BC HOSPICE PALLIATIVE CARE ASSOCIATION

HOSPICE PALLIATIVE CARE SERVICES SURVEY

2013

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BCHPCA

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Vancouver, BC V6P 6G5

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BC HOSPICE PALLIATIVE CARE ASSOCIATION

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and all who responded to the survey

Final Report on the Results of the Survey

Introduction

The BC Hospice and Palliative Care Association (BCHPCA) conducted a survey in August and September of 2013 to provide data that could assist the organization and its members in documenting the benefits of providing hospice and palliative care and related services. The specific goals of this survey were:

- To begin the process of regularly collecting information about the breadth of hospice and palliative care services available in BC;
- To collect data that will help to describe the impact of BC's hospice and palliative care services; and
- To provide data to BCHPCA members for local advocacy initiatives and for BCHPCA to use for provincial advocacy.

This report summarizes the main findings of the survey and suggests directions for further efforts towards these goals.

Method

An on-line questionnaire was designed in consultation with a committee that included BCHPCA Board and staff members, the project director, a summer student and Dr. Barb Pesut of UBC Okanagan. The questionnaire was pilot tested by the 10 BCHPCA member organizations that make up the Vancouver Island Federation of Hospices (VIFoH). VIFoH members have been collecting similar data for over 10 years. Results were analyzed and several modifications were made. The final set of survey questions is included in the Appendix of this report.

A roster of organizations to be surveyed was compiled with the assistance of Dr. Pesut and her research team. This set of 68 organizations included 58 BCHPCA program members and 10 non-members. Contacts within each organization were identified, and an introductory letter was sent by the BCHPCA's Executive Director.

Follow-up contacts were made with organizations that had not responded by early September. The data collection phase was closed at the end of September.

Findings

Description of the Respondent Organizations

The number of respondents who provided useable data was 49. The response rate was 72%. The distribution of respondents operating within the five BC Health Authorities is

as follows: Fraser, 8; Interior, 18; Northern, 9; Vancouver Coastal, 3; and Vancouver Island, 10. One respondent was from the Yukon. Some organizations did not provide useable data for every question. The number of organizations with adequate data for a particular analysis is provided in each section of this report.

Note that throughout this report, responses are grouped and labelled by Health Authority. This is done to highlight regional similarities and differences in responses and does not imply that respondents are operating units of Health Authorities.

The organizations provided estimates of the population of their service areas (Question 4). The distribution of these service area populations is shown in the following table.

Count

		Health Authority						
		Fraser	Interior	Northern	Van Coastal	Van Island	Yukon	Total
Service Area Population	under 5000		2	1				3
	5000 - 9999	1	2	2		1		6
	10000 to 19999		4	2		1		7
	20000 to 49999		6	2	1	2	1	12
	50000 to 74999					3		3
	75000 plus	7	3	2	2	3		17
Total		8	17	9	3	10	1	48

Only three organizations serve communities of 5000 people or fewer while the majority (67%) serve communities of 20,000 people or more.

Organizations categorized themselves using one or more descriptive phrases provided in Question 5. The distribution of responses by respondents in each Health Authority is provided in the following table. Note that the sum of the counts in the table is larger than 49 because some organizations used more than one descriptor.

	Health Authority						
ORG TYPE (Q5)	**Fraser**	**Interior**	**Northern**	**VCH**	**VIHA**	**Yukon**	
Free-standing hospice with acute beds	0	1	0	0	0	0	1
Free-standing hospice with residential beds	1	1	1	0	0	0	3
Free-standing hospice on hospital campus	0	1	0	0	0	0	1
Hospital-based acute palliative care unit	1	4	0	0	1	0	6
Shared services model with dedicated beds in LTC facility	0	2	2	1	1	0	6
Hospice society without beds providing P support	4	11	4	1	7	1	28
Hospice society with beds affiliated with acute hospital	3	3	1	0	3	0	10
Other	1	5	2	1	4	0	13
	8	18	9	3	10	1	49

More than half (57%) of the organizations describe themselves as *Hospice society without beds providing psycho-social support*. The second most common type of

organization is *Hospice society with beds affiliated with acute hospital* (20%). There are no significant relationships between type of organization and either service area population or Health Authority. In other words there are no discernable differences among the Health Authorities with respect to the types of organizations located therein.

A large majority (90%) of the organizations reported **having paid staff** (Question 9), and all but one organization reported **using volunteers** (Question 18). Only 12% are **affiliated with a teaching institution** (Question 11): two in Interior HA, one in Northern HA and three in Vancouver Island HA.

Overall, almost two-thirds (63%) of respondents reported that they **serve children and youth** (Question 15). The proportion of organizations that provide child and youth services differed considerably across Health Authorities, however. In Fraser Health Authority and Yukon all respondents provide such services. The other Health Authorities' proportions are as follows: Interior, 44%; Northern, 67%; Vancouver Coastal, 33%; and Vancouver Island, 70%.

Operating Expenses and Revenue Sources in 2012

Forty-two of the organizations provided their total operating expenses for 2012 (Question 6). These expenses ranged from $700 to $7.2 million. The median value was $87,835, i.e., half the organizations reported a total above this amount, and half reported a lower total. The 25th and 75th centiles of the expenses distribution were $32,471 and $408,525, respectively.

The respondents' values for total operating expenses differ substantially by Health Authority. These Health Authority median values are: Fraser, $455,100; Interior, $51,035; Northern, $34,500; Vancouver Coastal, $75,000; and Vancouver, Island, $254,400.

