

Developmental Regression: The Power of Anxiety on the Maturing Brain

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Case

Connie is a 14-year-old female with a history of typical development and a complex early medical history including idiopathic intracranial hypertension, growth hormone deficiency, and multiple concussions, who began experiencing developmental regression starting at age 7 that was not believed to be causally mediated by any of her underlying diagnosed medical conditions. After thorough neurological, psychiatric, and other medical evaluations, she was diagnosed with conversion disorder and, due to her declining function, was referred to a partial hospital level of care for further assessment and treatment.

Her initial presentation to the partial hospitalization program (PHP) was one of a developmentally regressed child. At the time, she was 13 years old but functioned more like a preschooler and exhibited heightened sensory issues. She made little eye contact, appeared disheveled, would shrug her shoulders in response to questions, was orally fixated on a "chewy stick," her hair, or anything else she could put in her mouth, wore large headphones to block out any sound she perceived as loud, would engage in hand flapping at times, and would mimic other children's behaviors. Despite being able to demonstrate such abilities in first grade, she no longer would recognize or write letters or numbers, sing the ABCs, count or state her age, or show recognition of amounts or time. She would scribble indiscriminately when prompted

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to color and would draw freehand by scribbling rather than drawing an outline of an object and then shading it in. Additionally, upon initial presentation to the PHP, Connie exhibited poor ADLs, including needing parental reminders and assistance to brush her teeth and to wash her hair. She appeared, at times, to have weak muscle tone and poor fine motor skills, as demonstrated by her difficulties engaging in such tasks such as opening food packages or cutting up her food.

Paradoxically, what was most striking about Connie's presentation was both the consistency and inconsistency of her exhibited behaviors. For example, Connie never wavered in her avoidance of showing recognition of anything numerical, whether it was in the context of playing a game, answering questions, identifying her locker key, etc. However, other seemingly cognitive deficits were inconsistent. While Connie reported that she couldn't learn or sing or remember the ABCs, she could watch YouTube videos of other songs, not associated with learning or academics, and memorize and sing them. Connie demonstrated typical abilities with regard to memory and learning unless it was related to a task that she perceived to be associated with formal academics. For example, while in the program, she learned to crochet, played new games, and memorized short stories/word games in the context of interacting casually with peers. She could answer questions and repeat back words when prompted unless she associated these questions and tasks with learning or developmental assessment. For example, if staff said, "My favorite color is pink. What is my favorite color?" Connie would reply "pink." However, if staff said "You are 14 years old. How old are you?" Connie would say "I don't know" or "I don't remember." Additionally, Connie's speech abilities were inconsistent. At times, Connie would be able to engage in discussions around age-appropriate topics; however, other times, she would provide one-word responses, use the wrong tenses of verbs, or say the wrong word (i.e., stating "you're welcome" instead of "thank you" or using "maded" as the past tense for "make").

Clinical Pearl #1

While the DSM-5 includes conversion disorder and factitious disorder as separate disorders under the larger category of somatic symptom and other related disorders, there is no longer a requirement in DSM-5 to determine that symptoms are unintentionally produced in order to diagnose conversion disorder. In Connie's case, while some behaviors appear to be volitional and others not, the overall function of her behaviors can be understood in the same way, as they all appear to serve to protect her from her anxieties around growing up and demonstrating independence. Thus, while it is frustrating for her parents and for others to tolerate her behaviors when at times they seem clearly intentional, it is important to remember that they serve the same purpose as her seemingly more unconscious behaviors and can be treated in a similar fashion [1]. Also notably, while one might consider the diagnosis of Ganser syndrome with Connie's presentation, her developmental regression was more expansive and multidimensional than one would anticipate with this syndrome, which typically presents with paralogia (offering "approximate" answers to questions) and is usually associated more clearly with malingering for clear material or procedural secondary gain (e.g., avoidance of legal penalties).

