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The legacy of "Joanna": The role of ethical debate in nurse preparation ☆

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SUMMARY

Introduction: The author was involved in nursing "Joanna", a neonate who was born in 1980 with a serious form of spina bifida. A scenario describing the Joanna case was introduced to two groups of students in order to enhance critical thinking skills and encourage ethical debate in the classroom. Critical thinking skills, which are essential in professional practice, include the honest appraisal of intellectual positions adopted by one's self and others, and caring about the dignity and worth of each person (Ennis 1996, cited in Robinson, 2011).

Methodology: The scenario was presented as a case study to two classes, one of which comprised undergraduate nursing students, the other, mature-aged retirees. The International Council of Nurses Code of Ethics (2006) was used to critically analyze the concepts of quality of life and empowerment. The qualitative raw data was collected from both groups and compared.

Discussion: Nurses are in a key position to identify potential ethical conflicts but need adequate supports in place in order to become empowered and advocate for patients. The differing attitudes towards Joanna and the care she received reflected the different quantities and types of life experiences available in the two class groups.

Conclusion: Nurse education programs now accept greater numbers of students from diverse backgrounds; therefore, educators need to plan for these differences in life experience when inducting students into professional practice. The outcome of introducing the scenario into the classroom demonstrates the imperative of seeking a wide variety of perspectives to develop ethical debate and preparation for professional practice.

Introduction

The author was involved in nursing "Joanna", a neonate who was born in 1980 with a serious form of spina bifida. Due to anticipated poor quality of life, Joanna was assigned what today would be regarded as poor palliative care, with very little nursing intervention to manage signs of discomfort.

This article draws upon the author's experience of presenting Joanna's story as a case study to two different classes at an Australian regional university campus.

The aim of introducing the case study was to enhance critical thinking skills in both groups of students. Popil (2011) defines critical thinking as "purposeful thinking where people systematically and habitually impose criteria and intellectual standards upon their thoughts" (p. 205). Ennis (1996 cited in Robinson, 2011), identifies three key critical thinking dispositions: "caring that one's beliefs are true and one's decisions justified, representing honestly the intellectual positions adopted by oneself and others, and caring about the dignity and worth of every person". Robinson (2011) argues that the third disposition is a facilitating disposition or a habit of mind that ensures that critical thinking is conducted well wherever it happens to take place. As such, considering the dignity and worth of all people by inviting students to consider case studies such as Joanna's can help facilitate good critical thinking skills in the classroom.

Critical thinking skills are essential if professionals are to provide safe and holistic care. Such care should be directed by the clients' needs and by the relevant professional standards (Alfaro-LeFevre, 2004; International Council of Nurses, 2006; D'Cruz, 2009). Popil (2011) and Billings and Halstead (2005) argue that scenario based teaching provides the opportunity for students to critique the management of the case in a safe and non-threatening environment. Scenarios articulate the relevance of theory to action and therefore assist students in achieving deeper, richer learning (Billings and Halstead, 2005).

Mezirow's theory (1995) identifying three types of reflection: content (thinking back to what happened before), process (examining likely causes of the problem) and premise (examining own values) was used as a theoretical backdrop to the classroom discussions. These types of reflection aim to investigate and extend upon concepts, beliefs, judgment and feelings that are shaped by experience (Kitchenham, 2008).

The Scenario of Joanna

Joanna was born at full term with a myelomeningocele (spina bifida) on her upper back and congenital hip dysplasia. Myelomeningocele which is the most serious form of spina bifida often implicates parts of

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the spinal cord and nerves causing problems with mobility, incontinence and possible developmental disability (Seattle Children's Hospital Research Foundation website, 2011). Examinations by the pediatric consultant revealed that Joanna had little sphincter control or control of her lower limbs. Joanna was at risk of developing meningitis as there was neural tissue exposed; she was at risk of genito-urinary problems and hydrocephalus. X-rays of her skull, spine and chest revealed an extensive vertebral defect. Although treatment of such conditions requires major surgery, this may not be judged appropriate where there is extreme neurological involvement or strong possibility of infection. The lesion was high up on Joanna's back near her neck, indicating that many nerves would be involved.

The consultant pediatrician believed that the Joanna's quality of life would be poor as patients with severe spina bifida are likely to experience incontinence, paralysis of their lower limbs and orthopedic problems. Children with spina bifida often face repeated surgery placing stress upon the family unit and its finances. The daily management of such a child is intensive, placing further strain upon the family. The children are often confined to a wheel chair and they and their families may suffer from social prejudice. The situation took place at a regional center where resources were difficult to obtain. Eventually, Joanna was discharged from the neonatal intensive care unit and her parents obtained the services of a specialist overseas.