The total expenses reported by each organization are shown on the *Op Exp Rev* sheet in the accompanying Excel file (Details.xls). **Note that in this file organization names have been replaced by identification codes to preserve confidentiality of the data.**

Organizations were asked in Questions 7 and 8 of the survey to attribute their 2012 revenue to different sources: Health Authority funding (HA); Government grants such as Gaming grants (GG); Non-government grants (NG); Fundraising events (FE); Other fundraising (OF); Earned revenue from businesses or service contracts (ER); and Other (O). The responses to these questions were somewhat more sparse and difficult to analyze than the data on total operating expenses, and results should be interpreted with caution. The following table shows the minimum, maximum, 25th, 50th, and 75th centiles for reported **amounts** in each category.

	Revenue Source*						
	HA	GG	NG	FE	OF	ER	O
Number responding	31	31	29	30	30	31	31
Minimum	0	0	0	0	0	0	0
Maximum	$3.8mil	$119,201	$50,000	$2.8mil	$237,000	$780,000	$285,000
25th centile	$4000	0	0	$1659	0	0	0
Median	$157,000	$6000	$1000	$10,165	$4328	0	$5500
75th centile	$48,117	$80,000	$8500	$64,413	$21,750	$5000	$34,739

* See text for codes.

The following table shows the distribution of **proportions** of funding from each category computed using the organizations that provided the required data.

	Revenue Source*						
	HA	GG	NG	FE	OF	ER	O
Number responding	31	31	29	30	30	31	31
Minimum	0%	0%	0%	0%	0%	0%	0%
Maximum	99%	67%	71%	100%	70%	30%	57%
25th centile	3%	0%	0%	8%	0%	0%	0%
Median	11%	2%	3%	18%	3%	0%	4%
75th centile	53%	23%	7%	39%	18%	4%	10%

* See text for codes.

These percentages show that the organizations are very diverse in terms of their major sources of operating revenue. For five revenue sources—all but Health Authority funding and Fundraising Events—at least 25% of the data-providing organizations did not obtain any revenue. Some organizations received all of their revenue from Health Authorities while others depended entirely on Fundraising Events. These two sources appear to be the most important overall.

No organization received more than 67% of its revenue from Government Grants, while half the organizations received 2% or less of their revenue from such grants.

The revenue source diversity can be seen in more detail by examining the table of percentages at the right side of the *Op Exp Rev* sheet in the Excel file.

Types of Services Provided by Organizations

Organizations were asked to state the types of services they provide (Question 14). The following table summarizes regional counts of organizations providing each type of

service. Note that the total across cells is larger than 49 because organizations provide more than one type of service. The percentages in the rightmost column reflect the proportion of the 49 organizations providing each listed service.

Services Offered by Organizations	Health Authority							
	Fraser	Interior	Northern	VCH	VIHA	Yukon	Total	%
Disease /symptom management	1	3	2	0	3	0	9	18
Palliative 1:1 Support	8	12	6	1	10	1	38	78
Home-based palliative care	1	10	3	1	7	0	22	45
Physical support	1	2	2	1	2	0	8	16
Spiritual support	7	12	4	0	10	1	34	69
Anticipatory grief support	6	16	6	2	10	1	41	84
Grief/ Bereavement 1:1	6	10	3	1	10	1	31	63
Grief/ Bereavement support	8	12	5	3	9	1	38	78
Vigil support	8	14	5	3	10	1	41	84
Practical support	3	9	6	0	8	0	26	53
Companionship	8	15	5	3	9	0	40	82
Day programs	3	2	0	2	2	0	9	18
Respite care	3	5	3	2	6	0	19	39
Complementary therapies	8	10	4	2	10	1	35	71
Caregiver support clinics/ groups	7	5	0	2	7	1	22	45
Professional education	4	6	3	1	10	1	25	51
Community education	8	15	6	3	10	1	43	88
Lending libraries	8	16	6	2	9	1	42	86
Advance care planning support	2	11	3	1	9	0	26	53
Other	4	3	2	1	6	0	16	33
	8	18	9	3	10	1	49	

Organizations can be grouped by the total number of services they provide. Seven organizations provide 1 to 5 services (Group 1); 31 provide 6 to 9 (Group 2); and 10 provide 10 or more of the list of 21 service options listed (Group 3).

The services most likely to be provided by the Group 1 organizations are: Palliative 1:1 support (43%); Home-based palliative care (43%); Anticipatory grief support (57%); Companionship (57%); Community education (71%); and Libraries (57%). None of these organizations provide: Disease/ symptom management, Physical support, Grief groups, Day programs, or Respite care.

The following eight service types are significantly associated with the service count group of the organization: Spiritual support, Anticipatory grief support, Grief/ Bereavement 1:1 Counselling, Grief/ Bereavement support groups, Vigil support, Practical, Respite Care and Complementary therapies. Group 3 organizations are more likely to offer these particular services than Group 2 organizations. Other types of services do not show a pronounced pattern.

Not surprisingly, these three groups differ in terms of their average operating budgets. The total expenses median for Group 1 organizations is $17,761. The medians for Groups 2 and 3 are $86,817 and $250,000, respectively.

The following table shows the distribution of organizations by Group (1, 2, 3) and Health Authority.

			Group			
			1	2	3	Total
Health Authority	Fraser	Count		6	2	8
		% within HA		75.0%	25.0%	100.0%
		% within Group		19.4%	20.0%	16.7%
	Interior	Count	5	11	2	18
		% within HA	27.8%	61.1%	11.1%	100.0%
		% within Group	71.4%	35.5%	20.0%	37.5%
	Northern	Count	2	6		8
		% within HA	25.0%	75.0%		100.0%
		% within Group	28.6%	19.4%		16.7%
	Van Coastal	Count		3		3
		% within HA		100.0%		100.0%
		% within Group		9.7%		6.3%
	Van Island	Count		4	6	10
		% within HA		40.0%	60.0%	100.0%
		% within Group		12.9%	60.0%	20.8%
	Yukon	Count		1		1
		% within HA		100.0%		100.0%
		% within Group		3.2%		2.1%
Total		Count	7	31	10	48
		% within HA	14.6%	64.6%	20.8%	100.0%
		% within Group	100.0%	100.0%	100.0%	100.0%

Organizations within the Interior and Northern Health Authorities are more likely to provide a small range of services than organizations elsewhere. Vancouver Island organizations tend to provide a broader range of services than organizations in other parts of BC.

