

**PLACE OF DEATH CORRELATED  
TO SOCIO-DEMOGRAPHIC FACTORS  
IN A SOUTH AFRICAN HOSPICE**

**BY  
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University of Cape Town  
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IN A  
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**P.A. KRAUS**

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**In memory of my father,  
Paul Robert Kraus  
- our time together was short,  
but I will always be the richer for it.**

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#### **ABBREVIATIONS**

<b>UK</b>	<b>United Kingdom</b>
<b>USA</b>	<b>United States of America</b>
<b>NHS</b>	<b>National Health Service</b>
<b>AIDS</b>	<b>Acquired Immuno-Deficiency Syndrome</b>
<b>MPhil</b>	<b>Master of Philosophy</b>
<b>Std Dev.</b>	<b>Standard Deviation</b>

# ABSTRACT

**Background:** The palliative care literature continually supports the view that home remains the preferred place of death of most patients with terminal illness<sup>(11, 22, 33, 43, 58, 68)</sup>. However, it also reports that in many countries, palliative care patients sometimes change their minds with regard to this preference<sup>(33, 68)</sup>. A variety of factors appears to intervene preventing patients from dying at home.

The socio-demographics of patients presenting to St. Luke's Hospice, and how this relates to place of death, has never been evaluated. It is believed that in this setting, there is ironically more likelihood of many patients from poorer socio-economic circumstances dying at home. This could be as a result of living with larger families, more difficulty in obtaining access to institutional beds and cultural beliefs.

**Aim:** To determine factors which influence the place of death of patients referred to St. Luke's Hospice over a one year period.

**Method :** This is a prospective, descriptive, quantitative study of the place of death of new patients referred to St. Luke's Hospice, a palliative care service with an inpatient unit and home care programme, between 1 May 2001 and 30 April 2002. Only those patients who died within this time frame were analysed.

A "teleform" was designed with the assistance of the Alberta Cancer Board Palliative Care Research Initiative. This form allowed the information to be entered directly into a database for analysis. The variables to be analysed with regard to place of death include :-

- Age
- Gender
- Race
- Social Structure
- Category of Patient i.e. State or Private
- Formal Educational Level
- Duration of Illness
- Palliative Performance Scale

**Result:** This study suggests that almost two-thirds of patients with a terminal illness can be supported in their homes by a home care programme, without referral to an institution. These statistics correlate well with death statistics of other palliative home care services in industrialised countries.

Variables such as age, gender, category of patient, palliative performance scale and duration of illness bore no significant relationship to place of death. However, place of death was strongly associated with race, social structure and socio-economic status. Interestingly, black patients were more likely to die in an institution.

**Conclusion :** Studying socio-demographic factors related to place of death is only one aspect of evaluating and determining the needs of the terminally ill and their families in South Africa.

Should or can more people die at home? Are home deaths feasible, and if so how?

The task that lies ahead of us in South Africa is to decide what kind of palliative care or other service is optimal, cost effective and appropriate to meet the needs of our multi-cultural society.

# **PLACE OF DEATH CORRELATED TO SOCIO-DEMOGRAPHIC FACTORS IN A SOUTH AFRICAN HOSPICE**

## **CHAPTER 1**

### **INTRODUCTION**

The palliative care literature continually supports the view that home remains the preferred place of death of most patients with a terminal illness<sup>(11, 22, 33, 43, 58, 68)</sup>. However, it also reports that in many countries, palliative care patients sometimes change their minds about this preference<sup>(33, 68)</sup>. A variety of factors may appear to intervene to prevent patients from dying at home.

The socio-demographic factors of patients presenting to St Luke's Hospice, and how this relates to place of death, has never been evaluated. It is believed that in our setting, there is more likelihood of patients from poorer socio-economic circumstances dying at home. This could be as a result of, among other things, being part of larger families, more difficulty obtaining access to institutional beds and/or cultural beliefs.