Relevant History and Course

Connie was born at full term with no complications and developed typically in early to mid-childhood, reaching all developmental milestones accordingly. She had a reported mild milk allergy as an infant that she outgrew but continued to experience ongoing constipation issues throughout childhood. Parents describe her as being very stubborn starting as a toddler but functioning well until around first grade. She was able to read at grade level, draw in an age-appropriate manner, retain information, perform simple math tasks, and speak normally. She exhibited some mild academic difficulty around the ages of 6 or 7 that prompted a neuropsychological evaluation, which indicated mild dyslexia and a nonverbal learning disorder. Of note, in first grade, Connie passed vision screenings at school but then went to an ophthalmologist in second grade, and her vision was determined to be very poor and requiring glasses. After results of the neuropsychological evaluation and vision evaluation, an individualized education program (IEP) was implemented at school. However, Connie's functioning began to decline during second and third grades, and, by fourth grade, she had lost almost all of her academic abilities. She could no longer read, write, or do simple math, but she was still able to draw very well. By sixth grade, though, Connie's artistic abilities regressed to scribbling. Between ages 12 and 13, she also exhibited some memory loss, such as not remembering a recent family trip to Disney World. Parents also noted more physical changes as well, including some loss of muscle tone, walking with a different gait, and more physical awkwardness, such as climbing stairs one step at a time instead of alternating her feet.

As Connie's functioning declined over the years, her parents were at first concerned about an underlying neurological or other medical cause, especially in the context of her medical history. Around the time of first grade, for example, Connie was the tallest child in her class, but then stopped growing. There is a family history of growth hormone deficiency, and Connie herself was diagnosed with this condition and subsequently has been followed by an endocrinologist. Additional medical history includes pseudotumor cerebri (otherwise referred to as idiopathic intracranial hypertension) [2] diagnosed at age 11 that has been treated with acetazolamide and followed closely by ophthalmology and neuro-ophthalmology. Connie also notably has a history of sustaining three reported concussions in less than 3 years. In third grade, she fell in the bathroom, hitting her head and breaking her ankle, and was subsequently diagnosed with nerve impingement from her lower extremity cast. She experienced significant hyperalgesia thought to be related to this nerve impingement. She had difficulty tolerating the sensation of a tissue or feather on her leg, requiring a desensitization regimen and a period of time in which she required crutches for ambulation. This lasted for approximately 90 days at which point she was seen by a chiropractor who did several one-time manipulations, after which Connie was able to walk without the crutches. Also of note, Connie's family medical history is notable for confirmed diagnoses of amyotrophic lateral sclerosis (ALS) in two members of the extended family.

Given the complex medical history described above, Connie's parents expressed concern to her multiple medical providers regarding a possible structural and/or otherwise discretely identifiable etiology for the multi-year history of developmental regression described above. She accordingly underwent an extensive multidisciplinary workup that included MRI studies, an EEG, and a lumbar puncture. Ultimately, she was diagnosed by the outpatient team as having conversion disorder. Of note, while her medical history was certainly complex, her parents received a clear message from this team (and subsequently from her partial hospital team upon her admission to the program) that her history of developmental regression was not explained by the medical issues detailed above and that her ongoing and notably inconsistent cognitive, gross motor, and fine motor regression were best understood in the context of an emotional etiology [3].

Relevant Family Factors and Stressors

Connie lives with her parents and two older brothers. Connie has some social difficulties but overall is interested in peers and tends to gravitate toward younger ones. She also had made some friends in the neighborhood as well as through school and enjoys activities such as making slime and watching age-appropriate television shows such as *Full House* or *Girl Meets World*. She used to be engaged in some more physical activities such as Irish step-dancing, ballet, gymnastics, and softball but has struggled to participate recently given increasing physical coordination difficulties.

In terms of stressors, Connie's parents have noted that her symptoms seemed to coincide with the time when her mother started graduate school and thus was not as present in her daily life. Her mother has a history of attention-deficit hyperactivity disorder and found her program challenging and time-intensive, leading to her feeling as though she was not sufficiently available to assist Connie with her struggles academically or with her vision around the time of first grade. Additionally, around that same time, her older brother was struggling with anxiety and depression and was subsequently admitted to a psychiatric inpatient unit for a week. This appeared to exacerbate some of the existing stress within the parental relationship, and, soon after the hospitalization, Connie's parents separated, with her mother moving out of the home and into an apartment in which she stayed for a few nights each week (the remainder of the time staying in the home with the family). When Connie's parents told her that they were going to separate, they reported a noticeable negative change in her. This living situation lasted for about a year, at which time Connie's mother moved permanently back into the home, and, since then, Connie's parents have functioned more like housemates, living on separate floors of the home but engaging together in family activities while avoiding overt fighting or conflict.

