Maternal coping and adaptation: A case study examination of chronic sorrow in caring for an adolescent with a progressive neurodegenerative disease

By Amanda M.E. Bettel and Margot A. Latimer

Abstract
A single case study approach was used to examine the maternal experience of chronic sorrow in caring for an adolescent with a progressive neurodegenerative condition. A family systems model was used to examine maternal coping and adaptation. A diagnosis of a childhood neurodegenerative illness will inevitably result in periods of deterioration, increased physical, financial and health care needs. These periods of increased demands result in a build-up of stressors over time. During these different transitions, maternal coping and adaptation have been recognized as important components that affect the health and well-being of the whole family. McCubbin and Patterson’s (1983) Double ABCX model of Adjustment and Adaptation was used to explore ongoing maternal coping and adaptation. By using a strengths-based approach, an advanced practice nurse (APN) was able to validate the maternal experience of chronic sorrow and identify factors influencing maternal coping and adaptation. Despite the emotional response of feeling hopeless and helpless, this mother was able to recognize and talk about her strengths and how they have contributed to the health and well-being of the whole family.

Introduction
This single case study examines the maternal experience of caring for an adolescent with a debilitating, progressive neurodegenerative condition. The concept of chronic sorrow will be defined and described, a theory for coping and adaptation will be presented, and a strengths-based nursing approach will be considered. In this specific case, the maternal perspective was explored because maternal adjustment and adaptation has the potential to influence the health and well-being of all family members (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Gravelle, 1997; Melnyk, Moldenhauer, Feinstein, & Small, 2001). The importance of supporting positive coping in mothers is critical because, in many cases, mothers bear the responsibility as the primary caregiver (Coffey, 2006; Gravelle, 1997). Without adequate support, mothers are at risk for high levels of stress, which, if left unrecognized, may lead to emotional exhaustion and burnout (Dellve et al., 2006; Gravelle, 1997). This negative outcome not only affects the mother’s health and well-being, but also will inevitably impact the whole family. Advanced practice nurses (APNs) can play a vital role in supporting these mothers.

Family and clinical case details
To maintain anonymity, family members’ names have been changed. This case study focuses on the Bennet family. Josie, the mother, is middle-aged and works full-time outside of the home as an elementary school teacher. She has been able to maintain her job despite her son’s deteriorating progressive condition. Her husband Mike is also middle-aged and is working outside the home as a professional engineer. They also share their home with Mike’s parents who are in their early 90s and have many care needs. Josie and Mike have
three children who all live at home. The oldest daughter, Marie, is 23 and has global developmental delay. Since finishing a modified program in high school, Marie has been struggling to find work. As a result, Josie has been searching and advocating for employment opportunities for Marie. The second eldest daughter, Jen, is 20 years old and is studying neurosciences at a local university. She has chosen this field of study because of her family’s experience of caring for her ill brother, Jim.

Josie’s third child, Jim, is a 16-year-old adolescent with an unknown progressive neurodegenerative condition. His illness trajectory has contributed to ongoing family stressors. Jim was a previously well, normal-developing child until he began elementary school. In the first grade, he struggled with learning and was required to repeat a grade. By grade three, he developed weakness and decreased coordination in his legs and was tripping and falling. These episodes were increasing in frequency and severity to the point that he was requiring visits to the local emergency department. It was at this point that the family and health care professionals acknowledged the severity of his condition. He was followed by a neurologist at the local children’s hospital and had a complete diagnostic workup including biopsies, blood work, MRIs, and EEGs, all of which were inconclusive. He went to another pediatric institution for a second opinion and had further testing; these were also inconclusive. His condition continued to deteriorate and by grade six he required assistance to mobilize and began to struggle with his speech. Over the next three years, he developed seizures and myoclonic jerks, and became wheelchair dependent. Because of this recent deterioration, he is unable to mobilize and is physically dependent for all of his care needs and requires respite care. The family has also renovated their house to accommodate his wheelchair and have had lifts installed in anticipation of his continued disease progression. He has recently developed significant speech impairment and developmental deterioration. Josie and Mike continue to experience uncertainty related to his nonspecific diagnosis. The response to Jim’s physical demands is obvious, however the emotional response is murkier. Their struggle to support their son through this degeneration is painful and there is no prescription, set plan or straightforward trajectory that they can follow.

