successful due to agreement of clinical expertise, supporting relevant literature, and acceptance to implementation by the established stakeholders, including patient and family.

**Discussion** The utility of the clinical and ethical frameworks in successfully guiding clinical decision-making were illustrated in this case.

## **Background and Purpose**

### **Problem Statement**

Patients with congenital, non-progressive conditions, such as cerebral palsy (CP), are major utilizers of rehabilitation services<sup>1</sup>. Beginning with the end in mind when planning treatment for these children<sup>2</sup>, as with all patients, should be a theoretical underpinning for clinical planning and decision-making<sup>3</sup>. Chronic conditions such as CP are typified by their non-progressive physical limitations, making decisions concerning the point at which discharge may be appropriate less than straightforward. As there are multiple elements to consider when making the decision to cease or reduce services for this population, physical therapists (PTs) can use a mixed-methods approach<sup>4</sup> grounded in the evidence-based practice<sup>5</sup> (EBP) model to guide this complex process.

## **Background**

Multiple evaluation and assessment tools for use in pediatric patients with CP have been described in the literature and are commonly used clinically to quantify a functional baseline and gauge patient progress. These tools include the Gross Motor Function Classification Scale (GMFCS)<sup>6,7</sup>, which classifies patients with CP from I-V in terms of increasing requirements for assistance in mobility and ambulation, the GMFM<sup>1,6,8</sup>, often considered a gold standard for motor performance in children with CP, and BOT-II<sup>9,10</sup>, utilized

in school-aged children of varying diagnoses to assess gross and fine motor as well as motor planning. The BOT-29 is norm referenced to a typically developing population, while the GMFM is referenced specifically for a population with CP. As such, in individual patients with a non-progressive condition, such measures can establish a baseline upon which to assess change over time. The GMFCS establishes a broad category considered more descriptive then mutable, expected to plateau near early school age<sup>6</sup>. Despite the reported utility of these outcome assessments in quantifying limitations in body function, they may not be adequate to capture patients' full rehabilitation potential<sup>4,11</sup>, particularly true for patients with a LLD. A functional plateau in a patient with a non-progressive lifelong disability (LLD) is expected<sup>6,12</sup>, but whether it is indicative of stasis at a poor condition or an individual's peak performance is beyond the utility of these instruments; therefore, rehabilitation therapists must view plateaus in standard assessments not particularly sensitive to this population, such as the BOT-II<sup>9</sup>, or classifications in which change is not expected, such as the GMFCS<sup>6</sup>, cautiously and as isolated elements in a greater clinical picture<sup>6,11</sup>. Rather than relying on individual tools with questionable applicability to a given case, and that, more importantly, provide a snapshot rather than the complex global assessment that considered clinical decision making demands, the question may be viewed as one of complex patient management.

Three interconnected pillars comprise the EBP matrix now widely utilized by health care practitioners: research, clinical expertise, and patient preference<sup>5,13</sup>. Health care professionals have further developed and utilized models to guide clinical decision making in evaluation, such as the World Health Organization (WHO)'s International Classification of Functioning, Health and Disability (ICF) model<sup>11,14</sup> and in ethics, such as the Realm-Individual Process-Situation (RIPS) model<sup>15</sup>. Physical therapists have described and analyzed the use of such models in a rehabilitation specific context in children with CP<sup>16</sup> and have further proposed the RIPS model and American Physical Therapy Association (APTA) Code of Ethics<sup>17</sup> to assess the ethical aspect involved in decisions to discharge or reduce services<sup>18</sup>. Tools such as the ICF model, RIPS model, and the APTA Code of Ethics, respectively, encompass the breadth and depth of case-specific decision making more adequately<sup>4,11,18,19</sup>. These models have been described in the literature, and may be used to formalize the clinical expertise portion and patient preference portions of our EBP model as an integral, sometimes overlooked, adjunct to the former<sup>4</sup>.

#### Purpose

The purpose of this case report is to analyze a particular case of a nine-yearold female patient with spastic hemiplegic cerebral palsy receiving weekly home-based physical therapy services, in which the ultimate decision was to reduce services, based on established frameworks in the literature, highlighting the utility and limitations of such an analysis.

