Case history
Matthew (a pseudonym) was a 20-year-old student attending university and living with his parents and sister when he was diagnosed with B-lymphoblastic leukemia (B-ALL). B-ALL is the most common type of acute lymphoblastic leukemia in which too many B-cell lymphoblasts are found in the bone marrow and blood (Puig, Robison, & Look, 2008). Following bone marrow biopsy confirmation of B-ALL, chemotherapy was commenced and complete remission was achieved.

Two years later, Matthew presented to the hospital with a one-week history of abdominal and shoulder pain, fatigue, ecchymosis to both legs, and epistaxis. Blood work confirmed relapsed B-ALL and Matthew received re-induction therapy. Matthew developed febrile neutropenia and a presumed fungal pneumonia and received antifungal treatment.

Several weeks after initiation of the re-induction therapy, Matthew developed a lesion on his right upper arm. The biopsy showed the lesion as aseptic mycetoma, which is highly suggestive of mucormycosis, a rare fungal infection that has increased in incidence over the past decade (Pagano et al., 1997). Mucormycosis can invade the vascular system and occurs most frequently in patients with acute leukemia, in patients with lymphoma who are neutropenic, and in patients who have received transplants and are receiving immunosuppressive therapy (Skikoda et al., 2012).

Shortly after the development of the arm lesion, Matthew had a sudden cardiac arrest. The arrest was secondary to a massive hemoptysis that resulted from a fistula formation between his lung and his right axillary artery. This type of aggressive tissue invasion is consistent with disseminated mucormycosis and is usually associated with extremely high rates of mortality. Matthew was resuscitated and transferred to the intensive care unit for a bronchial artery embolization and stent placement. The development of further lesions on his arm and hand was ongoing and Matthew continued to deteriorate. With great reluctance, Matthew, his family, and the primary physician, made the decision to institute a ‘Do Not Resuscitate’ (DNR) status. This shifted the goal of therapy towards comfort measures, and a recommendation that Matthew be discharged home on a new antifungal medication. While the previous antifungal therapy was covered under public insurance for both institutional and home use, the new antifungal medication was not. Matthew and his family had no private insurance coverage, and the cost of the new antifungal medication was approximately $2,000 per week, which Matthew and his family could not afford. In such circumstances, the Ontario Ministry of Health and Long-Term Care (MoH LTC) have a special access program that facilitates patient access to drugs not funded on the public formulary, or where no listed alternative is available (Government of Ontario, 2012). A request was made to the ministry to cover the cost of antifungal therapy for Matthew. However, it was denied on the basis that there was a lack of published research showing efficacy of this particular antifungal medication in treating mucormycosis in immunosuppressed patients. It was suggested that his drug costs may be covered at home if he was placed on an alternative, previously used medication, which was less expensive, but for which efficacy was questionable in relation to the treatment of mucormycosis.

Although Matthew wanted to go home, the denial of funding for the antifungal therapy meant that he could stay in hospital on the new medication or go home on those that had proven ineffective. Subsequently, Matthew remained in hospital for the last 15 months of his life. His family incurred considerable inconvenience and expense in visiting him because they lived 45 minutes by bus from the hospital. Several weeks after the initiation of the DNR order, Matthew died.

Introduction
In 2013, more than 180,000 Canadians will be diagnosed with cancer. Approximately 75,000 will die from the disease and nearly one million will continue to live with cancer 10 years after diagnosis (Canadian Cancer Society, 2013). Although the care of cancer patients involves professionals from several health disciplines, nurses are the largest body of health care providers who work with oncology patients on an hour-to-hour basis (McLennon, Uhrlrich, Laster, Channness, & Helft, 2013). To provide high-quality care, oncology nurses require a specialized skill set to manage the complex physical, psychosocial, emotional, and spiritual needs of cancer patients. This complexity is complicated even further by the sometimes competing beliefs, values, and goals of the patient, family, and health care team and the various duties of the interprofessional team that can lead to conflicts about best approaches to care and fragmentation in communication (Abma, 2005; Pergert & Lutzen, 2012). Not surprisingly, nurses routinely encounter ethical issues or concerns related to providing care to cancer patients and families (Leung & Espelen, 2010).