In response to Jim’s recent deterioration, the pediatric palliative care team, including a palliative care physician and an APN, became involved. The APN has maintained regular contact with Josie and family through home visits, emergency department care, and outpatient clinic appointments, and has participated in multidisciplinary team meetings to discuss Jim’s care.

In summary, this complex family system consists of three generations in one shared household. The progressive nature of Jim’s condition has contributed to parental chronic sorrow resulting from a build-up of stressors over time. Each family member has had to find ways to cope and adapt to the many transitions and continuing losses. Throughout Jim’s illness trajectory and progressive deterioration, Josie has played a vital role in advocating for supports and resources to achieve and optimize family coping and adaptation. Considering the complexity of this case and the unpredictability of Jim’s chronic illness, it is important to further understand the impact of the emotional response in terms of chronic sorrow. It is equally important to understand maternal coping and adaptation in response to chronic sorrow and its impact on family functioning. With this knowledge, an advanced practice nurse (APN) can assess and support optimal coping. In this specific case, the role of the APN was important for validating and supporting the maternal experience of chronic sorrow.

In this case study, the mother is the primary caregiver and comforter, and she has been able to recognize and care for each family member’s needs despite the build-up of both normative and non-normative stressors. These stressors result from normal family transitions, as well as periods of increased care needs related to the progression of her son’s illness. The family systems approach recognizes that each family member brings individual experiences, expectations and stressors that influence and impact the process of both individual and family coping. Maternal coping in this case occurs when the mother is able to adapt to the ongoing individual family member’s needs in addition to the increased demands associated with caring for her son with a progressive debilitating condition. The purpose of this single-case study is to examine the mother’s emotional experience of chronic sorrow and adaptation in caring for an adolescent with an undiagnosed neurodegenerative condition. Caring for children with neurological conditions is demanding and many mothers can benefit from the support of an advanced practice nurse.

**Childhood neurodegenerative disease**

A neurodegenerative condition is a “disease characterized both by loss of skills and by symptoms arising mainly from central nervous system disease” (Hunt & Burne, 1995, p. 20). In most cases, illness progression is unpredictable. Some children’s symptoms rapidly deteriorate while others progress over a long period of time (Wong, 1997). In addition, the illness typically results in progressive disability, increased physical dependence, impaired speech, and developmental deterioration (Hunt & Burne; Mc Nelis, 2009).

---

<table>
<thead>
<tr>
<th>Table 1. Understanding chronic sorrow</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics of Chronic Sorrow</strong></td>
</tr>
<tr>
<td>• Normal parent reaction to having a child with chronic illness/disability</td>
</tr>
<tr>
<td>• Periodic emotional reaction to losses related to child’s illness and may be manifested as anger, frustration, sadness, grief, guilt, fear, and hopelessness</td>
</tr>
<tr>
<td>• Emotional response is recurrent and intensifies during initial presentation of illness, developmental transitions, increasing health care demands, and during periods of new or worsened symptoms</td>
</tr>
<tr>
<td>• Does not interfere with individual’s daily functioning</td>
</tr>
</tbody>
</table>
Buelow, Myers, & Johnson, 2007; Steele & Davies, 2006). When the degenerative process involves the brain, many children develop seizures that are predicted to increase in frequency and intensity (Hunt & Burne). To accommodate and cope with the progressive nature of this disease, most families experience emotional and physical fatigue and, as a result, can benefit from increased health care and respite supports (Hunt & Burne; McNelis, Buelow, Myers, & Johnson; Steele & Davies).

