

Cognitive-Behavioral Interventions for Physical Symptom Management in Pediatric Palliative Medicine

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The prevalence and management of physical symptoms in children with progressive diseases have garnered increasing interest over the last several years [1–3]. Symptoms vary relative to diagnosis, stage of disease, and which therapeutic interventions have been attempted. The alleviation of symptoms, with the ultimate intention of improvement of quality of life, is a fundamental component of pediatric palliative medicine. Although symptoms in individuals who are dying often are divided into physical and psychological, it is evident that there is an interaction between the physical and psychological determinants of symptoms. Factors such as anxiety, depression, symptom preoccupation, cognitive appraisal, and perceived control can exacerbate physical symptoms or influence perceptions of symptoms [4]. Developmentally sensitive assessment of physiologic and psychological contributors to symptoms is indicated.

Common physical symptoms in dying children include pain, fatigue, insomnia, and nutritional concerns (eg, anorexia, nausea/emesis, feeding difficulties). Cognitive-behavioral interventions for the management of these symptoms have been widely researched in various chronic illness populations. There is a paucity of research specific to the pediatric palliative population, and this area is ripe for further investigation. Overall, clinical and empirical evidence suggests good promise for the application of cognitive-behavioral principles and interventions, at least as an adjunct to pharmacologic or surgical interventions, if not as the primary intervention, for the amelioration of symptoms in pediatric palliation. The ultimate goal when

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using these interventions in palliative patients is to promote healthy cognitions and behaviors that facilitate coping with physical and psychological discomfort and improve quality of life.

Overview of cognitive-behavioral interventions

The focus of cognitive-behavioral interventions for symptom management is multifaceted and includes (1) alteration of maladaptive behaviors; (2) alteration of self-statements, images, and feelings that interfere with adaptive functioning; (3) alteration of assumptions and beliefs that contribute to habitual perceptions and reactions [4]; and (4) training in new behaviors and ways of thinking that promote healthier functioning. Symptoms that might be perceived as vague and overwhelming are translated into identifiable difficulties that can be actively addressed.

Cognitive restructuring can be taught as a method for identifying and changing thoughts and feelings that might exacerbate physical symptoms. In an empathetic manner, the palliative patient can be encouraged to self-monitor maladaptive thoughts and emotions that precede, accompany, or follow the exacerbation of symptoms. Awareness of increased emotional distress and muscle tension that might surround the exacerbation of symptoms is encouraged. The pediatric palliative patient also can be guided in the use of *positive self-statements* for symptom management (eg, "I have been able to cope with this symptom before, and I can do it again").

Cognitive distraction is a particularly useful technique, because the child with an advanced disease is likely to overattend to bodily sensations that otherwise might have been ignored if the child were healthy. The child might perceive each new sensation as a symptom of physical decline. Because it is difficult to attend fully to more than one thing at any given time, simply encouraging a child to distract himself or herself with activities, such as reading a book, watching television, playing a game, or talking with a friend, can be useful for symptom management.

Activity-rest cycling, an activity pacing method, also can be helpful in managing discomfort. Activities that might be encouraged to some degree, but also might be difficult for a child with an advanced disease to tolerate (eg, walking), can be broken up into periods of activity followed by rest (eg, 10 minutes of activity followed by 5 minutes of rest), with cycling repeated as appropriate.

Decreasing distress associated with various components of medical management can be useful in managing a child's overall distress, which can have an impact on physical symptoms. Several behavioral strategies using applied behavioral analysis can facilitate medication administrations. Walco [5] developed a behavioral protocol for pill swallowing, and various adaptations of this treatment have been applied to several pediatric populations [6,7]. As with other medical procedures, it is beneficial to make medication administration predictable, brief, and rewarding.

Numerous specific relaxation exercises can be implemented in anticipation of a stressful event or as a response to stress and physical discomfort. Examples of these techniques include *diaphragmatic breathing*, *guided imagery*, and *progressive muscle relaxation*. Each of these techniques is easy to teach and simple for children to learn. Use of these techniques can facilitate adaptive coping and be an effective means of symptom management. It is generally recommended that these techniques be taught to patients as early in the illness as possible. Patients initially should be encouraged to practice these techniques as frequently as possible, including during times when symptoms are less overwhelming, to gain mastery of the techniques and appreciate greater benefit from their use.

Diaphragmatic breathing can be used in any situation with no behavioral indication in which the child is doing anything different from “normal.” This technique can be especially appealing for children and adolescents. Diaphragmatic breathing can be used alone or in combination with other techniques. Guidelines for instructing patients on the use of this technique are presented in Box 1. Instructions can be adapted and modified for children at various developmental levels. *Guided imagery* involves the use of one’s imagination for visualization of a relaxing scene or experience. This technique is typically most effective when the child chooses the specific image to visualize. *Progressive muscle relaxation* involves the systematic tensing and relaxing of specific muscle groups. The child can be taught to begin with the muscles in the feet, tensing all of these muscles and holding the tension for 10 seconds, followed by relaxation of these same muscles for 10 seconds. The child is taught to repeat this process with the next set of muscles (eg, legs, stomach) until every area of the body has been relaxed. In clinical practice, this technique is most useful for managing insomnia or anticipatory anxiety associated with uncomfortable procedures. Because muscle tensing can exacerbate pain in some patients, this technique is less often recommended for the specific management of pain.

