

A NARRATIVE: MEDITATION IN THE LIVES OF CHILDREN WITH CHRONIC ILLNESS

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Abstract

The presence of chronic illness in one's life often entails endless appointments, tests, medications, treatments, and procedures. In the instances of children with chronic illness, they do not know what life consists of without their illness, and consequently, have lived with many restrictions. Children with chronic illness and their families are not only in need of traditional methods and strategies from the medical model but are often in need of additional strategies to support and cope with the nature and effects of the chronic illness. This paper focuses on how mediation, mindfulness, and visualization strategies aid individuals with chronic illness.

Meditation in the lives of children with chronic illness

Chronic illness quickly fills one's life with appointments, tests, medications, treatments, and procedures. The life of the individual known prior to the onset of the illness completely disappears. Many children with chronic illness do not know life without their illness and have consequently, lived with many restrictions. The lives of children with chronic illness have been dominated with a strong presence of the medical community. Children with chronic illness and their families are in need of traditional methods and strategies from the medical model but are often also in need of additional psychological support to cope with the nature of the illness and

its effects (Frels, Leggett, & Larocca, 2009). The focus of this paper is to examine how meditative, mindful, and visualization strategies can help children with chronic illnesses cope with both their physical and psychological symptoms.

Defining Chronic Illness

The multiple definitions associated with chronic illness effect the accuracy of identifying an exact percentage about the prevalence of chronic illness in children and adolescence. Current research estimates suggest the prevalence of children with chronic illness is approximately 30%, and an estimated 98% of children diagnosed with chronic illness will live to adulthood (Asprey & Nash, 2006; Martinez & Ercikan, 2009). Children with chronic illness are able to pursue their personal and educational endeavors due to increases in children surviving life-threatening and life-limiting illness, increases in technological advancements, and increases in outpatient care. The benefits of the improved health accommodations are permitting children with chronic illness the opportunity to actively participate in the educational community (Asprey & Nash, 2006).

The difficulty in defining chronic illness poses a challenge to identifying a static definition applicable to all chronic illnesses. The medical model defines chronic illness in the following way:

Chronic illnesses are disorders, diseases, or disabilities involving physical and/or mental impairment, interfering with daily activities for at least three months, potentially requiring hospitalization for one month in a year, and that may not progressively worsen or become fatal. Chronic illnesses can be treated but not cured and, because of their protracted nature, disease management now falls largely upon family and community caregivers, including school personnel. (Duggan, Medway, & Bunke, 2004)

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The medical model's definition does not address the complexity of the diseases, symptoms, and uniqueness of each chronic illness.

For the purposes of this paper, chronic illness is defined as “a medical condition of extended duration that creates impairment in adaptive behaviour and socially defined roles” (McCabe & Shaw, 2008, p. 74). The adaptive behaviours chronic illness impairs are communication, everyday living, self-care, academic achievement, and motor behaviours. The socially defined roles hindered by having a chronic illness are social skills, family roles, education and schooling experience, and communication with medical and psychological professionals (McCabe & Shaw, 2008).

Methodology

My personal experiences of living with a chronic illness fostered my quest for literature focusing on meditation in the lives of individuals with chronic illness. The following paper is a narrative inquiry of my journey bringing meditation into my life and my investigation of how meditation can aid others with chronic illness.

Narrative inquiry is grounded in qualitative research that investigates an individual's inner thoughts and experiences (Gall, Gall, & Borg, 2005). Furthermore, narrative inquiry is defined as “stories lived and told” (Clandinin and Connelly, 2000, p. 20). The narrative perspective permits individuals to do their best to understand present conditions although there may be other explanations and alternatives. Within narrative inquiry it is the individual within their setting that is the primary interest (Clandinin and Connelly, 2000).

The limited knowledge about the nature of living with a chronic illness and the need for additional coping strategies motivated me to investigate if and how meditation can improve the lives of individuals with a chronic illness. Having lived with a chronic illness for years, I have

had to develop my own meditative practice to aid with managing the continuous presence of my symptoms and discomfort. I had to accept that I have an illness for the rest of my life. Accepting my chronic illness will have an endless presence in my life, was and continues to be, very daunting and challenging; although I am still hopeful strategies and methods to improve my life will continue to be developed. When initially diagnosed with my chronic illness I was extremely angry with my body. I felt my body had defied my mind and soul. I did not view my mind, body, and soul as one, but felt my physical body was my enemy. Learning and practicing meditation has helped and continues to aid me in identifying my feelings and learning to create a balance between my mind, body, and soul. Meditation as described by Fisher (2006) has improved my metacognition or “me-cognition” referring “to what I know and think about myself in the private theatre of my thoughts” (Fisher, 2006, p. 149). From integrating meditation into my life, I have realized how my mind, body, and soul need to engage jointly in identifying my inner emotions, wisdom and strength.