While there are some neurodegenerative diseases that can be linked to a metabolic, infectious or genetic etiology, many families live with uncertainty of not knowing the specific cause of their child’s illness (Wong, 1997). Because of the rarity of neurodegenerative diseases in children, finding a specific diagnosis to explain and validate the symptom trajectory remains a challenge (Wong). Families may feel anxious, frustrated and hopeless, as they try to understand and predict the illness trajectory and make treatment decisions (Steele, 2006). This uncertainty factor creates high anxiety for all family members and, in particular, the mother of the child who is in most cases the primary caregiver. For the purpose of this case study, the maternal emotional response of chronic sorrow will be further explored.

Parental chronic sorrow

The concept of chronic sorrow has been used to describe a common parental emotional response to having a child with a chronic and/or progressive deteriorating illness (Hobdell & Deatrick, 1996; Hobdell et al., 2007; Krafft & Krafft, 1998; Scornaienchi, 2003). Chronic sorrow is a “cyclical, recurring, and potentially progressive pattern of pervasive sadness that is experienced in response to continual loss, throughout the trajectory of an illness or disability” (Mosby, 2006) and is characterized by periodic feelings of anger, frustration, sadness, grief, guilt, fear, and hopelessness (Hobdell et al., 2007; Mosby; Scornaienchi). Symptoms of chronic sorrow intensify during stressful events such as the initial presentation of illness, developmental transitions, ongoing and increasing health care demands, and periods of new or worsened symptoms (Hobdell et al., 2007; Hobdell, 2004; Kearney & Griffin, 2001; Krafft & Krafft; Melnyk et al., 2001; Scornaienchi). The literature suggests that many families experiencing chronic sorrow do not receive adequate empathetic support from the health care team (Kearney & Griffin; Roos & Neimeyer, 2007; Scornaienchi). In fact, many health care professionals do not acknowledge this normal parental reaction and label parents as “dysfunctional” and unable to accept the inevitability of their child’s illness (Kearney & Griffin; Roos & Neimeyer; Scornaienchi). These perceptions may have negative implications for family coping and can result in the family feeling unsupported, vulnerable and hopeless (Kearney & Griffin). In contrast, most parents acknowledge the reality of their child’s condition and they engage in information-seeking and advocacy, as a way to maintain hope and optimism in knowing that they are doing everything possible to ensure their child receives optimal care (Gravelle, 1997; Hobdell & Deatrick; Kearney & Griffin; Scornaienchi).

The process of adapting to chronic sorrow is a phenomenon that is not well understood. The literature suggests that most parents, despite ongoing losses, are able to function on a daily basis (Hobdell & Deatrick, 1996; Scornaienchi, 2003). What strengths and coping strategies do mothers use to successfully navigate this difficult journey? Further research is necessary to examine individual family members’ experiences of chronic sorrow. It is also important for nurses and health care professionals to recognize and understand the implications of chronic sorrow. With adequate knowledge, nurses are in an excellent position to support positive coping in families during this difficult journey. Despite much adversity, the mother in this case tapped into her many strengths. These strengths played a fundamental role in propelling her and her family forward in this difficult experience.

Table 2. Strengths-based nursing interventions

<table>
<thead>
<tr>
<th>Advanced Practice Nurse (APN)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategies to Strengthen and Support</td>
</tr>
<tr>
<td>• Develop trusting relationship through active listening, empathetic support</td>
</tr>
<tr>
<td>• Validate the presence of maternal chronic sorrow</td>
</tr>
<tr>
<td>• Recognize that mothers have many strengths and capabilities</td>
</tr>
<tr>
<td>• Help mothers recognize their strengths, so that they can gain a sense of control and mastery over their family’s situation</td>
</tr>
<tr>
<td>• Empower mothers to recognize and build upon their existing strengths. Once empowered, mothers can cope with the many demands</td>
</tr>
</tbody>
</table>