### **SETTING**

Cape Town is located in the Western Cape Province of South Africa. The population of the Cape Town City Centre is 1.123.188 million, and that of the Cape Town Metropolitan Area is 3.080.874 million<sup>(52)</sup>. Although the Metropolitan Area includes the Helderberg, Oostenberg, Blouberg, South Peninsula, Tygerberg and Cape Town Central substructures, St. Luke's Hospice does not cover the Helderberg, Oostenberg and part of the Tygerberg substructure. The racial breakdown (see figure 1) for the Metropolitan Area is Asians 1.5%, Blacks 32.3%, Coloureds 45.4 % and Whites 20.8%<sup>(52)</sup> (based on population data of Professor Dorrington, Department of Actuarial Science, University of Cape Town). This breakdown differs from the one covered by St Luke's Hospice, which is Asians 1.8%, Blacks 41.7%, Coloured 40.3% and Whites 16.2%. The religious breakdown of Cape Town is Christian 90%, Muslim 6%, and Jewish, Hindu and others 4%<sup>(16)</sup>.

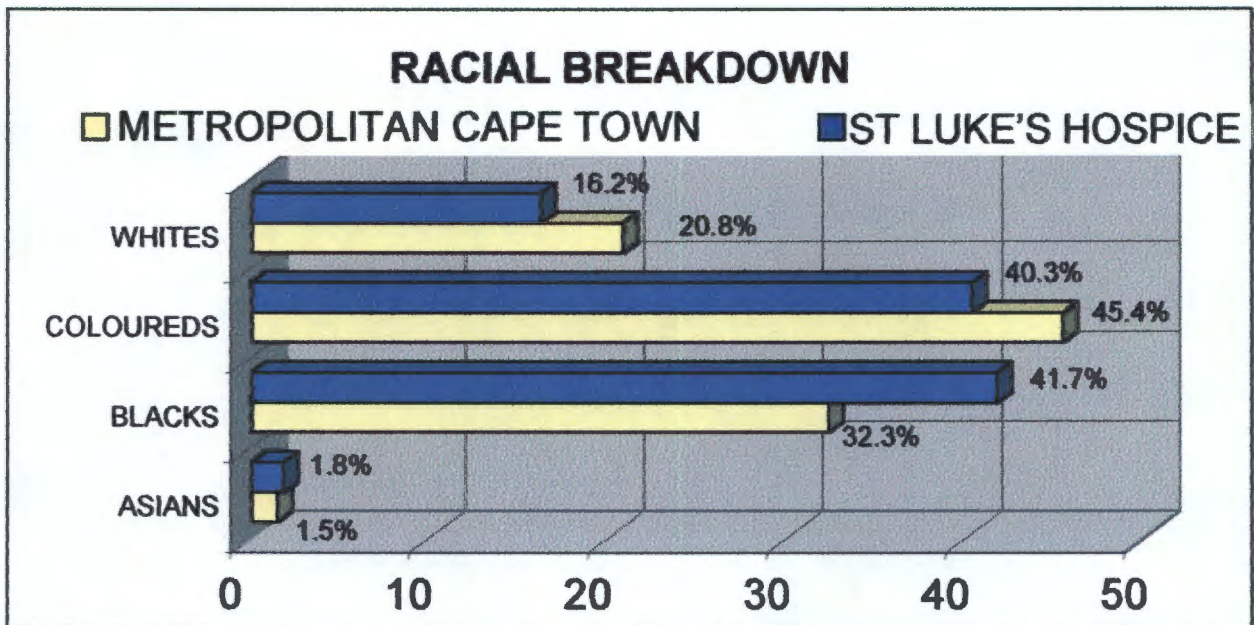


FIGURE 1

The mission statement of St Luke's Hospice is to provide, within the greater Cape Town area, facilities and services to respond to the physical, emotional, social and spiritual needs of individuals and their families having an illness which no longer responds to curative treatment and having a short life expectancy; and to demonstrate, teach and promote values, skills and knowledge to this end.

St Luke's Hospice provides palliative care to the population of greater Cape Town, suffering from a terminal illness. Diseases managed in 2001 were cancer 90,8%, AIDS 7,2%, MND/ALS 1,4%, end stage renal disease 0,3 % and fibrosing alveolitis 0,3%. New referrals have been in excess of 1000 patients per year since 1996 with the highest being 1098 in 2000. Total referrals for the year 2001 were 1038 of which 72% were state patients and 28% private patients. (This was collected from referral data by the Chief Medical Officer at St. Luke's Hospice).

