Truth-telling and an adolescent diagnosed with a malignant brain tumour: Who are we protecting?

Arbelle Manicat-Emo, RN(EC), MS, NP-Paediatrics, Dzigbordi Bankas, RN, BScN, Laura Bradbury, RN, BScN, and Beverly Espedido, RN, BSc(Hons), BScN

Case report summary
A previously healthy 16-year-old female of Asian descent presented to a pediatric hospital with a three-month history of headaches, and having missed her menstrual cycles for approximately seven months. She was first seen by a family physician who ordered a brain CT scan, which showed a lesion in the right frontal area. She was taken to hospital after awaking with left-sided numbness and weakness, facial weakness, and slurred speech. On neurological exam, she had bilateral sixth cranial nerve palsies and bilateral disc edema. A brain MRI also confirmed the right frontal lesion.

She underwent a right frontal craniotomy for biopsy of the lesion a day after admission. Resection was not attempted given the diffuse and infiltrating nature of the tumour. The pathology was Gliomatosis Cerebri, high-grade glioma. She was initiated on Dexamethasone and Phenytoin for seizure prophylaxis.

Neuro-oncology was asked to consult and a disclosure of the diagnosis and poor prognostic outlook was shared with the girl’s parents. The father spoke limited English, but assumed the role of interpreter for the mother, as was his request. The parents were grief-stricken. Chemotherapy and radiation therapy were offered as treatments, but it was made clear to the parents that they were not curative interventions. Palliative care was raised as an option, but refused by the parents. They requested that they be the ones to disclose the news to their daughter. She was started on her first cycle of Temozolomide.

During her course of chemotherapy, she was considerably unstable, ataxic, fatigued, and demonstrated a left upper extremity neglect. She was impulsive, required constant supervision and, yet, remained lucid. Parents had still not disclosed their daughter’s prognosis to her, but the patient was aware she had a “cancerous tumour”. Radiation therapy was also initiated at this time. She was heard to make statements about returning to school and finishing her senior year, and seeing her friends again. Staff nurses also noted her saying, “…people live with this”, when referring to her tumour. As well, she was observed by a nurse to have been researching her diagnosis on the world-wide-web on the unit computer.

A follow-up meeting with the parents revealed that although the patient was aware of her diagnosis, she was not aware of the grim prognosis. The parents expressed that they were “hoping for the best” and for any recovery. At this point in time, the patient was noted to be “teary” and “sad” by the nursing staff, partly due to her hair loss and exhaustion from her treatments, and to the side effects of her steroid therapy. The members of the health care team, particularly the nursing staff, grew increasingly uncomfortable with this ethical dilemma: Should the patient have the right to know the truth and who should tell her? Whose rights were they protecting, the patient or her parents? Did ethical or moral distress play a factor in this dilemma?

It is these complex questions and additional contributing variables that presented a challenge for the nursing and inter-professional health care team. With reference to the posed case study, the following discussion will highlight the notion of truth-telling, from the perspective of the adolescent patient, along with the ethical principles that relate to the situation. Although this article does not strive to reach a universal decision for practice, recommendations for nursing care will be shared. Given the patient’s diagnosis of a malignant brain tumour and anticipated illness trajectory, neuroscience nurses will appreciate the following discussion and its applicability to their practice from an ethical standpoint.

Background to the diagnosis
Gliomatosis Cerebri (GC) or infiltrative diffuse astrocytosis is a rare primary brain tumour that was initially described by Nevin in 1938. It most commonly presents as a diffusely infiltrating glial neoplasm of the central nervous system and is associated with a variable clinical course and generally poor prognostic outcome (Armstrong et al., 2006). The World Health Organization (Kleihues & Cavenee, 2000) had further classified GC as a neuroepithelial tumour of uncertain origin, composed of elongated cells resembling astrocytes that affect at least two brain lobes, as confirmed by magnetic resonance imaging (MRI) studies. This tumour may also infiltrate infratentorial structures of the brain and the spinal cord. All age groups may be affected by GC, but the vast majority of patients reported in the literature are adults (Armstrong et al., 2006), with few cases reported in children (Jennings, Frenchman, & Shehab, 1995). An optimal treatment strategy has not yet been well established. Surgery is limited to biopsy given the infiltrative nature of the tumour (Levin, Gomori, & Siegal, 2004). Radiation therapy is an option, but can lead to substantial delayed toxicity (Elshaikh et al., 2002). Chemotherapy such as Temozolomide can be offered as an initial treatment (Levin et al., 2004; Sanson, Cartalat-Carel, & Taillibert, 2004).