More recent stressors include the impact that Connie's functioning has had over the years on the dynamic at home, notably creating a rift between her and her brothers as they are scared for what will happen to her, embarrassed by her behaviors, and frustrated by her stubbornness and attention-seeking. At school, Connie should be in the eighth grade but performs at a kindergarten level or younger. For a time, she had been placed in an alternative school setting but generally exhibited no improvement in that setting and had started to mimic the developmental level of her cohort, thus exacerbating her regressive behavior. Moreover, Connie is aware of her academic and social difficulties, which has affected her motivation to be in a school setting with same-aged peers. Furthermore, an additional current family stressor is that a family member has late-stage ALS, and her mother has increasingly needed to travel out of state to help provide care. This has not only been stressful in the context of Connie's desire to have her mother remain close but also in the context of Connie's mother's ability to tolerate Connie's distress as the family tries to push her forward in her treatment.

Discussion

Connie's pattern of symptoms is being conceptualized along the spectrum of conversion disorder, specifically a type of conversion-based developmental regression. Her decline in functioning appears linked to underlying psychiatric symptoms (viz., anxiety) and relevant stressors including the presence of a history of learning/academic disabilities and vision issues, in addition to family/environmental stressors around the time that symptoms began. Additionally, it appears that her symptoms and behavioral patterns were inadvertently reinforced over a period of 5–6 years, thus resulting in more ingrained patterns of responding to her surroundings, as well as her own fixed belief that there is something structurally wrong with her brain. All of the above was also likely further exacerbated by Connie's baseline temperament, as described by her parents, as a child who has always been extremely stubborn and emotionally immature and who now understandably but maladaptively appears to seek "crutches" in her life to hold onto in order to prevent age-appropriate expectations about her functioning.

The theme of all of Connie's symptoms is one that points to her significant anxiety around growing up in the context of her apparent traumatic stressors. This is illustrated by her perceived inability to engage in tasks related to demonstrating growth, whether this be numerically related (e.g., counting, saying her age), academically related (e.g., reading, singing the ABCs), or just the ability to learn in general (e.g., avoidance of acknowledging that her brain "can work"). While there may be components of Connie's behaviors that appear to be more conscious or volitional, her presentation overall is reflective of a conversion spectrum, and a similar treatment approach would be recommended regardless of whether some of her demonstrated behaviors appear to be more in her control than others [1].

Therapy Course

The focus of Connie's treatment in the partial hospital program (PHP) was primarily centered around highlighting two main points: (1) *We know your brain is capable of learning, remembering, and functioning,* and (2) *We know it feels scary to believe that.* Connie continues to maintain very strong fixed beliefs that she was born with something wrong with her brain; that doctors cannot disprove that idea for sure, and thus she cannot learn. Similar to someone with fixed delusional or paranoid thoughts, it has not been helpful to continue to challenge such fixed beliefs, as any evidence

to the contrary can be countered in Connie's mind by her own beliefs. Rather, the approach has been to try to help her acknowledge the emotional basis behind these thoughts and to progressively get her to be more emotionally expressive [3]. This has been done by reframing her statements of "I can't do it" or "There's something wrong with my brain" with "I know it feels scary to do it," "It feels scary so you are choosing not to do it," or "We know your brain can learn, and it feels scary to do so."

During her admission to the PHP, which Connie attended weekdays during school hours, treatment was instilled throughout Connie's day, from the language that was used as described above to the behavioral strategies to guide her treatment forward. Each day, Connie had two layers of behavioral goals on which she was working. First, there was an overarching reinforcement system in which Connie could earn checks on her point card for following directions at each part of the day as well as for "good behavior" which was defined as "putting in appropriate effort, using full sentences to participate in conversation, and engaging in tasks she has shown the ability to do." At the end of each program day, Connie could redeem the checks she earned for different levels of small prizes from the program Point Store. However, an additional layer of goals that she also worked on was to set one daily goal each morning with staff (identified from a list of possible goals) in order to earn a puzzle piece. Once she earned enough puzzle pieces to complete her puzzle (a picture of some bigger reward decided on together by Connie and her parents), her parents rewarded her at home with the actual prize. Her goals included things that were challenging for her as they were all indicative of being able to learn or of growing up (i.e., counting to 10, saying her age, coloring within the lines, opening food packages independently, tracing her name, identifying letters, etc.). If Connie was not able to complete her goal prior to the afternoon activity time, she would sit out of the activity and instead work 1:1 with a staff person on her goal. Once she completed it, she was able to move on with the rest of her day and rejoin the group in addition to having access to her electronics at home that evening or engaging in a fun outing if desired. However, if she wasn't able to complete her goal by the end of the program day, the message to Connie was that she needed to spend more time that day "retraining her brain" and therefore wouldn't have access to electronics at home or doing other fun outings. Instead, her parents would continue to either work with her on the goal in the evening or, if she refused, they could engage her in other activities as long as there was still a focus on "retraining her brain." Instead of playing an easy or preferred game, they would choose something that required counting/ numbers, sequencing, or other tasks that she would typically avoid.