Ethical issues and concerns may occur when there is tension between what the nurse believes is the right thing to do in a certain situation and the views of other health care providers, or between what the patient desires and what is possible or recommended from a system or treatment perspective (Ahmed & Ali, 2013). Pavlish and colleagues (2011), in their study of clinical ethical incidences, found that nurses reported two major areas of patient care concerns: those related to quality of life in the context of pain and suffering and those related to promotion of patient autonomy and decision-making. Nurses in the study also reported having regrets about witnessing patient suffering (physical and emotional), as well as a perception that they were not doing enough to help patients and that the health care system had failed. Ethical concerns faced by nurses also involve communication issues between patients, families, physicians, and other health care providers. Reineke et al. (2010) reported that nurses who cared for patients with terminal conditions, identified that communication issues, specifically those relating to the reluctance of physicians to discuss prognostic-related topics with patients, were a major ethical concern for nurses. Similarly, McLennon et al. (2013) found that oncology nurses who cared for advanced cancer patients reported common ethical concerns such as problems with truth telling, conflicting obligations, and futility. Truth telling was related to...
the nurses’ perception that the patient may not fully know what prognostic information was given to patients by the physicians, who were often reluctant to communicate difficult news. Subsequently, nurses were unsure of what to communicate to patients, because the nurses did not want to diminish hope (by sharing life-limiting information that may discourage patients from continuing treatment). Nurses also described conflicting obligations that involved the patients’ families. Family members, at times, did not want patients to know the prognosis and nurses felt conflicted about the right course of action. In summary, nurses frequently experience ethical issues and concerns that challenge their own attitudes, values and beliefs.

The purpose of this paper is twofold. First, to share a story about a specific patient case and the ethical concerns that the nurses experienced while caring for Matthew and his family during his extended hospital admission. Before Matthew died, he and his family requested that his story be told to nurses and other health care providers in order to show that some lessons may be learned about providing ethical care. Second, using relational ethics as a background, the paper will explore this story, as told through a case history, and suggest that relational ethics may offer guidance to nurses who care for complex oncology patients.

**Ethics**

Ethics is concerned with whether or not our actions are morally good (Pesut & Johnson, 2013) and with judgments about what is right or wrong (Fry & Veatch, 2011). In addition to right and wrong, these judgments are recognized by words such as ought, should, desire, harm, good, or bad (Fry & Veatch, 2011). Ethics is seen as integral to everyday practice, such that the Canadian Nurses Association (CNA) (2008) states that nurses “attend to ethics in carrying out their daily interactions, including how they approach their practice and reflect on their ethical commitment to the people they serve, is the substance of everyday ethics” (p. 4-5).

Traditionally, nursing ethics has been heavily influenced by bioethics, which is the dominant model in medical ethics (Gastmans, 2013). This model suggests that ethical problems are largely related to rights and duties, which are expressed through four principles: autonomy (the freedom to make meaningful choices), beneficence (doing what is best for the patient), non-maleficence (doing no harm), and justice (fairness) (Oberle & Raffin Bouchal, 2009). These principles are easily recognizable in the values that are articulated in the current CNA Code of Ethics, which includes providing safe, competent, compassionate, and ethical care; promoting and respecting informed decision-making; maintaining confidentiality and privacy; promoting justice; being accountable; promoting health and well-being; and preserving dignity (CNA, 2008; Oberle & Raffin Bouchal, 2009).

While bioethics remains an important model for ethical decision-making in health care, criticisms of bioethics include its emphasis on the specific obligation or duty that the physician owes the patient and its failure to fully acknowledge issues related to the relational nature of ethical decision-making (Oberle & Raffin Bouchal, 2009). For example, in the situation where the patient wishes to go home against medical advice, what principle should be followed? Autonomy or beneficence? If you advocate for the patient’s wishes and the patient goes home, the principle of autonomy or the right of the patient to make a choice (Oberle & Raffin Bouchal, 2009) is honoured. If, however, you advocate against the patient’s wishes because this choice will place the patient in danger, you may be observing the principle of beneficence or doing what is best for the patient (Oberle & Raffin Bouchal, 2009), or are you? Gadow (1996) suggests that a conflict such as this is between private and particular values, or consumerism and public and general values, or paternalism. She suggests such a conflict can be resolved by looking to an ethical approach that arises out of engagement between the nurse and the patient and combines their joint views of what is good or right. This thinking has been influential in the development of relational ethics, which assumes that general principles alone are insufficient to recognize the particularity of personal situations and that personal stories, in themselves, cannot overcome the vulnerability of overwhelming circumstances.

