

CASE 10

Moving Towards an Inclusive Society: Implementing Epilepsy Awareness Education in the Ontario Elementary School Health Curriculum

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BACKGROUND

Epilepsy is one of the world's oldest and most recognized medical conditions, with archives dating back to 4000 BC (WHO, n.d.). The World Health Organization (n.d.) describes epilepsy as a "chronic, non-communicable disorder of the brain that affects people of all ages." It is "characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve part of the body (partial) or the entire body (generalized) and is sometimes accompanied by loss of consciousness and of control of bowel and bladder function" (IOM, 2012). Epilepsy affects about 70 million individuals globally. It is a "major public health problem, not only because of its health implications but also for its social, cultural, psychological, and economic effects" (Murthy, Govindappa, & Sinha, 2016).

Martha Stein, a strategic planner at the Epilepsy Support Centre in London, Ontario, was sitting in her office chatting with the Executive Director, Morrison Longos. Martha was concerned about the increasing number of youth living with epilepsy in the London area. She explained to Morrison that her clients missed many opportunities in their lives, such as receiving better health care or pursuing higher education. For instance, adults with epilepsy face difficulties in accessing services such as dental care, optical prescriptions, and renewing driver's licenses, while school-aged children with epilepsy face problems such as difficulties in learning, absenteeism due to fatigue from seizures, and social exclusion. Six out of ten parents reported that their children with epilepsy experienced challenges with learning in school, behaviour, or memory (Clinic to Community, 2017). Martha, who had more than 10 years of experience working with youth with epilepsy, found that they struggle with social stigma and feel 'different' at a time when fitting in is of the utmost importance. These difficulties, if unsupported, affect their overall well-being and success in life. Martha previously spoke with the Thames Valley District School Board and the London District Catholic School Board to understand whether there was any health promotion curriculum on epilepsy awareness for teachers and students. She was surprised that there wasn't a health promotion program for epilepsy, despite the significant number of children diagnosed with this common disorder. Martha decided to propose an initiative to Morrison to create a pilot, school-based health promotion program for epilepsy awareness. This pilot program would be designed to help bridge knowledge gaps about epilepsy in school, promote empathy among elementary school students, and create a safe environment for children with epilepsy to learn, play, and grow.

Being the head of the Strategic Planning department at the Epilepsy Support Centre, Martha saw the need to develop, advocate for, and promote an evidence-based educational program.

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Morrison was fully supportive of Martha's idea and suggested that Martha consider creating this program in alignment with the Ontario elementary curriculum. This would encourage schools and school boards to be involved in the program. This initiative would also teach school teachers how to incorporate the program into their curriculum. The pilot program would not only raise awareness amongst students, but it would also improve teachers' understanding about epilepsy.

THE EPILEPSY SUPPORT CENTRE HISTORY

The Epilepsy Support Centre is one of the many support centres that provide community support services for people with epilepsy. It was first established in 1977 as Epilepsy Ontario's Midwest Chapter on London's Dundas Street as a not-for-profit and non-governmental organization (Epilepsy Support Centre, 2015a). The original founders of the Chapter were a group of parents who had children diagnosed with epilepsy. Their mission was to enhance the lives of people who are affected by epilepsy and seizure disorders by providing a network of services that educate, support, and build community awareness. In view of the rising number of people with epilepsy, the group was renamed in 1983 as Epilepsy London and Area and began serving London-Middlesex, Elgin, and Oxford counties. Despite the change in the Centre's name, the mission remained the same. In 2001, the organization expanded its service area to include Sarnia-Lambton, Chatham-Kent, and Windsor-Essex. Since then, the organization has been renamed once more, and is now known as the Epilepsy Support Centre, reflecting the organization's greater geographic coverage of services (Epilepsy Support Centre, 2015b). Subsequently, the Centre took a leadership role in serving the Southwestern Ontario region by providing and promoting public education programs, creating community activities for people living with epilepsy, and developing support programs such as Clinic to Community (C2C), which helps individuals transition from acute to community care. Over the years, the Centre saw a four-fold increase in the number of clients from 379 in 2013 to 1846 in 2016 (Epilepsy Support Centre, 2013 & 2016). As the number of clients who seek support is increasing, the Centre has also noticed an increase in school requests to present about epilepsy and epilepsy management, from 109 presentations in 2014 to 150 presentations in 2016 (Epilepsy Support Centre, 2014 & 2016).

CURRENT PROBLEMS FACED BY CHILDREN AND ADOLESCENTS WITH EPILEPSY

As Martha was planning for her program proposal, she continued to visit her clients and follow up with their social issues. Her young clients often raised the same issues regarding both school and home. According to the Centre's statistics, 81 of 109 parents with children aged four to 12 years identified that there was a lack of support from the school (Clinic to Community, 2017). Martha found, based on her research and observations, that children and adolescents living with epilepsy face difficulties adjusting in four major domains (Elliot, Lach, & Smith, 2005):

Physical Domain

Many school-aged children and adolescents living with epilepsy often report fatigue as a major complaint. Fatigue often sets in immediately after a seizure. In addition, fatigue makes thinking and learning at school difficult for children and adolescents with epilepsy. Post-seizure sleep could be extensive and last for the entire day. Because of this fatigue, children's and adolescents' ability to be physically and mentally present in class, or to participate in their favourite activities, is limited (Elliot et al., 2005). This could lead to fellow peers not inviting them to participate in community activities, which could result in gradual social exclusion. As a result, children and adolescents with epilepsy often choose to stay at home, leading to a reduction in their physical activities.

