

**UTILIZATION OF PALLIATIVE CARE SERVICES
IN VANCOUVER: 1990-1993**

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Utilization of Palliative Care Services in Vancouver: 1990-1993

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Utilization of Palliative Care Services in Vancouver: 1990-1993

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Background

Palliative care is the care of terminally ill patients and their families. It includes physical, psycho-social, and spiritual dimensions. Palliative care is not simply passive care; it may involve active interventions. However, the focus is not on cure, but rather on comfort and quality of life. The Canadian Palliative Care Association (CPCA) document 'Palliative Care: Towards a Consensus in Standardized Principles of Practice' (1990) reviews a number of definitions of palliative care, including that of the World Health Organization:

'The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.'

Throughout Canada, there is a growing recognition of the need for regional approaches to palliative care services. The forces promoting regionalization have been twofold. First, service providers in many Canadian centres recognized the need for information sharing and coordination of services. Second, and more recently, provincial governments across Canada have endorsed a decentralized, regional approach to health care service planning and delivery. This reorganization of health care is encouraging palliative care/hospice providers to form regional groups.

In British Columbia at least two regional groups have been meeting for several years: the Vancouver Palliative Care Coordinating Group (VPCCG), and the Capital Region District Palliative Care Advisory Committee. Membership of the VPCCG represents the acute and continuing care sectors, and includes Vancouver Hospital, St. Paul's Hospital, Mt. St. Joseph's Hospital, St. Vincent's Hospital, B.C. Cancer Agency (BCCA), May Gutteridge Community Home, Vancouver/Richmond Health Board Home Hospice Program, Holy Family and Friends for Life. Recently, representation from palliative/ hospice services in Richmond has been added. The 'Closer to Home' initiatives, which followed from the Seaton Commission Report (1994), have led to the increasing recognition of the importance of palliative care services, and the need to develop an integrated plan for services in Vancouver.

Although it could be argued that all dying patients require formalized palliative services, it may be too encompassing to suggest that the population at need is simply the entire annual mortality in Vancouver. There certainly should be elements of palliative care in the care of any dying patient, but to a degree, such care can be considered as part of the good general medical/health care of any patient. For example, in sudden deaths from trauma, there are elements of grief and bereavement that need to be addressed. Or, in situations of chronic illness such as chronic obstructive pulmonary disease, renal failure, or Alzheimer's disease, there often are elements of symptom control.

The more usually accepted working applications of palliative services centre on a terminal illness, with prognosis generally up to weeks/months, rather than years. Historically, palliative care has been associated with care of patients with terminal cancer. This report has focused on cancer and AIDS as diseases which in later stages may require more formalized palliative services. Clearly, there are other instances where terminal care may require palliative care (e.g. endstage heart disease, endstage renal disease, degenerative neurological disease), and issues surrounding services to these patients need to be addressed in any planning of palliative care services.

The VPCCG received funding from the B.C. Ministry of Health, to undertake a number of projects related to the delivery of palliative care services. One of the projects is presented in this report, which analyzes utilization of palliative care services in Vancouver during the period 1990-93.

This report begins with a brief overview of the methods involved in the study. This is followed by a description of all adult deaths in Vancouver 1990-93, looking at factors such as age/sex distribution and causes of death. Much of the remainder of the report focuses on deaths from cancer or AIDS, and data are presented on contacts of these patients with the then existing palliative care system. Simplifying assumptions and caveats must be kept in mind. Palliative care is provided by a number of different service providers. In this particular study, it was not possible to collect data on the full range of encounters that take place between a terminally ill patient and the health care system (e.g. family physicians who provide elements of palliative care in their general practice). One of the major issues around death and dying relates to place of death, i.e. home vs hospital. This report presents data on place of death for the 1990-93 period. There is some discussion as to the assumptions regarding palliative care as primarily applicable to cancer/HIV patients. Finally, drawing upon the results of the data analysis, the report offers some recommendations.

A brief description of palliative services in Vancouver during the 1990-93 study period can be found in Appendix A.

Methods

Study Design

The major objective of this study was to examine the utilization of publicly funded palliative care services in the Vancouver region by adult¹ residents of Vancouver, in the one year prior to their death. In particular the intent of this study was to:

- determine the proportion of terminally ill patients who were accessing palliative care services prior to death
- document the trends in location of death (i.e., home vs institution²) for terminally ill patients
- determine if a relationship between access to palliative care services and location of death exists

To address these questions administrative data were analyzed retrospectively³.

Sampling Strategy

The study population was based on data routinely collected by the B.C. Ministry of Health and included all adult Vancouver residents who died during the period of 1990 through 1993. The study population also included all adult non-Vancouver residents who died in Vancouver during the same time frame (N=18,480).

Analysis

The analysis involved several steps. First, the study population data were linked to community and hospital based administrative data. Then death rates and causes of death for the entire study population were examined. Because the major focus of this study was on terminally ill patients, a sample was selected from the study population which included all deaths related to cancer and AIDS. This sample formed the basis for much of the remainder of our analysis. Using bivariate analysis and a logistic regression procedure, utilization of publicly funded palliative care services and location of death was examined for these individuals.

¹ In this study 'adult' was defined as being over 16 years of age.

² In this study, acute care, extended care and long-term care facilities were categorized as 'institutions'.

³ This included administrative data routinely collected by the BC Ministry of Health, the Vancouver/Richmond Health Board, the BC Cancer Agency, and a number of hospice units located in Vancouver.

Results and Discussion

Death Rates and Causes of Death

The total number of adult deaths (from all causes) in Vancouver from 1990 through 1993 was 18,480. Figure 1 shows that the number of deaths per year in Vancouver increased slightly from 4,474 deaths in 1990 to 4,873 deaths in 1993.

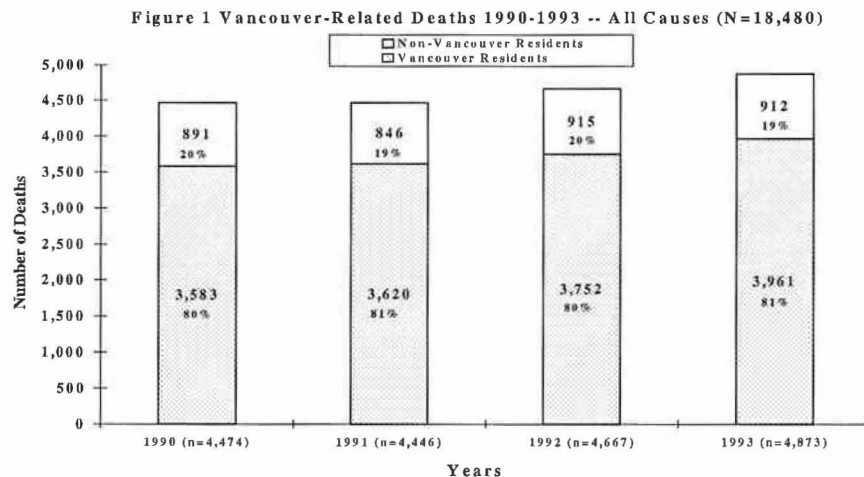
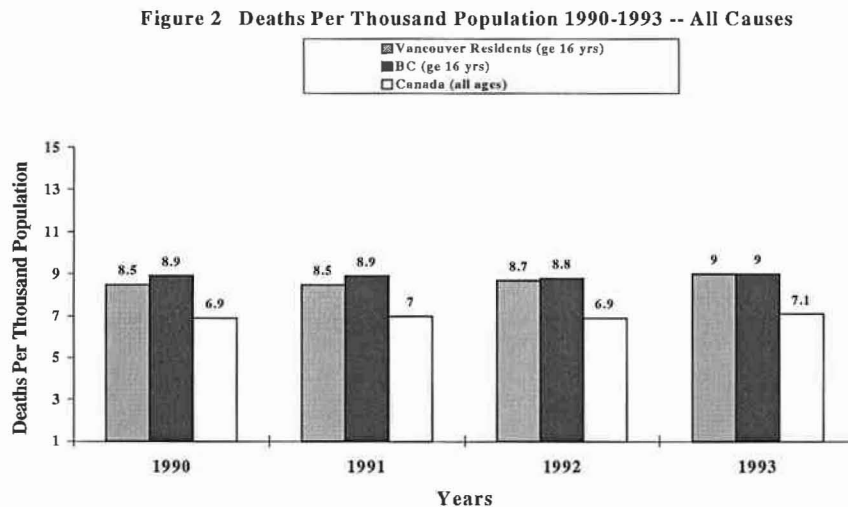
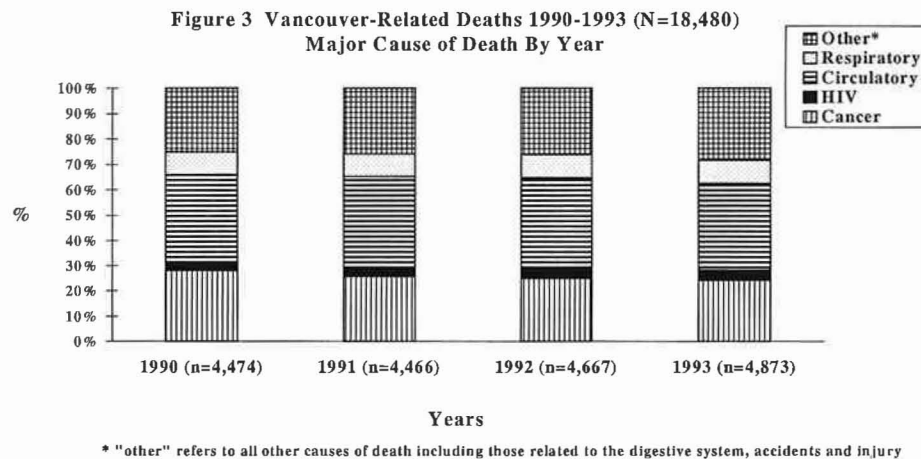


Figure 2 shows that there was a concomitant increase in deaths per thousand population during this same period of time. In 1990 and 1991 deaths per thousand population remained stable at 8.5 deaths per 1,000. In 1992 deaths per thousand increased to 8.7 and in 1993 there were 9 deaths per thousand population. Figure 2 also describes deaths per thousand population for the rest of British Columbia and Canada. The deaths per thousand population described for Canada include 'all ages'; therefore, the rates are slightly lower than those described for either Vancouver or British Columbia.