For a supplementary analysis, responses to Question 5 (type of organization) were used to group the organizations into three categories. In this categorization, Group A consisted of 10 organizations that have beds and are affiliated with an acute hospital; Group B had 26 organizations with no beds that provide psycho-social support; and Group C included the other 13 organizations of different types, e.g., hospital-based palliative care (1 organization); shared service beds in LTC facilities (4), and free-standing hospice (3).

The distribution of the organizations by Group and region was examined. Fraser and Vancouver Island had the largest proportions of Group A organizations (38% and 30%, respectively); Vancouver Island and Yukon had the highest proportions of organizations

in Group B (60% and 100%); and Northern had the highest proportion of Group C organizations (44%).

The three groups of organizations differ significantly with respect to their service offerings. Group C organizations are most likely to provide Disease/ Symptom management, Respite care and Physical support while Group B organizations are least likely to provide these types of services.

Service Volumes

Organizations were asked to record the approximate numbers of people they served during calendar year 2012 (Questions 16 and 17). The instructions specified that an individual who received more than one category of service was to be counted in each category.

Inpatient service volumes were quantified in terms of number of admissions and number of patient days. For outpatient services, the following categories were provided for recording the number served: Palliative, Bereavement, Caregiver support, Community education and Information referral.

The number of organizations answering these questions was quite low. In part because not all organizations provide inpatient services, only 25 reported the number of admissions, and 15 reported their count of patient days. Only 35 reported* their total number of outpatients. The data used in these analyses are shown for each organization (again, with organization codes to preserve confidentiality) in the *Persons Served* sheet of the accompanying Excel file.

Inpatient Services

The median number of admissions was 60 and the mean was 177. The smallest number of admissions was 1, and the largest was 2000. The 25th and 75th centiles were 11.5 and 184, respectively. The total number of admissions for these organizations was 4424. The mean, median and total admissions within each Health Authority are as follows:

Admissions

Health Authority	N	Mean	Median	Total
Fraser	5	146.00	173.00	730
Interior	6	90.83	58.50	545
Northern	5	53.80	8.00	269
Van Coastal	2	1013.50	1013.50	2027
Van Island	7	121.86	60.00	853
Total	25	176.96	60.00	4424

For the organizations that reported patient days, the mean and median were 1257 and 150, respectively. The smallest and largest values reported were 0 and 6500. The 25th and 75th centiles were 8 and 3120, respectively. The total number of patient days for these 15 organizations was 18,852.

Outpatient Services

For the organizations that reported* their total number of outpatients, the mean and median were 1757 and 263, respectively. The smallest and largest counts were 2 and 40,574. The 25th and 75th centiles were 52 and 1033, respectively. The total number of outpatients served by these 35 organizations was 61,511. The following table shows the distributional statistics for each outpatient service.

Statistic	Palliative	Bereavement	Caregiver Support	Community Education	Info Referral
N	30	31	21	18	19
Minimum	1	2	1	15	1
Maximum	1100	2700	624	2756	40,000
Mean	160	255	118	370	2228
25th Centile	5.75	19	10.5	40.5	20
Median	36.5	76	42	185	70
75th Centile	138.5	281	196.5	496.25	330
Total Clients	4787	7892	2487	6656	42,333

The mean, median and total outpatient counts for each Health Authority are as follows:

Outpatients

Health Authority	N	Mean	Median	Total
Fraser	6	739.17	704.00	4435
Interior	11	3792.36	151.00	41716
Northern	5	106.60	52.00	533
Van Coastal	2	297.00	297.00	594
Van Island	10	1309.40	1027.50	13094
Yukon	1	1139.00	1139.00	1139
Total	35	1757.46	263.00	61511

Volunteer Services and Staff Complements

Volunteers

As noted earlier, 48 of the 49 respondents reported using the services of volunteers. The organizations differed considerably, however, in both the numbers of volunteers they engaged (Question 19) and in the nature of the services volunteers provided (Question 20). The data used in these analyses are shown for each organization (again,

* Several organizations' totals were derived from their individual services' totals.

with organization codes to preserve confidentiality) in the *Volunteers* sheet of the accompanying Excel file.

The following table shows the number of organizations in each Health Authority whose volunteers provide each type of service.

Services Offered by Volunteers	Health Authority						N	% of Orgs
	Fraser	Interior	Northern	VCH	VIHA	Yukon		
Companionship	8	14	8	1	10	0	41	83.7%
Vigil support	8	14	5	3	9	1	40	81.6%
Complementary therapies	8	10	6	2	10	1	37	75.5%
Spiritual support	7	12	6	0	10	1	36	73.5%
Support group facilitation	8	9	5	3	9	1	35	71.4%
Lending libraries	6	11	7	2	7	0	33	67.3%
Community education	6	11	3	2	7	1	30	61.2%
Practical support	3	11	6	0	8	0	28	57.1%
Respite care	3	9	3	2	5	0	22	44.9%
Advance care planning support	2	8	2	1	8	0	21	42.9%
Caregiver support clinics/ groups	7	3	1	2	5	1	19	38.8%
Other	3	4	0	1	5	0	13	26.5%
Day programs	3	1	0	1	1	0	6	12.2%
	8	18	9	3	10	1	49	

Thirty-three* organizations reported the number of client (patient-based) hours their volunteers provide, and 29* organizations reported their numbers of non-client hours, i.e., those involving governance, fundraising, office support, etc. The following table shows the distributional statistics for the two types of service hours.

