



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

CHPCA Volunteer Issues Interest Group Meeting

Palais des Congrès, Québec City, Québec

Sunday, June 15, 2003

1. Welcome and Introductions

- Jerry Rothstein, Chair of the CHPCA Volunteer Issues Special Interest Group, welcomed everyone to the meeting and gave a brief overview of the Special Interest Group and its purpose.
- Edith Tribe, Chair of the CHPCA Volunteer Issues Committee (VIC) welcomed everyone on behalf of the Volunteer Issues Committee.
- The meeting agenda was discussed and approved.

2. Regional Check-in and Discussion Groups

The meeting divided into regional discussion groups. The regions were: Western Canada, Ontario, Québec, and Atlantic Canada. Due to the large number of participants, the Québec group divided into two sub-groups. To assist with discussion, the VIC provided the groups with three questions to consider:

1. As a volunteer, what is happening in hospice palliative care that you feel really good about? What are the main issues and challenges you experience?
2. How does your provincial association and the national association relate to your situation?
3. Are there any volunteer programs or initiatives operating in your communities that are working really well? What makes them so good? Do you think this program or initiative could work in other parts of Canada?

3. Break

4. Regional Check-in and Discussion Groups – Report Back

Ontario

1. Ontario has experienced a growth in volunteerism in hospice palliative care
2. Noted a need to have access to the same information as paid staff
3. Staff turnover is a consistent problem – both with volunteers and paid staff
4. The Hospice Association of Ontario has volunteer resources available
5. A need for bereavement training
6. The group spoke about day-programs in existence in the province and those that are working to start this type of service
7. Shared about a resource manual being used in Renfrew, Ontario that brings the interdisciplinary groups together for shared learning

Atlantic Canada

1. Discussed the home support workers training program
2. Noted that in Nova Scotia, palliative care physicians are good at accepting volunteers as a part of the interdisciplinary team
3. Discussed the importance of the recently published Model to Guide Hospice Palliative Care
4. A major challenge is the lack of consistent programs across the Atlantic provinces
5. Some groups lack medical staff trained in hospice palliative care

Atlantic Canada - continued

6. Discussed the “turf” issues that can get in the way of caring for patients and their families
7. Community programs – some communities have them and some don’t
8. Noted a lack of standardized training across provinces
9. Bereavement services are working well in some provinces
10. Noted a “therapeutic care clown” program – an innovative program that is working well

Québec - Group 1

1. Discussed issues around what motivates volunteers to stay in hospice palliative care
2. Stressed that proper training gives assurance to the volunteer
3. Noted that it is a privilege to be a volunteer
4. Discussed discretion and confidentiality issues
5. Noted a new phrase used to describe volunteers – “Natural Love Givers”
6. Recognized the need for basic training and structure
7. Funding challenges – time spent on fundraising takes time away from work with patients
8. AQSP bulletin – a network to contribute to the basic training that is uniform across Québec
9. Selection criteria to choose volunteers would be helpful
10. Members of this group indicated that they all had teams that worked well – but feel that volunteers need more time to meet as a group and share experiences. However, meetings require funding ... when we have the funds we do get a good turnout at meetings. Much of the time volunteers are expected to pay their own way, and meetings are usually very expensive.

Québec - Group 2

1. Satisfaction comes from helping people, patients and their families
2. Volunteers tend to be good listeners
3. Volunteers like to assist and reduce suffering
4. Noted that volunteers need to be accepted by the family and the patient
5. A continuing challenge – getting used to death, and how to deal with death
6. Another challenge is to remember that the patient is human... sometimes all we see is the disease.
7. Volunteers need to establish a good relationship with spiritual counselors
8. Volunteers need to have a good relationship with the spouse of the dying person
9. The group realized that many of us don’t have a relationship with the AQSP or the CHPCA. We need to learn more and build a relationship.
10. Noted the importance of social gatherings to share and relate with each other. In doing this we gain a team spirit.
11. Distances are a problem and a challenge. Moving around can become quite expensive.
12. Need to find tools to assist volunteers that address each volunteer where they are.