## **Literature Review**

## **Evidence Based Practice: Models for Application**

The models used for analysis have been described in the literature presented above. Specifically, the ICF is the new standard format for representing complete patient management, comprised of an interconnected, non-linear analysis of the following domains: health condition, body structure and function, activity, participation, environmental and personal factors<sup>14</sup>. This language and structure, adopted in the latest version of the APTA's guide to practice<sup>20</sup>, will be utilized throughout this report.

The model has been lauded as an organizational tool that effectively draws clinical attention away from a narrow focus on limitations in isolated body structure and function, which may not correlate with meaningful gains or patients goals, and toward a more complete picture of patient as a whole for the general popuation<sup>4</sup> and in regards to patients with CP specifically<sup>11</sup>. Rauscher and Greenfield<sup>4</sup> argue for a mixed-method approach in which quantitative data is augmented by an investigation of contextual factors, personal and environmental, to capture the complexity of an individual patient case in a more holistic sense. Qualitative research can further provide guidance in identifying stakeholders whose perspectives the PT

should seek and incorporate, as well as anticipated areas of greater and less concern for the focus of rehabilitation<sup>4,21,22</sup>.

The models are just a tool to organize the myriad of data considered in administration of this patient case. Further literature provides guidance in the types of abilities and limitations that may be expected in this patient population, as well as potential interventions to optimize or address them, respectively.

## **Body Structure, Function, and Activity**

Several studies have described limitations in function and activity in elementary school aged pediatric patients with spastic hemiplegic CP. Research has highlighted the importance of access to direct services for pediatric patients with CP beyond the early intervention age range, particularly in an effort remediate students that may never have received services, who may not have had follow through at home or school, or who may benefit from the application of new understanding of the concepts of motor control or motor learning that may lead to real gains in function and participation for this population<sup>23</sup>. Multiple applications are described in the literature.

Goble, Hurvitz, and Brown tracked proprioceptive ability through arm targeting activities in eight children with spastic hemiplegic CP versus a typically developing control group <sup>24</sup>. A difference in proprioception as gauged by performance was noted, primarily in patients with right side

damage. Kenyon and Blackinton described the use motor control strategies to address a five-year-old boy's limitations in safety and attention to task in a complex environment <sup>25</sup>. Akbari, Javad Zadeh, Shahraki, and Jahanshahi Javaran noted improvements in tonicity and increased GMFM scoring in a control group trial of 15 children with CP, seven of which were hemiplegic<sup>8</sup>, with a therapy goal of subsequently reducing dependence on parents or caregivers following the period of intensive treatment. Anwer, Equebal, Kumar, and Nezamuddin found improved gait parameters and an improved WeeFIM score in another 12-year-old male with right hemiplegic CP, after completing closed kinetic chain therapeutic exercise and lower extremity (LE) stretching for 30 minutes per session, three times weekly for four weeks<sup>26</sup>. A systematic review on the effects of stretching in children with CP encouraged novel approaches and a move towards community-based activity in gaining and maintaining flexibility long term. A systematic review by Chiu and Ada on the effects of functional electrical stimulation in children with CP suggested benefits in some children over no therapy, but little difference compared to activity training<sup>27</sup>. A systemic review by Frankie on EBP for physical therapy for lower extremity function found some benefits predominantly in the area of body structure and function, and those that effect patients with a higher GMFCS, such as increasing bone density<sup>28</sup>. Some benefits in activity were noted in the activity domain regarding gait, while a paucity in the literature addressing participation was noted<sup>28</sup>.

this is the area we can impact most but least cited by parents of children with CP in qualitative reflection<sup>29</sup>.