Joanna's Legacy

In 2008 and 2009, the author introduced Joanna as a case study to two different instructional groups. There is extensive debate even today on how best to manage such cases. Access to palliative care for babies is still limited with few professionals qualified in this area (Beauchamp and Childress, 2001; Nuffield Council on Bioethics, 2006). Therefore, the scenario was considered suitable to introduce into the classroom.

Methodology

The two classes were devoted to exploring and critically analyzing the concepts of quality of life and empowerment. One instructional group comprised undergraduate nursing students, the other instructional group comprised mature-aged retired people who had previously been employed in a wide variety of backgrounds including nursing. This second group was a class conducted on behalf of the University of the Third Age. The University of the Third Age, which was first established in France in the 1970s, to meet the expressed educational needs of students over the age of fifty, now operates in many countries including the United Kingdom, New Zealand, Australia and the United States of America. At this particular regional center, the University of the Third Age utilized the principles of self-help and self-determination in accordance with the wishes of the participants, to engage in informal teaching strategies using volunteers (Formosa, 2005; University of the Third Age website, nd).

At this time, the author consulted with a university ethics advisor about using Joanna's case in the classroom, in conference proceedings and publications, and was advised to remove all identifying details. It was not possible to consult with Joanna or her family.

The undergraduate nursing students were studying a course entitled "Professional Issues in Nursing Two: Law, Ethics and Critical Analysis", a second year subject that the author taught into. Twenty students were enrolled in this on-campus class. One of the main aims of Professional Issues Two was to demonstrate the application of critical thinking to clinical and ethical decision-making (University of South Australia, 2006). The presentation of the Joanna scenario took place in the ethics module of the course. The aims and objectives of this particular module were to discuss utilitarian and deontological theories of ethics and how these are relevant to ethical decision-making (University of South Australia, 2006). The tutorial provided a "brain storming" session where the undergraduate students could critique situations. Group work utilizing lecture, pre-readings and case studies was used to encourage critical thinking. The students presented their findings to the rest of the class.

At the time that the author was teaching into Professional Issues in Nursing Two, she accepted an invitation from the University of the Third Age study group to present the scenario. The aims and objectives of the two curricula were similar in encouraging critical thinking. For this reason, the author believed that the learning experience was transferrable to other groups of students and would be beneficial to this particular instructional group. Introducing the scenario to this new group of students provided an opportunity to compare and contrast the responses of the nursing students with those of a set of educated lay people.

The University of the Third Age cohort consisted of twelve students who already had a good grounding in deontological and utilitarian ethical theory. The same brainstorming tutorial exercise that the nursing students had received was used, incorporating the International Council of Nurses Code of Ethics (2006). The qualitative raw data was collected from both brainstorming exercises and compared. Verbal consent was obtained to use the qualitative data obtained from both cohorts.

Discussion

The undergraduate nursing students expressed the opinion that the care that Joanna received was poor as she received no relief for any discomfort. However, they maintained that Joanna should have received palliative care to keep her comfortable rather than active treatment. The nursing students believed it was best to allow Joanna to die because her condition would have been unbearable to both herself and her parents. Their concerns were that Joanna would be developmentally disabled and unable to control elimination resulting in lack of dignity. The students' opinion may have been guided by some of the tutorial pre-readings. For instance Beauchamp and Childress (2001) suggest that it may be morally obligatory to refrain from actively treating cases similar to that of Joanna because of the anticipated poor prognosis. The nursing students were concerned about the day-to-day and financial burdens upon the parents, the scarce resources and the notion that society would not accept Joanna. The undergraduate students apparently were invoking something like a medical model of disability, which conceptualizes disability as a defect or disease of the individual, which is diagnosed through medical intervention (World Health Organization, 2002). However, they had demonstrated heightened awareness of some social problems associated with disability.

The nursing students maintained the imperative of advocating for patients. Advocacy involves speaking up for or acting on behalf of others. Malik (1997) considers the two key reasons for advocacy to be the patient's vulnerability as the result of their illness and their vulnerability due to exposure to processes within the health care system. Malik argues that there are multiple interpretations of the term 'advocacy' and it is far from clear how advocacy should be practiced. Clinical situations can be complex and there are often mismatches between the various perspectives of the patient, family and other professionals. Malik considers that advocacy has potential risks to the nurse because often, support systems are inadequate, with nurses feeling they would be going out alone. Other barriers to advocacy include nurses' perceptions of powerlessness, poor communication and lack of time to enter into discussions with the family, other health professionals and health care managers (Jameton, 1984; Malik, 1997; Schluter et al., 2008). Several nursing students were concerned about these barriers, arguing that there are limits on what can realistically be achieved.

Perhaps the most remarkable result of introducing the scenario to the two classes was the sharp contrast between the expressed opinions of the undergraduate students and those of the University of the Third Age students. The University of the Third Age students maintained that Joanna should have had active treatment right from the beginning. This opinion chimes with that expressed in the Nuffield Council on