St Luke's Hospice has a 12 bed inpatient unit for the care of terminally ill patients which is staffed by an interdisciplinary team consisting of a doctor, nursing staff, social worker and spiritual counsellors of different denominations. In the early 1990s, when the emphasis of health care became more community orientated, St Luke's developed 12 community branches in different suburbs of Cape Town. Each branch has a home care sister, social worker and

volunteers. The medical backup is provided by the hospice doctor running a weekly or biweekly outpatient clinic in the branch, and/or by the patient's state or private primary care physician. The inpatient unit serves as a back up to the home care community service, and as a result, the staff in the unit and the community teams work very closely with one another.

South Africa is a large, diverse nation with a multi-cultural population. Decades of colonialism and apartheid have resulted in two contrasting societies: one highly developed, educated and relatively well off; the other underdeveloped, illiterate and poor. The needs of the terminally ill patients in South Africa are addressed by a mix of first and third world health care options: one private, relatively well equipped and servicing the well-off, the other public, poorly equipped and under-serviced providing care for the remainder of the population. Hospices in South Africa fill a void in the care of patients with a terminal illness across a broad racial and financial spectrum.

## **AIM OF STUDY**

The aim of this study is to determine factors which influence the place of death of patients referred to St Luke's Hospice over a one-year period.

The specific factors related to the place of death are age; gender; race; formal education level; social support structures; category of patient [state/private]; duration of illness, and palliative performance scale at time of registration with the hospice.

## **THE RATIONALE FOR THE STUDY**

For both the patient and the family, quality of care and place of death are two essential components of terminal care. There should be no need to make a choice between a good home, hospital, hospice or nursing home. All these facilities are needed; and crucial to the planning of appropriate services in a developing country is an understanding of the trends in place of death, particularly in the different age, ethnic and socio-economic groups.

In the early 20<sup>th</sup> century, most people died at home but that number has fallen progressively in the highly industrialised countries of Europe and North America. In England and Wales, from

1965 to 1987, cancer deaths at home fell from 37% to 27%, whilst those in hospital rose from 60% to 68%<sup>(39)</sup>. In America 61% (Foley 1997- as cited in O'Henley, Curzio & Hunt 1997)<sup>(57)</sup> and in Australia 65% (1979) of deaths from cancer occur in hospitals<sup>(4)</sup>.

Thorpe (cited in O'Henley et al)<sup>(57)</sup> suggests three main reasons for this trend :

- More elderly people live in nursing or residential homes
- More people live alone and have smaller families
- There are fewer people to share the burden of looking after the terminally ill

Since the advent of AIDS in Sub-Saharan Africa, there is a greater emphasis on providing homebased care, which has necessitated changes in health care. The focus of this type of care is on comprehensive care with terminal care being merely one aspect. The downscaling and decentralisation of existing facilities has come about as a result of limited resources in the country. There is no specialised palliative care service planned by the state and to date there is no fixed direction in the Healthcare Policy of the Western Cape. As a result, hospices and other non-government organisations provide terminal care.

Factors that may influence place of death in our society include:

- **Cultural Variability**

Culture may be defined as:

*"A relatively specialised lifestyle of a group of people, consisting of their values, beliefs, artefacts, ways of behaviour and communication (De Vito 1992)"* <sup>(56)</sup>

Culture is learned and passed on from one generation to the next. This fact is important in understanding culture, and its influence should never be underestimated. Culture includes ethnic and religious factors, which strongly affect the dying process and the death itself. Despite the strong associations between religion and culture, they remain two different entities. Understanding, recognising and accepting differences in, as well as across, cultural groups is crucial to future health care planning in South Africa. Kagawa-Singer stated that cultural beliefs and behaviours will significantly affect how individuals meet the adversity of impending death (as cited in Boyle)<sup>(47)</sup>.