Who are we protecting?
Should the patient have the right to know the truth and who should tell her?

The College of Nurses of Ontario (CNO) Practice Standard for Ethics (2009a) states that “truthfulness means speaking or acting without intending to deceive. Truthfulness also refers to providing enough information to ensure the client is informed. Omissions are as untrue as false information” (p. 13). It is legislated that nurses are not authorized to communicate a diagnosis except for nurse practitioners (CNO, 2009b), and the disclosure of prognosis is widely and legally recognized as the responsibility of the primary or attending physician. In this patient’s case, that was her oncologist. There were a number of behavioural directives outlined by the CNO (2009a). The only one met by the nurses involved in this case was “giving consideration to families’ and/or significant other(s)’ points of view when they do not want clients to be told about their health condition” (p. 14). This directive is in keeping with the nurses honouring the parents’ wishes to withhold the truth. However, the patient in this case demonstrated her desire to know the truth by attempting to find out about her disease. A staff nurse witnessed and documented the patient researching her diagnosis on an internet search site. It could then be argued that the nurses were not effectuvely advocating for her right to receive information. This was evidenced by the nurses not facilitating the patient’s search for answers. One could question whether the nurses were acting deliberately deceitful. It is not within the nurses’ scope of practice to disclose the diagnosis and prognosis to a patient. However, it is within the profession’s ethical accountability, and deemed as an important ethical value to advocate for the patient’s wish to seek the truth (CNO, 2009a).

Purposefully withholding information from a patient can be justified by the concept of ‘benevolent deception’ whereby disclosure of a diagnosis would violate the duties of beneficence (do good) and nonmaleficence (do no harm) by causing serious consequences (Leikin, 1981). The College of Nurses (2009a) Practice Standard: Ethics, further stresses, that “honesty builds on trust, which is successful to the therapeutic relationship between nurses and clients” (p. 13). If honesty is lacking, this could be perceived as a breach of trust in the therapeutic relationship between the nurses and this patient. The pediatric patient with a life-threatening illness starting treatment must be able to trust the professionals providing care, as well as trust his or her family members. Non-disclosure of diagnosis may jeopardize both the parent-child relationship and the professional-child relationship (Gupta, Willert, Pian, & Stein, 2008).

As demonstrated in the case report, “withholding information or lying to young people seriously threatens this trusting relationship if, as frequently happens, the juvenile learns the truth from other sources” (Leikin, 1993, p. 3345). Tuckett (2004) outlines arguments for and against truth-telling, but emphasizes there are no absolutes. However, current practices among North American health care professionals have shifted towards truthful and honest disclosure of diagnosis and prognosis, which embodies the ethical principle of patient autonomy.

Whose rights were being protected?

Patient autonomy is an integral ethical principle that holds that a person be allowed to be self-determining and independent in his or her decision-making (Edwards, 1996). Respect for autonomy is also respect for people and their capacity to reason and to make decisions. A more specific definition of “capacity” refers to a person’s ability to understand information relevant to a treatment decision and to appreciate the consequences of a decision or lack of a decision (Etchells, Sharpe, Elliott, & Singer, 1996). Autonomy is protected by the instrument of informed consent (Freyer, 2004). Not to elicit consent for treatment from patients is to violate a patient’s autonomy and to fail to respect them as persons (Leikin, 1981).

