

## Commentary

# Supporting children with chronic pain in their return to school

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Pediatric chronic pain is increasingly recognized as a highly prevalent health concern that affects children's daily activities and quality of life (Palermo, 2000; Perquin et al., 2000; King et al., 2011). One daily activity that is often affected by chronic pain is school functioning, as children who experience pain tend to experience a number of challenges including decreased school attendance, disrupted social functioning, disrupted cognitive processes, and overall decreased academic performance (Logan et al., 2008; Dick & Pillai Riddell, 2010; Forgeron et al., 2010). Given that school attendance is the primary task of childhood (Harris, 2009), it is essential to ensure that children with chronic pain are able to meet the demands of the school environment. Although children with chronic pain face many challenges with respect to school success, the following commentary will focus specifically on school attendance and the challenges inherent in facilitating school integration and reintegration for these children. While we would suggest it is imperative for clinicians to recognize and address all of the challenges children with chronic pain face in relation to school (e.g. cognitive and social disruption), examining each of these challenges extensively is beyond the scope of this commentary.

Due to persistent pain and frequent medical appointments, children with chronic pain exhibit more frequent school absences than their healthy peers (Sato, 2007; Logan et al., 2008). Indeed, in a study involving adolescents with chronic pain, Logan et al. (2008) found that 44% of students with pain missed at least 25% of school days and 20% of students missed more than 50% of school days. Not

only do these students miss valuable academic time, but they also miss other important aspects of the school experience such as developing independence, their identity, and social relationships with other children and adults (Geist et al., 2003). Further highlighting the critical importance of school attendance, Kearney (2001) suggests that prolonged school absenteeism is one of the most disruptive events in the healthy development of a child. As a result, it is important to consider ways in which children with chronic pain can be supported in their school attendance so that academic and other developmental goals can be achieved.

In a recent commentary, Boutilier and King (2013) discussed the silo approach commonly taken by education and health care systems to address the needs of children with chronic pain; that is, multiple systems often work independently of each other, meaning that the child's needs are never completely addressed or met. The authors therefore suggest an interinstitutional approach to the management of chronic pain in which education and health care systems work collaboratively together. One method for increasing interinstitutional collaboration between school and health care systems is the use of a formal school reintegration program. In a systematic review of interventions to facilitate school reentry for children with chronic health conditions, Canter and Roberts (2012) found that school reintegration programs are effective at increasing illness-specific knowledge and generating positive attitudinal change in both teachers and peers. Improving knowledge and attitudes in teachers and peers enables them to more effectively support children with chronic health

conditions making school attendance easier for them and, consequently, allowing them to reintegrate more successfully (Canter & Roberts, 2012). This review provides a summative indication that school reentry programs involving interinstitutional collaboration are an effective method for assisting children with chronic illnesses return to school following an extended or frequently occurring school absence.

### **School reintegration programs**

In the late 1990s, the Leukemia Society of America identified the development and evaluation of school reintegration programs as a health priority (McCarthy et al., 1998). This resulted in the development of several school reintegration programs specific to pediatric cancer (e.g. Power et al., 2003; Harris, 2009). In his presidential address to the Society of Pediatric Psychology, Brown (2002) reiterated the importance of continued work on school reintegration programs and called for an expansion of these models to other chronic health conditions. Whereas much of the school reintegration literature continues to focus primarily on children with cancer, there has been some expansion of school reintegration programs to other health conditions such as pediatric organ transplant (e.g. Weil et al., 2006) and pediatric burns (e.g. Girolami, 2004).

In a review of currently published school reintegration programs for children with cancer, Prevatt and colleagues (2000) report that most school reintegration programs incorporate at least one of three components. First, school personnel workshops designed to increase knowledge about the specific health condition and ease anxiety about the child's return to school. Depending on the needs of the individual student, these meetings/workshops could take place in a group setting or be targeted to individual school staff who work closely with the child and family. Second, peer education initiatives that aim to provide age-appropriate knowledge about the specific health condition and discuss questions/concerns peers may have through small group discussions and activities. Third, comprehensive models that involve collaboration between school personnel, health care personnel, and the child and family to develop a formal plan

for the child's return to school. In addition to this formal plan, comprehensive models also typically include school personnel workshops and peer education initiatives.