**Relational ethics**

The relational aspect of nursing ethics considers how we interact with others in our care (Oberle & Raffin Bouchal, 2009), and attention is given to the moral space, or the relationship between self and others. Because this space is where morality is enacted, relational ethics assumes that ethical practice is consistently situated in relationships—with patients, family members, other caregivers, the community, and the health care system (Bergum, 2013; Pergert & Lutzen, 2012). Nurses need to have connection with the patient, as a person, in order to understand what is important and what would serve the best interests of that person. Bergum and Dossetor (2005) suggest that ethical relationships require several key elements: embodiment, mutuality, engagement, non-coercion, freedom, choice, and consideration of the environment.

Embodiment recognizes that healing for the person requires a focus on both the mind and body. This requires nurses to connect with others in a way that they can really understand what the person is experiencing. Bergum and Dossetor suggest this requires going beyond “just being nice to people” (cited in Oberle & Raffin Bouchal, 2009, p. 42) and requires a commitment to care about others and a willingness to participate in a relationship. Mutuality involves a relationship that is beneficial to both parties, and encompasses a deep understanding of the values, beliefs, and goals of the other. It is a reciprocal and interactive process; a human exchange that rewards the nurse with truly knowing the person and the patient with a sense that his or her participation in care is respected and invited. Engagement, which takes time and skill, requires the nurse to connect with the patient with openness, trust, and responsiveness and to set appropriate boundaries (Bergum & Dossetor, 2005). Non-coercion is the opposite of coercion. It means not forcing someone to do something against that person’s wishes (Bergum & Dossetor, 2005). While coercion should be avoided because it limits choice and freedom, non-coercion, within the context of relational ethics, means the person should be regarded as someone who is capable of self-determination and moral decision-making (Bergum & Dossetor, 2005). Choice is the ability to make one’s own decisions and is directly tied to freedom (Bergum & Dossetor, 2005). Within this context, the capacity for choice or autonomy is seen as interdependent, and emerges out of the moral space that asks “what are you going through?” and “what is the best thing to do in this situation?” (Wright & Brajman, 2011, p. 24).

The relational autonomy of this ethical framework is reflected in how the environment is considered “each of us... a living system... that changes through daily action” (Bergum, as cited in Oberle & Raffin Bouchal, 2009, p. 42). Bergum suggests that nurses must consider how the environment (e.g., patient, family member, health care providers) directly or indirectly affects each other. Having an awareness of the interconnectedness of the environment helps the nurse to understand the bigger picture. Moreover, being aware of how the environment is connected assists nurses with understanding the impact/influence of political and power structures that play a role in relationships and patient care. The elements described above are important to an ethical relationship, as they assist nurses to have open dialogue with patients/families in order to determine their goals and wishes.

**Relational ethics applied to case history**

The authors suggest that relational ethics may provide an important model for guiding nurses and other health providers in the care of patients with incurable cancers. The key elements of ethical relationships according to Bergum and Dossetor (as cited in Oberle & Raffin Bouchal, 2009) can be applied to the aforementioned case history, as a strategy to assist nurses with supporting and advocating for patients at the end of their lives.