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Emotional and Behavioural Domains

Children and adolescents living with epilepsy often experience a wide variety of mood swings. They can switch from intense emotional distress after a seizure to feeling happy when they “forget” about their seizures. However, because of the unpredictability of seizures, they often feel worried, fearful, frustrated, embarrassed, and depressed (Elliot et al., 2005). The feeling of frustration stems not just from the unpredictability of seizures but also from over-protection and supervision from their parents. Parents, for fear of their child’s seizures, restrict their child’s activity choices. This reduces the child’s autonomy in decision making, which can lead to frustration and anger. As such, most children and youth remain indoors and gradually “enclose” themselves by not interacting with family members or friends.

Social Domain

Children and adolescents living with epilepsy experience internal (i.e. lack of self-esteem or confidence) and external (i.e. social exclusion by peers and excessive parental monitoring) constraints. These individuals are afraid to have friends because they assume that if they were to disclose their condition, peers would shun them. As a result, most choose to have only one close friend who knows about their condition and can help them in school (Elliot et al., 2005). Moreover, children with epilepsy may experience bullying that further hinders their ability to make friends (Jacoby & Austin, 2007). Due to these exposures that alter their perception of what “friendship” is, many children and adolescents with epilepsy choose to isolate themselves to avoid being treated differently.

Cognitive/Academic Domain

Seizures take a toll on a child’s mental and physical abilities, resulting in an inability to focus on or remember what they were taught in school. Overtime, this impacts their ability to integrate and synthesize their learning. When peers and teachers are unaware of a seizure condition, they often assume that children and adolescents with epilepsy are simply lazy or daydreaming, hence the poor academic performance (Elliot et al., 2005). The fear of asking teachers to repeat information causes these children to miss out on important information at school. Due to the lack of a supportive environment, these children and adolescents might quit school altogether.

The problems faced by children and adolescents with epilepsy lead to barriers in normal child development and growth. They experience social exclusion and isolation, which can interfere with their ability to adapt in different social environments. At times, these individuals perceive a “seizure as a barrier to normalcy” (Elliot et al., 2005). This could be further seen in students attending different programs such as special education classes, where such programs serve to further divide people’s perceptions of what is normal and what is not normal.

EPILEPSY IN THE CANADIAN CONTEXT

According to a registered Canadian charity, Epilepsy Canada (2016), approximately one in 100 Canadians are diagnosed with epilepsy. This is a pressing public health issue because an average of 42 Canadians learn that they have epilepsy each day (i.e. 15,500 Canadians per year). In this population, 44% are diagnosed before the age of five, 55% before the age of 10, 75% before age 18, and 1.3% over the age of 40. It has been observed that about 60% of new patients are young children and senior citizens (Centers for Disease Control and Prevention, 2016). The Canadian League Against Epilepsy (CLAE) reported that at any given time, the total number of Canadians living with epilepsy is 300,000. In this population, 70% can control their seizures with medications and lead a normal life. However, the remaining 30% often have other social and learning problems (CLAE, n.d.).

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Even though the total number of Canadians living with epilepsy is high, this condition is still poorly understood in Canada (CLAE, n.d.). This lack of knowledge about epilepsy has resulted in misconceptions and stigma. In light of these misconceptions, epilepsy is perceived as a “less important” condition compared to other public health issues, such as cancer and HIV. Funding availability for epilepsy awareness and education is also less than for other public health issues. Currently, only the Ontario Trillium Foundation and the Ontario Brain Institute have been funding epilepsy awareness campaigns consistently over the years.

Martha knew that in order to dispel these myths and misconceptions of the general public towards epilepsy, epilepsy funding, political support for epilepsy, and the right window of opportunity would be necessary to help create greater awareness in society. The Ontario Ministry of Education was in the process of making changes to the Ontario Health and Physical Education Curriculum. Martha saw this as an opportunity to integrate epilepsy awareness educational programs as part of this new curriculum. She began to research the new Ontario Ministry of Education Grade 1-8: Health and Physical Education Curriculum (2015) to identify where best to incorporate epilepsy awareness programming.

EPILEPSY & STIGMA (A PUBLIC HEALTH PERSPECTIVE)

Szaflarski (2014) reported that adults with epilepsy report worse mental health, cognitive impairment, limitations in social participation, and experience health and social disparities (i.e. worse health-related quality of life and low socioeconomic status). These negative outcomes experienced by individuals with epilepsy are attributed to stigma. Stigma is how society perceives or labels an individual or group to be different based on their abilities, which can create stereotypes, disapproval, and discrimination (Goffman, 1986). Stigma can severely impact an individual’s ability to live a normal, healthy, and productive life. In addition, individuals who have seizures can make poorer choices in life when they lack social support. This can potentially cause their seizures to worsen or relapse.