Harris (2009) indicates that the appointment of an individual to act as a consultant-liaison is a key component of a comprehensive and successful school reintegration plan. The consultant-liaison is informed about all the needs of the child and takes responsibility for communicating important information between the family, health care team, and school team. Harris (2009) suggests the consultant-liaison can assist in ongoing monitoring and implementation of the formal plan and/or other supports that have been recommended by school and health care teams. Recognizing the already overflowing role of both health care and school team members, Harris (2009) suggests the school psychologist as an appropriate professional to fill this role. Many psychologists who work in schools are knowledgeable about both health care and education systems, as well as the immediate school environment. They often also possess the necessary training in consultation skills to effectively liaise between the family, health care system, and school system. Psychologists working in schools with this expertise could be valuable assets in the school reintegration process. Prevatt and colleagues (2000) also support this role for school psychologists and suggest they can efficiently navigate and oversee the school reintegration process for children with chronic health conditions.

### **School reintegration programs and chronic pain**

Currently, a universally accepted school reintegration program for children with chronic pain is not available. Anecdotally, however, many pediatric pain programs incorporate some school collaboration. Boutilier and King (2013) identified examples of pediatric pain programs that successfully incorporate a school reintegration or educational component into pain management protocols. For example, both the Chronic Pain Rehabilitation Program at the Lucile Packard Children's Hospital in Palo Alto, California and the Pediatric Pain Rehabilitation Clinic at the Kennedy Krieger Institute in Baltimore, Maryland collaborate

with schools to support their patients' academic success. Additionally, both programs incorporate neuropsychological or psychoeducational assessments and interventions to ensure a smooth transition back to school. Cognitive behavioral interventions have also been used to target academic impairment and have shown to have positive effects on school attendance (Eccleston et al., 2009; Logan & Simons, 2010). In considering school reintegration for this population, cognitive behavioral strategies should certainly be considered and incorporated in relation to school reintegration.

In a discussion of return to school in children with recurrent abdominal pain (RAP), Walker (2004) identifies a number of common obstacles to school attendance and offers simple interventions that can be used to help children with RAP reintegrate to school following an absence. Walker (2004) highlights obstacles such as extensive make-up work, worry about providing explanations of their absence to teachers and peers, and fear of being unable to manage a pain episode at school. She recommends the use of interventions such as gradual reintroduction (e.g. returning for half of a school day then slowly increasing attendance to a full day) and the use of a behavior reinforcement program (e.g., star chart) to track and reward the child's school attendance. The interinstitutional collaboration observed in the applied practice of the pediatric pain programs mentioned above along with Walker's (2004) more concrete guidelines for supporting children with RAP can serve as important models for developing supports for children with chronic pain in their return to school.

Similar to the challenges identified by Walker (2004), clinicians often report difficulty making decisions about modified or reduced school schedules for children with chronic pain. On one hand the child may experience increased school success if the demands are kept at a more minimal expectation for the child. However, from a behavioral perspective, allowing escape/avoidance behavior around school attendance will not result in successful school reintegration. In considering school reintegration for children with chronic pain, difficult clinical decisions or dilemmas such as this one represent important areas that must be addressed by clinical research.