## **Case Description**

### **Patient**

The patient was a 9-year-old Caucasian female with right spastic hemiplegic CP who had been receiving uninterrupted rehabilitation therapy weekly in her home since she was seen for Early Intervention (EI) as a child. She was classified as GMFCS I, meaning that she was independently ambulatory without assistive devices over level ground and stairs. The patient was being seen once weekly for an hour per session in her home after school. Her condition had led to interventions throughout her development. She has not received any systemic tone management but has undergone two bouts of serial casting, most recently just a few months prior to beginning with the current PT. At this time she had no active dorsiflexion, but her passive range was functional. She had day and night ankle foot orthoses (AFO)s, but reported wearing only the night braces for reasons of cosmesis. She was receiving concurrent speech and occupational therapy services in her home. She lived at home with both parents and a typically developing sister one year older. Her mother and sister were home, but not present for therapy. The PT routinely arrived a few minutes before the patient returned from school to obtain subjective history from her mother. She and family

reported being able to participate functionally in all of her roles as student, daughter, and cheerleader. They reported her occasionally needing additional time for learning routines or adaptations such as basing for a stunt on one rather than the other side of a pyramid to take advantage of her stronger side. With these minor adjustments she was always able to perform to her own and her team's expectations. She attended a mainstream school where she received speech services, but did not qualify for PT services as her limitations were not found to have an educational impact, per parent report.

## Setting

The researcher, a student physical therapist (SPT) treated her over a course of seven weeks. The clinical instructor (CI) had treated the child in EI and again from ages six to nine, weekly in her home. At the outset of this episode of care, the SPT and CI began to outline a plan of care based on her history, current functional limitations, and expressed goals. Stemming from discussions between the SPT and CI as to the effectiveness of continued PT for the patient, the focus of therapy became to assess the benefit of PT based on her current functional status.

This home-health setting is a relevant site for inquiry into the utility of applying established clinical decision-making frameworks as the PT is often alone in this setting; such isolation highlights the need for a normalized framework by which to record, analyze, and share one's process of analysis

to aspire to quality care that withstands critical, objective analysis. The format of therapy was also such that the PT was the main point of contact in the treatment team for the patient and family, further emphasizing the PT's role and responsibility in integrating the patient and family's needs into therapy, and providing them timely and accurate recommendations, referrals, and education. The SPT-CI relationship of inquiry and dialectical reasoning further encouraged exploration of a mixed methods analysis of discharge planning for the patient.

## **Development of Process**

### **Considerations and Rationale**

To elucidate the extent to which this patient will continue to benefit from skilled PT, it may be more efficacious to begin the point of inquiry not through an analysis of the patient's performance, but an analysis of PT practice and, therefore, its potential impact.

**RIPS: Stakeholders and ethical considerations.** The RIPS<sup>8</sup> model, illustrated in Figure 1, was initially employed to identify the stakeholders involved and most appropriate agents and areas of intervention.

Figure 1: RIPS: Model (adapted from Kirsch)<sup>15,18</sup>

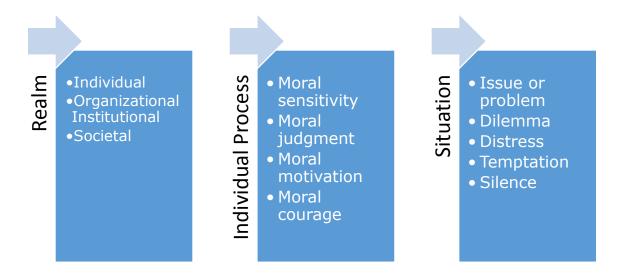
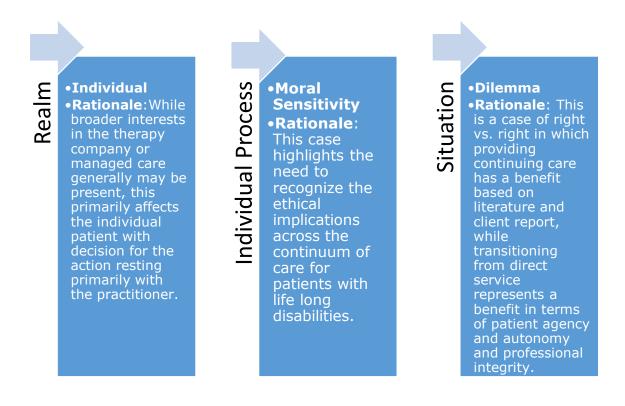


Figure 2: RIPS: Application (adapted from Kirsch)<sup>15,18</sup>



The findings are illustrated in Figure 2. The realm identified was primarily individual, as the patient and her family, and the treating PTs were the essential parties of interest. Additional areas of concern were at the organizational level, considering the interest of the physical therapy company through consultation with the senior therapist in the organization, and societal, addressing professional accountability to insurance for reimbursement and high professional standards of care<sup>17</sup>. These were the primary stakeholders in the process, whose interests were to be incorporated in the decision.