Regarding treatment progress, Connie made slow but forward progress during an extended 4-month admission to the PHP. She typically did best when the message that she needed to work on "retraining her brain" was not overly emphasized as she tended to get angry and resistant around continued reminders of what she needed to do. That being said, she did display some motivation to work toward earning the bigger rewards that she set for herself and was successful in completing two puzzles with different sets of goals (about 14 goals each). She typically would struggle for about a week after she completed a puzzle when a new set of goals was introduced. This would manifest as frustration and refusal to work on her goals as well as more tantrums and dysregulated behaviors at home. However, after about a week, with all expectations

and limits remaining consistent, Connie would typically start to make slow progress again. Connie struggled as well when expectations increased to both completing a new goal each day as well as reviewing three goals she had already completed in order to reinforce the need to retain her successes, as she tended to maintain that she couldn't remember how to do things she was successful with the day before.

Clinical Pearl #2

One of the primary treatment strategies for Connie was a behavioral approach that included gradual shaping of age-appropriate behaviors and utilized a contingency management system that included both reinforcers for positive behaviors and negative consequences for others. As with any good behavioral plan, consistency is the key. It is common for parents to become frustrated when they are not seeing forward progress or when problematic behaviors resurface. It is also common for a reward structure to shift over time in order to maintain motivation and incorporate new interests that may become incentives.

With Connie, it was not surprising that each time a new set of goals was introduced, she worsened emotionally and behaviorally for a period of time. In her eyes, she had completed what she needed to do and was upset that more was being asked of her. Parents understandably expressed distress and uncertainty about the plan during times when her behavior would escalate at home. However, with psychoeducation and reassurance, Connie's parents were able to hold steady with expectations and consequences at home, and, inevitably, Connie's behavior would deescalate after a period of time and she would start to show progress again. This serves to highlight how important consistency is when using a behavioral treatment approach rather than letting a child's behavior dictate when to make changes in the plan.

Despite the slower progress in working on these more "academic" goals, Connie overall made significant progress in areas such as acting more socially appropriate and engaged (especially in the context of being in a milieu with same-age and typically developing peers), doing more of her ADLs independently, caring more about her appearance such as wanting to brush her hair and showing interest in makeup, and participating more appropriately throughout the day in activities and conversations with staff and peers. Notably, Connie happened to start her menses for the first time while admitted to the PHP. Despite her clear angst and avoidance of acknowledging her age at the start of her admission, her reaction to this normative developmental milestone was surprising in that she handled it quite well, possibly a reflection of some of her growth in the area of becoming more comfortable with herself and having the desire to be more like her peers. Toward the end of her admission, Connie also seemed to be a little more connected with her emotions, voicing more concerns around feelings of anxiety and depression and wanting to address this. However, she continued to prefer to only talk to her mother and not open up emotionally when prompted, and, at times, it appeared that her desire to focus on emotions was in part her way to deflect attention from needing to also work on "retraining her brain."

Another major theme of therapeutic work with Connie over the course of her admission included "disproving" her worry that her parents might one day cease to provide her with emotional and social support when she makes a certain amount of developmental/cognitive progress. As she made steps toward progress, Connie was able to eventually acknowledge that her parents continued to provide her with support, and her parents expressed to her that they would continue to do so throughout her life and, in fact, would never anticipate a time in Connie's life when she would not need their support in the future, thus allaying part of her anxiety that she would be "on her own."

