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Commentary

Have To's Before Want To's: An accessible framework for breaking the cycle of avoidance and reestablishing routine in youth with chronic pain

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Chronic pain is prevalent in children and adolescents, often resulting in functional disability and impaired quality of life across physical, emotional, and social domains (Huguet & Miró, 2008; King et al., 2011). It impacts participation and performance in activities related to family and peer relationships, education, leisure, household responsibilities, community engagement, and more. Pain-related disability can disrupt identity formation and achievement of developmental milestones in childhood and adolescence (Palermo et al., 2014).

When pain management is directed toward symptom reduction, youth are often excused from normal activities until pain has subsided. However, without pain reduction, such reduced expectations may extend indefinitely (Celedon et al., 2014). Daily routines shift and structure fades, as activity participation is altered. Over time, physical symptoms facilitate not only avoidance of pain itself, but also avoidance of uncomfortable, effortful, and/or stressful activities. With pain dictating activity expectations, avoidance can be complicated by increased reliance upon others, social withdrawal, and declines in physical functioning. As time passes, these patterns of avoidance become increasingly entrenched (Asmundson et al., 2012, Simons & Kaczynski, 2012).

Given its debilitating nature, youth with chronic pain often require complex treatment that integrates multiple perspectives (Simons et al., 2013). To this end, intensive interdisciplinary pain treatment (IIPT) programs offer comprehensive care following a rehabilitative model. The focus of IIPT is on restoring function, rather than on symptom reduction, and aim to break the cycle of activity avoidance (Odell & Logan, 2013). There is considerable empirical support for this shift away from pain elimination towards functioning, given the consistent finding that, in youth with chronic pain, functioning must improve before pain reduces (e.g. Lynch-Jordan et al., 2014; Bruce et al., 2017). A systematic review of IIPTs (Hechler et al., 2015) demonstrated large improvements in functional disability, with small-moderate improvements in pain intensity after IIPT. Similarly, when examining IIPT response trajectories, Simons and colleagues (2018) indicated that the majority of IIPT patients exhibited significant functional improvement post-treatment through one-year follow-up, even when pain was still present. Randall and colleagues (2018) reported longer-term functional success. The majority of former IIPT patients (≥5 years post-treatment) reported minimal to no ongoing functional disability, complete/partial resolution of pain, and developmentally appropriate progression toward goals.

For IIPT to be successful, interventions must be generalizable across settings and accessible to

youth, parents, and clinicians. (Maynard et al., 2010). In this commentary, we present a novel framework for explaining, organizing, and implementing a functional restoration approach to pain treatment to young people, parents, and the greater health community. Ideally, with a relatable framework, youth may have greater success breaking the cycle of avoidance. This framework was developed through collaboration between psychologists and occupational therapists (OTs) in our IIPT. While its behavioral elements have roots in psychology, OTs are well versed in rehabilitation and share the overarching treatment goal of functional restoration (American Occupational Therapy Association, 2014). OTs provide the foundation for behavioral change by exploring patients' roles, routines, and habits (collectively known as occupational performance patterns; AOTA, 2014).

Researchers have long attempted to explain the mechanisms through which chronic pain is maintained. Behaviorists purport that persistent pain and activity avoidance are learned responses, influenced by their consequences (Fordyce, 1989; Asmundson et al., 2012). In avoidance learning, when symptoms are followed by negative reinforcement (i.e. removing aversive stimuli, such as challenging activities or expectations), symptom frequency increases. Similarly, when symptoms are followed by positive reinforcement (i.e. rewarding stimuli, such as attention), symptom frequency increases. Celedon and colleagues (2014) offer a detailed application of these principles to IIPT.

Recognizing barriers to role engagement is critical in restoring function, as interpersonal and environmental factors beyond pain may influence role participation and engagement in routines (AOTA, 2014). For example, the degree to which youth had been engaged/successful in roles prior to pain onset may impact their pain experience and subsequent avoidance. For youth who had not developed competence in particular roles, the sick role (Walker et al., 2002) may offer reinforcing relief from challenges presented by age-typical academic and social environments. Therefore, establishing structure, by reintroducing routines, resuming roles, and replacing maladaptive habits, is an effective tool in facilitating functional restoration (Simon & Collins, 2017).