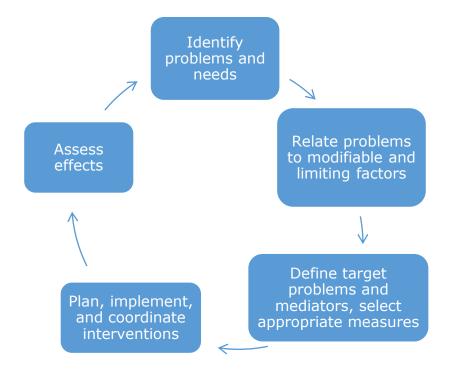
The individual process identified was that of moral sensitivity, in which the decision-making party recognizes the situation as moral decision out of maintaining status quo, which in this case was continued direct care. The ethical situation involved was found to be the issue, in which values are challenged as multiple courses of action could be viewed as right. A final analysis with the RIPS model and APTA Code of Conduct should ensure that the outcome of the prior steps satisfied professional and ethical obligations on the part of the PT.

## **Determining outcome**

ICF model. The ICF model will be utilized to identify areas of limitation and potential associated goals and interventions. The Rehab-CYCLE model, shown in Figure 3, a cyclical process model based on the ICF framework, will be utilized to document the evolving PT diagnosis and

prognosis. The PT diagnosis, based on this analysis, will describe the health condition, body structure and function, activity, participation, and the personal and environmental factors. A prognosis will be established based on the elements identified that can be addressed by PT interventions, including clinical appropriateness describing the degree to which PT can be anticipated to mitigate those elements.

Figure 3. Rehab-CYCLE based on Steiner et al.<sup>11</sup>



**Investigators.** The CI and SPT independently, based on each practitioner's clinical reasoning, detailed the patient's clinical presentation and results of subjective reports through the models described, then compared results. In the event of disagreement, a senior clinician was to provide additional clinical input on the items in question. In the event of

agreement, the mutually devised plan would be presented to a senior clinician, the patient, and the family.

**Rationale**. These analyses should encompass all areas of the EBP model, demonstrating through theoretical triangulation that the clinical decision reached complies with current definitions of high quality care. The application of different paradigms through "dialectical reasoning," has been described as a key element of expert clinical reasoning<sup>21</sup>. Therefore, rationale for the use of mixed methods and concordance of multiple investigators follows from the theoretical base in the literature<sup>4,21,30</sup>. Integration of data through concurrent and theory triangulation through concordance of multiple stakeholders and multiple methods of inquiry improves content validity strengthening completeness of the process<sup>30</sup> and of the clinical picture<sup>4</sup>. The use of investigator triangulation through independent analysis of multiple investigators increased the reliability of the use of these tools<sup>30</sup>.

## **Measuring success**

Success, based on the EBP model, should be demonstrated through consistency with the literature, agreement of clinicians, and expressed satisfaction by the patient, and in this case, the parent. Concurrent triangulation of those interconnected pillars of the EBP matrix, research, clinical expertise, and patient preference, indicate the holistic clinical picture was satisfactorily encompassed in the decision-making process. The

development of the process, as described, addresses consistency with the literature. Agreement of clinicians, and established guides to clinical practice, address the element of clinical expertise. Parent and patient reports of satisfaction will indicate successful integration of their qualitative input in the process<sup>2,31</sup>.

The ICF, Rehab-CYCLE, and RIPS models would be completed by the SPT responsible for this seven-week episode of care as well as the CI. The practitioners would then compare their analyses to improve reliability of their individual clinical expertise. The practitioners should agree in at least 80% of the information entered, with another senior PT being consulted on any areas of disagreement. Failure to resolve the decision in this way will be considered a failure of the decision-making process. The independent analyses of two practitioners, with a third PT consulted, improves accountability and reliability of the process, encouraging replication of the process for other clinicians.

While the patient, and in case of this minor, family's preferences are a key part of the decision-making process, the decision will ultimately be made by the health care team. The patient and family's satisfaction with this decision will be further sign of success of the process<sup>31</sup>.

