

Accommodating Students Affected By Chronic Illnesses

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I. Introduction

The prevalence of chronic illness is increasing among all age groups, including the student population. This increase is coincident with improvements in medicine that have converted once-terminal diseases, such as cancer, into chronic conditions, and with the overall rise in prevalence of chronic conditions such as diabetes, asthma, autoimmune diseases, depression and autism.

Education, poverty and chronic illness are intertwined, as school-age children with chronic conditions (or who are caring for family members with chronic conditions) are at higher risk for school absenteeism and drop-out, and lack of education is a major cause of lifetime poverty and poor health.

Educational institutions are challenged to accommodate chronically ill students to maintain students' participation in the educational process, comply with disability law, avoid disparities among the acutely (statically) ill, chronically (dynamically) ill, and the non-disabled population, and minimize the long-term impact of under-education on income and health outcomes.

Our goal is to assist teachers, policymakers, administrators, students and governments in better understanding chronic illness and in establishing programs and policies that accommodate the chronically ill and family members of the chronically ill to aid their participation in the educational process and contribute toward their long-term economic security and health.

II. Chronic Illness and Education

A. Chronic Illness

Chronic conditions are defined by the World Health Organization as "health problems that require ongoing management over a period of years or decades."¹ They include illnesses such as diabetes, cardiovascular disease, mental illness, autoimmune diseases, asthma and communicable diseases such as HIV/AIDS.

Managing and accommodating chronic illness is one of the greatest challenges facing our health care, employment and educational systems today. In America alone, there were 129 million people with

chronic conditions in 2005; this is expected to grow by 32 percent to 171 million in 2030, according to Partnership for Solutions, a research cooperative led by Johns Hopkins University.² The costs of chronic illness to the United States are huge, accounting for at least 75 percent of all health care spending, or about \$1.65 trillion of the \$2.2 trillion spent on health care in America each year.³

Worldwide, chronic conditions are responsible for 60% of the global disease burden; by 2020, 80% of the disease burden in developing countries will be tied to chronic conditions. In developing countries as few as 20% of individuals with chronic illnesses adhere to treatment protocols, placing added stress on systems of care and individuals and families. The escalating costs of chronic conditions have serious economic, social and health-care resource consequences for governments worldwide.⁴

The link between chronic illness and poverty is clear, as individuals with chronic conditions face higher levels of unemployment, underemployment and school absenteeism and increased costs for medical care.⁵ Education is key to erasing poverty: a year of primary school increases an individual's lifetime wages by 5-15%; each additional year of secondary school increases wages 15-25%.⁶ Education is also crucial in improving health and enabling people to cope better with illness: the Global Campaign for Education estimates that educating all children could prevent 7 million cases of HIV/AIDS in the next decade and reports that children born to illiterate mothers are 50 percent less likely to survive past 5 years of age.⁷

Worldwide, 75 million children are not receiving an education; a third of them have a disability. Millions more leave school to care for a family member who suffers from a chronic condition or to join the workforce to help support their families. Girls in developing countries are at particular risk, given cultural norms that place greater value on education of boys.⁸

B. The Burden of Chronic Conditions

Chronic conditions have a widespread impact on individuals, governments, educational systems, employment systems and economies worldwide. On one level, students who are chronically ill may be unable to participate fully in the educational system. On another level, children and siblings of the chronically ill and/or dying may have added responsibilities for the medical care or economic stability of the family, and therefore are unable to attend school. In addition, a family member's death from a

chronic condition may add to the student's burden, particularly when the death results in a loss of income, stability or caregiving for the family, and the student must step in to provide these essential elements.