Conceptual model

The process of coping with a childhood chronic illness is complex and multidimensional. McCubbin and Patterson’s (1983) theoretical model of Adjustment and Adaptation was used to identify stressors contributing to chronic sorrow. This model was also used to guide the APN’s assessment of maternal coping and adaptation and to develop theory-driven nursing interventions to optimize maternal and family functioning. McCubbin and Patterson developed this model to understand the complex process of coping and adaptation in response to a family crisis and the build-up of stressors over time (McCubbin & Patterson, 1983). The childhood diagnosis of a neurological condition is a major stressor that impacts the whole family system. A stressor is a “life event or transition impacting upon the family unit, which produces or has the potential of producing, change in the family social system” (McCubbin & Patterson, p. 8). Non-normative stressors, or those events that are unexpected, result from transitions such
as the diagnosis of a childhood illness, while normative stressors result from expected, naturally occurring family transitions. When one family member is able to cope and adapt, the whole family system benefits and is closer to achieving balance. The outcome of family coping and adaptation depends on the interaction of several factors and includes the pile-up of normative and non-normative stressors, the use of new and existing resources, and the perception and meaning that the family gives to the whole situation. Optimal adaptation is a process that occurs over time; the family draws from existing resources and seeks out new resources to meet ongoing demands. In addition, the meaning that the family gives to the whole situation influences the adaptation outcome. This model provided the APN insight into the process of maternal coping and adaptation in response to caring for a chronically ill child.

**Maternal chronic sorrow and associated build-up of stressors**

The stressors experienced from caring for a child with a progressive neurological illness are multiple and ongoing. In this specific case study, there were persistent themes of maternal uncertainty, sadness, grief, fear, and anger associated with the initial presentation of Jim's illness, developmental transitions, ongoing and progressive health care needs, and periods of new or worsened symptoms. These themes occurred in response to non-normative stressors associated with Jim's condition and are consistent with the experience of other mothers experiencing chronic sorrow (Gravelle, 1997; Melnyk, et al., 2001; Scornaienchi, 2003).

**Initial presentation of illness**

When Josie described Jim's initial illness presentation, she expressed many emotions including uncertainty, grief, and guilt. She spoke of when he was a "normal" developing child and how he was able to keep up with all of the other children. Since his illness presentation, she is constantly reminded of the dreams and aspirations that she had hoped for and that Jim will never achieve. It was difficult for Josie to talk about the initial realization of her son's illness. This realization occurred one day when Jim was having difficulties getting ready for school. She thought he was being difficult and stalling, a behaviour that could be considered typical for many children. Josie entered his room and was angry because he was sitting on his bed undressed. He looked up at her with frustration and started to cry and said he could not dress himself. As she watched him struggle with buttoning his shirt, she was overwhelmed with guilt for not recognizing his illness sooner. For children with neurological conditions, this slow progression of symptoms may impair earlier detection and diagnosis. She also experienced deep sadness in realizing that her child's condition was impacting his ability to perform simple daily tasks. This realization can be considered the crisis point that triggered the ongoing experience of losses associated with maternal chronic sorrow.

After this crisis point, it was acknowledged that Jim's condition was more serious than initially expected and, as mentioned previously, he underwent a series of diagnostic investigations, which were inconclusive. Josie, at this point, was beginning her difficult journey in search of answers. The uncertain diagnosis also contributes to maternal chronic sorrow and perpetuates feelings of uncertainty, helplessness, and loss (Cherry, 1989).