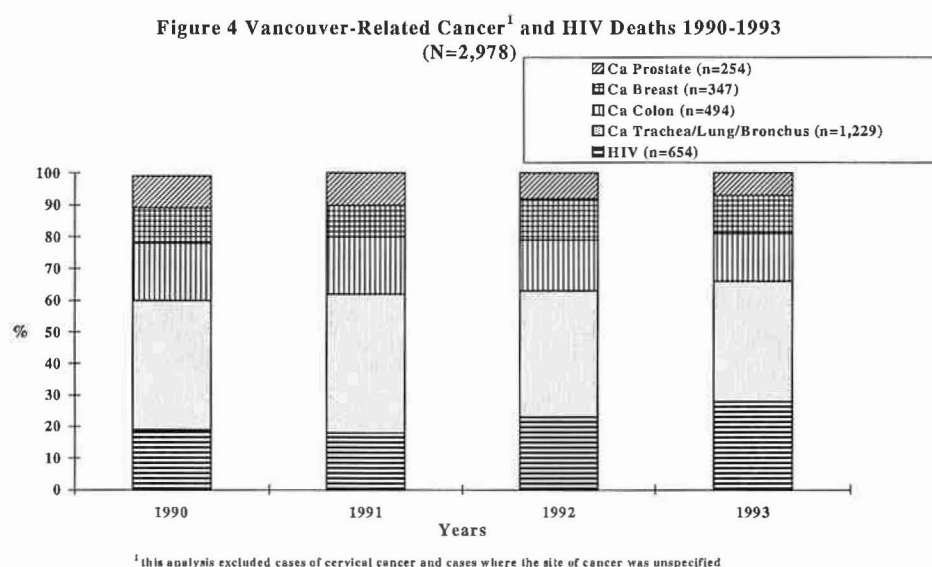


Although the number of deaths in Vancouver increased slightly from year to year, the major cause of death, by broad category, remained consistent as to relative proportions over the study period. These are shown in Figure 3.



With respect to deaths related to cancer, the major causes are lung cancer, colon cancer, breast cancer and prostate cancer. Details on the incidence of cancer deaths for each of this sites (described by age group) can be found in Appendix B. The incidence of HIV-related deaths (described by age group) can be found in Appendix C.

Figure 4 shows that the annual number of deaths in Vancouver from HIV, while less than lung cancer, is more than that for colon cancer, breast cancer or prostate cancer. However, more recently, with the advent of new therapies for patients with AIDS the rate of HIV-related deaths has been decreasing.

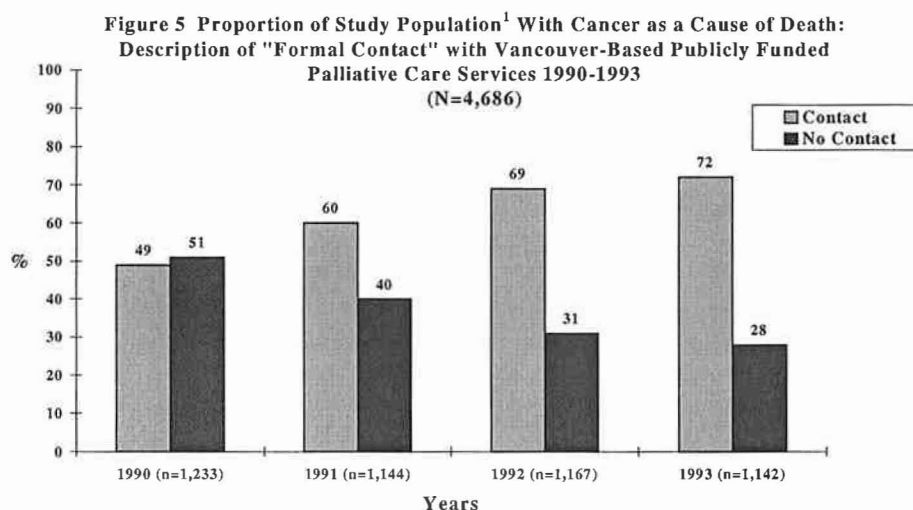


Utilization of Palliative Care Services: Cancer and HIV

The history of palliative care in Canada and elsewhere has been closely associated with the treatment of terminal cancer patients. More recently, with the AIDS epidemic and emphasis on terminal care for AIDS patients, palliative care has also been seen as an integral part of AIDS care. Figure 3 showed that about 30% of deaths in Vancouver during the period 1990-1993 were due to cancer/AIDS. In terms of actual number of deaths, this means that about 1400 deaths per year are from cancer/AIDS in Vancouver (approximately 88% of these are due to cancer). In contrast to cancer/AIDS deaths, deaths from other causes, such as heart disease or chronic lung disease, are not generally thought of as being regularly in the domain of palliative care. For the purposes of this report, most of the focus has therefore been on cancer/AIDS deaths in Vancouver. However, as discussed in a later section of this report, the validity of such an assumption may need to be reevaluated.

This study was designed on the basis that contact with any one of the following organizations would be considered 'formal contact' with the palliative care system, as it existed in Vancouver during the period from 1990 through 1993: the Vancouver/Richmond Health Board (V/RHB) Community Home Hospice Program, May's Place, Normandy House, St. Paul's Hospital Palliative Care Unit, Vancouver Hospital and Health Sciences Palliative Care Unit (or in-hospital consultation by the respective hospitals' palliative care services), or admission to the British Columbia Cancer Agency (BCCA) 5th Floor Unit. Palliative care provided by family physicians and other health care personnel, and by various other agencies or groups (e.g. private home care agencies and the volunteer sector) was not included in our definition of 'formal contact' because access to data about these sorts of encounters was not readily available.

As Figure 5 shows, 'formal contact' with the palliative care system for patients with cancer has increased from about 50% in 1990 to 72% in 1993. This analysis included both Vancouver and non-Vancouver residents. When we examined the pattern for Vancouver residents alone, we found that 60% had 'formal contact' in 1990, 67% had 'formal contact' in 1991, and 75% and 77% had 'formal contact' in 1992 and 1993 respectively.

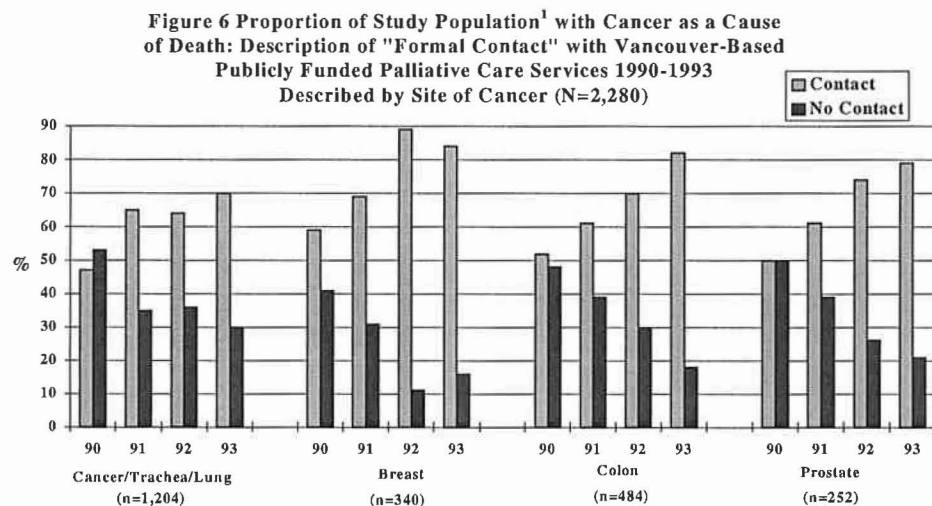


¹ this analysis included both Vancouver and non-Vancouver residents

There are a some factors which may have influenced the observed change in contact over time. Various educational endeavors have targeted physician groups with the goal of increasing awareness about the important role palliative care can play in terminal illness. Efforts have also been directed towards improving physicians' awareness of how to access palliative care services for their patients.