Diabetes: Hyperglycemia, raised blood sugar, is an effect of uncontrolled diabetes that must often be dealt with in school. According to the World Health Organization, more than 180 million people worldwide have diabetes and that number is likely to more than double by 2030. In 2005, an estimated 1.1 million people died from diabetes and deaths from diabetes are projected to increase by 50% in the next 10 years.⁹

HIV/AIDS: According to UNICEF, 15 million children have lost one or both parents to AIDS, and the number of AIDS orphans worldwide is expected to reach 18 million by 2010. Orphans throughout the world face many challenges -- malnutrition, starvation, abuse, disease, loss of family property, decreased school attendance, and death. 2.3 million children under age 15 are living with HIV; every day more than 1,400 are newly infected, even though mother-to-child transmission is 98% to 99% preventable when anti-retroviral treatment is taken during pregnancy.¹⁰ Approximately 700,000 new cases of HIV can be prevented each year, if all children receive a complete primary education, reports UNICEF.¹¹

Asthma: Asthma, a chronic disease with no cure, causes American children to miss 14 million school days a year, according to the U.S. Centers for Disease Control and Prevention (CDC). Companies lose 12 million work days because of asthma in adults.¹² Worldwide, asthma affects over 300 million people; although the prevalence is 8-10 times higher in industrialized countries than in developing ones, the majority of asthma-related deaths occur in low- and lower-middle income countries.^{13,14} Children age 10 and younger account for 50% of asthma cases; the rates in children under age 5 increased more than 160% from 1980-1994.¹⁵

Tuberculosis: Tuberculosis is a bacterial disease that is spread through the air and can be fatal if not treated properly with antibiotics. While TB is declining in the U.S., globally the disease continues to claim many lives, with 9 million new cases and 1.7 million deaths in 2006, particularly in communities of poverty. The World Health Organization estimates that 14 million are people living with TB, of whom

14% also had AIDS; people with weakened immune systems are at particular risk for a drug-resistant form of TB that has developed.¹⁶

Autoimmune Diseases: Autoimmune disease is a condition in which the immune system mistakenly attacks and destroys healthy body tissue. There are more than 80 known autoimmune diseases, including lupus, multiple sclerosis, rheumatoid arthritis and celiac disease. The prevalence of autoimmune disease is rising and, collectively, they are among the most prevalent diseases in the U.S., affecting between 14.7 and 23.5 million people -- up to 8 percent of the population.¹⁷ While there are many different treatments to reduce the symptoms, autoimmune diseases are chronic conditions with sudden flare ups that can cause the person to lose time from school and work.¹⁸

Cancer: Cancer rates are predicted to increase by 50 percent to 15 million new cases annually by 2020, according to the World Health Organization. The rise is attributed to the aging population, poor diet, smoking and obesity. With the advent of more effective treatments, many cancers have become manageable chronic diseases in the developed world due to early diagnosis and intervention. In developing countries, 80 percent of cancer patients die, compared to 50 percent in developed nations. The WHO reports, "In developing countries, up to 23 percent of malignancies are caused by infectious agents, including hepatitis B and C virus (liver cancer), human papillomaviruses (cervical and ano-genital cancers), and *Helicobacter pylori* (stomach cancer). In developed countries, cancers caused by chronic infections only amount to approximately 8 percent of all malignancies."¹⁹

C. School Drop-Outs

In developed countries, students who drop out of school are a serious concern because of the link between under-education with poverty and crime. According to the Alliance for Excellent Education, "High school dropouts face long odds of landing a good-paying job in the ultra-competitive job market of the twenty-first century. In addition, they are generally less healthy, die earlier, more likely to become parents when very young, more at risk of tangling with the criminal justice system, and are more likely to need social welfare assistance."²⁰

In the United States, 30% of students drop out of school and fail to earn their high school diploma, the minimum requirement for most jobs available in America. Minorities are at even higher risk; while 76

percent of white students and 80 percent of Asian Americans graduate with a regular diploma, among minority students, only 58 percent of Hispanic, 53 percent of African American, and 49 percent of American Indian and Alaska Native students do.²¹

Globally, about 75 million children are out of school, with the vast majority of them being girls. Of the children not in school, 35 million live in Africa and 28 million in Asia.²²

D. Chronic Illness and School Attendance

Many students drop out of school due to their own or a family member's chronic physical or mental illness (including addiction) which makes attending school difficult. Many children have to work to support their families or can't afford the costs associated with going to school; others have disabilities for which they are discriminated; still others live in war-torn or rural areas where there are no schools nearby.

Chronic illness presents a series of issues that make school attendance difficult. Many of the challenges of accommodating chronically ill students are due to the nature of chronic illness itself. Chronic illnesses often have a relapsing-remitting pattern, can be static or dynamic²³ and are frequently "invisible" (as contrasted with obvious disabilities like blindness, hearing impairment or mobility disorders). There is also a lack standardized protocols for accommodating students with chronic illness.