In **Black nations** there is an interconnectedness between the individual, the community, the environment and the ancestors. A belief in an imbalance between any of these aspects can result in sickness and therefore one of the key aspects of this culture is the focus on “who” rather than “what” causes disease. Two components of African traditional healing are therefore ascertaining who or what is causing the illness. This is done by rituals, ministrations to neutralise the sorcerer or herbal medicines in an attempt to re-establish an equilibrium between the physical, social and psychological<sup>(1)</sup>. While “African” tradition is diverse, there are strong unifying factors in the belief of a supernatural power, the life hereafter, the importance of ancestors and the performance of rituals<sup>(45)</sup>. Many black patients believe that an illness is a punishment from the ancestors.

Despite the influence of western education and culture, and the fact that there are Christian converts today, as well as traditionalists in Black African religion, the patterns of behaviour and belief continue to tend to be traditional,<sup>(45)</sup> especially in a time of crisis.

Many cultures of the black nations in Africa are “cultures of acceptance”. Despite cultural differences in expressions of symptoms, for example, the Zulu nation are a very stoical people, these nations are very accepting of life threatening illnesses and do not have the same issues around dying as westerners.

In the Black African context, home is regarded as a physical structure which includes the biological, sociological and spiritual roots of the individual. On the whole, this group of patients prefers to be cared for at home by their own family, and to die at home. This allows for the traditional customs and rituals of their clan to take place. Indeed, anyone buried away from the clan’s burial ground is believed to have been deserted by the community and may present a problem for the clan in future.

The three main reasons why the black population avoid hospitals when they have a terminal illness are<sup>(45)</sup>

- Hospitals are seen as places of healing and curing.
- The dying person’s wishes are not always addressed.
- Traditional approaches and rituals are not always respected.

**Muslims** believe that death is God's will and they generally prefer to die at home. This is particularly the case with patients older than 50 years, as shown in a pilot study by Hosking et al at St Luke's Hospice<sup>(35)</sup>. Hospitals are seen as places of healing, but as long as customs and rituals are respected and adhered to, Muslims have no objection to dying there.

Muslim patients have in the past been reluctant to be admitted to the inpatient unit at St Luke's Hospice; the reasons were<sup>(66)</sup>

- The stigma associated with cancer.
- St Luke's traditionally being seen as a Christian, white, elitist organisation.
- A "death house" – it must be noted that this comment represents a general perception in the areas serviced by the hospice, and is not unique to the Muslim people.

A special emphasis is put on the sanctity of life in the Jewish tradition, so preservation of life becomes of supreme importance<sup>(63)</sup>. This does not mean that death is not recognised as a part of God's plan but Jews believe that everything possible should be done, within reason, to preserve life. As a result, death in a hospital is more likely than in a hospice.

In summary, therefore, it can be seen that differences in beliefs can lead to different choices of health care service and different places of death. On the whole, Whites, Coloureds and Asians tend to seek western medical care while the Black African seeks a traditional healer, instead of, or in addition to, westernised medicine.

## • **Resources**

Key issues include :

- Accessibility to health care is a major problem for large groups of the population because of the lack of a cheap, reliable and efficient transport system.
- The high rate of crime in some of the areas serviced by St. Luke's Hospice results in poor home care services during the day and no access to support at night. Even ambulances appear to have "no go" areas as a result of crime.
- The lack of telephones complicates the follow-up of patients by the primary care physician and limits the patients' access to health care services and support.

- Shortages of staff and support personnel at state institutions, especially in the rural areas, limit the accessibility and quality of care for the patients.
- The limited supply of medication dispensed at community hospital clinics and at day hospitals restricts the care provided there for the terminally ill, resulting in patients being referred back to the tertiary institutions.

- **Communication**

Despite there being eleven official languages in South Africa, there is not one that is common to all. This results in the need for interpreters which can complicate the sensitive communication about diagnosis, prognosis, disease process, care plan and cross-cultural issues. The problem is further compounded by a high illiteracy rate in some population groups.

- **Teamwork**

Teamwork does not exist in all settings and professional boundary issues interfere with effective care giving. There continues to be a lack of cooperation between the state, the private sector, and the non-profit organisations, which influences patient care. Necessary referrals, for example, are not made to appropriate community resources or professionals.