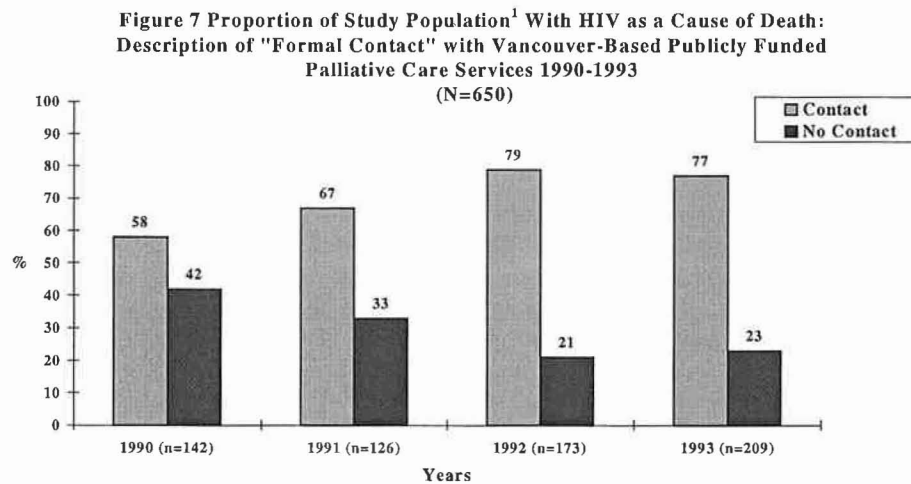
One of the major limitations of this study is that we did not capture important information about the amount of contact, the quality of contact, or the timing of the contact relative to the individual's date of death.

Examination of specific cancer sites shows that the pattern of contact with the palliative care system varies according to the site of cancer; however, all cancer sites show a similar pattern of increasing 'contact' over time (see Figure 6). The observed variation in contact, depending on the site of cancer, could be attributed to a number of factors including: the level of symptom control required by the type of cancer; the degree of psycho-social support needed; gender; and age differences. Different practice patterns amongst oncology specialists might also influence the pattern of patient referrals to the palliative care system.



¹ this analysis included both Vancouver and non-Vancouver residents

Figure 7 shows a similar pattern for the HIV group, with contact increasing from 58% in 1990, to 77% in 1993. Virtually all of this group resided in Vancouver at the time of their death.



¹ this analysis included both Vancouver and non-Vancouver residents

With respect to the specific components of the 'formal' palliative care system (as defined above), 63% of all cancer patients who died (and who were residents of Vancouver) had contact with the V/RHB Community Home Hospice Program, ranging from 59% in 1990 to 67% in 1993. Seventy-one percent of all AIDS patients who died had contact with the V/RHB Community Home Hospice Program, ranging from 69% in 1990, to 72% in 1993. Approximately 20% of the cancer/AIDS group were admitted to one of the hospital palliative care units. About 10% of the cancer/AIDS deaths were referred to a palliative care consultation team during an inpatient stay in acute care. Approximately eight percent were seen at BCCA (5th floor unit). There is obviously some overlap with these, as patients may have had contact with more than one component of the palliative care system. And in fact, the patterns of overlap are of some importance. For example, approximately 30% of the cancer/AIDS patients who had contact with one of the palliative care units were not known to the V/RHB Community Home Hospice Program. Approximately 40% of palliative care consultation referrals (that were cancer or AIDS related) and approximately 50% of the cancer patients seen at BCCA were not known to the V/RHB Community Home Hospice Program. If palliative care is to be a continuum of care, the degree of referral (or non-referral) to the Community Home Hospice Program has implications as to the effectiveness of the 'system'.

It is also of interest that, at both Vancouver Hospital and St. Paul's Hospital, about 50% of the patients seen by the palliative care consult team were admitted to one of the palliative care units within the respective hospitals. This most likely occurred as a transfer to the palliative care unit from an acute care bed within the same facility. About 25% of the patients admitted to BCCA (5th floor unit) were also admitted, at some point during their illness, to a palliative care unit (i.e. within Vancouver Hospital or St. Paul's Hospital).

A logistic regression procedure was applied to the data to determine if there were any variables which predicted a person's contact with the 'formal' palliative care system. In this particular instance we have defined 'contact with the formal system' as those individuals who had contact with the V/RHB Home

Hospice Program (individuals in this group may or may not have had some contact with the other components of the publicly funded palliative care system, as described above). A separate analysis was undertaken for cancer and HIV deaths.

With respect to cancer deaths Table 1 shows that individuals living in the 'City Centre' were more likely to have contact with the V/RHB Home Hospice Program compared to individuals living on the 'West Side' (odds ratio=1.5). There was no socioeconomic gradient noted for the other areas of the city ($p>.05$) (i.e. individuals living in the 'Downtown East Side', 'North East', 'Midtown' and 'South Vancouver' areas of the city were no more, and perhaps more importantly, no less likely to have contact with the V/RHB Home Hospice Program, compared to individuals living on the 'West Side' of the city). However, the analysis does not take into consideration how variation in demand for services (across socio-economic gradients) might have influenced the results. The analysis fails to answer important questions related to both the appropriateness of the contact (in areas where the demand for services might be high) and the degree of unmet needs (in areas where the demand for services might be low). A map of the geographic areas described in our analysis can be found in Appendix D.

Individuals under the age of 75 years were more likely to have contact with the Program, compared to those individuals 86 years of age or older (i.e., individuals 16-50 years of age: odds ratios=1.7; individuals aged 51-65: odds ratio=1.8; and individuals aged 66-75: odds ratio=1.5). Women were slightly more likely (odds ratio=1.3) to have contact with the Program, compared to men. This is not that surprising when one considers that women are typically the primary caregivers in a relationship, thus potentially minimizing the need for men to seek formal care. Finally, the likelihood of having contact with the Program increased substantially over time – in 1993, individuals were almost twice as likely to have contact with the Program, compared to individuals who died in 1990. Again, this is not surprising when one considers that palliative care was beginning to gain a higher profile by 1993.

**Table 1 Logistic Regression Procedure for "Contact"¹
Major Cause of Death: Cancer (N=3,315)**

	Variable	Chi-Square	Odds Ratio
Location of Home Residence² <i>(compared with West Side)</i>	City Centre	0.0043*	1.57
	Downtown East Side	0.7842	0.963
Age Group <i>(compared with Age Group age 86 yrs)</i>	North East	0.8009	0.972
	Midtown	0.0612	0.804
	South Vancouver	0.4104	0.9
	Age Group (16-50 years)	0.0038*	1.737
Time <i>(compared with 1990)</i>	Age Group (51-65 years)	0.0001*	1.821
	Age Group (66-75 years)	0.0011*	1.592
	Age Group (76-80 years)	0.0825	1.304
	Age Group (81-85 years)	0.1467	1.257
	Marital Status	0.0344*	1.187
Time <i>(compared with 1990)</i>	Gender	0.0002*	1.35
	Year (1991)	0.0864	1.19
	Year (1992)	0.0001*	1.774
	Year (1993)	0.0001*	1.934

* indicates statistically significant results

¹ in this particular analysis "contact" was defined as those individuals who were clients of the V/RHB Home Hospice Program -- these individuals may or may not have had some contact with the other components of the publicly funded palliative care system

² A map of the geographic areas described in the analysis can be found in Appendix A

With respect to HIV deaths Table 2 shows that contact with the V/RHB Home Hospice Program was not dependent on the location of an individual's home residence. Age group does not appear to have an influence either. It's curious that individuals were more likely to have contact with the program in 1992 compared to the other three years (odds ratio =2.6). It is recognized that the delivery of home-based palliative care is dependent on the presence of adequate levels of informal support. Changes, between 1992 and 1993 in the number of AIDS patients who had access to informal caregiver support from a well-partner might assist in explaining the results.

Table 2 Logistic Regression Procedure for "Contact" ¹
Major Cause of Death: HIV (N=494)

	Variable	Chi-Square	Odds Ratio
Location of Home	City Centre	0.9657	1.013
	Downtown East Side	0.9184	1.046
Residence²	North East	0.4337	0.694
<u>(compared with</u>	Midtown	0.2557	0.6
<u>West Side)</u>	South Vancouver	0.9867	1.012
Age Group	Age Group ge 31 years	0.2929	0.686
<u>(compared with</u>			
<u>Age Group ge 16 years</u>			
<u>and le 30 years)</u>			
Time	Year (1991)	0.6912	1.31
	Year (1992)	0.0034*	2.616
	Year (1993)	0.1003	1.577
<u>(compared with 1990)</u>			

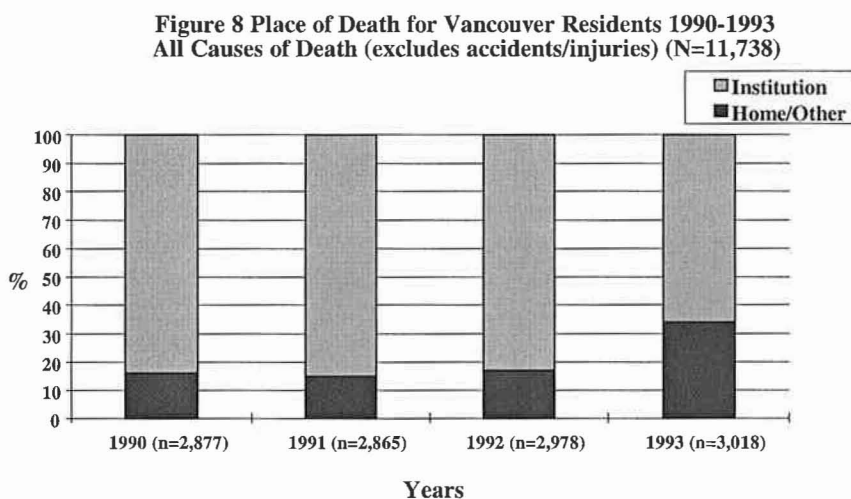
* indicates statistically significant results