Yet the fact that students with chronic illnesses are a vital part of the education system in developed nations, like the United States and the United Kingdom, is a credit to improvements in education and policy that have opened up the classroom to those who may not have had access only a few decades ago.

Ensuring that students with chronic conditions have access to the fullest range possible of educational services is essential, not only because it is required by federal disability law, but also because these individuals need to be trained to join the workforce as adults. Education is an essential component of managing chronic conditions; research shows that people with higher levels of education are less likely to engage in lifestyle choices that lead to some of the most common chronic illnesses (i.e., obesity and

smoking as etiological factors in cardiovascular disease, cancer, diabetes, etc.), and are more compliant with treatment protocols.

Our mission is to improve the educational outcomes of chronically ill students through training of educational institutions about the unique nature of chronic vs. static illness and how to manage, mainstream, and accommodate students with chronic illness using established pedagogical strategies and the Fennell Four Phase Model of chronic illness.

III. International policy

On an international basis, many children leave, drop out or never attend school for many reasons. They may be taking care of sick parents; raising siblings when parents have died of AIDS or other diseases; working to provide income for the family; taking care of crops and livestock; obtaining water or needed supplies; and providing for the safety and security of family members.

In war zones, there are additional reasons children do not attend school. These include the personal safety of teachers and students, as well as the fact that many schools in war-torn regions have been destroyed by warring factions or are run by insurgents who are not providing an academic education. The international humanitarian news agency IRIN reports that "more than two decades of war have severely damaged education in Afghanistan, resulting in very low literacy rates: 12.6 percent among females and 43.1 percent among males, an average of 28.1 percent nationwide."²⁴

The national and global statistics on education and chronic illness are sobering, particularly as they relate to developing countries. Clearly, to address these problems, international organizations will need to develop partnerships among themselves and with the countries at the highest risk. Some of the programs currently in place include:

- The World Health Organization's Global School Health Initiative, which defines a "health promoting school" as a school that constantly strengthens its capacity as a place for students and teachers and all others to work in a healthy setting for living, learning and working. This school creates conditions for best practices and choices in health, and education with success, knowledge, attitude and guidance available.²⁵

- The World Education Forum in Dakar and the United Nations Millennium Development Goals in 2000 set goals of increasing the global literacy rate by 50%, improving early childhood education, achieving gender parity in schools and improving the quality of schools worldwide by 2015.²⁶
- School nutrition programs increase school attendance in poverty-stricken communities by ensuring parents that their children will receive at least one healthy meal per day. In the poorest parts of the world, the United Nations World Food Programme says it can double primary school enrollment in one year, particularly among girls, who otherwise may never be sent to school.²⁷
- In November 2008, UNESCO's 48th International Conference on Education (ICE) concluded that the current global financial crisis should not be a justification for reduction in the funding of the resources for national and international educational needs.²⁸
- The National Education Association in the United States has proposed eight principles for improving the No Child Left Behind act, formerly known as the Education for All Children Act, and ensuring that children receive an education that prepares them to live and work in the 21st century.²⁹
- Yet not all the news is good. UNESCO reports that donors in 2005 pledged to increase international education aid by \$50 billion (U.S.) by 2010, but it appears that contributions will fall \$30 billion short, almost half of it in sub-Saharan Africa.³⁰

IV. Fennell Four-Phase Treatment Model

The Fennell Four-Phase Model (FFPM) It is a validated framework for explaining how people who are experiencing chronic illness or trauma can adapt to the changes in their lives.^{31,32,33,34,35,36,37} It outlines four phases that people commonly pass through as they learn to incorporate their altered physical abilities or psychological outlook into their personality and lifestyle.

The Fennell Four Phases are: **Crisis**, **Stabilization**, **Resolution**, and **Integration**. Within each phase, FFPM addresses three domains: the physical/behavioral, the psychological, and the social/interactive.

In **Phase 1 Crisis**, the individual moves from onset of the condition to an emergency period when he or she knows that something is seriously wrong. Onset may be specifically detectable, such as a serious and

disabling automobile accident, or may happen gradually, as in the case of multiple sclerosis, where a period of symptoms precedes diagnosis. The task of the individual, caregivers, and clinicians during this phase is to cope with and contain urgency and trauma.