## **Application of Process**

The following section details the clinical impressions as documented by both PTs, the concordance with literature on interventions and ethics as relevant

to the case, as well as the acceptance for implementation of the decision taken by the other stakeholders, the senior clinician, and the patient and her family.

#### **ICF: WHO Model**

Figure 4: ICF:WHO Model to analyze clinical situation. Adapted from 11,14

Health Condition: Spastic hemiplegic cerebral palsy GMFS I. Not modifiable through physical therapy.

**Body structure & function**: multiple limitations identified

Activity: a series of skills identified and addressed through GAS goals

Participation: No limitations currently reported in roles in family, school, friendship, or cheerleading team

Environmental Factors:
Family encourages
participation, financial
resources for therapy &
community activities,
emphasis on cosmesis

Personal Factors: very competitive, difficulty attending to task, views therapy as hassle.

**Health Condition.** In terms of her health condition, both clinicians and literature concurred that physical therapy interventions cannot affect this domain for patients with CP. It is a non-progressive, congenital disorder not modifiable in this fashion.

**Body Structure and Function.** In the realm of body structure and function, multiple limitations, and corresponding opportunities for PT intervention, were identified by both clinicians. These limitations, as well as history of and potential for treatment through physical therapy are detailed

as follows. Limitations in passive range of motion (PROM), could be addressed through stretching<sup>26,28,32</sup> or orthoses. Limited active range of motion (AROM) could be addressed through FES<sup>27</sup>. Strength could be addressed through a variety of resistive and functional exercise methods<sup>8,26,28,33</sup>.

**Activity**. Gait deviations were noted through formal observation by both clinicians, though she was considered to have plateaued based on her history of therapy. Her mild deviation were in part due to the body structure and function limitations described above, including absent active right ankle dorsiflexion. She was fully independent and did not report complaints of gait. She was found by both clinicians to require increased time as well as verbal, visual, and tactile cuing for motor control/motor learning. A series of skills the patient wanted to master were identified, including the ability to jump and kick in prescribed ways as required by her cheerleading team. Establishment, progression, and attainment of these goals were documented through goal attainment scale (GAS) goals<sup>33</sup>. These goals are set by and for patients individually with a self-designated goals, allowing them to be more sensitive to change for children being seen long-terms with a nonprogressive disorder. Because of the non-standard nature of the instrument, standardized psychometrics are not established, however their utility remains clinically<sup>33</sup>. Though the skills changed over the course of therapy, the methods applied to facilitate motor control and motor learning were

consistent, using knowledge of performance and results to improve quality and timing of movements<sup>12</sup>.

**Participation.** The patient and her family reported no limitation in participation in her various roles as student, cheerleader, and family member. They reported limitations primarily in the domains of body structure and function and activity, the latter indicated as being of greater interest than the former.

Personal. She participated in therapy sessions but did not follow through with home programs, making her adherence inconsistent, as sometimes noted in the literature<sup>31</sup>. Cosmesis was another major factor for her, as she avoided activities or devices that drew attention to her health condition. The factors that brought a positive impact were her sociability, willingness to try, and competitive drive in pushing herself to improve on her previous best. This pediatric patient, age nine, assented to transition away from PT services. Although she was not yet of age to legally make decisions, her input and expressed satisfaction were integral to development of her plan of care, including reduction in services<sup>34</sup>

**Environmental**. Parent attitude was a significant environmental factor. The mother often reported that the child had completed more of her HEP than the child claimed to. She expressed frustration and relative low value to the HEP as it added stress for the parent, was difficult to enforce with her child, added fatigue, and took away from other activities, such as

homework time, the same complaints reported in the a qualitative study of parents of children with CP and HEP compliance<sup>31</sup>. <sup>29,31,35</sup> Low adherence to other recommendations of PT, such as use of AFOs, was explained through an emphasis on cosmesis, echoing parent concerns on their child standing out or appearing different<sup>31</sup>. This sentiment also contributed to the positive influence of the parental influence on environment, as her parents encouraged her full participation in mainstream activities without projecting difference or disability on her performance. The patient's mother reported having assuming her daughter needed to continue therapy, having never been aware that transitioning away was an option.