Age of consent to treatments is not nationally decided; it is determined at the provincial level. Each province and territory varies significantly in how they mandate the rights of children and adolescents with respect to consenting to their own treatment. Certain provinces and territories have established an age of consent while others have implemented a process to determine capacity to consent rather than age (Canadian Paediatric Society [CPS], 2004). In Ontario, under the Health Care Consent Act (College of Physicians & Surgeons of Ontario, 1996), there is no minimum age of consent, and people under the age of 18 years should be assessed for their decision-making capacity in the same manner as an adult. Patients just have to demonstrate that they truly understand the risks and potential benefits of going ahead or refusing a treatment. Conversely, in Manitoba a person who is under 16 years of age does not have the capacity to make health care decisions. Thus, people under 16 do not have capacity to give consent for any medical decisions (CPS, 2008).

The patient described in the case report is an adolescent, a developmental stage where autonomous decision-making is approaching almost-adult capacity (Weithorn & Campbell, 1982). However, discrepancies exist within the definition of ‘adolescence’, which could impact the legal, ethical and developmental factors that relate to this stage (Freyer, 2004). Adolescence can be defined chronologically (Lind, Anderson & Oberle, 2003) or by assessing a young person’s mental capacity (CPS, 2004). Adolescent involvement in various aspects of the current health care system continues to be a source of debate among many pediatric health care professionals. Thus, there is possibly no definite consensus as to how to approach ethical dilemmas of truth-telling among this population. It can be argued that adolescent patients deemed competent have the legal and ethical right to determine their own care. However, in order to avoid ambiguity and confusion among health care professionals, patient competency must be defined.

Among the majority of modern-day North American pediatric health care environments, autonomy is highly regarded as a fundamental framework for provision of care. A shift with regard to the communication and involvement of patients in health care decisions has occurred over the previous 50 years in North America (Parsons et al., 2007). Historically, a paternalistic or “knows best” approach to the care and disclosure of childhood and adolescent diagnoses was the foundation of many North American health care settings. Although this
philosophy may be currently viewed as a primitive means of care, its principles provide the basis of the “protectionist” approach (Lowden, 2002, p. 103).

A “protectionist” approach, as dictated by the National Children’s Bureau (1992; as cited in Lowden, 2002), to care of the adolescent views the parent or primary caregiver as the sole decision-maker. In this relationship, the adolescent (or child) does not bear any rights towards the involvement in his or her care. This individual is then deemed incompetent (Lowden, 2002). In the case study, a “protectionist” approach was clearly adopted by the health care team in choosing to withhold the truth about the patient’s prognosis from her. As a consequence, this patient’s ability to exercise her autonomy and make decisions related to her care was compromised. Although the patient was physically weakened by her disease process and the effects of the medications, was she capable or competent enough to have participated in decisions regarding her treatment options if given the opportunity? Clearly, she was demonstrating her autonomy by actively seeking information about the tumour, and her statement of being able to “live with it”, in reference to the tumour, seemed an attempt to affirm her future survival. Was the patient thinking the treatments she was being given were curative? Indeed, she was heard to make comments about returning to school and being with her friends again. It was unclear as to what the patient actually knew of her illness at this point in time, as she had not been given any information at all related to her prognosis other than what she may have gathered from the internet.

Conversely, the parents’ autonomy must also be considered. Parents are perceived as morally, ethically and legally accountable for their child’s care and well-being (Leikin, 1981). Thus, parents are recognized as the primary source of knowledge regarding their children. They are in an optimal position to advocate for the child’s needs to the health care team (Shields, Kristensson-Hallstrom, & O’Callaghan, 2003). Allowing parents to assert their rights in nondisclosure of their child’s prognosis, as in the case study, enables them to act autonomously as decision-makers of their child’s care. The health care team’s support of the parents’ wishes of non-disclosure was in keeping with the “protectionist” approach. Essentially, the parents’ rights were being protected, not those of their child. Candib (2002) argues that due to the strong international presence of the North American viewpoint on disclosure in medical settings, health care professionals may regard “a family’s preference not to disclose a cancer diagnosis to their loved one as, at best, paternalistic and at worst, hopelessly backward” (p. 214).