In **Phase 2 Stabilization**, the individual discovers that he or she fails, sometimes repeatedly, to return to normal, regardless of interventions or behavior. The task in this phase is to initiate stabilization and life restructuring.

In **Phase 3 Resolution**, the individual recognizes deeply that his or her old life will never return. Early in this phase, many experience significant grief and loss. The task of this phase is to begin establishing an authentic new self and start developing a supportive, meaningful philosophy.

In **Phase 4 Integration**, the individual defines a new self in which illness may be an important factor, but it is not the only or even the primary one in his or her life. Integration of the illness into a meaningful life is the goal the individual seeks.

The experience of chronic illness or trauma does not remain the same over time. The physical, emotional, and social needs of an individual in the early phases of the chronic experience can be considerably different from the needs of an individual who has been ill for several years.

Additionally, unlike other phase- or stage-based models, such as the Kübler-Ross theory of death and dying, FFPM does not assume that individuals move through the FFPM phases in a linear fashion. Rather, physical or emotional setbacks can precipitate a temporary move back to a previous phase.

V. Pedagogical approaches

Meeting the needs of all students, whether they are in grade two, grade nine or post-secondary education, requires that teachers pay attention to how students learn best, understand the needs of diverse learners, and employ best instructional practices. For students who have chronic illnesses it is especially important that their learning is supported through appropriate accommodations.

These accommodations need to be as varied as are the needs of students with chronic illness. For some students who are chronically ill, having to make up work that they already know is redundant and often the work then becomes boring and these students disengage from the learning process. However, for other students with chronic illness, missing school due to the illness causes larger "holes" in their learning, and trying to make up work that they never learned and/or do not understand becomes overwhelming and frustrating. Merely trying to make up the work does not assist these students in learning the important concepts or skills, as they are missing too much foundational knowledge.

An instructional practice that is designed to accommodate the varying learning needs of students is differentiation. Tomlinson defines differentiation as a teaching model, rather than an instructional strategy.³⁸ It is a way of thinking about teaching and learning that advocates beginning where individuals are rather than with a prescribed plan of action, which ignores student readiness, interest and learning profile. According to Tomlinson, differentiation is a way of thinking about teaching that looks at assessment, teaching, learning, classroom roles, use of time and curriculum in a different way.

The purpose of differentiation is to assist all students to focus on the key concepts or essential knowledge in an area or unit of study. Differentiation allows teachers to provide high-quality learning opportunities while engaging each class member at his or her own level.³⁹ Differentiation is also validating for students. It presents curriculum in a way that is relevant to their lives and helps them make connections between concepts, which in turn helps them to retain new ideas.⁴⁰

Working with children who are at risk due to chronic health conditions requires that the educator and the educational system come to understand the child's situation in detail. Their needs may not be obvious. In order for the teacher to discover the best ways to reach and teach the individual, the student must be in school on a consistent basis for a significant period of time, which can be a problem for students with chronic conditions.

An excellent educational approach for students with chronic illness is Brain Based Learning.⁴¹ In this system, the ways in which an individual's brain learns best are explored and applied. It assesses a student's learning and task approach styles along with knowledge of left and right brain functions. It is a combination of neurology, emotions and the environment.

Brain Based Learning can be used in combination with Gardner's Theories of Multiple Intelligences.⁴² There are 8 kinds of intelligences, according to Gardner: Bodily-kinesthetic; Interpersonal; Verbal-linguistic; Logical-mathematical; Naturalistic; Intrapersonal; Visual-spatial; and Musical. Use of these strengths will allow the learner to feel comfortable working within the setting and the subject matter, building an atmosphere of safety and willingness to attend and learn.⁴³

In this approach, the learning environment itself is in tune with the working areas of the brain that help the person learn to provide a stimulating environment for optimal brain functioning for learning. For example, in some schools the classroom walls are painted colors that are least offensive to the eyes, such light purple. White, the color of many institutional walls, is one of the hardest colors to learn in because it is so bright, particularly in combination with fluorescent lights and white paper often used in classrooms.