Findings. The PT diagnosis at the conclusion of this process was that her impairments were largely not modifiable by PT, except in the realms of body structure and function. This is the area found in subject interview of the patient and her family as well as in the literature to be of least importance to the patient and her family<sup>29,31,36</sup>. The activity realm can be, and had been up to that point, addressed by goals through the GAS<sup>33</sup> and ICF<sup>19</sup>. Ultimately, however, instead of achievement of a series of isolated skills, a higher-level and over-arching PT goal would be mastery of the processes for improved motor control/learning such as visual cues, breaking down skills, and varying practice. The process could then be repeated independently by the patient and her family as the need to learn new isolated skills inevitably arose.

Rather than continued weekly skilled PT, new community-based skilled recreation is the more appropriate arena for the selection development of such skills<sup>32,37,38</sup>. Participation in this type community-based recreation may also provide benefits in terms of some of the remaining limitations in body structure and function<sup>32</sup> through novel methods rather than home exercise and orthoses, which had met with inconsistent adherence in the patient previously. Furthermore, research indicates that locating appropriate leisure and recreational opportunities for their children is a chief concern among parents of children with CP, most markedly those with children of GMFCS Level I<sup>35</sup>. Client-centered rehabilitative care with an emphasis on collaboration can be an essential support in this transition to lifelong recreation for pediatric patients with chronic health conditions<sup>8</sup>.

## APTA Code of Ethics 17,18

Revisiting the RIPS model, the findings at the completion of the project indicated that while the ethical issue concerned a right-vs-right scenario, one outcome more completely addressed the patient's holistic needs.

Specifically, although the care provided was beneficial, freeing up the girl's time for other pleasurable activities while simultaneously empowering her and her family to take ownership of her condition was also an undeniable good.

Methods for decision-making based on the findings of the model included rules based, ends based, and care based<sup>15</sup>. In this particular case, the

degree to which the decision to transition away from direct and towards consultative services is consistent with established professional rules for conduct can be analyzed through several key principles established in the APTA code of ethics. They include:

Principle 2: Practice in a trustworthy manner

Principle 4. Demonstrate sound professional judgment

Principle 6. Adhere to high standards practice

Principle 7. Accept remuneration only as deserved for services

Principle 8. Provide accurate information to patients about care

In summation, upon analysis of the patient's case, the researchers' professional judgment that this plan of care no longer constituted a high standard of practice necessitated communication of that assessment to the patient and her family in order to provide the most complete and accurate information and to avoid the risk of accepting remuneration for care that was not consistent with those standards in their benefit to the client.

#### Outcome

The outcome of this patient's episode of care was a transition to consultative services, moving toward discharge from regular physical therapy. She had plateaued in therapy, and while some interventions were enjoyed or beneficial, there was not a case to consider her continued treatment in this manner skilled care. The patient was being seen once a week for 60

minutes for each treatment session. Her plateau is typical for a child such as her with a non-progressive disorder. Her continued weekly home PT at her age was not typical or standard practice. She was receiving, and would continue to receive, speech and occupational therapies to address limitations in other domains. She participated in therapy sessions but did not follow through with home programs, making her adherence inconsistent. She didn't possess the main barriers, physical, social, or financial, that may preclude her participation in community recreation<sup>38</sup>.

Referral to community based leisure activities was found to be the optimal solution for this patient. Rather than a full discharge, consultative services in which the PT assured that the patient was maintaining function, as hypothesized, rather than declining functionally, and provided educational interventions to coach the patient's independent application of the motor learning techniques, would be provided periodically, diminishing in frequency as the patient's independence with her home maintenance and leisure was established. This continuum based on a patient's individual needs from direct to consultative service to transition is supported in a recent large survey of school-based pediatric physical therapists as ideal practice<sup>39</sup>. The outcome of the process itself was successful as defined above in its coincidence with literature, agreement of the clinicians' expertise and published professional code of conduct, and the approval expressed by the company owner, as well as the patient and her family.