However, reinstituting normative expectations, regardless of pain intensity, presents a unique challenge for parents, who play a crucial role in their child's functional outcomes (see topical review by Palermo & Chambers, 2005). Standard medical advice primes parents to help their child avoid pain triggers, using pain intensity to guide decisions about activity participation (Martin & MacLeod, 2009). Without understanding the cycle of avoidance, parents may perceive the expectation that their child returns to activities with pain still present to be impossibly harsh. Further, promoting their child's return to functional activities may be particularly distressing for parents. Broadly, parenting a child with chronic pain may challenge one's sense of role competence and effectiveness, with many such parents reporting elevated levels of distress (Campo et al., 2007; Jordan et al., 2007). Such distress may elicit protective responses toward the child (Connelly et al., 2010; Caes et al., 2011), such as permitting school absence or excusing chores, rather than maintaining functional expectations. Observation of parental distress, combined with parent protective behaviors, can negatively impact child functioning (Sieberg et al., 2011).

Some parents may notice that their child's pain increases in non-preferred situations (e.g. school, homework, chores) as compared to preferred situations (e.g. sports, social events). They may observe their child coping more effectively in preferred contexts. Still, even observant parents may have difficulty helping their child to generalize normalized functioning from preferred to non-preferred situations. They may not wish to rock the boat by increasing expectations further or fear overwhelming their child. However, the key to breaking the cycle of avoidance is a generalizable approach that facilitates reintegration into all (i.e. preferred and non-preferred) aspects of functioning. For clinicians in IIPT programs, this comes naturally, as treatment is predicated on the notion that functional restoration occurs before pain reduces. However, youth asked to function in the presence of pain, parents asked to enforce renewed functional expectations, and clinicians less familiar

with IIPT may all struggle not only with implementation, but also with grasping the paradoxical nature of the functional restoration approach. Therefore, the manner in which this is presented to youth, parents, and clinicians must be accessible, understandable, and generalizable.

We propose a guiding framework for explaining, organizing, and facilitating the functional restoration approach in any setting: Have To's Before Want To's (HTBWT). In HTBWT, meaningful roles/occupations (both Have To's and Want To's) are first identified and the barriers to their participation are recognized. Then, the system is re-organized in a manner that facilitates generalized functioning across activities and settings. Preferred activities (Want To's) are available, contingent upon successful completion of/engagement in non-preferred activities (Have To's), with emphasis on temporal ordering in order to reestablish routines. Notably, the fundamental underpinnings of HTBWT are not novel; they follow directly from the behavioral reinforcement principles described earlier. It is the manner in which they are presented that has the potential to facilitate functional restoration effectively.

The HTBWT framework addresses perceived barriers to complete functional reintegration into all roles. It helps to reset functional expectations for youth and families to include full (vs. modified) participation in life. Pain intensity no longer serves as the indicator for functional expectations, so such expectations are more consistently met over time. There is no differentiation between the types of activities in which the child is/is not expected to partake, resulting in less opportunity for pain to serve the function of avoidance. HTBWT also provides both structure and rationale for establishing routines. Preferred activities motivate the completion of non-preferred activities, resulting in increased productivity. Again, preferred activities are not taken away (as is often feared); they merely depend upon successful completion of less preferred activities. For example, the expectation that a child completes homework before playing video games does not allow for pain-related avoidance of homework, while simultaneously utilizing video games to externally motivate homework completion.

Overall, HTBWT provides youth, parents, and clinicians a framework to guide decision-making around functional expectations for youth with chronic pain, in language that is accessible and understandable to all. Providing clear expectations and structure for activity engagement allows youth to follow through with functional expectations in the presence of pain. Its breadth allows for generalization to all life domains. For clinicians, HTBWT is not intended to be a singular intervention but rather an explanatory and organizational tool. For implementation, it is most consistent with cognitive behavioral and acceptance-based therapy approaches, given its behavioral roots. Related strategies, such as token economies, stimulus control, and graded exposure easily meld with this framework. It may also serve to decrease family conflict and parent distress by facilitating communication and assisting families with realigning with their values and goals amenable to family-systems modalities.

As noted earlier, there is considerable evidence supporting IIPT's functional restoration approach for youth with chronic pain. However, using the HTBWT framework to explain and facilitate this approach has not been empirically evaluated. Like most IIPT elements, it may be difficult to parse HTBWT-specific effects from the collective impact of all interventions IIPT patients receive. Future research goals include gathering qualitative information from youth, parents, and clinicians in IIPT about the feasibility and understandability of the HTBWT framework. Alternatively, disseminating HTBWT to outpatient pain providers may offer a more internally valid mechanism for comparing HTBWT with the current standard of care.

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