Due to the social inequalities and disparities faced by individuals with epilepsy, there has been a call for increased public health surveillance, health care system interventions, and community programs. Studies have shown that public health initiatives and programs have helped individuals and organizations to understand, manage, and prevent non-communicable chronic diseases, such as hypertension, asthma, diabetes, and epilepsy. Therefore, support organizations in Canada, such as Epilepsy Canada, Epilepsy Ontario, and the Epilepsy Support Centre, have provided social support to people living with epilepsy and research institutes, such as the Ontario Brain Institute, are committed to understanding epilepsy through research.

In spite of having epilepsy support services and programs, social stigma and misconceptions of epilepsy are still prevalent in schools (Keusch, Wilentz, & Kleinman, 2006). To deal with the repercussions of stigma faced by school-aged children, Martha had to understand what appropriate resources and personpower she should engage with. This would help her understand the interactions of social determinants of health and demonstrate the need to develop a sustainable, well-researched, and well-designed school curriculum.

WHAT’S NEXT?

Martha considered developing the proposed program using a health promotion model. She knew that using the six-step planning model developed by Public Health Ontario (2015) would provide systematic guidance on how to plan, manage, and effectively use available resources to design a school-based curriculum.

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School-based Educational Program

Martha knew that societal stigma about epilepsy was highly prevalent, and it would not dissipate without educational programs. Studies have proven that interventional education programs in elementary schools have long-lasting positive impacts on children's behaviours. For instance, healthy eating and exercise programs have been shown to create positive impacts on behavioural change from a young age (Racey et al., 2016). The frequent inclusion of such healthy living programs in the curriculum has allowed children and adolescents to "adopt healthy routines and disseminate accurate healthy living information to family and friends" (Gorga et al., 2016).

Although Martha had no up-to-date statistics that measured students' knowledge, attitudes, and perceptions towards epilepsy, her intensive research found that promoting epilepsy education, awareness, and empathy to children between ages nine and 11 is highly effective. Providing accurate information to children about epilepsy at an early age could decrease stigma and secrecy and promote positive attitudes towards epilepsy (Murthy et al., 2016).

To ensure that all relevant stakeholders were engaged in the decision-making surrounding this school-based health education program, Martha began to consider:

1. What information is required in order to plan an educational program or health promotion campaign?
2. What information is currently available? (e.g. from the Epilepsy Support Centre's database, literature reviews, Statistics Canada)
3. How should she go about doing this? What other information that is not already available is needed?
4. Who can Martha talk to? What else can Martha ask?
5. Who will her stakeholders be?
6. How would Martha determine which needs are relevant in delivering the program?
7. What incentives should she consider to ensure stakeholder buy-in?
8. How would she conduct a situational assessment and gather data?
9. How would she go about developing her six-step health promotion planning model?

She had many questions about the process of developing this health promotion program and was eager to actualize this pilot program with the goal of creating awareness about epilepsy.

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INSTRUCTOR GUIDANCE

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BACKGROUND

This case revolves around the stigma experienced by individuals living with epilepsy. It discusses how Martha, a strategic planner at the Epilepsy Support Centre in London, Ontario, identified the negative health and social implications that confront individuals living with epilepsy. It then sets the stage in terms of problems faced by children and adolescents with epilepsy who are living in London, Ontario, and in terms of public health issues, school boards and government, and future directions. As this is a new initiative that is designed to be introduced into the school curriculum, it is crucial to have appropriate and influential stakeholders on board to actualize this epilepsy awareness program.

OBJECTIVES

1. Become aware of how the different social determinants of health impact people living with epilepsy.
2. Apply the knowledge of how to complete a community needs assessment.
3. Analyze how different stakeholders play a role in creating the provincial-curriculum health promotion program.
4. Determine stakeholder values and effectively engage them.
5. Motivate fellow stakeholders and adapt to challenges.
6. Evaluate recommendations and outcomes.

DISCUSSION QUESTIONS

1. What are the dilemmas currently being faced by Martha and Morrison of the Epilepsy Support Centre?
2. Is it enough to just educate elementary school students about epilepsy? Why or why not?
3. Why do you think the Epilepsy Support Centre decided to introduce a health promotion program into the elementary school curriculum? Was this choice appropriate?
4. What elements make a health promotion program successful? How much does scientific knowledge matter in such a health promotion program?
5. Both Martha and Morrison agree that an elementary-school-based program would help increase awareness about epilepsy to younger populations. If you were Martha, how would you convince the Ontario Ministry of Education that this health promotion program is necessary?
6. What steps could Martha and Morrison take to determine the attitudes, knowledge, and perception of students in elementary schools?

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7. Who are the potential key stakeholders in this case? Would there be different levels of interests or values among stakeholders? Why?
8. What are the possible challenges that Martha and Morrison might encounter with implementing this health promotion program?
9. How would you effectively evaluate the recommendations made by Martha?
10. What would be the outcome of a needs assessment that was not properly planned?

KEYWORDS

Epilepsy; health education; health promotion; stigma; best-practice.