Statistic	Client-based Hours	Non-client-based Hours
N	34	30
Minimum	50	264
Maximum	27,000	25,000
Mean	4324	4582
25th Centile	834.38	837.13
Median	2178	2033
75th Centile	5440.75	5919.25
Total Hours	147,018	137,474

The following table shows the distribution of volunteer service hours within each Health Authority for these respondents.

* One other organization's hours were deduced from responses to the question about number of volunteers.

Health Authority		Client-based hours	Non-client-based hours
Fraser	N	5	5
	Mean	4278.10	9739.60
	Median	3726.00	7735.00
	Sum	21391	48698
Interior	N	11	7
	Mean	2757.73	2766.86
	Median	1589.00	1859.00
	Sum	30335	19368
Northern	N	7	7
	Mean	1278.71	1500.93
	Median	667.50	849.50
	Sum	8951	10507
Van Coastal	N	1	1
	Mean	7498.00	3386.00
	Median	7498.00	3386.00
	Sum	7498	3386
Van Island	N	10	10
	Mean	7884.32	5551.50
	Median	3792.63	2687.50
	Sum	78843	55515
Total	N	34	30
	Mean	4324.05	4582.45
	Median	2178.00	2033.00
	Sum	147018	137474

If these volunteer service hours were all valued at $20/ hour, the total contribution that volunteers provided to the responding organizations is **$5.69 million**.

Forty-two organizations provided information about the number of volunteers who provided service of seven different types: Client services, e.g., bereavement support; Governance; Fundraising; Office/ support; Earned revenue programs, e.g., thrift shops; Community education; and Other. Individuals who provided service in more than one category were counted in each category. The following two tables show, respectively, the distributional statistics for the volunteer counts in each service category and the distribution of counts by service category and region for the 42 respondents.

Statistic	Client	Govern-ance	Fund-raising	Office/ Support	Earned Revenue	Comm. Ed.	Other	Total
N	41	41	41	41	41	41	41	42
Minimum	0	0	0	0	0	0	0	10
Maximum	191	18	124	25	180	25	47	378
Mean	54.8	8.2	21.5	5.3	18.1	2.6	3.3	111.4
25th Centile	13.5	6.5	5	0.5	0	0	0	39
Median	30	8	12	3	0	0	0	73
75th Centile	89.5	10.5	24	10	3.5	2	0	167
Total Volunteers	2247	338	882	218	741	108	135	4679

Health Authority		Client	Govern.	Fund.	Office/ Support	Earned Revenue	Com. Ed.	Other	Total
Fraser	N	7	7	7	7	7	7	7	7
	Mean	82.86	9.29	12.86	11.00	71.29	5.43	3.57	196.29
	Median	74.00	8.00	11.00	10.00	53.00	1.00	.00	195.00
	Sum	580	65	90	77	499	38	25	1374
Interior	N	15	15	15	15	15	15	15	15
	Mean	33.20	7.73	10.13	2.87	2.40	.80	4.20	62.80
	Median	20.00	9.00	7.00	2.00	.00	.00	.00	43.00
	Sum	498	116	152	43	36	12	63	942
Northern	N	8	8	8	8	8	8	8	8
	Mean	11.50	7.75	17.50	3.25	5.38	5.75	5.88	57.00
	Median	12.00	8.00	6.00	2.50	.00	.00	.00	42.00
	Sum	92	62	140	26	43	46	47	456
Van Coastal	N	2	2	2	2	2	2	2	2
	Mean	128.50	3.50	24.00	5.00	.00	6.00	.00	167.00
	Median	128.50	3.50	24.00	5.00	.00	6.00	.00	167.00
	Sum	257	7	48	10	0	12	0	334
Van Island	N	9	9	9	9	9	9	9	9
	Mean	91.11	9.78	50.22	6.89	18.11	.00	.00	165.33
	Median	79.00	9.00	43.00	6.00	.00	.00	.00	156.00
	Sum	820	88	452	62	163	0	0	1488
Yukon	N								1
	Mean								85.00
	Median								85.00
	Sum								85
Total	N	41	41	41	41	41	41	41	42
	Mean	54.80	8.24	21.51	5.32	18.07	2.63	3.29	111.40
	Median	30.00	8.00	12.00	3.00	.00	.00	.00	73.00
	Sum	2247	338	882	218	741	108	135	4679

Client-based service engages more volunteers overall than other types of service. As a result, client-based service hours exceed non-client-based hours.

Staff Counts

Forty organizations provided data on their staff counts in Full-time-equivalents (FTEs). An FTE was defined in terms of a 37.5-hour work week. Most of these organizations also provided FTE counts for three staff categories: Clinical/ Professional, Support, and Other. The following table shows the distributional statistics for these staff counts.

Statistic	Clinical/ Professional	Support	Other	Total
N	35	35	37	40
Minimum	0	0	0	0
Maximum	20	20	7.2	55
Mean	2.7	2.3	0.5	6.2
25th Centile	0	0	0	0.6
Median	0.7	0.7	0	1.8
75th Centile	2.6	2.7	0.6	6.6
Total FTEs	93.2	79.7	19.2	250

The following table shows the distributions of these FTEs by Health Authority.