Given the Asian background of the parents in the case study, culture may have influenced their decision to withhold medical information from their daughter? Culture can be defined as the “thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups” (Office of Minority Health, 2001, pg. 2). Candib (2002) strongly emphasizes that current values, beliefs and means of practice within the North American health care system are not always shared with those of different cultures. It is paramount for practitioners and care providers to be cognizant that “we are culture-bound in our approach” (p. 226), in order to provide holistic care to the family and patient at the end of life. The parents’ statement of “hoping for the best” and for any recovery speaks of their hopes for a positive outcome for their daughter. For some cultures such as Asian ethnicities, nondisclosure of diagnosis and unfavourable prognosis to a patient is a means of fostering hope (Parsons et al., 2007). It is also important to note that in the case study, the parents’ mother tongue was not English and a formal interpreter was not used.

Did ethical or moral distress play a role in this dilemma?

The nurses caring for the patient in the case study were experiencing uneasiness and uncertainty with the decision to withhold the truth from her. For many of these nurses, this decision conflicted with their ethical and professional responsibilities, as trusted patient advocate and caregiver to the patient. The stress the nurses were feeling in this ethical dilemma is part of a growing phenomenon first conceptualized by Jameton in 1984 where he states, “Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (p. 6). The Canadian Nurses Association’s (CNA’s) Code of Ethics for Registered Nurses (2002) uses the terms “ethical” and “moral” distress interchangeably, and defines either as “situations in which nurses cannot fulfill their ethical obligations and commitments (i.e., their moral agency), or they fail to pursue what they believe to be the right course of action, or fail to live up to their own expectation of ethical practice, for one or more of the following reasons: error in judgment, insufficient personal resolve or other circumstances truly beyond their control (Webster & Baylis, 2000). They may feel guilt, concern or distaste as a result” (CNA, 2002, p. 6). Building upon this notion of ethical or moral distress, current research (Pauly, Varcoe, Storch, & Newton, 2009; Rodney et al., 2002) has further identified some of the constraints that nurses encounter in their care environment when attempting to enact their moral obligations. Often these constraints may be external to the nurses such as their relationships with their peers and the physicians, the patients themselves, and the policies or procedures of the hospital. The nurses in the case study were struggling with being unable to support the patient in her quest to seek the truth. They were constrained by a decision that they were not necessarily involved in making. The nurses were resigned to following the lead of their physician colleague who, in turn, took his direction from the parents. “Nurses feel a strong obligation to respect patients’ wishes and the desire to affect the appropriate outcome, yet often fail in their attempts. Nurses feel that they do not have a voice, as they struggle against powerful authorities” (Nathaniel, 2006, p. 428). As the patient received her treatments, which were meant to alleviate symptoms, but not to cure them, the nurses continued to experience the escalating stress of non-disclosure. Medical prolongation
Directions for future nursing care

Candib (2002) questions how practitioners can be “both patient-centred and family-centred in addressing end of life issues with patients from cultures other than [one’s] own” (p. 221). Within most pediatric health care settings, family-centred care is a model widely accepted as fundamental to the care and support of the patient and family (Harrison, Kenny, Sidarous, & Rowell, 1997). By definition, family-centred care, as an action, model and philosophy, notes the family and child as a unit, where all needs are recognized and paramount (Sheilds, Pratt, & Hunter, 2006). Dix, Klassen, Papsdorf, Klassen, Pritchard, and Sung (2010) highlight that family-centred care is a means in which the family and health care provider form a working partnership, so the families are “involved in every aspect of the child” (p. 1079). People employing this model of care recognize the needs of the entire inclusive family and consider how decisions affect each member. Further, this model strives to acknowledge that each family member has a responsibility to one another, with regard to the vulnerable patient (Dix et al., 2010; Harrison et al., 1997).