It is useful to guide parents and other members of the medical team in the use of various cognitive-behavioral strategies. Parents can practice these techniques with their children. Parents and other members of the care team can prompt and encourage children to use effective coping strategies that they have learned. These individuals, along with the psychologist, can model healthy coping behaviors for the child and encourage their practice. Positive reinforcement can be used to reward healthy coping behaviors and promote their continued use.

Symptom-specific recommendations

Pain

Pain is among the most common and distressing symptoms in patients with advanced disease. Pain can be related to the illness itself or to

Box 1. Guidelines for teaching diaphragmatic breathing to children

1. Instruct the child to sit or lie down in a comfortable position. Further instructions should be reviewed with the child first and the technique should be modeled before requiring the child's participation.
2. Help the child to locate his or her diaphragm muscle (eg, "the soft spot right underneath the middle of your ribcage and on top of your belly").
3. Instruct the child to take a slow, gentle breath in through the nose. The child should be guided to keep the upper body (eg, shoulders) relaxed. Using the metaphor of having a balloon in the belly that the child will attempt to fill slowly, just as much as feels comfortable, is often useful in helping the child to focus on the diaphragm muscle and keep the upper body relaxed.
4. Instruct the child to hold the breath for a few seconds or as long as feels comfortable and natural.
5. Instruct the child to exhale slowly and gently through the mouth, slowly releasing the air from the balloon. Children can be encouraged to blow out in the same way as they would if they were trying to blow a very large bubble with a bubble wand.
6. The cycle can be repeated several times.

treatments and procedures. Muscular tension and psychological distress can exacerbate pain, and anxiety in anticipation of or during painful medical procedures can exacerbate perceptions of procedural pain [8]. Several cognitive-behavioral interventions have been found to be useful in reducing pain, including modeling, use of diaphragmatic breathing, imagery, distraction, offering of positive incentives, and behavioral rehearsal [9–11]. Children who have significant anxiety in anticipation of painful procedures benefit from developmentally appropriate explanation of procedures, information regarding what any given procedure might sound or feel like from the child's perspective, and explanation of what benefits might be expected. Children should be encouraged to ask questions. Allowing children to have some control over procedures (eg, permission to choose which arm will be used for a needle stick) also can help reduce anxiety. Children also might benefit from instruction and practice in behaviors that promote a successful procedure (eg, lying still). Telling children when procedures are over can help to facilitate a return from heightened physiologic arousal to a more calm state.

In an adult population, systematic training of partners in cognitive-behavioral pain management techniques (specifically relaxation training,

imagery, and activity-rest cycling) was found to increase partner self-efficacy and to be beneficial for management of cancer pain and other end-of-life symptoms [12]. Similar findings have been observed in clinical practice in parents and their dying children.

Fatigue

Fatigue is common to many advanced diseases and can be attributed to inactivity, poor nutrition, dehydration, anemia, pain, depression, insomnia, medication side effects, and radiation side effects [13]. Increasing fatigue is often the first sign of deterioration in a patient with advanced disease [14], however, and it is common for patients to infer that fatigue indicates physical decline. Patients should be educated or reminded about possible alternative explanations for fatigue. Several nonpharmacologic strategies for management of fatigue have been shown to be beneficial, including performing essential functions in the morning, scheduling a regular afternoon nap, avoiding complete inactivity, and engaging in even very mild exercise if possible [15]. Psychologists can be instrumental in assisting children and their families in implementing these strategies. Because depression can contribute to fatigue, assessment of emotional functioning, with psychological or pharmacologic intervention as indicated, is essential.

Insomnia

Children with advanced illness also may experience insomnia. Several factors contribute to insomnia, including pain, lack of physical activity during the day, multiple medications that affect arousal, anxiety, and depression [13,14]. It is important to emphasize the distinction between day (time to be awake) and night (time to be asleep) [16]. To regulate sleep-wake patterns and induce relatively greater fatigue at night, children should be encouraged to be physically or mentally active (as able) during the day. Activities should be rotated throughout the child's day to maintain high levels of motivation and activity. Curtains should remain open, and although the child might require comfortable clothing, changing out of pajamas during the day is helpful. Activity should be kept to a minimum at night. The National Sleep Foundation [17] has provided basic recommendations for sleep hygiene, which include having a quiet room with dim lighting and minimal interruptions from others. To the extent that is possible, these recommendations should be encouraged in inpatients and outpatients. It may be helpful to postpone or alter nonurgent medical care during nighttime hours to promote better sleep hygiene.