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² A map of the geographic areas described in the analysis can be found in Appendix A

Location of Death: All Causes of Death⁴

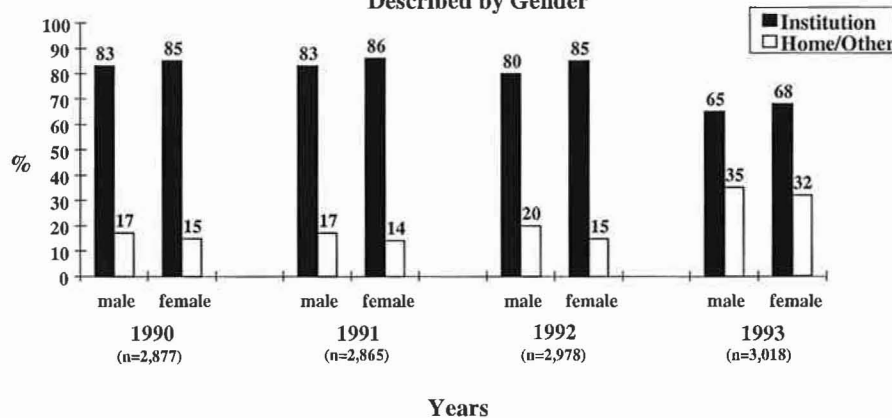
In terms of where people die, the place of death for adults who were also residents of Vancouver at the time of their death, is shown in Figure 8. The proportion of individuals who die at home has increased from 16%, in 1990, to 34% in 1993.



We examined place of death to determine if there was any relationship between place of death and a number of variables including: gender, age, and socio-economic status. It is important to note that deaths related to 'accidents/injuries' were excluded from this analysis. Figure 9 shows that for all years, a slightly higher percentage of home deaths was noted for males, relative to females ($p < .05$). This difference could be explained by a number of factors, directly or indirectly associated with gender. For example, it may be more likely that males have a caregiver at home and the support enables a home death. Or, the differing patterns of cause of death for males and females may allow for a larger proportion of males to die at home.

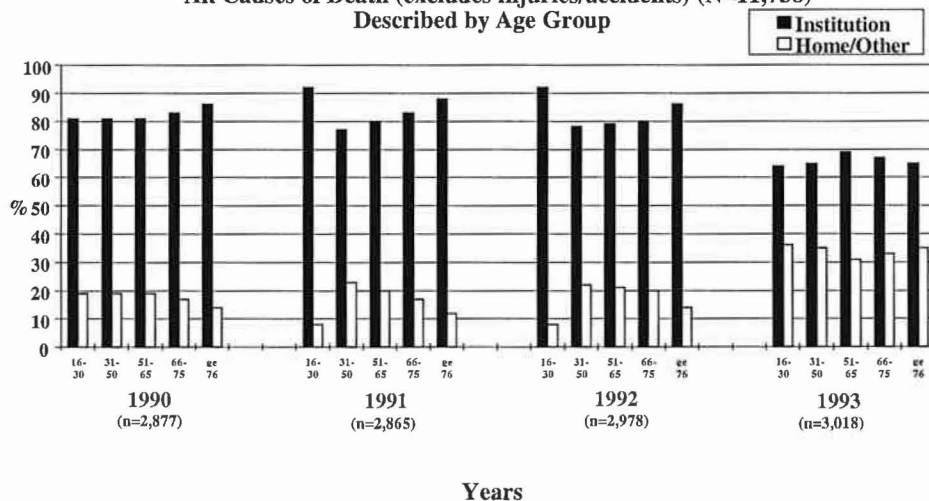
⁴ The analyses excluded cases where the major cause of death was related to an accident or injury.

Figure 9 Place of Death for Vancouver Residents 1990-1993
All Causes of Death (excludes injuries/accidents) (N=11,738)
Described by Gender



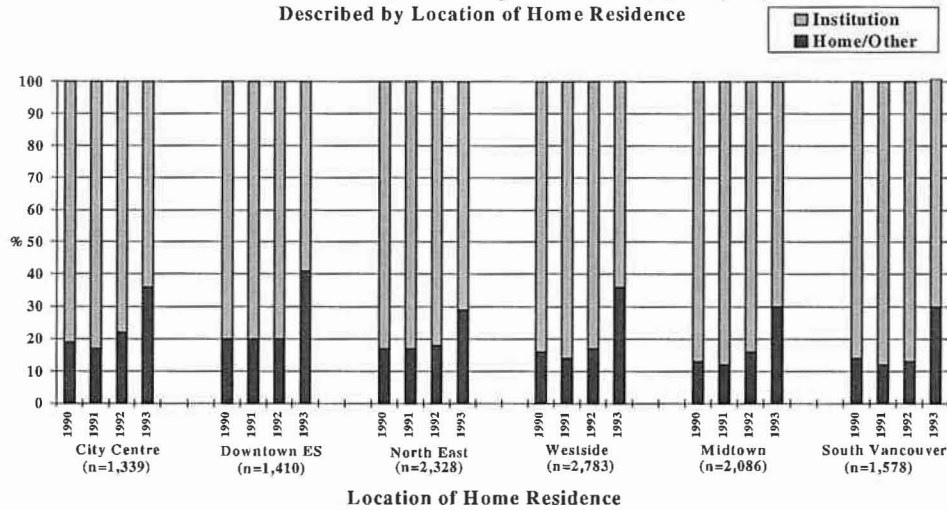
Age at the time of death might also explain some of the differences in location of death for males and females. Figure 10 shows for example that, with the exception of those between 16 - 30 years of age, the likelihood of dying in an institution increased with age ($p < .05$). Interestingly, this pattern disappeared, and even reversed somewhat in 1993. Given that there is generally a larger proportion of older females in the population, it's not surprising then to find a higher proportion of females dying in institutions. Although it could also be argued that there might be an interaction effect between age and gender, logistic regression analysis demonstrated that there was none ($p > .05$).

Figure 10 Place of Death for Vancouver Residents 1990-1993
All Causes of Death (excludes injuries/accidents) (N=11,738)
Described by Age Group



With respect to socio-economic status we used 'location of patient home residence' as a proxy for socio-economic status. Figure 11 describes the place of death for Vancouver residents by 'location of home residence'. There were significant differences noted, with fewer 'home' deaths observed in 'South Vancouver' and 'Midtown' (chi-square $p < .05$).

Figure 11 Place of Death for Vancouver Residents 1990-1993
All Causes of Death (excludes injuries/accidents) (N=11,524)
Described by Location of Home Residence



Location of Death: Cancer and HIV

Cancer Deaths

Figure 12 shows that by 1993 about 30% of deaths related to cancer were home deaths.

Figure 12 Place of Death for Vancouver Residents 1990-1993
Cause of Death: Cancer (N=3,631)

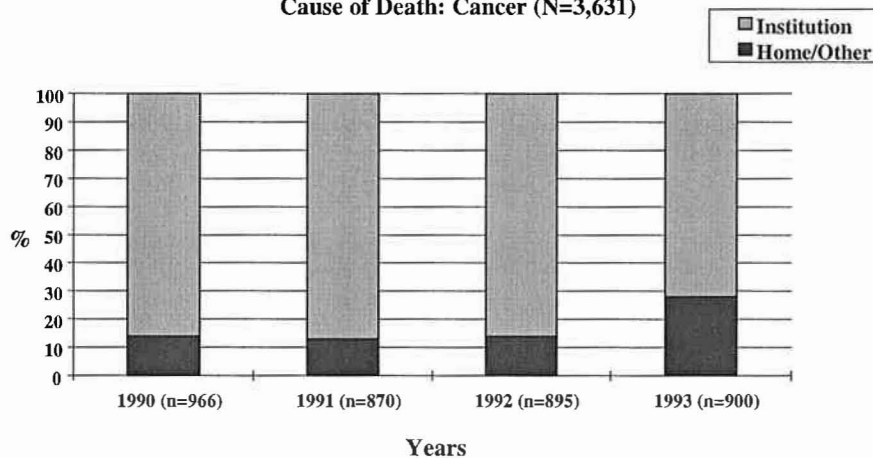


Figure 13 shows that there were virtually no differences with respect to gender and place of death for the cancer deaths (chi square $p > .05$).