Health Authority		Clin/ Prof	Support	Other	Total
Fraser	N	7	7	8	8
	Mean	2.6171	7.3800	.4750	9.2225
	Median	2.6000	5.7600	.1000	6.3800
	Sum	18.32	51.66	3.80	73.78
Interior	N	14	14	14	14
	Mean	3.8464	.9221	.7884	5.5619
	Median	.3600	.0000	7.35E-02	.7450
	Sum	53.85	12.91	11.04	77.87
Northern	N	6	6	6	6
	Mean	1.4167	.1250	.2600	1.7233
	Median	.5000	.0000	.2800	.9650
	Sum	8.50	.75	1.56	10.34
Van Coastal	N	2	2	2	2
	Mean	.2500	.8500	.0000	1.1000
	Median	.2500	.8500	.0000	1.1000
	Sum	.50	1.70	.00	2.20
Van Island	N	5	5	6	9
	Mean	2.2700	1.9600	.4583	9.1433
	Median	2.5500	1.3000	.4750	3.8500
	Sum	11.35	9.80	2.75	82.29
Yukon	N	1	1	1	1
	Mean	.6700	2.8300	.0000	3.5000
	Median	.6700	2.8300	.0000	3.5000
	Sum	.67	2.83	.00	3.50
Total	N	35	35	37	40
	Mean	2.6626	2.2757	.5175	6.2494
	Median	.6700	.7000	8.00E-02	1.7650
	Sum	93.19	79.65	19.15	249.98

The respondents differ considerably in terms of their organizations' allocations of staff FTEs. In Fraser, for example, the Support FTE total is much larger than the Clinical/ Professional total. In the Interior and Northern Health Authorities, the allocation is reversed.

Relationships Among Key Organizational Descriptors

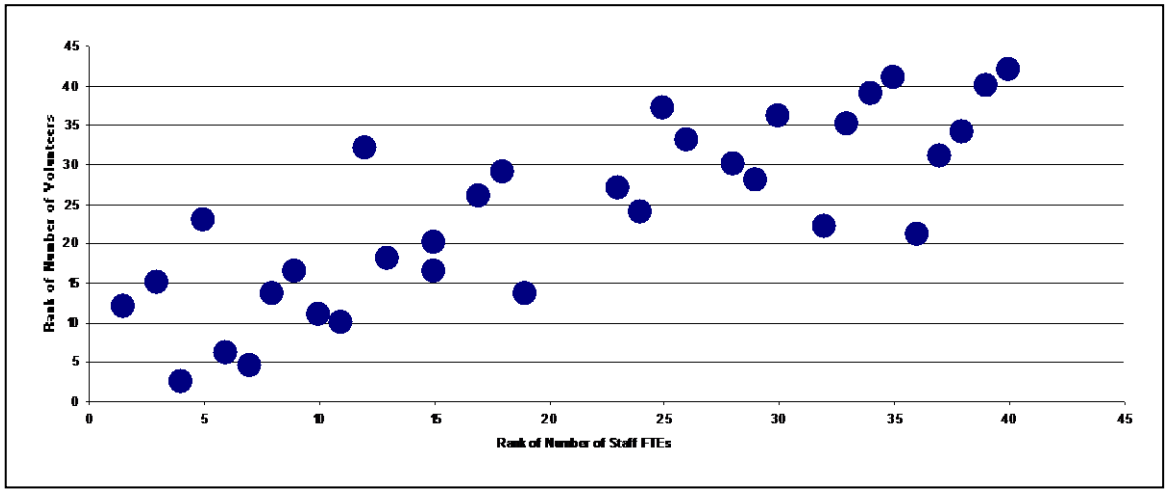
The survey data contain many important descriptors that characterize each organization. The quantitative descriptors—quantities that can be ranked—include: total operating expenses, total number of outpatients, number of admissions, number of client-related and non-client-related volunteer hours, total number of volunteers and total staff FTEs. An additional descriptor, number of services provided, was derived from responses to Question 14.

The ranks of the organizations that submitted data for each descriptor are provided in the *Ranks* sheet of the accompanying Excel file. The smallest value for each descriptor is given the number 1; larger values are given larger ranks. Non-integer ranks are assigned for tied values.

The ranked descriptors are highly and positively correlated indicating that these organizational features are closely connected. For example, unsurprisingly, the number of staff FTEs has a (Spearman) correlation, *r*, of 0.98 with total operating expenses. An

example of a smaller, but still important correlation is the association between total number of outpatients and the number of client-related volunteer hours (r = 0.84). Interestingly, the correlation between the number of outpatients and the number of non-client-related volunteer hours is almost as large (r = 0.79). The common threads underlying these organization features include organizational "size" and "capacity".

The following graph illustrates the relationship between the ranking of the number of staff FTEs and the ranking of the total number of volunteers.



Organizations with more paid staff tend to have more volunteers.

Interestingly, however, the number of different services provided is not highly correlated with the other descriptors. The correlation between the number of services and the number of volunteers is 0.55; the correlation with total operating expenses is 0.30. Organizations offering the most different services do not all engage the most volunteers or have the largest budgets.

As could be expected, all the descriptors have a significant positive association with the size of the community an organization serves. In general, the larger the community, the larger the budget, number of volunteers and so on.

Summary of Key Statistics by Region

The following table draws together key aggregate results for each Health Authority with respect to number of clients served, expenditures, staffing and volunteer service.

In making comparisons, it should be remembered that 28% of the sampled organizations did not respond to the survey, and some of the respondents did not provide data concerning some of the variables summarized above. The figures in the table are therefore underestimates of the true totals. Bearing in mind the small amount of data from organizations within the Vancouver Coastal Health Authority, the figures

do, however, provide a basis for some rough comparisons among the other four Health Authorities.

