



Complex care, Simple comforts

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Ethical Dilemmas in Home Care

Ethics is a hot topic these days. Whether it's in the business world, with corporate fiascos like Enron, or in the increasingly complex world of healthcare where new biomedical technologies such as cloning and stem-cell

research raise significant ethical debate. The burgeoning interest in ethics is evidenced by the number of web sites, books, journals, university courses, research/study centres, codes of ethics, and interest groups focused on the search for ethical principles that will help health care providers cope with the myriad of ethical dilemmas encountered in their work. In hospitals, Ethics Committees and the role of the ethicist have long been established. However, as the

focal point of health care delivery shifts to the community, interest in applied ethics is expanding to include the problems that arise in the delivery of care in the community. **Bioethicist, Elizabeth Peter at the University of Toronto, Faculty of Nursing** recently shared some of her perspectives on this growing field with VHA Home HealthCare*....



What is the definition of ethics? What makes an issue an "ethical issue" as opposed to a legal or professional issue?

Ethics can be thought of as doing what's right or good or "what one ought to do." A more recent discussion of ethics by Margaret Urban Walker has defined it as "practices of responsibility."

However you define it, an ethical issue is very difficult to separate from legal or professional

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issues. We hope that law will represent morality and/or require ethical action, but it doesn't always. Law is usually minimalist. If it represents morality, it is the minimum or floor, not the ideal of ethics. Again, hopefully, professional codes are ethical. We need to reflect on the responsibilities in professional codes to determine if the responsibilities make ethical sense at a practical level. It is the frontline workers who can tell us if the code is ethical when applied.

Why may "ethics" pose different conflicts in home care than in health care facilities?

Because a home is such a different place. In an institution, it is the professionals' turf and they set the rules. The home is the clients' turf; they have control. The professional is the outsider or the guest. And the professional is on his/her own.

Issues of privacy and professional boundaries are the most distinct in the two settings. People have an expectation of privacy in their own homes. It is where we have private communication of all kinds, not intended for professional providers to hear or use.

Professionals and in-home support providers can feel more pressed to overstep their scope of practice/assignment when in the

community because they see the broad scope of needs presented by the client and family in the home. In community nursing and personal support, we must consider whether overstepping one's scope of practice/assignment is the ethical problem, or whether the ethical problem stems from the rules that draw the practice/assignment so narrowly.

Questions of lack of funding are an ethical problem in all of health care, but it is very pronounced in the community sector.

How do culture and ethics mix?

They are inextricably intertwined and, in ethics, we have a long way to go in developing a more culturally sensitive way of looking at ethical decisions. If you look at some of the major principles of bioethics, like individual autonomy and decision-making, they come from a very western view of the world and don't fit with many other cultures, especially some eastern cultures.

For example, in western culture, we believe the individual receiving care should have the informed decision-making authority. In another culture, it may be an honoured elder who is the accepted decision-maker for the family and the patient. As well, there are many specific kinds of care where cultures have very different ethical

norms, such as infant care or end of life care.

In Toronto, this clash of western principles of ethics and the values of other cultures is accentuated because of our diversity. We need to talk to people who deliver and receive care to define where these culture clashes occur.



Can you describe some of the common ethical decisions/issues in home care?

Privacy and professional boundary issues are constant, as I've said.

Another common ethical decision is whether and when to transfer responsibility from professionals to the family for care of a family member; i.e., can the family manage it; will the care be good enough; will the family caregivers be harmed by having the responsibility for care (caregivers' health is often harmed by the heavy physical and emotional load and the stress of caring for a loved one); will

family relationships be harmed?

Issues of decision-making respecting care and consent occur as well. Family members' interests sometimes conflict with a client's interests. For example, a client may refuse pain medication or a treatment that the family members desire for the client.

How do we resolve these ethical issues in homecare?

Very interesting work is being done on frameworks for ethical decision-making in homecare. In the Toronto area, the Toronto Community Care Access Centre and the Community Health Centres of Toronto took the lead by forming the Committee To Advance Ethical Decision-Making in Community Health. Among other things, that Committee consulted with experts and health care providers (*VHA Home HealthCare was active in this process*), and is piloting a draft Code of Ethics and Ethical Decision-Making Framework. (See box above.)

Frameworks are helpful in guiding our thinking on ethical issues and in helping us to see the complexities of the issue. The ideal outcome is when the framework can help us find practical ways to avoid the problem or work around the conflict/decision. But at the end of the day, hard decisions need to be made. We never know if it is the "best" decision. Maybe we just know that our decision has done the least harm.