## **Generalizability of school reintegration programs**

Prevatt et al. (2000) suggest school reintegration models developed for cancer are easily generalized to other illnesses; however, when considering this proposition, the unique features of chronic pain prompt careful consideration. For example, research shows that some school team members maintain false perceptions about chronic pain that, in some cases, require unique psychoeducation (Logan et al., 2007). Teachers may believe, for example, that a student is faking their pain to avoid school (Chibnall & Tait, 1999; Logan et al., 2007). Similar beliefs regarding the real nature of chronic pain may also need to be addressed among peers of children with chronic pain. In this case, the school reintegration program should incorporate specific education about the nature and experience of chronic pain for both peers and teachers. In a study about school personnel's specific concerns about chronic pain, Logan & Curran (2005) identify that school personnel desire more education and communication regarding the specific needs of children with chronic pain indicating their potential openness to meetings/workshops. Additionally, chronic pain tends to produce a persistent unpredictable pattern of school absences and returns (Logan et al., 2008). A child may experience multiple absences associated with chronic pain over an extended period of time, resulting in the need for multiple school reintegration plans. Conversely, a child with cancer may experience a single extended school absence and then return to school illness-free, resulting in only one instance where school reintegration is necessary. In the case of the student with pain, the school reintegration program should be clear with respect to expectations regarding school attendance (e.g. full time regardless of pain or more flexible absences) and, if appropriate, determine how sporadic absences will be managed. Although generalizing school reintegration programs developed for other illnesses such as cancer to chronic pain requires caution on the part of clinicians, families, and educators, they are an important potential intervention, as they serve as models to learn from in the development of a

program specific to chronic pain. Walker's (2004) guidelines for supporting children with RAP identify obstacles to school attendance that are addressed by school reintegration programs developed for other illness. For example, Walker (2004) suggests children worry about explaining their absence to teachers and peers; this concern would be addressed in the school personnel workshop and peer education initiative components of current school reintegration programs (Prevatt et al., 2000). This example illustrates how it is possible to modify and use existing school reintegration programs to support the school reintegration needs of children with chronic pain. Furthermore, existing programs provide a useful and somewhat inspirational example of how school and health care systems can collaborate effectively with one another to ensure the academic success of children interacting with both systems.

### **Future directions and recommendations**

The development of school reintegration program guidelines for children with chronic pain would provide valuable guidance to clinicians, educators, and families. Whereas a set of school reintegration program guidelines for chronic pain could likely include a number of general recommendations, flexibility for individual differences and developmental considerations will also be important. Considering the variability of chronic pain, a specific school reintegration program will need to be flexible and allow for differences from student to student. Following the development of such a program, examination of its effectiveness will be necessary. This examination could occur through a randomized controlled trial or by using another equally rigorous method of comparison between the supports children currently receive in their return to school and the more formal application of support through a school reintegration program that incorporates the components described above. As previously mentioned, this commentary focused primarily on the school-related challenge of decreased school attendance. To ensure the child's needs are fully met, consideration of additional school-related challenges such as disrupted social functioning and

cognitive processes will be important in the development of such a program.

Furthermore, careful examination and consideration of the unique features of chronic pain (e.g. peer perception of faking pain) is imperative. For example, one future consideration related to peer involvement in the school reintegration process might be the implementation of a school-wide program that promotes and rewards peer inclusion, prosocial behavior, and healthy lifestyles more generally, as opposed to individual peer education sessions about chronic pain. A consideration such as this is informed by research examining whether disclosure and social-support seeking from peers might be harmful as opposed to helpful for children with chronic pain (e.g. see La Greca et al., 2002). Peer education provides only one of many examples of how unique features of chronic pain need to be considered in the development of a school reintegration program.

Following development of guidelines for school reintegration in children with chronic pain, it will be important to ensure that these guidelines are followed and that programming is implemented by appropriately trained personnel. Psychologists, nurses, and social workers who work in schools and who have adequate training in intervention may be an appropriate fit for this role and, consequently, could become an important part of school reintegration programs for children with chronic pain. These same professionals who also possess advanced research skills could contribute to the further development and monitoring of a chronic pain-specific school reintegration program.

Whereas we would like to offer concrete clinical guidelines for facilitating a positive return to school for children with chronic pain, we face the challenge of limited research in the areas of school-related support needs and school reintegration support strategies for this population. We agree that developing concrete guidelines for supporting this population in their return to school would be invaluable to the field and, as such, we recommend future research and development in this area. Our research team is currently examining adolescents' return to school needs following major spinal surgery, with a view to developing both general and condition-specific guidelines for supporting return

to school. In an attempt to offer applied recommendations for clinicians who are supporting children with chronic pain in their return to school, our research team has also included a case example

highlighting a hypothetical school reintegration experience. We hope to highlight some of the critical considerations discussed throughout this commentary in the case example.