Figure 13 Place of Death for Vancouver Residents 1990-1993
Cause of Death: Cancer (number of valid cases=3,406)
Described by Gender

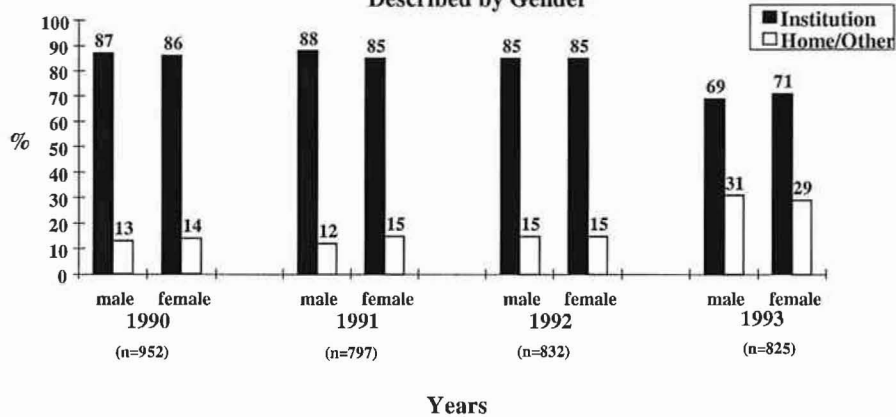
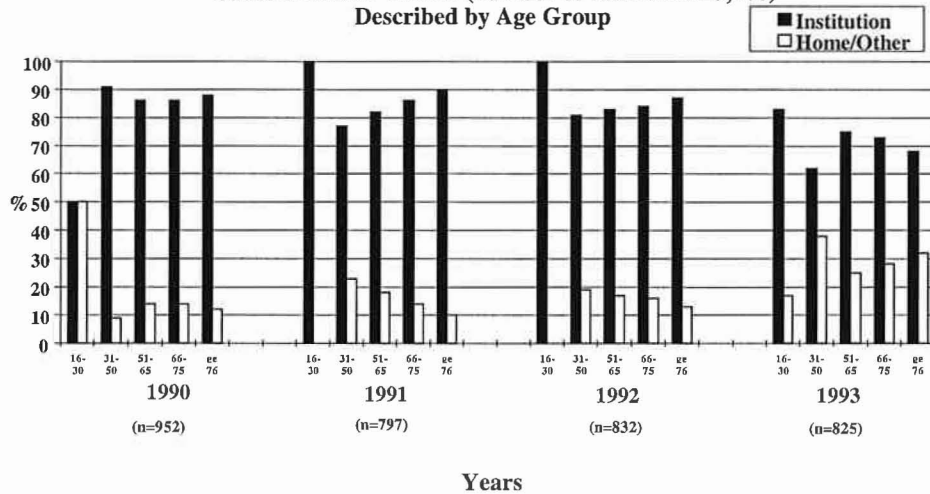


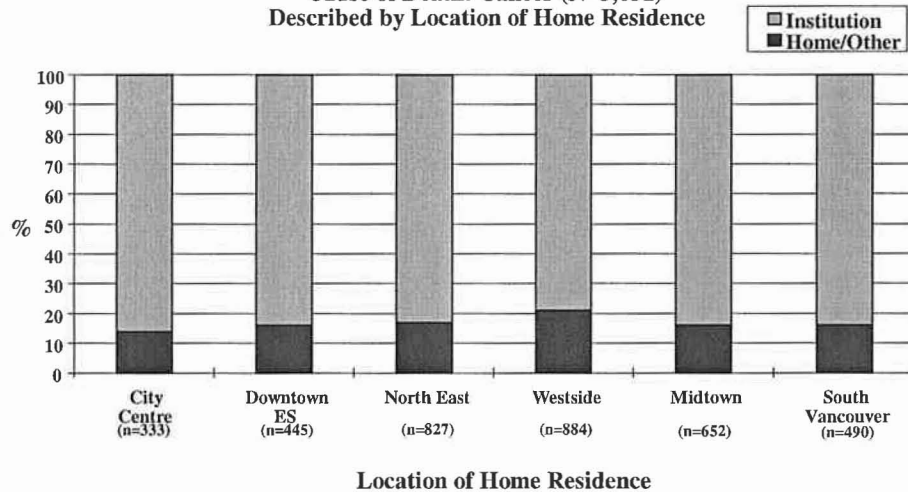
Figure 14 shows that for 1991 and 1992 the likelihood of dying in an institution increased with age (chi square $p < .05$).

Figure 14 Place of Death for Vancouver Residents 1990-1993
Cause of Death: Cancer (number of valid cases=3,406)
Described by Age Group



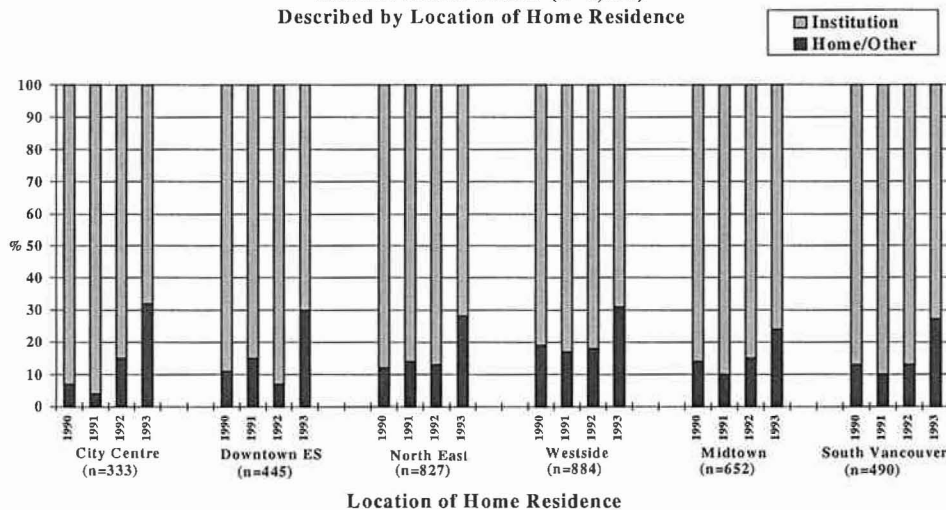
Figures 15 and 16 describe deaths related to cancer by location of home residence. Figure 15 shows a slightly higher proportion of home deaths amongst residents of the 'West Side' ($p < .05$).

Figure 15 Place of Death for Vancouver Residents 1990-1993
Cause of Death: Cancer (N=3,631)
Described by Location of Home Residence



When the data for cancer deaths were analyzed by year of death (see Figure 16) the results showed that there were differences in place of death, depending on the 'location of home residence' (chi square $p < .05$); however, each area was similar in that each showed an increase in home deaths over time.

Figure 16 Place of Death for Vancouver Residents 1990-1993
Cause of Death: Cancer (N=3,631)
Described by Location of Home Residence



A logistic regression procedure was applied to the data to determine if there were any variables which predicted 'place of death'. A separate analysis was undertaken for cancer and HIV deaths. With respect to cancer deaths the analysis suggested that some of the factors which determined place of death include the area of city in which the patient lived – individuals living on the 'West Side' were more likely to die at home, compared to individuals living in any other location.

With respect to contact with the publicly funded palliative care system, patients were almost twice as likely to die at home if they were clients with the V/RHB Home Hospice Program, compared to those who had no contact with the publicly funded palliative care system. Finally, those individuals who died in 1993 were almost 2.5 times as likely to die at home as those individuals who died in earlier years. The results of this analysis are shown in Table 3.

**Table 3 Logistic Regression Procedure for Place of Death
Major Cause of Death: Cancer (N=3,539)**

	Variable	Chi-Square	Odds Ratio
Location of Home Residence <i>(compared with West Side)</i>	City Centre	0.0028*	0.574
	Downtown East Side	0.0351*	0.701
	North East	0.0064*	0.698
	Midtown	0.013*	0.701
	South Vancouver	0.0119*	0.674
Age Group <i>(compared with Age Group ge 86 yrs)</i>	Age Group (16-50 years)	0.1354	1.411
	Age Group (51-65 years)	0.3359	1.209
	Age Group (66-75 years)	0.4259	1.162
	Age Group (76-80 years)	0.3132	1.226
	Age Group (81-85 years)	0.6888	1.088
	Marital Status	0.0401*	1.225
	Gender	0.873	0.985
Time <i>(compared with 1990)</i>	Year (1991)	0.8821	0.979
	Year (1992)	0.7315	1.049
	Year (1993)	0.0001*	2.574
Contact <i>(compared with Contact3 -- no contact)¹</i>	Contact1 ¹	0.0001*	1.88
	Contact2 ²	0.0001*	0.166

* indicates statistically significant results

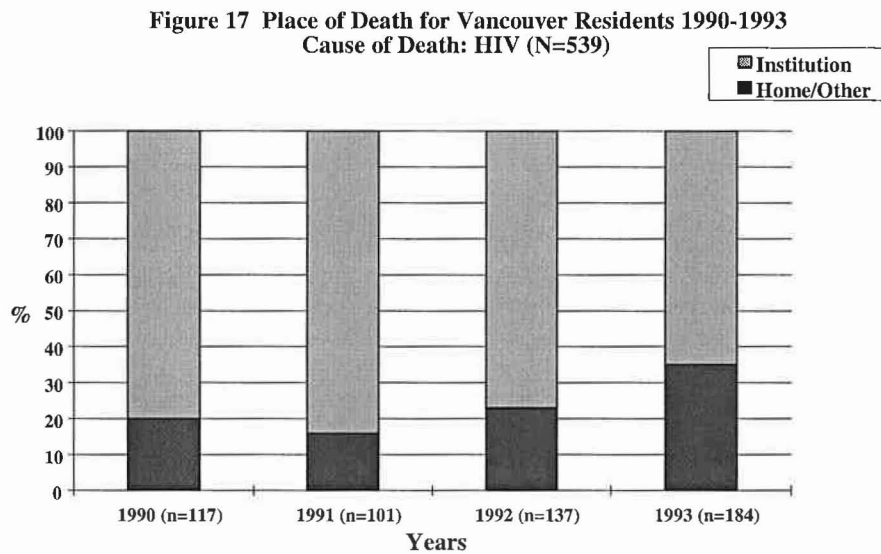
¹ in this particular analysis "Contact1" was defined as contact with the V/RHB Home Hospice Program -- there may or may not have been some contact with one (or more) of the other specialized hospice or hospital-based palliative care services (e.g., PCU, BCCA 5th floor, referral to a palliative care consult team)

² in this particular analysis "Contact2" was defined as contact with one of the following specialized hospice or hospital-based palliative care services: PCU, BCCA (5th floor), referral to a palliative care consult team

³ in this particular analysis "Contact3" was defined as no contact with any component of the publicly funded palliative care system in Vancouver

HIV Deaths

Figure 17 shows that by 1993 about 34% of AIDS deaths were home deaths.