Ethical Decision Making

Remember these key steps when you have an ethical dilemma.

I - D - E - A

Information gathering and Describe situation

- a) Gather information/facts on the case
- b) Describe the different emotions
- c) Identify ethical issues

Explore options and analyze

- d) Explore options and consider their strengths and weaknesses

Act on your decision and evaluate

- e) Develop an action plan
- f) Evaluate the plan
- g) Self-evaluate your decision

Remember:

Document the actual plan in the chart.
Seek help if necessary and consult with the person you report to.

For more information on this draft framework and the piloting of this framework, contact Jennifer Faraone, Project Coordinator at Toronto Community Care Access Centre.

What are the special challenges, if any, in applying these types of decision-making frameworks to ethical issues in home care?

There are many. Simply drawing a team together to look at a problem is difficult when staff are not physically together. The resources available are not yet as sophisticated in homecare. For instance, home care agencies cannot support a bioethicist on staff as hospitals can. Isolation is a problem, because there is no one to observe the client other than the individual provider/nurse, therefore, ethical issues can be missed altogether. Finally, working conditions such as lack of time for each visit,

isolation, low pay and so on can interfere with the ability to apply frameworks to everyday ethical issues.

*Responses condensed

For further reading and resources in ethics, see Dr. Peter's reference list on VHA's website, www.vha.ca

IF YOU

have any comments or suggestions regarding our newsletter, please feel free to contact the editor of

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Joy Klopp

at (416) 482-8782 or 1-888-314-6622
or visit our web site at www.vha.ca

What we ought to do... an ethical approach to a real problem

Nurse N was caring for a young child who had multiple, chronic health problems, including a very compromised chest. The parents of this child also had a new baby with no health issues. N assessed the older child and believed that deep suctioning of the airways was necessary. The parents were using less effective but gentler methods of clearing the child's breathing. The parents objected to the deep suctioning. N was concerned that the parents may have been emotionally withdrawing from their ill child and making inappropriate health decisions as a result, risking the child's long term well-being.

Here are Dr. Peter's comments, organized with reference to the I-D-E-A framework in the box on the previous page:

Information Gathering and Describe Situation

- (a) The first question I would ask is whether the parents' objection to deep suctioning is new? Did they feel differently about deep suctioning before the birth of their second child? How effective is the gentler suctioning? In addition, I would want to know the specific behaviours of the parents that warrant the nurse's concern. The background information we need is: the medical history of the child/patient; prognosis; doctor's orders; N's assessment and progress notes.
- (b) I would want to have a discussion with the parents about their hopes for their son. Depending on the pain the child is experiencing and the prognosis, it can be reasonable even to hope for death as a relief from suffering. The parents may feel the nurse is torturing their child with the deep suctioning, and



that it's not necessary. I would also want to explore the nurse's emotions? Is she concerned that her nursing will not meet the profession's code of practice if she does not follow her judgment as to suctioning? How was her relationship with the parents in the past?

- (c) The ethical issue is whether this is a legitimate refusal of care in the best interests of the child or the neglect of this child? Unless it is an end of life situation, the child is entitled to the best possible life-giving care.

Explore Options and Analyze

- (d) There may be an option to avoid this conflict by having a doctor see the child, reviewing both the nurse's assessment and the parent's objection. An open discussion of the issue with these parties may resolve the matter. Other family members may be able to help in talking with the parents and assisting them in caring for their child.

Depending on the child's prognosis, for instance, if this is an end of life situation, there may need to be a discussion about withdrawing treatment. Is gentler suctioning the way we want to do it? Is there another way that would make the child comfortable and pain-free?

Act on Your Decision and Evaluate

- (e) Once all of the information is gathered and if the conflict cannot be avoided, the assistance of a team review or the feedback of an ethicist would be useful to developing an action plan.

VHA salutes two Award Winners

Amelia, daughter of VHA employee Dora Quintanilla, wins a university scholarship!

The Union representing Dora at VHA, Service Employees International Union, Local 204 presents two children of union members with university scholarships each year. Amelia was chosen from among many applicants by an academic committee at McMasters who selects the winners for the Union.



Dora found herself knocking on doors in her new Toronto neighborhood asking for work. "VHA answered the door, gave me a chance and trained me as a PSW," says Dora, "I like the work because I help people who are suffering." Dora couldn't be prouder of her daughter.