Each student's differences are studied on an ongoing basis for planning and facilitating learning. Students are frequently guided in making interest-based learning choices. Student readiness, interest and learning profile shape his instruction and choices for completing assignments. These are just some of the differentiated classroom features using Brain Based research for the basis of teaching and learning. Tomlinson says, "We cannot achieve excellence for children at risk of school failure without emphatically, systematically vigorously and effectively seeing to the development of their full potential."^{44,45} It would seem that potential is as individual as each student that comes to school and should be addressed as such.

VI. Outcomes

By blending the FFPM approach with pedagogical approaches such as differentiated instruction and brain-based learning, educators can develop individualized approaches to teaching students with chronic conditions that meet the students "where they are." By taking into consideration the medical, social, familial and psychological situation the student is facing, using FFPM, curriculum and assignments can be developed, using differentiated instruction, that are relevant to the student's life, interests and abilities. Combining these approaches offers students a greater opportunity to maintain their education while coping with the relapsing/remitting nature of chronic illness.

Chronic Illness Strategies

1. Review and assess activities of daily living (ADLs) with the goal of stabilizing activity and health. Many times people with chronic conditions are trapped in a cycle of putting off responsibilities while they are in a crisis phase, then doing too much when they feel a bit better, thereby precipitating a relapse.

Reviewing and assessing ADLs gives the patient and the clinician insight into what activities are being done and how the patient is spending his or her time.

2. Restructure ADLs, work, socialization and personal development. The ADL assessment is then used to stabilize the patient, providing a guide for accomplishing essential ADLs, work/school requirements, social activities and personally fulfilling activities, while respecting the activity limitations imposed by the chronic condition.

3. Use symptom logs and activity logs to predict patterns of activity and health. Establish self-regulation and structure. Once the patient is stabilized, ongoing use of symptom and activity logs brings insight to the patient about what level of activities are possible without causing relapse and teaches him or her to respect and, when possible, stretch those limits.

4. Construct a personal narrative, find meaning for suffering. Part of having a productive life with a chronic condition is finding a personal meaning for the limits that the illness imposes. By making the illness meaningful, it is possible to comply with difficult treatment regimens and avoid the counterproductive fighting against the illness and its treatment that can hinder acceptance and recovery.

5. Use timers to establish priorities. Principles of interval training can be used effectively to help patients maintain and even extend their limits, as needed. Since most people naturally think in terms of task completion, rather than time orientation, using timers to limit activity into manageable blocks helps individuals accomplish goals - and feel satisfaction for achieving productivity - while getting rest necessary to preserve their function. For example, a student could be instructed to study for 25 minutes, followed by a 10-minute rest break, and then resume studying for 25 minutes, followed by another rest. Breaking activity into manageable blocks and building in time for rest allows patients to do more in the long run because it minimizes the detrimental effects of doing too much and then relapsing.

Pedagogical Strategies

1. *Daily, weekly task scheduling, establishing self regulation.* Managing study time and completion of tasks requires students to determine what each assignment requires for completion and a method for monitoring task completion.

2. *Scale assignments and establish priorities.* Energy and, therefore time, for learning is often diminished in chronic illnesses. Students may need guidance in prioritizing and scaling tasks, assignments and activities so that they accomplish the objectives required to achieve educational goals within their limitations. In chronic conditions where cognition is affected, students may need guidance in understanding when they have completed an assignment or learning objective.

3. *Curriculum compacting - eliminate redundancy in curriculum to establish core competencies.* Curriculum compacting is a differentiation strategy that streamlines schoolwork to a pace that corresponds with the student's ability in order to create a challenging learning environment. It is important to pre-assess students' competencies as related to specific objectives, and then reduce the practice, drill or instructional time for students who have learned the objectives.

4. *Make educational experience relevant to personal narrative.* For learning to occur it must be meaningful and relevant to a student's life. The experience of chronic illness offers unique opportunities to tie educational lessons to an individual's experience.

5. *Utilize study techniques and strategies and visual aids.* Using good studying skills, appropriate learning, retention, and analysis strategies and visual aids, can effectively help students become accomplished and independent learners. Graphic organizers (visual aids) are excellent tools for enhancing the content (making the content understandable) of an area of study.

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