In the South African context, the choice of place of death may possibly differ from that of developed countries owing to factors such as :

- The preferred place of death in the black African culture is in the home. This is because this category of patient believes that their ancestors surround them at home and that, rather than in unfamiliar surroundings, home is a better place for their ancestors to receive their spirit. This patient group tends to belong to larger families and also forms the larger part of the poorer socio economic group that have more difficulty obtaining access to institutional beds.
- Most of the practicing Muslims belong to the coloured population and prefer to be at home surrounded by family and friends before death. This ensures that all the appropriate prayers and rituals are carried out.

- In the white population, an increase in institutionalised deaths may be because of the increase in the emigration rate, which results in more elderly people living alone and smaller extended families and/or fewer family members sharing the care of the dying patient. In this group of patients, financial circumstances allow for wider choices of health care services.

### **LIMITATIONS OF THE STUDY**

- This is an objective study into the place of death over a one year period of patients in the St. Luke's Hospice system, and only describes what happened to those patients. It is not representative of the general population of Cape Town.
- Owing to the sensitivity around asking certain questions, data about choice of place of death was not collected. For the same reason, in some communities questions about formal education levels resulted in incomplete data collection.
- A subjective analysis to trend of place of death is impossible because perceptions and attitudes of patients and families to the various places of death are unknown.
- As only two of the St Luke's community branches are in predominantly black areas, there is a possibility that the numbers are too small to draw conclusions.
- This study was performed on a cohort of patients that was cared for by a palliative care service, and is not population based. Hospice participation in the literature is one of the strongest variables related to whether or not a patient dies at home<sup>(18, 23, 53)</sup>. Whether this is causal or selection bias will not be able to be determined. In comparison to the general population, are hospice patients people who prefer to die at home?
- The new death certificate form on which place of death is recorded, was introduced into South Africa in July 2000 by the Department of Health. It is still not possible to compare trends of place of death between hospice patients and the general population of the greater Cape Town as neither the Department of Health nor the Death Registry Office collates this data.

- The patients' occupations were not collected, making it difficult to use recognised social status scales e.g. O.D. Duncan's Socio-economic Index, Siegel's Prestige Scores, Nan-Powers Socio-economic Status Scores. Education level and patient category on a financial breakdown are used as indices for socio-economic status. Most scales use occupation and a combination of education, income and/or prestige.
  
- No comparison can be made of service provision and outcome between St. Luke's Hospice and conventional home nursing programmes due to lack of auditing of either.

## CHAPTER 2

### LITERATURE REVIEW

*'Today the man best protected against setting the stage for his own dying is the sick person in critical condition. Society acting through the medical system decides which and after what indignities and mutilation he shall die.'* <sup>(37)</sup>

To date, most of the studies done on place of death have been carried out in developed countries and these have shown a wide distribution of figures showing that the majority of cancer patients die in hospital. This is in contrast with the early 20<sup>th</sup> Century when most people died at home.

Regardless of whether patients with a terminal illness die at home, they usually spend most of their time there. Patients should not have to choose between good home care and good institutional care; they need both. Therefore the understanding of the trends in place of death of a particular town, city, region or country can be crucial to the planning of appropriate health care services.

The subject, place of death correlated to socio-demographic factors, was subdivided into appropriate headings. These formed the inclusion criteria for articles. Specialist palliative care journals at St. Luke's Hospice were hand searched. The hospice has four journals, namely Palliative Medicine, Journal of Palliative Care, Journal of Pain and Symptom Management and the International Journal of Palliative Nursing, dating back to 1994.

Bibliographies and reference lists were studied. These articles/chapters of books were sourced from available journals at the University of Cape Town Medical School Library. Journal articles or book chapters, not available in South Africa, were sourced through:

- Dr. Paul Glare, Head of Palliative Care, Royal Prince Alfred Hospital, Sydney Cancer Centre, Australia.
- Ms. Denise Brady and Ms. Avril Jackson, Hospice Information Centre, St. Christopher's Hospice, London.
- Dr. Robin Fainsinger, Director, Division of Palliative Care Medicine, Department of Oncology, University of Alberta, Canada.