**Developmental transitions**

Children with neurological conditions struggle with meeting developmental milestones. Their inability to meet these tasks presents as a stressor and further contributes to the experience of chronic sorrow (Melnyk, 2001). For children with neurodegenerative disorders, these milestones may be more obvious with the most basic cherished and proud moments for a mother lost to the disorder. A child who was previously able to walk, talk, and dress himself slowly loses the ability to perform these most basic skills. To watch a child achieve important milestones and gain independence only to lose them is heartbreaking for mothers. In this specific case, Josie was devastated and saddened by Jim's developmental deterioration. These losses have been gradual and have occurred over time. This slow loss of function and the anticipation of further deterioration are distressing for Josie. If Jim was following a normal developmental path, he should be moving through Erikson's adolescent stage of identity versus role confusion (Jolie-Pitt & Walton, 2008). Due to his illness, he is challenged to meet important milestones. During this stage of development, adolescents value socialization and independence. In addition, they establish their identity through peer relationships and autonomy. Jim's ability to achieve and foster peer relationships and independence is limited because of his physical, verbal and developmental deterioration.

Recently, Josie has recognized Jim's cognitive deterioration and has noticed his preference for watching children's television programs instead of those geared for young adults. Despite Jim's developmental deterioration, Josie has been able to accept and reframe her expectations and has identified ways to promote his growth and development. One of Jim's favourite activities is watching movies, so on weekends when he is feeling well his father takes him to the theatre. As well, Josie recognizes the importance of promoting his socialization and has been trying to find a volunteer to sit and interact with him. Despite his challenges with verbal communication, Josie speaks to him as if he is a typical teenager. The above examples are a few ways that Josie has been able to reframe her expectations of Jim's growth and development.

**Ongoing health care demands**

Symptoms of chronic sorrow were also prevalent when Josie spoke of Jim's progressive health care needs. There was a time when he was able to perform most of his activities of daily living independently. His condition has deteriorated to the point that he is completely dependent for all of his needs. This increased dependency is contributing to maternal physical and emotional exhaustion. It has been challenging for Josie to balance Jim's increasing physical care needs with normal daily responsibilities.
Periods of new symptoms or illness: Increased worry and sorrow

It was also clear that there was a build-up of stress related to new symptoms and periods of illness. One of the major stressors that Josie frequently discussed was her worry of seizures and infections, both of which have the potential to further compromise his deteriorating condition. Many parents experience anxiety and fear associated with the unpredictability of seizures (McNelis et al., 2007). Approximately two years ago, Jim developed his first seizure. This initial experience was frightening for the whole family. This new symptom signified progression of Jim’s disease and during this time Josie thought that Jim was going to die. He continues to have unpredicted seizures, which have increased in frequency and intensity. Although his seizures are a regular occurrence, they contribute to constant fear, anxiety and uncertainty. The development of seizures is a stressor that has also impacted decisions to promote Jim’s growth and development. Josie believes that Jim’s excitement in certain situations, like celebrating birthdays and holidays, triggers seizures. Josie has analyzed the patterns of Jim’s seizures and has noticed that they occur when Jim is excited. As a result, there is a high level of fear associated with activities that excite Jim. When they encounter situations that may increase Jim’s excitement they try not to draw attention to the experience and they avoid talking about it. This fear and uncertainty associated with new symptoms can be linked back to maternal chronic sorrow and has the potential to impact Jim’s developmental needs.

Maintaining hope

Similar to other mothers, Josie maintains hope through advocating and information-seeking (Gravelle, 1997; Hobdell & Deatrick, 1996; Kearney & Griffin, 2001; Scornaienchi, 2003). She believes that some health care professionals are misinterpreting her advocacy and information-seeking as denial. She wants to do everything possible to ensure that Jim receives the best possible care. She acknowledges that his disease will progress, but she also believes that someone else may have explanations for her son’s condition. It is difficult for parents to watch their child deteriorate and not have control over the situation. She compared her experience to the parent of a child with cancer; she could not live with herself if she did not explore every possible treatment. If she continues to advocate and search for answers, then she is doing her job as a parent. This advocacy is one of Josie’s strengths and provides her with hope and the ability to cope on a daily basis.

