



## COMMUNITY ETHICS NETWORK

### 2009 Fall Conference Report

On November 17, 2009, the Community Ethics Network (CEN) held its annual Fall Conference at the Vaughn Estates of Sunnybrook. The conference brought together management and leadership staff from community health care and support service organizations from across the Greater Toronto Area to discuss ethical issues in pandemic planning and response.

In the morning, there were approximately 40 participants from 35 member organizations and other community health care organizations interested in ethics. Claire Bryden, Executive Director of Bellwoods Centres for Community Living welcomed the conference participants and briefly spoke about the value of being part of the CEN. Following her opening remarks, the co-chairs of the CEN Steering Committee, Frank Wagner and Caroline Hunter, provided an overview of the accomplishments and activities of the Network for 2009, including the town hall meeting, the independent website, and presentations and posters at a number of national conferences.

The remainder of the morning session focused on priority setting and pandemic plan implementation for the H1N1 virus. The workshop facilitator for this year's conference was Karen Faith, a member of the University of Toronto Joint Centre for Bioethics and a former Director of Ethics Services at Sunnybrook Health Sciences Centre. She discussed the relevance ethics to addressing infectious diseases and the difficulty of priority setting during a pandemic. Past crises such as SARS and Hurricane Katrina were raised as sources of valuable lessons. The SARS outbreak highlighted the ethical challenges and considerations raised in such an infectious disease emergency, including how to address the disproportionate burden on ICU staff, how to place and enforce restrictions, and the importance of being aware of what values are most salient during these critical times. Hurricane Katrina was used as an example of how easily a system can break down when priority setting is unclear and there are conflicting models of triage being simultaneously employed by different caregivers. Faith also emphasized the moral dilemmas surrounding the duty to care as a health care professional, and identified the core guiding values which should inform the ethical decision-making process.

Following Faith's discussion on priority setting and pandemic plan implementation, the conference participants were asked to read three different scenarios which focused on various ethical dilemmas raised by a pandemic. Working in small groups, participants chose one scenario to examine, and discussed how decisions ought to be made and who ought to make decisions, the values underlying these decisions, how these decisions should be implemented, and the options that should be considered. Each group then briefly presented their responses. While scenarios differed, there were a number of recurring themes. Respecting the dignity of the client was raised as an important value, and balancing the duty to care and respect for a client's dignity with the allocation of scarce resources was mentioned as one ethical challenge facing workers. Transparency, trust, and honesty were consistently cited as important values in both the decision making process and the execution of these decisions. Many groups expressed the need

for these issues to be discussed upstream before critical decisions need to be made downstream. The question of how much risk is ethically defensible was also raised as something which needs to be clarified, and there was a call for risk assessment tools and a mechanism for conflict resolution, such as a decision review process.

The afternoon session was attended by 110 participants. The majority of which were personal support workers (PSWs). Karen Faith led a discussion, defining moral uncertainty, moral dilemma, moral distress, and moral residue, as well as emphasizing the need for health care workers to learn to use these constructs as a means for expressing what they are experiencing. She gave an overview of the potential outcomes of moral distress, including compassion fatigue, interprofessional conflict, and exit from the profession, as well as contributing factors, including the institutional culture, hierarchical structures, political/economic climate, social and cultural diversity, and technical advances. She then introduced some narratives which presented moral distress from the different perspectives of a nurse, a social worker, and a clinical ethicist. Though Faith focused primarily on how to deal with moral distress, including the strategy of debriefing, she also acknowledged that moral distress may be beneficial in terms of initiating a process of learning and healing, and bringing a greater appreciation for the burden placed on workers.

Participants were asked to form small groups and try to reach consensus on the top 3-5 ethical challenges in their daily practice that leads to moral distress. After each group had discussed and presented the top ethical challenges in their practice, one main issue seemed to emerge. The issue of **setting boundaries and limits**, or, more generally, of **defining the obligations to care**, was the most common source of moral distress expressed by the conference participants. Several examples were given of this issue in practice, the most common of which involved **staff being asked to perform duties that are not on the care plan and not directly for the client**, such as doing an entire family's laundry (rather than simply that belonging to the client). Other sources of moral distress which were raised included **abuse** and sexually inappropriate behaviour from the client (often linked with dementia), **lack of resources** and **workload, conflicting expectations** between client, family and/or organization, and the "***emboldened autonomy***" of clients.

The central issue of defining obligations of care was then illustrated in a role playing exercise presented by VHA Home HealthCare players. A scenario was depicted in which a home healthcare worker was attempting to define the limits of her care to an elderly dementia patient and her often unavailable son. The role playing exercise brought to light some of the communication difficulties involved in setting boundaries with a client, and showcased how such a situation could easily become morally distressing to a home healthcare worker.

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## **Top 5 Ethical Challenges Leading to Moral Distress in Home Care**

1. Professional boundaries – setting limits and defining obligations to care
2. Abuse – suspecting a client is being abused and/or being verbally abused or exposed to inappropriate behaviour by clients
3. Resource allocation and workload – working with a lack of resources and being asked to do more with less
4. Conflicting expectations – client, family and/or organization have conflicting expectations of what the staff member ought to be doing.
5. Emboldened autonomy of the client – client autonomy trumps all.