With respect to age group and place of death, Figure 18 shows that there was an increased likelihood of dying in an institution which increased with age (chi square $p < .05$).

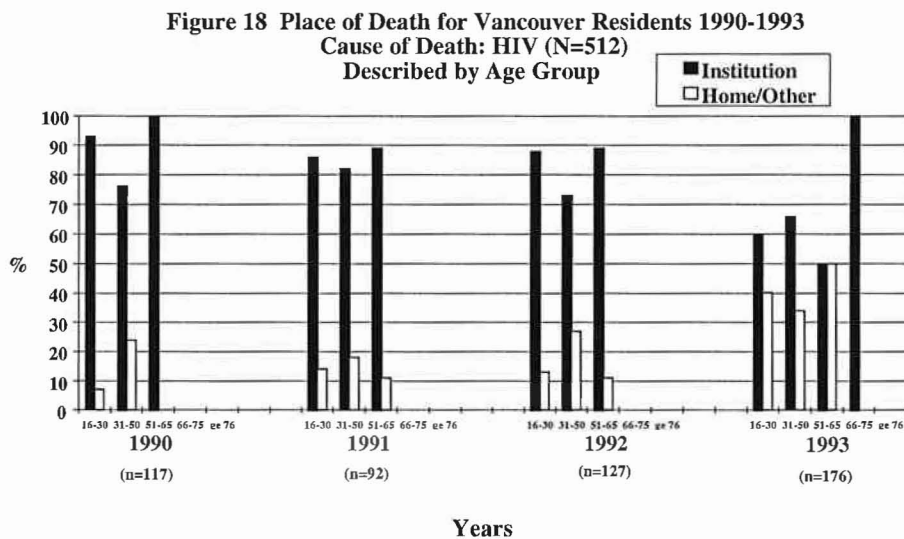
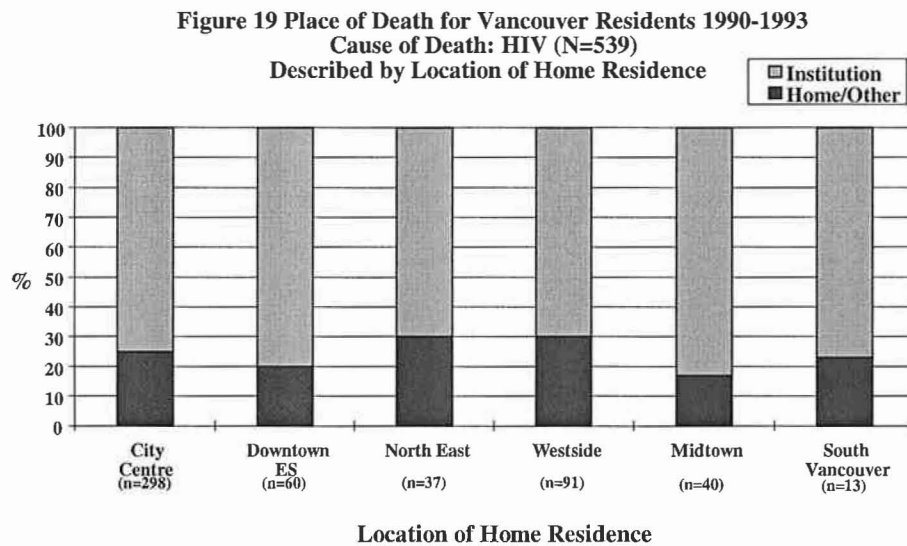


Figure 19 describes deaths related to HIV by location of home residence and shows a slightly higher proportion of home deaths amongst residents of the 'West Side' and 'North East' areas of Vancouver (chi square $p < .05$). Due to the small number of deaths for this group ($N=539$) the data were not analyzed by year of death.



With respect to HIV deaths the logistic regression analysis (see Table 4) shows that place of death was not dependent on the location of the patient's home residence or the age group of the patient. Individuals who died in 1993 were 2.3 times as likely to die at home compared to individuals who died in earlier years. Individuals who had some contact with specialized services within the palliative care system (i.e. contact with one of the following: PCU, BCCA (5th floor), referral to a palliative care unit) were less likely to die at home compared to those with no contact at all ($p=.03$ and odds ratio=.198). Interestingly, contact with the V/RHB Home Hospice Program did not seem to influence the location of death for HIV patients ($p=.0888$).

**Table 4 Logistic Regression Procedure for Place of Death
Major Cause of Death: HIV (N=533)**

	Variable	Chi-Square	Odds Ratio
Location of Home Residence <i>(compared with West Side)</i>	City Centre	0.8327	0.943
	Downtown East Side	0.1282	0.521
	North East	0.7857	1.12
	Midtown	0.215	0.543
	South Vancouver	0.6163	0.697
Age Group <i>(compared with Age Group ge 16 years and le 30 years)</i>	Age Group ge 31 years	0.5281	1.223
Time <i>(compared with 1990)</i>	Year (1991)	0.6493	0.847
	Year (1992)	0.4267	1.287
	Year (1993)	0.0025	2.385
Contact <i>(compared with Contact3 -- no contact)</i>	Contact1 ¹	0.0888	1.575
	Contact2 ²	0.0362*	0.198

* indicates statistically significant results

¹ in this particular analysis "Contact1" was defined as contact with the V/RHB Home Hospice Program -- there may or may not have been some contact with one (or more) of the other specialized hospice or hospital-based palliative care services (e.g., PCU, BCCA 5th floor, referral to a palliative care consult team)

² in this particular analysis "Contact2" was defined as contact with one of the following specialized hospice or hospital-based palliative care services: PCU, BCCA (5th floor), referral to a palliative care consult team

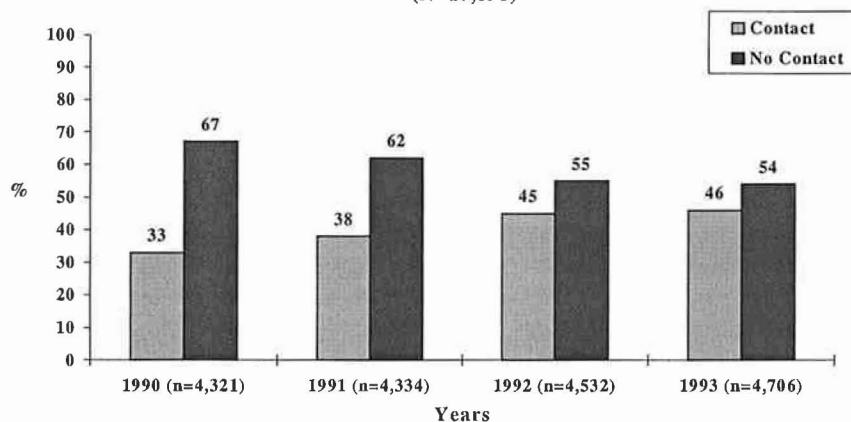
³ in this particular analysis "Contact3" was defined as no contact with any component of the publicly funded palliative care system in Vancouver

Unfortunately, the analyses of cancer and HIV deaths described above focused strictly on 'location of death'. It would be useful to distinguish between individuals, whose length of stay in hospital at the time of death was one or two days, and those whose length of stay was several days or weeks. The distinction is important because many individuals are able to remain at home until very close to the time of their death, but for personal reasons (e.g., religious, informal caregiver burnout, etc.) choose to die in hospital. In particular, it would be helpful to know to what extent length of stay in hospital at the time of death is influenced by use of formal support prior to hospitalization. This information would provide a more accurate picture of how pre-death home-based care impacts on the acute care system.

Other Causes of Death

Although the traditional concept of palliative care has focused on cancer, and more recently AIDS, data from this study suggests that palliative care may have a much broader focus. Figure 20 shows that 33% (n=1,425) of the deaths in 1990 had 'formal contact' with the Vancouver palliative care system. This increased to 38% (n=1,646) in 1991, 45% (n=2,039) in 1992 and 46% (n=2,164) in 1993. This analysis included all causes of death and included both Vancouver and non-Vancouver residents (N=17,893).