Further articles were identified from a systematic search of computerised databases (Pubmed, Silverplatter Medline). No local articles relating to place of death were found.

Other topics read included domiciliary care, different palliative care services, culture, religion and anthropology.

## **CHOOSING WHERE TO DIE**

The choice is often a compromise between what the patient wants and what is possible.

- **Home**

Dying at home enables patients to feel that their choice is being exercised and that they have some control of their destiny. People have a right to die with dignity in their own way, whether at home or elsewhere. The home environment is more natural, familiar and provides psychological comfort by virtue of its familiarity. Dying at home provides patients with the opportunity to influence the quality of their lives and allows them to be near loved ones and friends. They may feel more wanted and it is often more convenient for family members<sup>(11)</sup>. The guilt of the bereaved may be alleviated if they provide the care, but only if adequate support is given<sup>(11)</sup>.

Caring is both physically and emotionally draining. Family and friends carry the brunt of caring at home, the downside of which is that relationships between patient and carers can become strained and unhappy.

- **Hospitals**

Hospitals are often anxiety provoking places for patients, and generally not conducive to supporting a dying patient<sup>(58)</sup>. However, hospitals are also able to provide great security for patients. It is important therefore to emphasize that they do not always present as cold and dehumanising to them and their families, especially when there is a developed close relationship with the doctors and/or nurses in a particular ward or clinic. This often results in the patients choosing to die in the hospital. In addition, dying in a hospital means that there is access to various life prolonging or palliative treatments.

Research has shown that the negative aspects are that hospital staff withdraw from the terminally ill at the very time that they are needed, that is :<sup>(62)</sup>

- Nurses take longer to respond to calls, and
- Doctors appear to cope with death by avoiding dying patients.

In a UK based national survey of death and bereavement among the elderly, it was found that 74% of people who died in a hospital died alone with no relatives or friends at their side as opposed to 15% who died at home (cited in Bowling)<sup>(11)</sup>. As society becomes less familiar with death, so it may assume that the terminally ill are better cared for in hospitals. However Hinton (1979)<sup>(57)</sup> in a study comparing a reputable hospital and a hospice, with inpatient and outpatient care showed no consistent differences in the quality of terminal care provided. Minor differences were that patients were less depressed and anxious at the hospice and preferred the more open communication. Inpatients were less anxious than outpatients but patients gave most praise to the outpatient system of care despite being a little more anxious at home. These results were supported by a trial of hospice care by Kane et al (1984) (cited in O’Henley et al)<sup>(57)</sup>, in which he randomised 247 terminally ill cancer patients and their carers to either hospice or conventional care. With regards to pain and symptom measures as well as activities of daily living, hospice patients expressed more satisfaction, but there were no significant differences between the groups.

- **Hospices**

Hospices are usually smaller, quieter places with a less interventional approach. Hospice care has two main components – symptom management and psychosocial care. The psychological, social and spiritual needs of patients, and their families are addressed before and after the patient’s death. A better quality of life in hospices than in conventional hospitals was reported by Seale (1991) and Viney et al (1994)<sup>(57)</sup>. In a study carried out by Parkes at St Christopher’s Hospice, London, the hospice environment was viewed as being more “like a family” in comparison to the busy atmosphere of a hospital. (cited in Lee and Pang)<sup>(43)</sup>.

- **Nursing Homes**

Nursing homes are either private or state institutions and fill an essential gap in care facilities, offering short or long term stays for patients that require basic nursing care. In South Africa where hospices and hospitals are unable to provide long term chronic care owing to restricted beds, nursing homes are often the place of care for the elderly and with the worldwide trend of an ageing population, these will be increasingly needed. However, with regard to age, AIDS is predicted to take its toll in Sub-Saharan Africa.

## **TRENDS OF PLACE OF DEATH**

In the UK in 1966, 54% of deaths occurred in hospitals or other institutions. A decade later this rose to 60% with rates as high as 70% in the urban areas<sup>(11)</sup>. Cancer deaths at home, from 1965 to 1987, fell from 37% to 27%, whilst hospital deaths rose from 60% to 68%<sup>(39)</sup>.