### Case Example

Emily is a 16-year-old girl with recurrent abdominal pain, chronic daily headaches, and lower back pain. Emily has had pain for the past 3 years, but has experienced increased intensity, frequency, and duration of her pain over the past year. Emily is in grade 10 and has missed, on average, 2-3 days of school per week. On a few occasions, Emily has missed 2 full weeks of school. She sometimes pushes herself to attend for an entire week, but then usually ends up missing the next full week of school because of a pain flare. These absences have interfered with Emily's ability to complete her schoolwork (she has missed out on instruction and sometimes has difficulty getting assignments from her teachers). Before the onset of pain, Emily grades were in the A range, but over the past year they have dropped to B- range. When Emily misses school, it is always for the entire day and she decides whether to go on the morning of school. This decision is made based on how she feels in the morning; on days when her pain is more intense, she decides not to go because she would not be able to pay attention in class or sit through an entire class (her back pain is exacerbated by long periods of sitting). Emily reports that her pain is usually a little bit better when she stays home (because she can move around, lie down, and sleep), but that it is usually still fairly intense. Privately, Emily reports that she feels anxious about returning to school after a missed day (or days) because she is unsure of the work she has missed and unsure of her teachers' and friends' responses when she returns.

Emily has recently been evaluated by a chronic pain team who recommended that she start gabapentin, referred her to the team psychologist to learn relaxation and other cognitive behavioral strategies, and the team physiotherapist for activity planning. Emily reported a strong desire to improve her school attendance and ability to function at school. Emily, her mother, and the team discussed accommodations that Emily felt would be helpful in increasing school attendance and function. Emily and her mother thought that it would be helpful for her teachers to receive educational materials about chronic pain, particularly to correct misconceptions that Emily was faking or using her pain to get out of school. Emily also thought it would be helpful to have the ability to leave class without having to ask for permission (to walk and stretch). The team discussed the importance of having a plan for school attendance, rather than basing attendance solely on how Emily felt each morning. There were several rationales supporting this recommendation. First, Emily recognized that when she missed school she felt anxious about returning and thus felt more inclined to want to avoid the next day. Second, Emily tended to have a pattern of overexerting herself by attending school for several days in a row and then triggering a pain flare that would keep her out of school for several days. Third, Emily's current pattern meant that she and her teachers did not know when she would be absent therefore could not plan for how to get assignments and other work to her.

With consent from Emily, the team drafted a letter to the school describing her pain condition (including the physical and physiological aspects of Emily's pain). At the end of this letter, the team described accommodations discussed in the assessment visit. The team encouraged Emily and her mother to meet with her vice principal and teachers to discuss the letter and accommodations. In a follow-up phone call with the school, the chronic pain team nurse spoke to the vice principal to clarify recommendations for Emily's school plan. In discussions with Emily and school staff, it was identified that, because her classes were on a rotating schedule, having Emily start by attending only morning classes meant that she was able to attend all of her classes at least twice per week. This plan meant that Emily was attending about the same amount of school (2.5 days per week in total), but that these absences were planned and not based only on pain. A

further plan was developed for Emily to slowly increase her school attendance by a half day each week until she was attending full time. The school was satisfied with this plan as it provided the teachers the ability to anticipate when Emily would be present in order to receive work packages to complete at home. The school also suggested that Emily could have access to her teachers on lunch breaks if she needed extra help or had questions about assignments. The school also agreed to allow Emily to leave class if she needed to stretch and suggested that she have access to the nurses' office if she needed to lie down. Emily and her mother were both happy with this plan. Over the next few months, Emily slowly increased her school attendance. On several occasions, she was unable to tolerate increases in attendance, so was encouraged to drop back to a level where she had previously been successful. At one point, Emily had a week long absence secondary to the flu, but returned to school on a morning only plan and increased her attendance by two additional half days each week.

As the prevalence of pediatric chronic pain continues to affect children and, consequently, the family, education, and health care systems with which they interact, it is essential for these systems to work collaboratively with one another. School reintegration programs can serve as an important and effective tool to facilitate effective collaboration between these groups to ensure the most positive academic and social outcomes for children challenged by chronic pain.

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