**Patient and family perspective**

Matthew was a young man who wanted to live as long as he could, a goal that his family also shared. Matthew’s decisions regarding antifungal treatment and chemotherapy were based on his desire to receive life-prolonging therapies. Despite being informed of the potential unpleasant side effects of these non-curable treatments, Matthew
nurses were seldom invited into the discussions, and, thus, the con-

sidered sufficiently unproven that it could not be funded for use in the community, why was it acceptable for use in the hospital? Should the needs of Matthew have been subordinated to the policymakers and, thus, should he have been coerced into a decision that did not meet his need? If the Canadian health care system assumes that health decisions are based on need, then whose need should receive greater consideration; the system's need to conserve resources or that of Matthew? In this particular situation, the lack of engagement between Matthew, the health team, and the policymakers may further have disallowed a full understanding of needs, values, and beliefs of all involved. The lack of engagement may, therefore, have resulted in decisions that did not, as Gadow (1996) suggests, negotiate between the overwhelming vulnerability and particularity of Matthew's situation and public values and paternalism.

Nurses' perspective

Embodying recognizes that healing for the person requires a focus on both the mind and body. This requires nurses to connect with others in a way that they can really understand what the person is experienc-

ing. It requires a commitment to care about others and a willingness to participate in a relationship. Most of Matthew's life was spent in hospital, on one clinical unit, after the recurrence of his leukemia. Nursing staff on the unit developed a long-term relationship with the patient and his family. Nurses found it distressing to care for Matthew for several reasons. First, the progressive nature of his leukemia and the mucormycosis was demoralizing to nurses because they felt frustrated and powerless to provide embodied care to Matthew and his family that fully acknowledged the needs of both mind and body. The nurses were aware that his illness was incurable and that his overall health was deter-
rating. According to their values and beliefs, his quality of life was poor because of the side effects of futile treatments and his inability to live out the remainder of his life at home, with family and friends close by. Second, the nurses believed that the primary physician did not adequately discuss end-of-life issues with the patient and family despite Matthew's poor prognosis and the apparent futility of his treatment, partially because they were seldom involved in discussions between the physician and family. The lack of knowledge about what the patient had been told limited the capacity of the nurses to fully enact mutu-
ality. Subsequently, the nurses were limited in their advocacy for the patient and in engagement of Matthew and his family in open and honest discussions, including what Matthew and his family valued about life and believed was necessary for quality of life. The nurses felt they were unable to assist Matthew and his family towards full engagement because the environment (e.g., the hospital) prevented care that they believed was mindful of his need to be at home in an environment that

Policy makers' perspective

The suggestion made by the MoHLTC to fund a less-expensive drug is reasonable, given concerns about the lack of evidence to support the effectiveness of the antifungal medication, and is supportive of the bioethical principle of justice, which is concerned with fairness and, from a social perspective, with the fair and unbiased distribution of scarce resources. From a Canadian perspective, distributive jus-
tice assumes that no person is privileged in health care over another by reason of status or ability to pay; decisions about allocation of resources occurs on the basis of need alone (Oberle & Raffin Bouchal, 2009). In this particular situation, allocation of significant resources to one patient for an expensive drug when a less-expensive drug, with equally uncertain efficacy was available might have been seen as a fair decision. Valuable resources were conserved for other patients in the system and the greatest good was served. The policymakers (MoHLTC) were also enacting what they had determined would be in the best interests of the patient (beneficence) by refusing to fund a drug outside of the hospital that did not have established efficacy.

The decision of the MoHLTC meant that Matthew remained in hospital (in order to receive his antifungal medication). This prevented the in-hospital treatment of another patient who might have had a better prognosis. The decision raises a number of ethical issues, partially because the values and beliefs, which would have driven the decision of the policymakers are not fully clear. If the antifungal therapy was con-

sidered to be a therapy that was considered life prolonging, even if it meant that Matthew had to stay in hospital to avoid bur-

dening his family with additional financial costs.

Medical perspective

The treatment of Matthew’s acute leukemia occurred over an extended period of time, during which he, his family members, his primary physician, and the nurses developed closely interconnected relationships. Matthew and his physician, in particular, were highly engaged around Matthew’s treatment, the treatment plan, and the disorder itself. Together, Matthew and his physician pursued various treatment options to prolong Matthew’s life, despite the mounting evidence to suggest that treatment was futile. The disinclination to turn away from active therapy in the hope of prolonging life was evidenced in the reluctance with which the physician suggested DNR and with which Matthew agreed, as well as in the decision to continue with a therapy that was considered life prolonging, even though it meant that Matthew had to stay in hospital to avoid bur-

dening his family with additional financial costs.