Higginson et al<sup>(30)</sup> examined the trends in place of death for the whole of England between years 1985 – 1994. The results showed a decline in deaths in UK NHS hospitals or nursing homes from 58% (1985) to 47,3% (1994) with an increase in deaths in non-NHS hospitals, nursing homes and hospices. Home deaths decreased from 27% (1985) to 25,2% (1992) but then increased to 26,5% (1994). In a recent abstract, by Higginson and Thompson,<sup>(31)</sup> the hospital remained the most common place of death according to data of all cancer deaths registered in England and Wales between 1995 – 1999. These results were also similar to the results of a national population based investigation by Addington Hall et al<sup>(2)</sup> in 1990.

In a study of Yorkshire cancer deaths between 1989 and 1996, the fall in hospital and home deaths – 46 to 43% and 33 to 28% respectively – occurred during the period of increase in hospice deaths by 6%<sup>(5)</sup>. Doncaster Health Authority's analysis of place of death in 1995 also showed a 27% rate of death at home<sup>(64)</sup>.

In Sweden, in 1990, with the emergence of palliative care services, the breakdown of place of death of cancer patients compared favourably with those of England in the seventies and hospital based hospices in the USA. Of the 203 patients in a Swedish county, 12% died at home, 24% in a nursing home and 64% in hospital<sup>(7)</sup>.

Two medical oncology units in Sydney analysed data during 1979 – 1981 looking at factors influencing the place of death of patients. Both units had similar results with 73% of patients dying in hospital, 9% in nursing institutions and 18% at home<sup>(46)</sup>. This was similar to the 15,4% of patients dying at home for the whole of New South Wales drawn from the data of the Central Cancer Registry for 1972 – 1977.

In a sample of 1582 deaths (795 in 1981; 787 in 1985) among South Australian patients with cancer, there was a reduction in hospital deaths from 73,1% (1981) to 61,4% (1985). However, the deaths at home were static at about 14%. There was an increase in deaths in hospices and nursing homes which was thought to reflect the development of hospices and palliative care services at that time<sup>(60)</sup>.

In a multivariate analysis of 7697 deaths in 1988 in the state of Victoria, Australia, the proportion of cancer patients dying in hospital was similar to that found in South Australia. However, only 2% of all deaths occurred in a hospice<sup>(15)</sup>.

Data was obtained on 7,851,499 deceased persons from the Statistics Canada Mortality database, covering all deaths from 1950 to 1997. Over the 48 year period, 68,7% of all deaths took place in hospitals. In 1950, 50,9% of all deaths were in hospital and this incidence peaked in 1994 at 80,5%. A decline in hospital deaths followed in 1994, reaching 75,3% in 1997<sup>(71)</sup>. In this analysis, place of death was only divided into hospital or non-hospital deaths.

Reviewing archived pre-1950 British Columbia and Alberta provincial data highlighted the medicalisation of death. In 1927, 43% of all deaths recorded in British Columbia occurred in hospitals; by 1950 it had risen to 61%. In Alberta in 1930, 39% of all deaths took place in hospitals, by 1950 it was 51%<sup>(71)</sup>.

A recent article by Ida et al<sup>(36)</sup> highlights the medicalisation of death in Japan. On reviewing total cancer deaths from 1995 – 2000, it was noted that institutional deaths rose from 92.8% (1995) to 93,8% (2000). Home deaths decreased from 7% (1995) to 6% (2000) with other non-specified sites making up the difference.

There has been a trend towards increased home deaths in industrialised countries. With the advent of palliative home care services and hospices, this is especially important when rationalising future health care services for the terminally ill.

Palliative home care services in several countries have reported rates of death at home of 37-70%<sup>(50)</sup>.