Assessment and treatment of depressive and anxious symptoms, which might be contributing to insomnia, is essential. Relaxation exercises, particularly progressive muscle relaxation, can assist children in achieving sleep and in returning to sleep with repeated nighttime awakenings. Children

who spend a frequent amount of time awake in their beds have particular difficulty maintaining good sleep habits. In this situation, the classically conditioned drowsiness linked to lying in bed is disrupted or extinguished. The bed no longer provides a cue to promote sleep. To re-establish this conditioned response, children should be encouraged to leave their beds (or modify their position in bed by moving to a seated position) when they are unable to fall asleep after 20 to 30 minutes and to engage in a boring or repetitive activity to promote drowsiness. When they begin to feel drowsy, they are to return to bed (or return to a lying-down position) and attempt to fall asleep again.

Nutritional concerns

Children with advanced illness may show reduced caloric intake, food refusal, changes in food preference, nausea, and emesis. Nutritional concerns can have a negative impact on medical care and present as primary concerns for the child and family. Anorexia can result from altered taste and smell, pain, mouth sores, swallowing difficulties, nausea and vomiting, medication side effects, constipation, and depression [13]. Nausea and emesis may be secondary to treatment (eg, chemotherapy, opioids), metabolic disturbances, or constipation and might reflect a conditioned response [15].

Feeding difficulties have been addressed from a behavioral perspective across several disease populations. In a systematic review of the literature, Kerwin [18] found contingency management (with planned ignoring and positive reinforcement) to be an efficacious intervention. Linscheid et al [19] described four components of behavioral procedures to increase caloric intake. First, social attention can be made contingent on eating, whereas behaviors associated with food avoidance or refusal are blocked or ignored. Second, desirable and undesirable consequences can be used to increase compliance with eating demands and reduce food refusal or avoidance. Third, food intake can be controlled to increase appetite during mealtimes. Snacks may be refused between meals with the intention of increasing the chance that a child would be willing to eat during meals. Finally, adults can modify cues or prompts to eat or use additional shaping and prompt fading to promote a more complex or wider range of eating behaviors. In palliative patients, parents may be reluctant to employ certain behavioral procedures, however, which they might view as "forcing" children to eat or ignoring children. Education, guidance, and reassurance often are indicated.

Modifying situational factors (ie, antecedent management) also may provide benefit for children. Children may develop less appetite because of the frequency and duration that food is presented. Meal presentation may be altered to promote appetite. Smaller meals may be presented to avoid overwhelming a child with the demand to eat, allowing for the successful completion of a meal. In the hospital, food may be visually presented

only during certain times of the day, as opposed to food trays and snack foods frequently being present [16]. Children can be praised for eating even when they do not feel hungry. Verbal praise can be paired with rewarding activities (eg, a parent can play a favorite game with a child), to enhance the reinforcement of eating despite the absence of appetite. Additionally, stimuli may be present in the room that can limit one's appetite. Emesis buckets may prompt feelings of nausea instead of hunger. These stimuli should be placed out of sight, while remaining readily available. Measurable outcomes should be provided. Children may respond better to the demand to eat when they are striving for identified goals (eg, 3 cans of Pediasure before 2 PM or 50% of tray eaten). Parents and medical staff can limit the frequency of discussing a child's food avoidance and need to eat, to reduce cognitive focus on food and increase a child's self-efficacy regarding eating [20–22].

Additional research has focused on cognitive-behavioral interventions for management of nausea and emesis specifically among pediatric cancer patients. Research has suggested that children with cancer do not automatically engage in effective coping strategies for management of nausea and emesis [23]. Training children in the use of cognitive-behavioral interventions for the management of nausea and emesis yields promise as an adjunctive intervention. In a systematic review of empirically evaluated treatments [24], use of guided imagery combined with suggestion was considered a well-established treatment for management of nausea and emesis. This intervention was found to be effective for management of symptoms that occurred in anticipation of receiving chemotherapy and symptoms that occurred after chemotherapy had been administered. Cognitive distraction combined with relaxation was found to be a probably efficacious treatment, and use of other types of distraction (eg, playing video games) showed good promise.

Summary

The alleviation of symptoms, with the ultimate intention of improvement of quality of life, is a fundamental component of pediatric palliative medicine. Psychological factors can exacerbate physical symptoms or influence the perception of symptoms in children with advanced disease. Cognitive-behavioral interventions have yielded positive outcomes for the management of symptoms across various disease populations. There is a paucity of evidence specific to the application of these interventions in pediatric palliation, although evidence-based treatments developed through investigation of other disease populations can be applied in pediatric palliation. Children tend to be receptive to these noninvasive interventions, which can decrease fear and anxiety, increase self-efficacy and sense of control, and improve overall coping. Continued investigation into the use of these interventions in pediatric palliation is encouraged.

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