Medical Course

In addition to the behavioral therapeutic and family work during Connie's admission, treatment also included adjustments in her psychiatric medication regimen. Upon her admission to the PHP, Connie was being prescribed fluoxetine 50 mg daily and bupropion 150 mg daily. Her parents shared at the time that Connie had no clear past or present therapeutic response to fluoxetine, particularly in the realm of anxiety, and had differing opinions as to any positive mood response to the addition of the bupropion. Given the lack of any clear treatment response to fluoxetine, the decision was made to discontinue it within the first week of her admission. Lorazepam was started as a standing medication and eventually increased to 0.5 mg twice daily in order to address how Connie would get "stuck" and perseverate on not being able to work on her goals. Upon review of the pharmacogenomics testing previously obtained by Connie's outpatient psychiatrist, folic acid was also discontinued and 1-methylfolate was initiated in its place based on Connie's documented methylenetetrahydrofolate reductase (MTHFR) enzyme deficiency.

Clinical Pearl #3

The methylenetetrahydrofolate reductase (MTHFR) enzyme converts synthetic folic acid and dietary folate into l-methylfolate, the active form that crosses the blood-brain barrier and plays a critical role in neurotransmitter synthesis. Individuals who are heterozygous for a mutation at the C677T SNP of the MTHFR gene exhibit 45% reduction in enzyme activity, while the same homozygous mutation carries a 70% reduction in enzyme activity. Patients with such deficiency seem to produce fewer peptide precursors for important neurotransmitters, which may in turn negatively impact responsiveness to psychiatric medications. As such, supplementation with l-methylfolate can serve to optimize the efficacy of psychiatric medications in such patients [4–6].

Also of note, a course of sertraline was also initiated in particular to target what was formulated by Connie's PHP treatment team as an anxiety-based regressive pull to avoid moving into adolescence. Based on Connie being an extensive metabolizer in the c19 cytochrome p450 pathway – the primary pathway for sertraline metabolism – it was agreed that dosing of sertraline would need to be higher than what might be typical for Connie's age. Over the course of her admission, the dose was titrated to 100 mg daily, which Connie tolerated well. Additionally, in the context of lack of a clear historical response to bupropion, this medication was eventually weaned to discontinuation concomitant with sertraline titration.

Over time, it appeared that while Connie benefited intermittently from as needed lorazepam for acute agitation and/or anxiety, she did not appear to have benefited overall from her standing dosages. This medication was thus weaned to discontinuation, and a decision was made to replace it with standing aripiprazole, both as an adjunctive medication for her anxiety and mood as well as to help address significant behavioral impulsivity when emotionally distressed. Connie notably benefited behaviorally and emotionally from the initiation of this medication, with her parents reporting significant improvement at home in particular. She did gain approximately 17 lbs over the following 6 weeks after initiation of aripiprazole, prompting a decrease from 2.5 to 1 mg daily. However, Connie's behavioral and emotional dysregulation worsened significantly over the following week even with this modest decrease, prompting an increase to a dose of 2 mg. Of note, a baseline fasting metabolic panel done prior to initiating aripiprazole demonstrated a mildly elevated fasting glucose level of 103 and a normal hemoglobin A1C. Due to her weight gain as well as treatment with rhGH and aripiprazole, Connie will require regular monitoring for glucose intolerance and diabetes [7].

As noted above, Connie's weight gain was considered secondary to aripiprazole as well as her consistent pattern of sedentary behavior. With the implementation of a daily exercise routine including 30–60 min walking on the treadmill as well as implementation of dietary recommendations, her weight stabilized in the final 2 weeks of her admission. She continued to be followed by her outpatient ophthalmology team for her diagnosis of pseudotumor cerebri as well as by her outpatient endocrine team for her diagnosis of growth hormone deficiency. As noted above, while these medical issues were significant, they were assessed not to explain or directly relate to her developmental regression by both the PHP team and the multidisciplinary outpatient team that evaluated Connie prior to her PHP admission. Also of note, given the extensive medical workup that Connie underwent prior to the PHP admission and the clearly prominent role of the complex emotional factors noted above in driving her symptoms, Connie did not undergo further medical workup for her developmental regression during the PHP stay, which enabled the treatment to remain focused on her complex behavioral plan and family-based therapy.