Her apartment walls are festooned with Amelia's awards and certificates.

Amelia also describes her rough start. "I was 7 years old, knew no English, and walked into a classroom full of kids I couldn't understand." Between ESL and school, she picked up English and even excelled in French by the end of grade school. In high school, besides working part-time, she was VP of her student council for

three years, played basketball, rugby and ran cross country at various points, did theatre for three years, and in her last year, tutored students in English and math. She graduated first in her class and was valedictorian. Her graduation speech was about following your goals and dreams while always being proud of your roots.

With the help of the Union's scholarship, as well as other scholarships, Amelia is attending Queen's University in the General Arts program.

Congratulations to Amelia, and proud mother, Dora, from all of us at VHA!



Katharine (Kay) Masters, a former President of VHA's Board of Directors, has won the 2003 Caring Canadians award in recognition of her lifetime of volunteer work. She also won Toronto's Volunteer of the Year award in 2002.

So who is Kay? She is a frank-speaking, irreverent 91-year-old powerhouse who raised four children while actively volunteering in her community. As she says, "I've been bumbling about for thousands of years. I never had the sense to say "no" to anything."

Kay was in the second graduating class of U of T's physiotherapy department in 1932. While she worked in local hospitals as a PT, she became very active in establishing and growing the Canadian Physiotherapists Association. On a volunteer basis, she organized a branch of the Association that placed

physiotherapists with the military (RC Army Medical Corp., the Navy and Air Force) during WWII. After the war, Kay placed PTs into DVA hospitals all across the country.

"I got sidetracked into a volunteer career and never went back to being a PT."

Kay spent the next years volunteering in her children's schools, her church ("I didn't get all holy about it. I just did what needed to be done."), and the Garden Club.

In the late 1950's, Kay joined VHA's Board of Directors. She helped tremendously with the move to 170 Merton, and then was persuaded by the Executive Director to come on staff (though Kay was then past retirement age) to set up a new program and work in human resources.



While with VHA, Kay began volunteering at the ROM. She worked in the labs, sorting and labeling. Then she began docent work, which she loved, specializing in Canadiana and European furniture and natural history. She ultimately became

Chair of the Volunteers and served on the Board of Trustees, all the while continuing with her docent work. Kay has volunteered at the ROM for over 30 years now and the museum recently granted her Docent Emeritus status.

Kay received her award from the Lieutenant Governor in a ceremony on October 27th. Congratulations, Kay, from all of us at VHA!

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COMING SOON...

VHA Home HealthCare's Updated Website

Check out @ www.vha.ca in December.

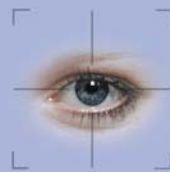
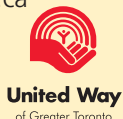


For more information, please call us at

(416) 489-2500

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Eye On QUALITY

Blackout Response or What a Learning Opportunity!

No power. No computers. No sophisticated scheduling system. Few phones. Scared, confused clients. That was the August blackout. VHA is proud to have continued service to all of our high risk clients and over 85% of our total clientele during this period.

How can we do even better in the next emergency?

That's the question VHA and many other providers are asking. VHA management held a productive debriefing meeting to identify what went well, and what didn't, during the blackout. To further explore possible enhancements and modifications to our systems, policies and procedures, two workgroups were established; one focused on information management/communication issues in emergency situations, and the other focused on technological issues. It is expected the work groups will make recommendations in the near future that will lead to improvements in VHA's emergency preparedness and response plans.

Other Quality News:

- Three pilot projects were recently conducted and are being evaluated. The projects are: a centralized intake system for CCAC referrals; a new staffing model for the Durham Region team that was implemented to better meet the reporting expectations of the CCAC; and a new on-line incident report form for internal reporting.
- A comprehensive employee survey was conducted over the summer with the assistance of NRC+Picker Group (formerly Smaller World Communications). Results will help to identify ways to make VHA an even better place to work.
- Gloria Kay, Quality Improvement Associate at VHA, recently presented a paper at the "Making Gains: Research, Recovery and Renewal in Mental Health and Addictions Conference", about an evaluation research study of a psychoeducational family support program adopting evidence-based practice.

Interested in sharing your personal experiences of the blackout on the web while contributing to research? Go to Blackout History Project at <http://blackout.gmu.edu/>. It is a site developed at George Mason University in the U.S. that has expanded its mandate to include Ontario's recent blackout.