HA	# Respon-dents	# Clients Served	# Comm. Ed. Clients	Budgets			# Paid Staff FTE	Volunteers		
				HA $	Other $	Total $		#	Total Hrs.	Value in $ @ $20/hr
FHA	8	5138	863	2.2M	3.3M	5.5M	74	1374	70K	1.4M
IHA	18	42176	595	3.8M	2.0M	5.8M	78	942	50K	990K
NHA	9	802	17	893K	893K	1.8M	10	456	19K	389K
VCH	3	2621	200	70K	80K	150K	2	334	11K	217K
VI	10	16703	4811	3.9M	5.3M	9.2M	82	1488	134K	2.7M
Yukon	1	1139	170	234K	20K	254K	4	85		
TOTAL	49	68579	6656	11.2M	11.6M	22.8M	250	4679	284K	5.7M

Overall, it appears that at least 69,000 clients in BC were served in a variety of ways during 2012. The organizations within the Interior Health Authority appear to have provided services to more than half of these. Vancouver Island organizations served the second largest number of clients, but serve the largest number of Community Education clients.

The Vancouver Island organizations had an aggregate total expenditure of $9.2 million—far larger than the aggregate expenditures for organizations in the Fraser or Interior Health Authorities.

In BC overall, less than half of the $22.8 million in total funding for the work of the responding organizations was provided by Health Authorities. The Interior Health Authority is a notable exception, however.

When an estimated value of volunteers' work time contributions is added in (based on a rate of $20 per volunteer hour), the total monetary value of the work done by the respondent organizations is $28.5 million. The volunteer time represents 20% of this total.

Top Five Challenges that Organizations Face

The final section of the questionnaire dealt with the challenges that organizations face and offered an opportunity to provide additional feedback. Organizations were asked to rank 10 suggested challenges including "Other" (to be specified by the respondent). Forty-four respondents provided data. The following table summarizes the results. Overall rank was determined from the means of the ranks assigned to each issue.

Challenge	Overall Rank	% Ranked #1	% Outside Top 5
Sustainable revenue sources	1	72.7	9.1
Advocacy education to support local and Health Authority Advocacy efforts	2	6.8	29.5
Access to competitive services such as employee extended health benefits…	3	2.3	43.2
Advocacy related to provincial issues	4	4.5	45.5
Governance development and support	5	4.5	52.3
Support for volunteer training	6	2.3	43.2
Support for professional training	7	6.8	52.3
Earned revenue support	8	11.4	68.2
Strategic planning	9	4.5	75.0
Other	10	2.3	81.8

The two most important issues overall and the two ranked as least important stand out quite clearly. The six mid-ranked issues are very close to being tied for equal importance.

The importance attached to two of the challenges appears to differ across Health Authorities. Advocacy related to provincial issues was ranked higher overall in Vancouver Coastal and Northern Health Authorities and lower in the Fraser Health Authority than in the other regions. Respondents in Vancouver Coastal and Vancouver Island Health Authorities gave higher priority to sustainable revenue sources than those in other regions.

There is no association between rankings of the issues and the size of the community an organization serves, nor is there any relationship between rankings and the number of services an organization offers.

Conclusions

This survey was an important first step by BCHPCA towards establishing a process of regularly collecting information about the breadth of hospice and palliative care services available in BC. The information collected can also serve as one component of a description and analysis of the impact of BC's hospice and palliative care services. Data about outcomes of services will be needed—in addition to the output/ utilization data collected in this survey—in order to present a complete picture of impact, however.

The quantity and quality of data obtained are at the same time encouraging and indicative of needed improvements. The response rate of 72% was sufficient to allow

for a reasonable degree of confidence in the overall picture presented by the data. The paucity of data from the VCH region, however, indicates that caution is needed in making regional comparisons.

Low response rates for particular questions such as the revenue category items are not unexpected, but nonetheless suggest that new methods are needed to facilitate accurate collection of these vital data. Inconsistencies in the current financial data indicate that caution is needed in making comparisons across regions or across funding source categories. An important caveat regarding conclusions drawn from the aggregated financial results is that totals are all underestimates of true provincial and most regional values.

This survey provided a very good opportunity to learn about the data collection capacity of respondent organizations and to identify possible methods for improving organizational capacity and data quality. An important problem that the survey uncovered, for example, is the inconsistent use of terminology across the province. The counting of outpatients served, for instance, was drastically affected by the fact that respondents differed in their interpretations of who to count in each service category. There were also differences in interpretation of the categories the questionnaire provided for organizations to describe themselves. Establishing a set of common definitions for terms used in future data collection and assisting organizations to incorporate these in their ongoing data recording systems should help to improve both completeness and accuracy in the future. Further, some organizations would probably benefit from assistance in developing simple easy-to-use electronic systems for recording volunteer hours and services to clients.

The data collected in the current survey present a picture of a very diverse group of organizations serving a common cause. There appear to be vast differences among organizations in terms of range of services offered, total budget, reliance on different funding sources, use of volunteers and numbers of clients served. These reflect, in part, the differences between the communities served and between the Health Authorities' approaches and funding with respect to hospice and palliative care. None of the organizations within the Northern Health Authority, for example, provided day programs or caregiver support clinics/ groups, while no organization within the Vancouver Coastal region offered medical disease / symptom management.

A major implication of this diversity is that British Columbians' access to different types of services varies considerably across the province. While some types of services are relatively widely available across BC—palliative one-to-one support and community education, for example—other services like home-based palliative care, respite care and caregiver support groups/ clinics are much less widely available. Only about half the organizations reported providing support in 2012 for advance care planning—an increasingly important area of focus for the BCHPCA. This inequity in access to services is a challenge that needs to be addressed.

Financial sustainability was the top concern voiced by respondents, and the budget data they provided suggest some possible reasons for their ranking. There are huge differences across regions in the medians of their organizations' total operating expenses. The median operating budget for organizations in the Fraser Health Authority ($455K) is over 10 times the median for organizations in the Northern Health Authority ($34.5K) and almost nine times the median for those in the Interior Health Authority ($51K). In 2011, the Fraser Health Authority region was more populous than the other two regions by factors of only 5.6 and 2.2, respectively, however.