Western Canada

1. Volunteer needs to know they make a difference as part of the team
2. Volunteers often feel a sense of distance from the provincial and national associations
3. Some volunteers are very busy so perhaps feel that they don’t have time for provincial or national associations, or don’t want to have a relationship with them
4. Some felt that the communication from the provincial and national associations is too cumbersome. They feel that communication could be more effective in small “bytes”.
5. Coordinators need to be encouraged to pass information on to their volunteers

General Discussion

The group spent a few minutes discussion issues related to confidentiality.

- Volunteers are sometimes not included when information is deemed confidential by the hospital.
- Some information is crucial for volunteers to know in order to give care.

- Volunteers need to know information such as name, religion, can they eat, can they drink water, do they have a hearing impairment, and are there any pain pressure points they need to be aware of?
- A communication sheet to share this information is critical
- What about diagnosis? Does a volunteer need to know this? Many patients share this information with the volunteer but this may not be relevant. It was generally felt that no information relevant to care should be held back. If this occurs, then the volunteer is not a full member of the care team and appropriate care cannot be given.
- Knowing the “lived history” of the patient ensures that the person is treated as a person until they die.
- It was suggested that the provincial and national associations could work together to create a standardized sheet or format that can be used across Canada
- It is important to remember that some volunteers feel that too much information impedes them from providing the care ... they can become judgmental without realizing it.

The Group spent a few minutes discussing local disaster plans

- A question was asked concerning provincial/local disaster plans with regards to community trauma, grief trauma
- It was reported that some hospitals do have volunteers that are a part of the emergency response team
- In the Calgary region a disaster plan is in place whereby volunteers are called when necessary

6. Presentation: Task Group of the Best Practices and Quality Care Working Group (Canadian Strategy on Palliative and End-of-Life Care)

- Jerry Rothstein gave a brief overview of the history and development of the CHPCA Volunteer Issues Committee and its recommendation to develop national volunteer standards.
- In 2001 the Federal Government created the Secretariat on Palliative and End-of-Life Care. Part of its mandate is to create a Canadian Strategy on Palliative and End-of-Life Care.
- To create this process the Secretariat created 5 Working Groups to address the different issues, and a Coordinating Committee to oversee the process.
- One of the Working Groups is the Best Practices and Quality Care Working Group. This Group has reviewed and endorsed *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. Part of its mandate includes the Volunteer Component. The Working Group agreed that it would be good to use the Model to create norms for the volunteer component in hospice palliative care.
- The Working Group asked Jerry Rothstein to bring together a group of people to begin to look at this topic.
- The result has been the creation of a Task Group charged with creating a framework for the creation of national volunteer norms.
- The task group has met a number of times and they are pleased to report that a framework has been established
- In the discussions today you have said you need: validation; where volunteers “fit”; standardized education and continuing education; support; and organizational development. This framework will address these issues.
- The Task Group is using the CHPCA Model and a document from the Canadian Council on Health Services Accreditation to assist with the development of volunteer norms.
- The group received a preliminary document describing the work that is underway.
- Jerry asked that people take the information sheets that were handed out and take some time to read them over and make comments where appropriate. Comments can be set to Jerry Rothstein at Jerry.Rothstein@caphealth.org

- The research community is also beginning to focus more on the volunteer component. Recently the Institute of Palliative Care at Ottawa University was awarded a five-year research grant that includes volunteer issues as part of the grant.
 - The group was reminded that there are many posters and presentations taking place during the Conference. Everyone was encouraged to support these presentations.
7. A special presentation was made to Jerry Rothstein in recognition of his efforts to move the volunteer component forward.
 8. Edith Tribe and Jerry Rothstein thanked everyone for attending the meeting and wished everyone a great conference!
 9. The meeting adjourned.