The patient and her parents could have benefited from the implementation of a family-centred care model. This framework of practice is crucial to facilitating family autonomy. In keeping with the concept of family autonomy, practical clinical applications for nursing may include inquiring upon admission about the family’s preferences for information disclosure, thus allowing the health care team to anticipate potential ethical conflicts. Tuckett (2004) suggests that rather than making assumptions, health care providers should utilize therapeutic communication and ask patients and their families what informational requirements are preferred. Beale, Baile and Aaron (2005) recommend the following six strategies for communicating with dying children and their families: establish, engage, explore, explain, empathize, and encourage. Establish early an open communication between the child, parents and caregivers. Engage the child in early discussion at key points such as disclosure of a new diagnosis or if their clinical status changes. Explore the child’s understanding and interpretation of their illness, and provide clarification. Explain the medical information in a manner that is developmentally appropriate for the child. Empathize with the child’s emotional response to the information given, acknowledging their reaction and providing the necessary supports. Encourage or reassure the child that he/she is being supported and that the nurse will be physically and emotionally attentive to the child’s needs. Nurses, by virtue of their front-line proximity to patients and families, are optimally situated to use these strategies as a means of developing therapeutic relationships that facilitate truth-telling.

In many care facilities, resources such as bioethics committees are available to support the patients and their families, as well as the members of the health care team in providing objective resolutions of ethical dilemmas. In this case study, the involvement of the bioethics committee was lacking and would have been of significant benefit to ameliorating the moral distress experienced by the nursing and the health care team. Furthermore, there was lack of consensus among the team members on what information was to be disclosed to the patient. The bioethics committee could have been instrumental in facilitating dialogue and ensuring collaboration regarding the best approach to the patient’s care. Storch et al. (2009) supports the involvement of these institutional resources in ethical decision-making. Consultation with an ethics committee can help to clarify the particular ethical problem and the barriers to the action the nurse desires (CNA, 2003).

Conclusion

Truth-telling in the context of the adolescent with a poor prognosis poses a challenge for all those involved, particularly the family and the health care team. Finding a peaceful solution is rarely simple and is more often a difficult and emotional process. Nurses are in a unique position to advocate for the needs of the patient, as well as the family, during this stressful time. Ethical situations such as the case study provided will encourage nurses and their colleagues to reflect on their own values, beliefs and practice, which will serve as the foundation to improve patient care. More specifically, neuroscience nurses have the specialized knowledge, skills and expertise to effectively support patients and families where curative measures are not an option, but rather the focus is on quality of life. Clinicians, particularly neuroscience nurses “can play a crucial role in helping the adolescent, in the face of death, to experience the richness of life and the dignity of self-determination” (Freyer, 2004, p. 381). This role may hold true for neuroscience nurses than those in other specialties because of the devastating diagnoses that they frequently encounter in their daily practice, thereby exposing them more often than not to the moral obligations of caring for these compromised patients. Neuroscience nurses have the distinct opportunity to advocate for such patients and their families, managing often unexpected, challenging and life-altering situations. Unlike other nursing specialties, neuroscience nurses care for a broad and highly complex set of patient acuities, traumas and chronic conditions that commonly affect cognitive function, and the emotional, physical and psychological body response. Thus, neuroscience nurses must demonstrate competence and moral insight in responding to these patient concerns that could, at any point, place those they serve, their families and themselves in complicated ethical dilemmas such as the dying young girl with a malignant brain tumour.

Canadian Journal of Neuroscience Nursing • Volume 32, Issue 3, 2010 39
About the authors
Arbelle Manicat-Emo, RN(EC), MS, NP-Paediatrics, is a Nurse Practitioner in the Division of Neurosurgery at The Hospital for Sick Children, Toronto, Ontario.

Dzigbordi Bankas, RN, BScN, Laura Bradbury, RN, BScN, and Beverly Expedido, RN, BSc(Hons.), BScN, are staff nurses on the Neurosciences/Trauma Unit at The Hospital for Sick Children, Toronto, Ontario.

Correspondence regarding this article should be addressed to Arbelle Manicat-Emo. Email: arbelle.manicat-emo@sickkids.ca

References