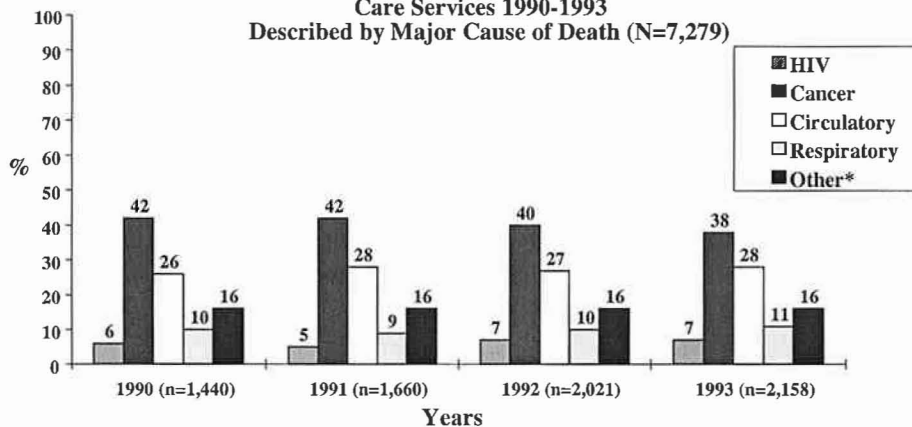
Figure 20 Proportion of Study Population¹ Who had "Formal Contact" with Vancouver-Based Publicly Funded Palliative Care Services 1990-1993 (N=17,893)



¹ this analysis included Vancouver and non-Vancouver residents

Forty-eight percent of patients seen by the Vancouver palliative care system were cancer or AIDS patients. Figure 21 shows that approximately 26% of patient contacts were related to those with circulatory disease and approximately 10% to those with respiratory disease. The cancer/HIV group accounted for almost half of the utilization of palliative care services, while those with circulatory disease accounted for about 25% of the utilization.

Figure 21 Proportion of Study Population Who had "Formal Contact" with Vancouver-Based Publicly Funded Palliative Care Services 1990-1993 Described by Major Cause of Death (N=7,279)



* "other" refers to all other causes of death including those related to the digestive system, accidents and injury

Conclusions and Recommendations

The history of palliative care in Canada and elsewhere has been closely associated with the treatment of patients with terminal cancer. More recently, with the advent of AIDS, there has been wide recognition for the role of palliative care as a component in AIDS care. For the period 1990-93, it would appear that there has been reasonable (and improving) accessibility to the formal palliative care system in Vancouver for patients who died of cancer/AIDS. The data indicate that by 1993, about 77% of Vancouver residents who died of cancer/AIDS had some contact with the palliative care system. Of particular note, there did not seem to be a strong socio-economic gradient (as measured by patient's geographic residence) associated with the degree of access to palliative care services. It is unclear at this point whether the trend seen in the 1990-93 period will continue to increase, or whether there will be a leveling off, since one would anticipate that even for cancer/AIDS patients, that not every patient would require formal palliative care services.

This study did not quantify the length of 'contact' with the palliative care service, the timing of the contact relative to the date of death, nor the qualitative aspects of the palliative care service.

Recommendations:

1. Maintain and build upon the existing palliative care services, which seem to be providing good access to care for cancer/AIDS patients.
2. Continue data analysis of utilization of palliative care services for the 1993-97 period, including Richmond as well as Vancouver. Expand the study to include more information on the length of contact, timeliness of contact, appropriateness and effectiveness of palliative services provided. Include estimates of costing for the various components of the formal palliative care services.

There are differences in the patterns of use of palliative care services according to the type of cancer, e.g. 70% contact for lung cancer Vs 85% contact for breast cancer. Further study of such patterns may be useful to uncover any gaps in services, and also plan for future needs for palliative services.

Recommendation:

3. Further study of the patterns of delivery of palliative care services according to the site of cancer, including referral patterns.

Although the data in this study is somewhat limited, it does suggest that patients known to one component of the system are not necessarily known to other parts. In particular, one would expect that most of the patients who had hospital admissions (either to the PCU or other parts of the hospital but seen by the consult service) would be known to the community Hospice Program. However, it appears that 30-50% of such contacts were not seen by the community Hospice Program (it is understood that there would be a certain proportion of these patients who initially presented to hospital with their terminal diagnosis and died in hospital; therefore, not returning to the community).

Recommendations:

4. Continue to inform the general community, and also physicians as to the availability of the Home Hospice Program.
5. Improve the coordination/integration of community and institutional (both hospital and long term care facility) palliative care services.

One of the thrusts of palliative care, and in particular the Home Hospice Program, has been to support the patient and their families if they choose to remain at home to die. By 1993, about 30% of cancer/AIDS deaths were at home (increasing over the 1990-93 study period). Regression analysis of the data shows that for cancer deaths, there was much higher likelihood of a home death if there was contact with the Home Hospice Program. Of interest, a similar finding was not found for AIDS patients, suggesting very different patterns of dying and health care/social factors. The data, although suggesting few deaths from cancer/AIDS in long term care facilities, did not allow more detailed analysis.

Recommendations:

6. Maintain and enhance the Home Hospice Program, both increasing the availability of adequate home care staff and shift care nursing resources to support palliative care for people at home.
7. More detailed study of deaths in Long Term Care Facilities.

While the focus of this report was on patients who died of cancer/AIDS, it became clear that palliative care has a much broader focus. Thus, while some 90% of patients in the PCU's had cancer/AIDS, when you include the community contacts, over 50% of the patients who had contact with the formal palliative care services died from non cancer/AIDS illnesses (most notably circulatory and respiratory ailments). Further study is required as to whether the palliative care needs of the non cancer/AIDS patients are being met, and even whether there is adequate recognition of such needs.

Recommendations:

7. Further study of non cancer/AIDS patients who have contact with palliative care services, and also whether there are non cancer/AIDS patients who may have benefited from palliative care services who did not have contact.
8. Based on the recommended further studies and an improved palliative care information system, develop a regional plan for services in Vancouver/Richmond.

References

Canadian Palliative Care Association. Palliative Care: Towards a Consensus in Standardized Principles of Practice, 1990.

British Columbia. Royal Commission on Health Care and Costs. Closer to Home. Victoria, 1991.

Cardiff K, LeMire N, Robens-Paradise Y, Fryer M. Evaluation of the Closer to Home Program: Integrated Palliative Care Program. Vancouver/Richmond Health Board, Vancouver, March 1997.

Appendix A

Palliative Care Services in Vancouver

Palliative care is provided in a variety of settings: home, "hospice", general hospital ward, or hospital palliative care unit. The palliative care team varies somewhat according to the setting, but generally includes nurses, physicians, social workers, pastoral care, physiotherapy (PT)/occupational therapy (OT), music therapy (in some settings), pharmacist, dietitian, volunteers and administrative and support services. This section provides a descriptive summary of the formalized palliative care services in Vancouver over the 1990-93 study period:

1) Hospitals

- Palliative Care Units (PCU's) at Vancouver Hospital and St. Paul's Hospital
- B.C. Cancer Agency (BCCA)

2) "Hospice"

- May Gutteridge Community Home (May's Place)
- Normandy House

3) Community home care

- Vancouver Health Board Home Hospice Program

Hospitals

The hospital based palliative care units provide terminal care for patients who require its resources to deal with symptom management, and/or are unable to remain at home or other facility. A percentage of these patients die on the PCU. Patients admitted to the PCU for acute symptom management (e.g. pain or nausea) are discharged once they are stabilized. Thirdly, there is a group of patients who come to the PCU for respite care, which allows care-givers and family members to take a break from patient care. The policy of both PCU's in Vancouver is that all admissions are DNR (do not resuscitate in case of cardiorespiratory arrest).

Vancouver Hospital PCU and Consult Service

The PCU was established in 1982, and consists of a 17 bed unit on the 3rd floor of Willow Chest Pavilion at Vancouver Hospital. Generally, one bed is kept available for emergency admissions from the community, and a maximum of two beds at any given time are used for respite care. The rooms are single (seven) or doubles (five), with washrooms in each room. Allocation of the single rooms is based on need, with no additional charges. Efforts are made to provide as home-like an environment as possible. The palliative consult service consists mainly of the palliative care physician and/or clinical nurse specialist who see patients requiring palliative care on other wards of the hospital or the Cancer Agency. Many of these patients are later transferred or admitted to the PCU.

St. Paul's Hospital PCU and Consult Service

The PCU was established in 1989. It consists of a 15 bed unit on the 10th floor, D wing of St. Paul's Hospital. About 40-50% of the beds are used for AIDS patients. Two beds are allocated for respite care. An effort is made to keep one bed available for emergency admissions. There are four single rooms, two double, and one 3-bed room, and one 4-bed room. Allocation of the single rooms is on an as-need basis, with no additional charges. Palliative care physicians do consultations to other units in the hospital, and to the Emergency on request. A palliative care outpatient clinic is also held once a week.

B.C. Cancer Agency

The B.C Cancer Agency plays an important role in the palliative and supportive care of cancer patients throughout the province. Estimates based on 1980 stats from the U.S. suggest that seven percent of cancer patients will receive palliative chemotherapy. Between 1985 and 1991, 45.6% of radiation therapy courses in B.C. were palliative.

Palliative care is provided in both inpatient and outpatient settings in the BCCA centres, including the Vancouver Centre. The Cancer Agency in Vancouver has 60 inpatient beds, and at any given time there are about 15 patients who are likely to require palliative care services.