The respondents' levels of funding from their Health Authorities also vary considerably. Half the organizations that provided the required data received 11% or less of their operating expenses from their Health Authority, while only one-quarter received more than 53% of their budget from this source. Half the organizations received $6000 or less from government grants (including gaming grants) possibly leading to a greater reliance on fundraising events with their associated risks. Earned revenue contributed only a small proportion of almost all organizations' budgets.

The respondents served about 70,000 British Columbians in 2012 in a wide range of ways. These organizations' capacity to deliver services was considerably enhanced by the time contributions of over 4600 volunteers. The financial value of their donated time, when estimated using a very reasonable hourly wage, was 25% of the aggregate operating budgets, and about half the total of the Health Authorities' contributions.

The investment of over $11.2 million by the Health Authorities in the respondents' services during 2012 was more than matched by the funds raised by the respondents through other means. When the value of the services provided by the volunteers is considered, the "multiplier effect" of the respondents operations was over 1.54 (= [11.6 + 5.7]/ 11.2). In other words, for every dollar invested by the Health Authorities, the respondents were able to generate an additional $1.54 in value.

Recommendations

This survey has been a valuable first step in assisting the BCHPCA and its members in describing, in broad strokes, the state of hospice, palliative care and related services provided in BC. It highlights the value of collecting, summarizing and analyzing data to create actionable information. At the same time it points to a need for refinement and expansion of data collection capacity and processes. The following recommendations outline some specific steps in making these improvements.

1 Strike a small task group to devise a common set of definitions for terms and categories needed in future province-wide data collection. This group could include Health Authority representatives.

2 Update the questions from the current data collection instrument for use in 2014. Consider developing specialized sets of questions for particular subsets of the surveyed organizations and about particular topics, e.g., community education activities. Consider developing a data collection schedule whereby some data are collected every year and other data are gathered less frequently.

3 Invest in the creation of database software to facilitate ongoing data collection and improve accuracy and completeness of data. A training component for new data collection procedures would also be required.

4 Continue to encourage the annual participation of all programs by providing them with reports of findings, assistance in data collection and other resources.

5 Partner with Health Authorities and BCHPCA members to ensure that collected data are useful to all parties.

6 To supplement and provide context for members' data, pursue the obtaining of relevant aggregate data from Health Authorities, e.g., on palliative care programs they operate, broken down by units / programs. Ensure that data provided are interpretable, e.g., ensure that data collection procedures and terminology are well understood and that any inconsistencies across Health Authorities are known.

7 Again, to supplement information derived from members' data gathering, request the Canadian Institute for Health Information (CIHI) update and enhance its 2008 study *Health Care Use at the End of Life in Western Canada*.

In 2008 CIHI published an important analysis of health care utilization by British Columbians during their last two years of life. The goal of this study, whose audiences included health system planners and decision makers as well as service providers, was to provide a quantitative description of end-of-life care, focusing on volume of health service usage and service use patterns.

The study provided detailed aggregate descriptions concerning:

- the demographic profiles of a cohort of British Columbians who died during a one-year period—for the province as a whole and by Health Authority—and the causes and places of death (hospital, residential care facility, home, other);
- the most typical combinations and temporal patterns of health services used during cohort members' last two years of life; and
- the volume and cost of utilization of a wide range of specific categories of health services including acute care visits, general practitioner and specialist physician

services, prescription medications, residential care and home care services and palliative care services.

The data used in the analyses were drawn from service event records within the province's vital statistics and health care administrative databases. These records pertain to deaths, physician billings, hospital discharges, prescription medication dispensings, ambulance conveyances, home care delivery and residential care stays. Individual patients' records were linked by their personal health number to examine service combinations and patterns. In addition, flags were developed, based on the occurrence of specific events, to identify individuals who had received palliative care.

The study provided important information at the provincial level about the wide variation in service use volumes and patterns for different population subgroups and the general trend of increased service use during the last three months of life compared with the twenty-first through twenty-fourth months prior to death. Many issues, however—some of which were noted in the Discussion chapter of the report—were not addressed fully or left for future studies. Several pertain directly to palliative care.

APPENDIX

2013 HOSPICE and PALLIATIVE CARE SERVICES SURVEY

INTRODUCTION

Greetings from the Board of Directors of the BC Hospice Palliative Care Association (BCHPCA).

At the recent BCHPCA conference in Vancouver, we mentioned a data gathering project which hopefully will benefit future advocacy and resource development activities by BCHPCA and its Members.

Under the direction of Dr. Bob Prosser, a retired health statistician (and knowledge philanthropist) and with the support of Balraj Kahlon, an SFU Master of Public Policy Co-Op student who is with us for the summer, BCHPCA is embarking on a "fact and data gathering" mission. And…we need your help.

Our intent is to gather information and data about the breadth of Hospice Palliative Care (HPC) services currently available across the province. We are particularly interested in data that will help describe the impact of BC's HPC services. Once data is analyzed, we will provide it to the BCHPCA membership, in a way that describes service availability and delivery both regionally and provincially. We hope these analyses will inform both your own resource development and local advocacy activities. BCHPCA plans to use the information for provincial advocacy initiatives.

While we ask you to identify your HPC program for tabulation purposes, the roll out of information will not include any program identification. The survey should take about 10-15 minutes to complete; you may need a little background information at hand before you begin (e.g. operating budget, numbers of staff and volunteers, etc.) Please complete the survey by August 20, 2013.

We understand that for some HPC programs, the collection of data may be an onerous task – please complete those portions of the survey that you can and provide comments on areas where the information requested is not easily available. As a follow-up to the survey, BCHPCA will be making suggestions and recommendations for future data gathering, so that we can regularly update the data that we share with the BCHPCA Membership.