Stressors associated with other family members’ needs

Josie is also experiencing stress related to other family members’ needs. Her oldest daughter, Marie, who has a developmental disability, has been a significant stressor. Marie is in Erikson’s stage of Intimacy versus Isolation and has been struggling to meet important developmental milestones (Jolie-Pitt & Walton, 2008). Marie cries every night because she has no friends and is socially isolated. As a result, Josie is worried about her daughter’s health and ability to meet growth and developmental needs. Josie also cares for her aging in-laws who live in the same house. She has also verbalized the ongoing stress associated with continuing to support her spouse who is emotionally fragile. Any time Jim’s condition worsens or he has a seizure, Josie spends a significant amount of time comforting and supporting her spouse.

In summary, Josie has been experiencing a build-up of stressors related to caring for her family. Despite the build-up of stressors, she has managed to maintain and promote family functioning. In the circumstance of caring for a child with an undiagnosed neurodegenerative disorder, the experience of chronic sorrow and anticipation are both heightened. These mothers will continue to experience hardships and adversity in response to their child’s health care needs. Neurological conditions are especially challenging for mothers because the disease starts off with subtle symptoms that progress to more obvious physical and developmental disabilities.

Maternal adaptation and coping: Health care professionals can offer help

The APN was able to recognize and validate Josie’s emotional response. In addition, the APN identified Josie’s many strengths and competencies that promote family coping and adaptation. This theory-driven, strengths-based approach recognizes that every family has strengths and abilities that influence the process of coping with ongoing adversity (Dunst & Trivette, 1994). APNs can develop and use interventions that empower and enable maternal recognition of these strengths and abilities (Dunst & Trivette). Empowerment is a “health promoting and curing social process by which individuals gain control over their lives” (Deelve et al., 2006, p. 394). Instead of focusing on problems and negative outcomes, this approach identifies and promotes maternal capabilities to enhance family functioning. Initially, it was clear that Josie was struggling with identifying her own strengths and abilities, as she frequently verbalized feelings of hopelessness, sadness, frustration, uncertainty and anger. She also expressed her lack of confidence in her ability to make a difference with her son’s condition. Josie failed to recognize her many strengths and ability to support her whole family. After many interactions with Josie, the APN was able to recognize, and help Josie recognize her numerous strengths that have contributed and continue to contribute to family functioning. Considering McCubbin and Patterson’s Model (1983) and Dunst and Trivette’s (1994) strengths-based approach, the APN was able to identify strengths and develop theory-driven, evidence-based interventions that enabled Josie to recognize and talk about her many contributions.

New and existing resources

One of the most significant strengths included Josie’s strong advocacy. She has had to develop these skills in response to Jim’s increasing care needs. At present, many of the...
resources in place are the result of Josie's ability to advocate. Over time, these supports have built upon existing family resources. Through continuing advocacy, Josie has been able to establish new resources including Jim's enrolment in a specialized school program, a one-on-one school assistant, respite care, physician home visits, and the installation of home care equipment to meet Jim's anticipated care needs. In addition, her advocacy has played a role in finding work for her oldest daughter with developmental delay. She consistently expressed how difficult it was to establish these resources. She expressed frustration and anger at times when she was recounting the many challenges associated with continuing advocacy. However, she appears to gain strength and confidence from her accomplishments and this propels her forward to deal with the future challenges. It takes incredible emotional and physical strength to be the advocate in this situation. Despite describing all of her efforts to meet her family's needs, she failed to acknowledge the significance of her advocacy as she expressed feelings of helplessness and hopelessness.

After several interactions with the APN, it was clear that this family has a strong sense of cohesion and support. Josie talked about how her family draws most of its supports from the family system. They share common interests, goals, and ambitions, and have been able to collectively nurture and meet each other’s needs. One example of this strong family cohesion occurred when their regular respite worker was off work for a couple of months. In this specific situation, each family member took turns sitting with Jim in the evenings. Initially, Josie did not acknowledge her family's strengths, but after many interactions with the APN, she began to identify and talk about the support she receives from her family. To prevent a house from collapsing, it is necessary for it to be built with a strong frame. This frame is built strongly to provide core strength and to withstand harsh weather. In a similar way, Josie’s ability to cope on a continuing basis is dependent on the strength that she draws from her family. Without her family, she would not be able to endure the struggles associated with caring for her son. She talked about how her family has promoted and supported her own coping and adaptation and ability to move forward. In addition, Josie and her spouse have strong communication, which is demonstrated in their decision-making processes. When they make medical decisions that will affect Jim’s care, they collectively come up with solutions.