Next Steps

After thorough consideration of academic placement options, it was ultimately decided that Connie would do best returning to her regular middle school with certain accommodations in place. First, she needs to continue to have a structured school day but would do best with one that is weighted toward being able to participate in nonacademic subjects with her peers. This would include electives such as art, music, photography, gym, etc. The idea would be for Connie to have a period of structured time in a school setting where she is with similar aged/developed peers and engaging in age-appropriate activities. Second, while Connie needs to participate in some academic blocks, it would be counterproductive for her to sit in regular classes where she is not going to be able to participate. Instead, these would be times when Connie could continue to work 1:1 in the school setting on similar academic/cognitive goals to what she was working on at the PHP. This 1:1 time would be seen more as behavioral/therapeutic tutoring that could continue to focus on consistent expectations around moving forward with goals as well as maintaining consistency with consequences for refusing to do work and ongoing communication and collaboration with Connie's parents and outpatient providers. Third, Connie's school schedule should also include other therapeutic opportunities such as meeting with a support person such as the school psychologist or social worker or taking part in a social skills lunch club. Fourth, Connie would continue to receive PT and OT services in the school setting which could continue to work with her on skills such as writing, ADLs, muscle tone, and physical coordination. Fifth, outside of the school day, Connie would continue to see an outpatient psychiatrist as well as an outpatient therapist skilled in principles of cognitive behavioral therapy and parenting/family work in order to continue to work with Connie and her family in a similar manner to the treatment approach she had been engaged in at the PHP.

Lessons Learned About Neuropsychiatry

What could be so powerful so as to disrupt development, lead to a regression in emotions and behaviors, and keep a child "stuck" in a maladaptive pattern of functioning? The answer is anxiety. While anxiety is a normative emotion and an essential one to survival, excessive anxiety can be debilitating. Treating anxiety is even more complicated when the person experiencing it isn't even aware of this emotional experience. In cases like Connie's, the root of anxiety likely took hold when she was 5 or 6 years old and she began to internalize stressors such as changes in the dynamics at home and struggles in school. Connie's way of coping with this anxiety seemed to be to unconsciously create a world in which she needed to be cared for as she showed that she could no longer do things for herself that she used to do. The thought of demonstrating skills and growth was threatening in that it would mean that she needed less attention, care, or love from those closest to her, and she would effectively be on her own. The anxiety and internal stress that this seemingly created was powerful enough and remained fixed for such a long period of time that this became Connie's world. Her beliefs that there was something wrong with her brain and that she couldn't learn became her reality. No matter what physical or biological evidence to the contrary was presented, Connie's anxiety was more powerful.

The mind-body connection is a fascinating relationship, and some facets of it are easy to conceptualize than others. For example, most people are familiar with the notion that when someone says they feel like they have butterflies in their stomach, they are referring to the fact that they feel nervous, and that sensation is felt physically in their stomach. However, when talking about more unusual symptoms, namely, neurological ones, it's often harder for people to accept the mind-body connection. For example, how can someone's emotions or stress lead to physical manifestations such as seizure activity, paralysis, dysphonia, or blindness? This speaks to an important lesson in the power of emotions, namely, stress and anxiety, to supersede many aspects of brain function as it did with Connie.

Brain regions currently implicated in the precipitation and perpetuation of conversion disorder currently include the amygdala, striatum, precuneus, dorsolateral and ventromedial prefrontal cortices, dorsal anterior cingulate, supplementary motor complex, and temporoparietal junction. For a comprehensive summary of the known underlying pathophysiology of functional neurological disorders, please see the publication by Voon et al. [8] in the Journal of Neuropsychiatry and Clinical Neurosciences. As more becomes understood about the structural and physiological etiologies and correlates of anxiety, the ability to explain some of this underlying pathophysiology in biological terms will hopefully serve to reinforce the connectedness of anxiety and neurological symptoms for patients and families, thereby destigmatizing and demystifying this connection.

Family Reflections

In trying to understand Connie's struggles over the years, her parents have been able to see the stressors that were occurring around the time when her symptoms started as playing a role in what happened but have struggled to explain how her behaviors became so severe given the seemingly "low" level of trauma they created compared to more significant traumatic events that families could experience. They ultimately have viewed Connie as, at baseline, a very emotionally immature and very strongwilled/stubborn child who seemed to find any way to establish "crutches" in her life to hold on to so that she doesn't have to grow up and function independently.

Throughout Connie's lengthy admission to the PHP, Connie's mother was able to be very open and honest around how draining this whole process has been, especially in the context of other major family stressors, including caring for her own dying mother. There were times when parental frustration would come out in a way that Connie would internalize as her mother not caring about her (i.e., if mom made a statement such as "I'm done with this"). While the family was able to address these themes in family sessions, they described how it remained very difficult to balance the needs of the whole family. However, Connie's parents remained generally committed to the treatment strategies and course as they recognized that they have already spent years letting Connie direct her own course and pace, which had not resulted in any forward progress.

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