Thank you in advance for your participation; we look forward to sharing the results of the survey and suggestions on how best to use the results to further support quality end of life care in BC.

1. Name of Organization

2. Organization is located in:

a. Northern Health
b. Interior Health
c. Vancouver Island Health
d. Vancouver Coastal Health
e. Fraser Health

3. Which cities or towns do you serve? (Please specify)

4. What is the approximate population of your service area?

a. Less than 5,000
b. 5,000 – 9,999
c. 10,000 – 19,999
d. 20,000 – 49,999
e. 50,000 – 74,999
f. 75,000+

5. How would you describe your organization?

a. Free-standing hospice with acute beds
b. Free-standing hospice with residential beds
c. Free-standing hospice on hospital campus
d. Hospital-based acute palliative care unit
e. Shared services model with dedicated beds in LTC facility
f. Hospice Society (without bed complement providing psycho-social support)
g. Hospice Society (with bed complement and affiliated with acute hospital)
h. Supportive housing model home-based palliative support
i. Other (specify)

6. What were your total 2012 operating expenses? (Pease round to the nearest whole number)

Answer **<u>either</u>** question 7 or 8

7. What amount of your 2012 revenue was attributable to each of the following sources by dollar amount? (Please ensure these totals the answer in Question 6)

a. Health Authority funding
b. Government grants (e.g. Community Gaming Grants)
c. Non-government grants
d. Fundraising events
e. Other fundraising
f. Earned income (from businesses or service contracts)
g. Other (please specify)

8. What amount of your 2012 revenue was attributable to each of the following sources by percentage? (Please ensure totals is 100%)

a. Health Authority funding
b. Government grants (e.g. Community Gaming Grants)
c. Non-government grants
d. Fundraising events
e. Other fundraising
f. Earned income (from businesses or service contracts)
g. Other (please specify)

9. Does your organization have paid staff?

a. Yes
b. No

10. If yes, how many Full Time Equivalents (defined as 37.5hours/week per 1.0 FTE) does your organization employ?

To calculate FTE's add total hours worked by staff in one week (7 day period) and divide by 37.5

a. Clinical/Professional
b. Support Staff
c. Other (please describe)
d. TotaI

11. Is your organization affiliated with a teaching institution?

a. Yes
b. No

12. Does someone in your organization participate in community or hospital-based hospice palliative care rounds

a. Yes
b. No

13. If your organization does not participate in community hospice palliative rounds, what are the reasons?

a. Not permitted due to confidentiality
b. Do not have adequate staff
c. Do not see need
d. Other (please specify)

14. Which of the following services does your organization provide?

(Please check all that apply.)

a. Disease/Symptom Management (medical)
b. Palliative 1:1 support or counselling
c. Home-based palliative care
d. Physical Support (e.g. Support daily activities such as feeding, bathing, etc.)
e. Spiritual Support
f. Anticipatory Grief Support
g. Grief/Bereavement 1:1 Counselling

h. Grief/Bereavement Support Groups
i. Vigil Support
j. Practical Support (e.g. running errands, shopping, pet care, etc.)
k. Companionship
l. Day Programs
m. Respite Care
n. Complimentary Therapies (Reiki, healing touch, massage, etc.)
o. Caregiver Support Clinics/Groups
p. Professional Education
q. Community Education
r. Lending Libraries
s. Advance Care Planning Support
t. Other (please specify)

15. Does your organization serve children and youth?

a. Yes
b. No

16. Approximately how many inpatients did your organization serve in 2012?

(Note: count people for each service they receive e.g. if two caregivers provide support to one person, count as two below).

a. Admissions
b. Patient days

17. Approximately how many outpatients did your organization serve in 2012?

a. Palliative
b. Bereavement
c. Caregiver support
d. Community education
e. Information/referral
f. Total

18. Does your organization use the services of volunteers:

a. Yes
b. No

19. If yes, please list the 2012 number(s) of volunteers in each program area.

(Note: If an individual volunteers in more than one category, count the person for each category.)

a. Client/patient volunteers (palliative/bereavement/vigil/caregiver support)
b. Governance volunteers (Board members)
c. Fundraising volunteers
d. Office/support volunteers
e. Volunteers in earned revenue programs/services (i.e. thrift shop, fee for service contracts)
f. Community education/outreach
g. Other
h. Total

20. What services do client/patient volunteers provide in your organization?

a. Spiritual Support
b. Vigil Support
c. Practical Support (e.g. running errands, shopping, pet care, etc.)
d. Companionship (e.g. facility or home-based emotional support)
e. Support Group Facilitation
f. Day Programs
g. Respite Care
h. Complimentary Therapies (Reiki, healing touch, massage, etc.)
i. Caregiver Support Clinics/Groups
j. Community Education
k. Lending Libraries
l. Advance Care Planning Support
m. Other (please specify)

21. Do you record the number of volunteer hours each volunteer provides to your organization?

a. Yes
b. No

22. If yes, how many volunteer hours in 2012 were donated in the following categories?

a. Client/patient based volunteer hours
b. Non-client based volunteer hours (e.g. governance, office support, fundraising, etc.)

23. Please select your organization's top 5 challenges and/or needs among the following choices

(1 being the greatest need).

a. Access to price competitive services such as employee benefits, liability insurance, etc.
b. Advocacy education to support local and health region advocacy efforts
c. Advocacy related to provincial issues
d. Earned revenue support (from business or service contracts)
e. Governance development and support
f. Strategic Planning
g. Support for professional training
h. Support for volunteer training
i. Sustainable revenue sources
j. Other

24. If you ranked "other" in your top 3, please provide details

25. Please provide any additional information or comments you would like to share.

Thank you for participating in the 2013 BCHPCA pilot survey.