I continue to incorporate mediation into my daily life. Learning about how to meditate has provided me the ability to cope with my day to day symptoms of my chronic illness. I have uncontrollable and painful symptoms that I try to maintain with multiple medications, but mediation offers an alternative. From learning meditation, my first response to counter the pain is to stop and breathe while thinking of the word *calm* as I inhale and *relaxed* as I exhale. This meditative strategy may seem incredibly simple but has taken me years to develop. The notion of even thinking about my breath while in pain has involved considerable effort. Initially, when first confronted with the chronic symptoms of my illness, my first response was to hold my breath and reach for pain medication. This point is not to enforce that pain medication is unnecessary, but that mediation can provide an alternative strategy to coping with my symptoms. From having

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a chronic illness there are many medical procedures I endure. Having the skill to concentrate on something other than the current experiences of my body is extremely beneficial. Regular and continuous invasive procedures are my body's norm and having the ability to clear my mind is essential for me to cope with the constant intrusions my body encounters. Meditation has and continues to be an essential practice and strategy I utilize in my day to day life with a chronic illness. Meditation has revealed the importance and necessity for me to unite my mind, body, and soul.

Meditation in my life as an individual with a chronic illness does not only provide immediate benefits by improving my symptoms but has provided opportunities for personal growth and acceptance of my life's circumstances. Although I always experience the symptoms of my illness; I am not solely an illness but an individual with an illness. Meditation has served as a means for me to explore how I define myself and what my purpose is.

Spiritual distress among children with chronic illness

When defining the word spiritual it can include different meanings and images depending on the religious, cultural, and personal beliefs of the individual. Carr and Haldane (2004) discuss the meaning of spiritual as reference to something beyond the present moment and a further awareness that illuminates the human experience. The manifested awareness may illicit a "religious, spiritual, or aesthetic" experience (Fisher, 2006, p. 147). The spiritual aspects of meditation have been described to increase access to a divine or universal connection and opening the mind (Fisher, 2006).

Pridmore and Pridmore (2004) have acknowledged and referred to the needs of individuals with chronic illness that exist outside of the medical model as "spiritual distress"

(Pridmore & Pridmore, 2004, p. 22). Spiritual distress has been linked to both spiritual and religious explanations and is usually associated with adults who are ill. The emphasis of discussing spiritual distress is not to identify the precise definition of what spiritual distress is but rather to reveal the need to provide spiritual education for individuals with chronic illness, adults, adolescents, and children. A response to spiritual distress is the possible exploration of spiritual development. Spiritual development for children with chronic illness is a method utilized to expand the growth of their inner lives and well-being by viewing the spiritual as part of the child's whole being (Pridmore & Pridmore, 2004). Pridmore and Pridmore (2004) suggest the importance of educating children with chronic illness is about spiritual development "to encourage their discovery of meaning, purpose, value-and especially joy- in life today" (p. 29). It is essential for children with chronic illness to be given the opportunity to ponder the question, "What it means to be me?" (Pridmore & Pridmore, 2004, p. 33).

Children respond and act in the present whether they are healthy or unhealthy; this notion of how children interact with their environment reveals a further pressing dimension on children with chronic illness as their destination is completely uncertain (Pridmore & Pridmore, 2004). Children with chronic illness lack the ability to control what is happening to their body and are in need of strategies to help relieve the stress and provided with opportunities to express themselves (Silver, 2004). Meditation encourages children with chronic illness to engage in deep thought and the opportunity to attend to the uncertainty their illness has on their life.

Addressing the issues of spiritual distress in lives of children with chronic illness

Children can be aided by exposure to strategies to help to counteract negative feelings and experiences by learning meditative and relaxation techniques to produce calm and positive feelings (Napper-Owen, 2006). Meditation and visualization approaches are two strategies that

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can aid children with chronic illness in being able to cope with the effects of having a chronic illness.