Although the physician spent considerable time with Matthew, nurses were seldom invited into the discussions, and, thus, the content of these discussions was not fully known to the nurses. The nurses wondered if the physician was overly optimistic in discussions with Matthew about the treatment, which might have unrealistically raised Matthew’s expectations. While full engagement and mutual respect may have characterized the relationship between Matthew and his physi-

ician, this did not extend to the nurses who, as part of Matthew’s envi-

ronment, were affected negatively. Subsequently, the nurses felt that they could not sufficiently support either Matthew or the physician, whose motivation for continuing what seemed to be futile treatment was unclear. Was the physician unable to abandon life-prolonging efforts either because he did not want to strip Matthew of hope, or because of such a prolonged investment in cure? Because of lack of engagement between the physician and the nurses, this motivation was not shared or known. Subsequently, the nurses may have felt coerced or forced into complying with a plan with which they did not fully agree simply because they lacked relevant knowledge about the decisions that were made in the relational space between the physician and Matthew and about the moral decision-making of the physician.

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was familiar and caring in a way that he best understood. Similarly, the nurses felt constrained by the environment because it prevented their caring for Matthew according to their beliefs, goals and from fulfilling their obligation to provide care that was best for the patient.

Discomfort, which is referred to as moral distress, is experienced in situations where an individual is unable to exercise moral agency or to act according to his/her own values, beliefs, and obligations due to internal and/or external obligations and pressures (Ahmed & Ali, 2013; Oberle & Raffin Bouchal, 2009). In this instance, the nurses expressed moral distress in a situation where they believed there was unjustifiable life support and unnecessary tests and, thus, ineffective treatment and care, which included an inability to establish a relationship in which the needs of the patient could be fully known and respected.

**Discussion**

Ethical issues are common in the care of cancer patients because the care requires the expertise of many professions and different health systems (e.g., hospital, community). This paper shared the story of a patient case history and the ethical concerns experienced by oncology nurses. We suggest that the elements of relational ethics, which are embodiment, mutuality, engagement, non-coercion, freedom and choice, and consideration of the environment offer useful guidance to nurses when faced with challenging situations. This case history, in particular, illustrates the interconnectedness of patient, family, system, and health care provider responses, and how it is difficult in ethical situations to proceed without understanding who is involved and what values, beliefs, and goals of each might be. The case history of Matthew shows that distress partially arose because everyone—the patient, nurses, physician, and the policymakers—was acting with good intent, but each from a somewhat different perspective of what was best for Matthew (beneficence), which reflected unique views about what was important. For example, the patient and family's main goal was to prolong his life without jeopardizing the well-being of his family. The physician wanted primarily to prolong life, through whatever means was possible once it was evident that Matthew’s disease was incurable. The goal of the policymakers was focused on economics and justice by providing therapies that were deemed as serving Matthew well at less cost to the system. Lastly, the main goal of the nurses was to improve the quality of Matthew’s life.

The complexity of this situation suggests there are limitations in a purely bioethical approach. It offers little guidance in sorting out which path to follow, especially when each has moral value and can be argued as being justifiable because it is concerned with doing good. Within this context, relational space must be expanded to include those who are most responsible for negotiating and enacting decisions. In this case history, this would have involved Matthew, his family, his doctor, the nurses, and potentially even a government representative and an ethics broker, in open discussions about what is important to each and about their guiding beliefs. Within this expanded space, questions can be asked that facilitate the development of mutuality: What is important to you? How do you think this might happen? What can we do to maximize the good in this situation? As Gadwo (1996) suggests, decisions made within this space offer neither the moral certainty of expert opinion and paternalism, nor with that of the full particularity of the patient and the patient’s autonomy, but emerge from a jointly constructed ethical narrative that transcends the subjectivity of each viewpoint, the authority of which resides in the relationship itself. The challenge in this situation was to sort out which, if any, view of beneficence was most appropriate for Matthew, a complexity that could only be accomplished within a relational space that considered the values, beliefs, and goals of everyone. This situation strongly suggests the value of significant discourse that brings together those most involved in a complex situation and that is guided by questions that enable mutuality to occur.

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