Hospices

Normandy House

This 10 bed unit opened in 1992 (and closed in 1998) for patients with AIDS who did not require hospital care but who could not remain in the community. Although one bed was originally designated for respite, the demand for beds resulted in all 10 beds being used for permanent residents for most of the time. Thus, some patients were admitted for terminal care, some patients for a structured, safe place to live, and on occasion, patients were admitted for one-two week respite.

May's Place

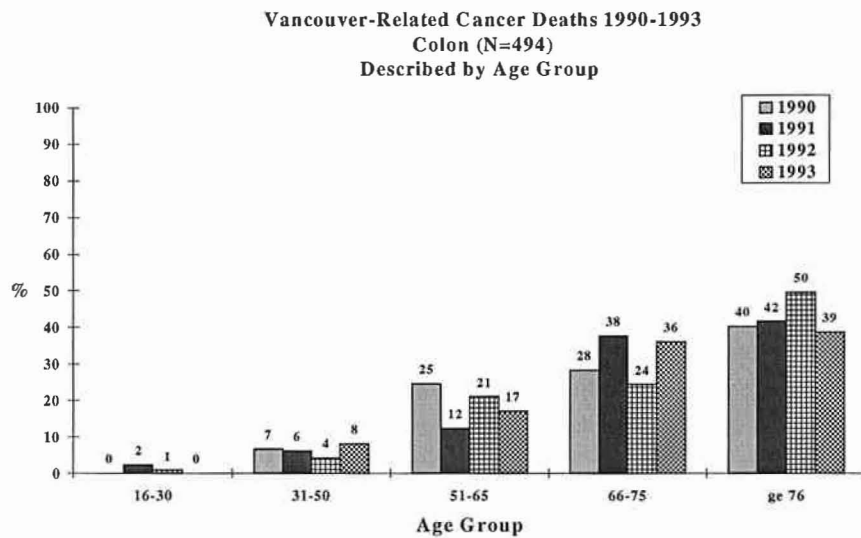
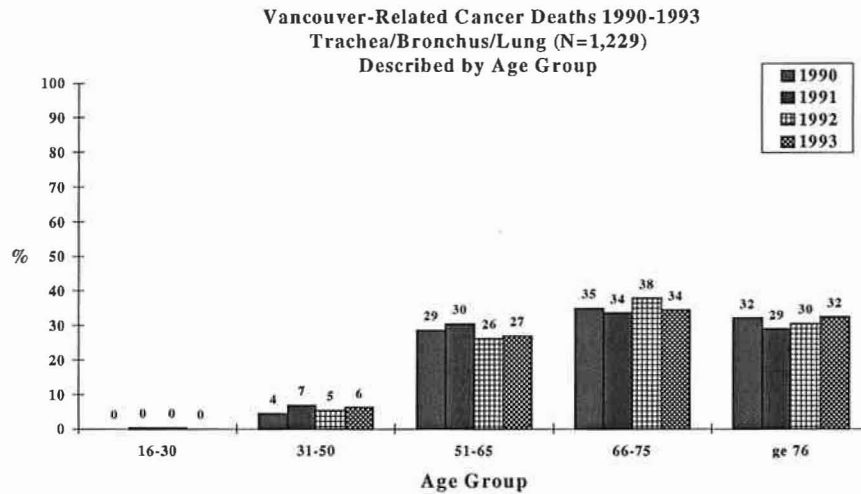
May Gutteridge Community Home or "May's Place" began in October 1990. It is located in Vancouver's downtown Eastside, on the top floor of a three storey building. There are six beds (two with private baths and the other four beds share two baths). May's Place is a non-profit, community based facility that provides comfort care to adults who are facing the end stages of terminal illness. Residents are admitted with the full understanding that their disease is terminal and that active treatments will not be pursued while at May's Place.

Community Home Care

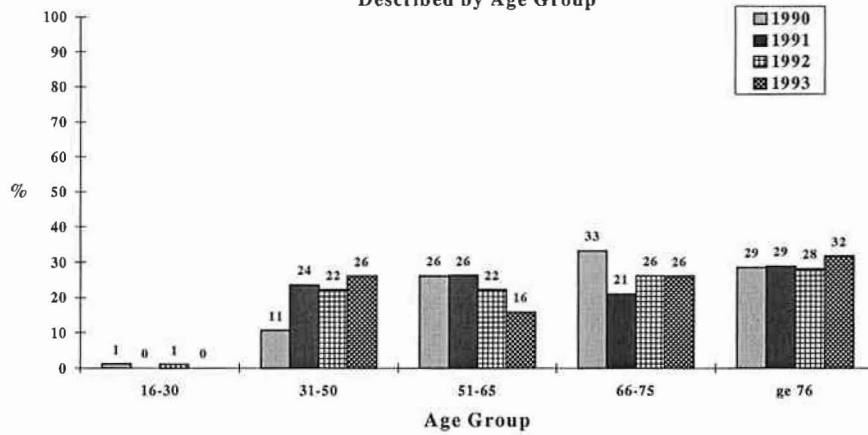
The Vancouver Health Board Home Hospice Program was started in 1983. Being a community based program (i.e. patients are seen in their homes), there is no facility with "beds". The Hospice Program provides support and palliative care services for patients in the "community". These are primarily at home, but may be in long term care facilities as well.

Appendix B

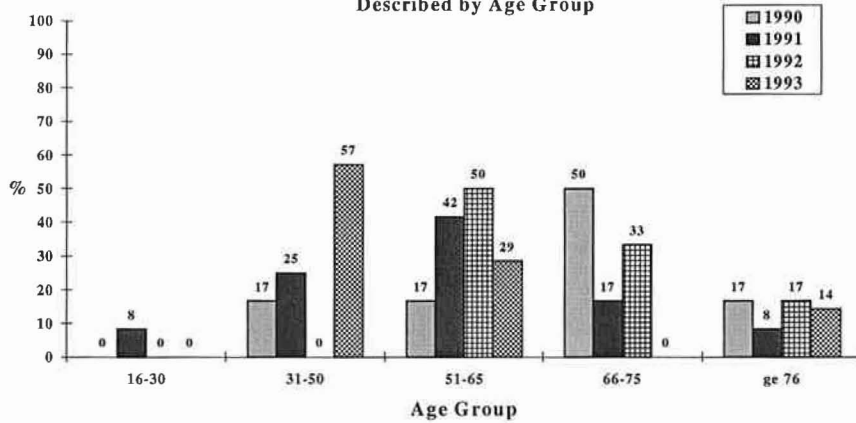
Vancouver-Related Cancer Deaths – Described by Age Group



Vancouver-Related Cancer Deaths 1990-1993
Breast (N=347)
Described by Age Group

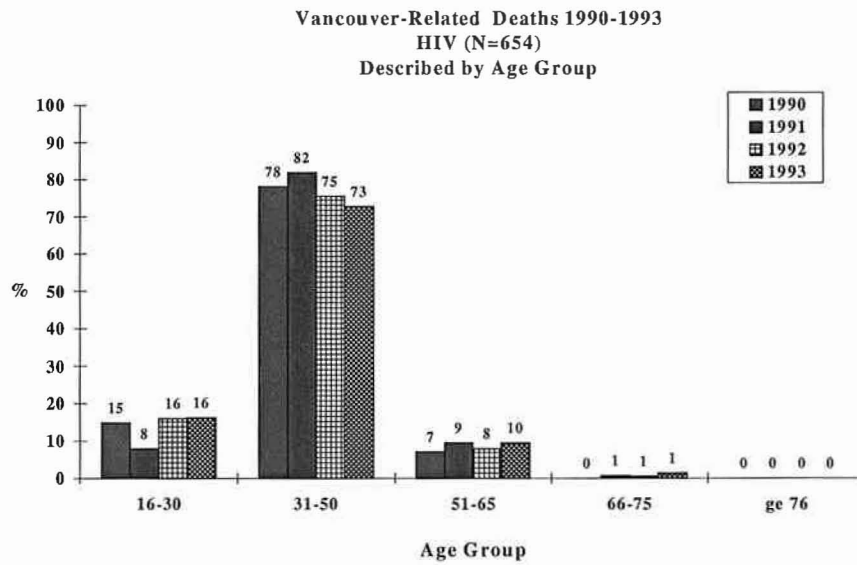


Vancouver-Related Cancer Deaths 1990-1993
Prostate (N=254)
Described by Age Group



Appendix C

Vancouver-Related HIV Deaths – Described by Age Group



Appendix D

1 City Centre

- West End
- False Creek
- Sth. Granville
- Central Business District
- Yaletown & Downtown Sth.
- Fairview

2

- Downtown Eastside
- Strathcona
- Grandview Woodlands
- Gastown
- Citygate

3

North East

- Hastings Sunrise
- Cedar Cottage
- Renfrew Collingwood

4

Westside

- Musqueam
- University Endowment Lands
- West Point Grey
- Kitsilano
- Dunbar-Southlands
- Arbutus Ridge
- Shaughnessy
- Kerrisdale

5

Midtown

- Mt. Pleasant
- Sth. Cambie
- Little Mt./Riley Park
- Kensington

6

Sth. Vancouver

- Oakridge
- Merpole
- Sunset
- Victoria Fraserview
- Killarney
- Champlain Heights