Meditation as a strategy

Meditation is focused on the individual quieting the mind and body simultaneously. Meditation can facilitate discussions with children with chronic illness including the exploration of mind and body consciousness, knowledge, and their imagination (Fisher, 2006). There are many different definitions, approaches, and strategies to facilitate and guide individuals to learn and develop their meditative process. Miller (2008) defines meditation as the process that “involves quieting and focusing of the mind” (Miller, 2008, p. 179). Fontana and Slack provide an alternate definition of meditation, “It is a very special kind of sitting quietly doing nothing, in which the mind is held clear and still, alert and watchful, and free from losing itself in thinking” (Fontana & Slack, 1997, p. 5).

This simple notion of concentrating and opening the mind to inner peace with the mental, physical, and spiritual benefits is often a daunting practice for individuals to attempt, although there are many benefits to practicing meditation. Research by Benson (1976) indicates the effects of meditation aid in coping with stress, lower blood pressure, and breathing (Miller, 2008). There is additional research identifying the benefits of adults with chronic illness engaging in meditative practices while research investigating the positive effects of children with chronic illnesses practicing meditative practices is still fairly limited (Ott, 2002).

Mindfulness as a meditative strategy

Ott (2002) investigated mindfulness meditation to help in addressing the needs of a child with a chronic illness. Ott (2002) defined mindful meditation as the “process of purposefully paying attention to what is happening in the present moment without being distracted by what

has already happened or what might happen” (p. 487). The meditative approaches utilized in mindful mediation can incorporate a body scan (appendix a), mindful eating, and mindful walking. Once the skill of mindful meditation is acquired it can aid in reducing stress, anxiety and pain (Ott, 2002).

Mindful meditation gives the individual the opportunity to expand their awareness of the present. The body scan is an example of a mindful meditation that can aid the individually in focusing their attention on their breath. When the mind wanders the individual will simply return their focus to their breath. When beginning to incorporate meditative practices with a child with a chronic illness it is important to establish arrangements concerning when and where the meditation can be practiced as well as how long the meditation will be.

Ott (2002) exposed a child with a chronic illness to mindful eating by utilizing Jon Kabat-Zinn’s approach with two raisons. The child was given two raisons and instructed to eat one and set the other raison aside. Before eating the second raison the child was invited to pretend she was discovering a raison for the first time. The child was encouraged to investigate the raison by feeling it, smelling it, observing it, and listening to it (Ott, 2002).

Mindful walking was also incorporated into the meditative practice to reveal to the child that meditation can be brought into her daily life. The intention of mindful walking is to invite the individual to be aware of the whole experience of walking, not just as a method to reach a destination (Ott, 2002).

Encouraging the child to keep a meditation journal as well as recording when the child meditated may be suggested. The intent of the journal is for the child to be given the opportunity to discuss and reflect on the meditation with particular reference to the feelings and emotions the meditation released (Ott, 2002).

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The child in Ott's research revealed the benefits of engaging and developing mindful meditation practices:

I learned how to practice quiet breathing every day. She saw me several times to help me practice and to see how I was doing. Now I feel much better. I still use medicine, and I practice my meditation most days. (Ott, 2002, p. 488)

The whole approach to incorporating mindful meditation in the lives of children with chronic illness is to allow the child the opportunity to connect their mind, body, and spirit by practicing complete attentiveness to their feelings, sensations, and experiences. The Japanese Zen tradition refers to meditation as 'just sitting' involving being relaxed with the mind and at peace with what is happening by not trying to alter our present experience (Austin, 1998). Existing within a body affected by a chronic illness that continues to have undesirable symptoms and pain, manifests much frustration and anxiety.

Visualization as a strategy

Visualization is a form of meditation that can also be utilized for children with chronic illness. Visualization is described as gently focusing the mind by guiding the mind on an imaginary journey (Fisher, 2006). Miller (2008) further reveals "Visualization uses a set of images in either a directed or undirected manner" (p. 96). Visualization engages the mind's eye and gives the individual the opportunity to engage with a specific set of images. The images can include a variety of different settings and descriptions (Miller, 2008). Visualization can include a variety of methods including simply visualizing or a direct imagery approach including metaphor and storytelling (Utay & Miller, 2006). Visualization is also referred to as generative or guided imagery (Fisher, 2006).