#### Discussion

The purpose of this case report was to analyze the utility of established clinical and ethical frameworks in guiding decision-making in decreasing physical therapy services for a pediatric patient with a lifelong disability. In this case, the process was successful in that it lead to an outcome that affirmed the clinicians' impressions, correlated with literature, and met with satisfaction of patient, family, and other identified stakeholders, confirming through concurrent triangulation of theory and investigators the validity of the decision.

A recent report by Sim and Sharp<sup>30</sup> has questioned the validity that triangulation provides in nursing research. They argue against use of multiple modes of inquiry where one reliable and valid method would suffice, against this method for establishing criterion vs. content validity, and against combining diverse methods of inquiry that may not correlate or which may share systemic bias rather than being complementary. They urge a cautious and critical application, rather than indiscriminate, application of this methodology.

Jensen, Gwyer, Shepard, and Hack<sup>22</sup>, however, emphasize that mastery in psychosocial and self-monitoring elements of patient care are essential to expert clinical reasoning in pediatric physical therapy. These elements, as addressed here through use of the ICF<sup>11,19</sup> and RIPS<sup>18</sup> models, should then be incorporated to provide credibility and dependability through their

concurrence<sup>22</sup>. Rauscher and Greenfield<sup>4</sup>, further emphasize the utility of mixed-methods research in PT in addressing gaps in empirical data concerning contextual elements of patients' condition, arguing that the confluence of multiple methods of analysis lead to high-quality inferences. Therefore, in the case of the present report, the validity and reliability provided through theory and investigatory triangulation, respectively, are appropriate to the scope and goals of the inquiry.

The specific outcome of the decision making process, transition from direct weekly to periodic consultative services is not well described in research. Literature on transition in particular in this population is scarce. The literature describing the contextual elements considered herein is also lacking<sup>28</sup>. However, the process itself has demonstrated the same utility in this case as has been reported in the research<sup>11,18</sup>.

The basis of this decision, a plateau in benefits from therapy, was less consistent with the literature. Several studies have established measurable benefits in the realms of body structure and function as well as activity<sup>28</sup>. Case studies have described benefits of direct PT services in patients with similar age and impairments in terms of improved gait<sup>26</sup>, improvement in tonicity<sup>8</sup>, increased GMFM<sup>8</sup>, and improved safety awareness and attention to task<sup>25</sup>. This would suggest that further therapy could be beneficial and would counter arguments to reduce or terminate services.

Despite the wealth in the literature of beneficial interventions, the cases differ from our patient's in several key ways. While some literature has reported gains in GMFCS class through PT care, the cases presented are not representative of our patient as they began with a baseline of no prior therapy while hers had been continuous. The treatment type described was intensive in duration and frequency, while hers, due to history and the constraints of a company and therapist providing mainly EI, was provided for an hour weekly. Though improvements were noted in tonicity and dependence after intensive treatment, the main goal was reduced dependence<sup>8</sup> which was not relevant to our patient, as she and her family hadn't reported limitations in independence. The long term outcome and absolute time frames were not addressed, and the programs were from baseline without prior skilled PT<sup>26</sup>.

Other reports did parallel our findings, as the systematic review on stretching supported flexibility in patients with LLD through novel, community-based approaches<sup>32</sup>. Parent-reported interest in recreational opportunities in this population were also high<sup>35</sup>.

This report in no way implies that the decision for transition from direct services should be generalized to other pediatric patients with lifelong disabilities, who may indeed benefit from such services. Indeed, the plentiful literature cited would argue otherwise. The researchers here intended to illustrate a course of action to critically evaluate one's decision

making when the research was not directly representative of the clinical picture for a given case. It is the purpose of this case report to demonstrate the usefulness of the described clinical decision-making process in guiding PTs when the research for this particular patient.

Limitations. While the process was successful in its application to this specific patient case, the decision made thereby is by no means generalizable, as would be anticipated due to the nature of the case report. Further limitations of this case report include lack of follow-up data to determine the long-term effects and acceptance of the change in status based on the time-frame of the retrospective study. This administrative case report centered on clinical decision making considering the complexities of this individual patient. This choice in emphasis necessitated less focus on empirical data which could have provided greater reliability in its measures.

Implications for further research. Further research would be warranted to explore the utility of formalized clinical and ethical decision making processes in areas such as this with a paucity of research establishing transition or discharge recommendations.

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