## Evaluation Results

Seventy-nine participants completed evaluation forms. Overall, 65% of participants thought that the session was 'excellent'; 34% thought it was 'good' and only 1% thought it was 'fair'. The conference 'far exceeded expectations' for 13% of respondents, was 'above expectations' for 49%, and met the expectations of 33%. Only 4% of respondents indicated that it was 'below expectations' and 1% indicated that it was 'well below expectations.' One participant indicated that the venue was "*really nice*" and the "*food was great*".

The majority of respondents thought that the session was well organized; with 61 % indicating that the organization was 'excellent' and 35% indicating that it was 'good'. Of respondents, 63% thought that the session provided 'excellent' education value, 30% thought it was 'good', and 6% thought it was 'fair'. Respondents also felt that the session was relevant to their work. Sixty-three percent indicated that the level of relevance was 'excellent' and 35% thought it was good. Finally, 73% of respondents thought that the presenter's knowledge of the subject was excellent and 23% thought it was good.

Participants thought the conference was valuable and provided "*a lot of information*" that they can use in the future. One participant noted that it was excellent and the session "*really opened my eyes*". In particular, participants found the morning session case studies to be the most valuable and "*very interesting*". One participant, however, thought that while the case studies were "*good to drive the themes home*", too much time was devoted to them. Another thought that the ethical framework presented in the morning was "*very difficult to understand.*" Nevertheless, participants thought that the case scenarios, along with the "*in depth discussion*" and Karen's presentation on ethics and pandemic implementation were "*insightful*", "*well presented*" and timely. Some participants thought that Karen's presentation was excellent and "*the way she presents the subject is very sympathetic to our current reality*". They appreciated her knowledge, experience and comments "*when she spoke to each slide*".

The majority of participants found the afternoon session presentation on moral distress to be the most valuable information they received. They especially valued the "*acknowledgement that moral distress is normal and not reflective of one's ability to do the job*" and "*the process of incorporating ethical debriefing in our practice to discuss and alleviate moral distress*". They also appreciated the table and group discussion on the top 3 issues leading to moral distress. One manager thought that "*staff feedback on what they consider the most significant moral distress they face*" to be of particular value. Finally, participants thought that "*the speaker made the content relevant to community ethical issues encountered daily.*" Participants also "*loved the role playing*", citing that it was a "*valuable way to educate*" and a "*great vehicle to illustrate the themes discussed*". They enjoyed "*actually seeing an example of what happens in a client – worker situation*".

Some participants also thought that it was great to hear different opinions and the different perspectives "*from a variety of people in various workplaces*" and that "*all needs are the same, it doesn't matter which organization you belong to.*" They cited that it was valuable to learn the process of how to address common ethical issues and stress in the workplace. Participants thought that the discussion around needs and expectations in community, staff safety versus client needs, verbal abuse, and boundaries and limitations were very useful and wanted "*more*

*opportunities for open discussion.*” Finally, one participant thanked this conference for “*dealing with the community*” since “*home care normally gets lumped in with hospitals*”.

Participants found the research results presented by Karen Faith to be the least valuable information of the conference. Specifically, participants cited that there was too much research and most was “*not community based... Time would have been better spent talking about what moral distress participants were facing and what could be done to alleviate it.*” They also cited that “*it was too long*” and they thought it “*was just going on and on.*” Some noted that it could have been “*broken up more*” – that “*in the middle she could have addressed some humour and walk[ed] around instead of standing in place.*” While most participants thought the moral distress presentation was interesting, some thought this was the least valuable part of the session. They thought the “*more detailed practical value of the session should [have been] emphasized*” – that it would have been useful to have a discussion around how to practically apply the information to their jobs. Finally, participants thought there should have been more discussion and it should have been “*more PSW friendly*”.

For future education sessions, participants suggested including different voices in future sessions. For example, one participant wanted an ethics workshop offered to front-line staff in Long-Term Care Homes. Another participant wanted clients and families to be able access this information – so they know how to treat workers and what to expect. One participant thought that the client perspective should be included – to understand their behaviour in certain scenarios. Many participants suggested bringing the ethical framework to the executive leadership teams – to educate “*senior managers/ corporate leaders on the need for an ethical framework and culture*”. They also suggested a presentation on the “*ethical considerations for leadership in ensuring quality of services while supporting staff on the verge of burnout*” and helping leadership work through these issues.

Many participants wanted more role playing and interactive exercises. One participant suggested using role playing for the morning leadership session as well. They also suggested more case studies, particularly examples that are specific to PSWs. Some specific examples suggested by participants are how to deal with difficult clients, power differentials in the client’s home, staff expectations, how to deal with challenging families, how to deal with abusive clients, and how to enhance client and worker relationships.

Other suggestions for future sessions included sharing policies regarding staff abuse, including expectations and support for staff; expanding on specific ethical principles; train the trainer model; and how to develop ethical plans dealing with duty to care and disclosure of risks to clients. One participant wondered if through the website, the CEN would be able to provide “*sample short inserts for smaller agencies to include in their company newsletters*”. Finally, participants noted that they wanted more of the same, that the session is “*educational and includes front-line workers in ethical discussions*”.

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