Utay and Miller (2006) discussed three possible goals of visualization: to aid in relaxation, instilling positive views about the future, and increasing problem solving strategies. The intention of visualization is not to develop a standard set of imagery but to create images based on the needs of the individual. Individuals involved in sports, rehabilitation, and illness are all examples of who has benefitted from engaging in visualization strategies (Utay & Miller, 2006).

Murphy (1992) identified the positive effects identified by engaging in visualization to alleviate the symptoms of chronic pain, cancer, and other diseases. When introducing and practicing visualization with children it is important to gently remind them that there is no right way to imagine and whatever they see is unique to them. If they see an image that frightens them all they need to do is open their eyes (Miller, 2008). Ball, Shapiro, Monheim, and Weydert (2003) conducted a pilot study that revealed how children who experience chronic abdominal pain decreased their pain 67% after engaging in the practice of visualization (Utay & Miller, 2006). Martinez and Ercikan (2009) researched the educational and psychological effects of children with chronic illness and concluded additional research is required in order to understand and administer services for children with chronic illnesses at home, in hospital and school settings (Martinez & Ercikan, 2009).

Discussion

Engaging in meditation to aid the effects of a chronic illness can positively influence the individual experience of coping with disease (Bonadonna, 2003). Meditation is a multi-faceted strategy that provides different experiences and fulfills different purposes to each individual engaging in the meditative approach. The magnificence of meditation is the individual who engages in meditating will find he/she is able to identify and pursue their own personal journey

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of self-discovery. Furthermore, the benefits of students engaging in meditative practices extend beyond students with chronic illness and have the potential to positively affect all students (Miller, 2008).

Providing children with chronic illness the opportunities to develop and practice meditation releases a positive experience to aid understanding and coping with the psychological and physical complexities of having a chronic illness. Meditation not only provides a coping mechanism for the symptoms and pain but provides the opportunity to engage in reflective thought. The positive effects of meditation are best summarized by a child in Fisher's research by revealing, "It's like a shower. It cleans your mind, so you can do your best thinking" (Fisher, 2006, p. 146). The limited amount of research on children with chronic illness and strategies to aid their symptoms reinforces the need for researchers to continue to investigate and examine both the perspectives and strategies for children with chronic illness.

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Journal of Unschooling and Alternative Learning Vol. 6, Issue 11, Winter, 2012.

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appendix a

Body Scan

When doing the body scan, it is important to be in a safe, comfortable place free from distractions and interruptions. It is also important to wear loose, comfortable clothing that will not restrict the body's breathing in any way. The body tends to cool when doing a body scan, so a light cover may be needed to keep the body comfortable and warm. The body scan can be learned either lying down or in a seated position, although it is more easily learned lying down.

Begin by assuming a comfortable position lying on the floor or on a bed. (A pillow or rolled towel under the knees may be used to relieve pressure on the lower back.) Take a few slow, deep breaths focusing on the breath itself. Then gently allow your attention to move to the entire body as it is breathing.

Now, focus on the toes of the left foot so that the full attention is on the toes of the left foot. Then move the awareness to the left foot, ankle, on up the calf to the knee, the thigh, and on to the left hip. Breath is allowed to move in and out of each part of the body as it is scanned. Next, allow awareness to move across the pelvis and down to the toes on the right foot, then to the whole foot and up the calf to the knee, the thigh, and to the hip and pelvis. From here move awareness up through the lower abdomen and lower back, up to the chest, upper back and shoulders.

Next focus awareness on the fingers of both hands, moving up the hands to the wrists and both arms and returning to the shoulders. From here move through the neck, throat, all parts of the face, the ears, and then the top of the head.

When this is completed, the breath is invited in through the toes, up through the entire body, and out an imaginary opening at the crown of the head, so that the breath is moving freely from one end of the body to the other. Finally, the breath is allowed to flow in through the top of

the head, down through the whole body and out the toes. End by feeling the entire body lying down breathing. When ready, gently deepen the breath bringing small movements to the fingers and toes, the arms and legs. Roll over to one side, pause briefly, and then using the arms, slowly push up to a seated position, bringing the head up last. Pause in a seated position for a few breaths noticing how the body feels before proceeding to the next activity. (Ott, 2002, p. 489)