Perception of situation

Parental perceptions of stressors may have a significant impact on family coping and adaptation (McCubbin & Patterson, 1983; Melnyk et al., 2001). One of the key roles of an APN is to spend time with family members, especially mothers, to assist them in identifying their strengths and capabilities. Once a trusting relationship was established with the APN, Josie was able to recognize and talk about her positive perceptions of her family’s situation. Similar to other parents of children with life-limiting illnesses, Josie uses her religious spiritual beliefs to cope on an ongoing basis (Robinson, Thiel, Backus, & Meyer, 2006; Schneider & Mannell, 2005). These beliefs provide meaning to her life and her son’s illness. In times of increased stress, when Josie does not think she has the ability to cope, she prays to God. Through prayer as a coping strategy, Josie is able to gain the strength to persevere on a continuing basis. In addition, with the support of the APN, Josie talked about her important role in supporting all family members. Despite the many stressors associated with Jim's deterioration, Josie has been able to find hope and meaning in their experience. Josie openly talks about the joy that she experiences in caring for Jim. With assistance from the APN, Josie was able to reframe her perceptions of feeling hopeless and talked about how her advocacy has made a difference for her whole family. She also talked about her important mothering role and she recognizes the need to stay strong in order to provide the needed ongoing support to her whole family.

Challenges

Initially, it was challenging for the APN because Josie continually expressed her sense of hopelessness and failed to recognize her important contributions. Another challenge that was identified was Josie's fear of seizures that resulted in limiting of specific activities. Further nursing interventions should focus on increasing parent knowledge and confidence with managing new symptoms. The results of this case study are also limited to the maternal experience. Therefore, it would be advantageous to explore other family members' experiences and contributions to family coping and adaptation.

In conclusion, mothers of children with progressive neurological conditions face many hardships in response to their child’s changing condition. APNs can play a vital role in supporting mothers, as they navigate through this difficult journey. This case study provides deep insight into one mother’s experience of caring for a child with an undiagnosed neurodegenerative condition. The APN examined maternal coping and adaptation and applied strengths-based nursing interventions. Through validation, ongoing support, and empathy, the APN was able to empower maternal recognition of strengths in the midst of chronic sorrow. This mother, through recognition of her own strengths, was able to talk about her important role in supporting the whole family. Further research should look at both maternal and paternal experiences with chronic sorrow and should explore the effective use of coping strategies.

About the authors

Amanda M.E. Bettle, BN, RN, is the IWK Health Centre's Research Nurse Coordinator for the "CIHR Team in Children's Pain" team grant, and a master's in nursing student, Dalhousie University, Halifax, NS.

Correspondence regarding this article should be addressed to Amanda Bettle, e-mail: amanda.bettle@iwk.nshealth.ca

Margot A. Latimer, RN, PhD, is an assistant professor for the School of Nursing at Dalhousie University and IWK Health Centre, Halifax, NS.
References


Websites of interest

Canadian Association of Neuroscience Nurses and Canadian Journal of Neuroscience Nursing website: www.cann.ca

Check this site often for updates on information.

Reports will be on the website.

Canadian Nurses Association: www.cna-nurses.com

Canadian Congress of Neurological Society: www.ccns.org

Please check out the web page to learn more about the society to which we belong.

CANN is an affiliate of this society.

Canadian Journal of Neurological Sciences: www.CJNS.org

World Federation of Neuroscience Nurses: www.WFNN.org

All CANN members are automatically members of WFNN.