- Constantini<sup>(18)</sup> found that the provision of palliative home care was the strongest predictor of a home death in a multivariate analysis of a population-based study in Genoa, Italy. It accounted for a 5% increase in home deaths from 27,9% (1986) to 33% (1990) and was twice as frequent among palliative home care users (60,8%) than among non-users (29,3%).
- In Edinburgh, Scotland, the provision of home care services enabled 41% of patients with cancer to die at home<sup>(21)</sup>.
- In Perth, Western Australia,<sup>(4)</sup> the provision of home care services enabled 70% of cancer patients to die at home. Over a 22-month period, 70% of the patients admitted to the Western Australian Hospice Palliative Care Service died at home, with most of the remaining patients dying in their hospice units. Few died in the original hospitals that referred them.
- In a retrospective review of all patients cared for by St. Joseph's Hospice, Hackney, London during 1988, 61% of the home care patients died at home<sup>(23)</sup>.
- A large study of 28,828 residents of 13 Washington states, showed that patients who had hospice involvement in their care were 2,8 times more likely to die at home when compared with non-hospice patients<sup>(53)</sup>.

Despite few randomised controlled trials on palliative care, numerous authors (Seale 1991, Higginson and McCarthy 1989, Irvine 1993, McIlmurray and Warren 1989 and Viney et al 1994) from comparative studies, suggest that hospice and specialist home care services are as effective and probably more efficient than conventional care. However, Ventafridda et al (1990), Mills et al (1994) and Larue et al (1995) found terminal care, especially in the area of symptom management inadequate across all health care services (cited in O'Henley et al)<sup>(57)</sup>.

## **PATIENT'S AND FAMILY'S DESIRE FOR HOME DEATH**

In the early seventies, Kalish and Reynolds<sup>(40)</sup> in their survey of terminal care, found that most patients preferred to die at home. Their relatives supported this preference. When asked, 91% of the widowed were comforted by the fact that their spouses had died at home.

Studies in developed countries, have found that between 50-70% of cancer patients would prefer to die at home<sup>(22, 33, 58, 68)</sup>. However, Hinton<sup>(33)</sup> found that as death approached, some patients changed their minds. Preferences for home death fell steadily from 100% to 54% for patients, and 45% for relatives. Unfortunately the reasons for these changes were not explored in that study.

In a prospective study from Northwick Park Hospital, Harrow, UK, Townsend et al<sup>(68)</sup> (1987) found that patient's initial choices for place of death were 58% at home, 20% in hospital, 20% in hospice and 2% elsewhere. The patient's final preferences were 49% at home, 24% in hospital, 25% in hospice and 2% elsewhere. However, given ideal circumstances their choices would have been 70% at home, 10% in hospital, 18% in hospice and 2% elsewhere.

In a prospective study by Lee and Pang, in Singapore,<sup>(43)</sup> 52% of patients interviewed preferred to die at home, especially those older than 65 years. In contrast, relatives expressed an almost equal preference of home (45%) and institution (42%).

In a South Australian survey of public awareness of palliative care and hospice, patients were asked to consider where they would prefer to die, 61,6% responded at home, 13% hospital and 10% hospice<sup>(58)</sup>.

The statistics of these studies tended to be fairly universal and highlighted the patient's choice of a home death. Interestingly, informal carers were more likely to state that place of death was right if patient died at home rather than in a hospital. Addington-Hall et al<sup>(3)</sup> found that 30 out of 31 carers of patients who died at home were satisfied with place of death, as opposed to only 50% of carers of patients who died in hospital.

## QUALITY OF CARE

In a Sheffield (UK) study on terminal care in hospital and at home, Wilkes<sup>(70)</sup> examined 262 deaths and in his study he found that quality of life was “good” in 40% of patients and “poor or very poor” in 44% . In these cases 3% of the relatives had wished for a hospital death. It must be noted that Wilkes did not qualify what he meant by “quality of life”.

Home care may need complementing by inpatient care to maintain optimal standards of care and support for both patients with a terminal illness, and their relatives. From spouses’ retrospective accounts, Parkes<sup>(59)</sup> concluded that, for acceptable comfort, both home and inpatient care are necessary.

A prospective study by Hinton,<sup>(33)</sup> in the mid eighties, on whether home care can maintain an acceptable quality of life for patients and their relatives, found psychological morbidity. Although three quarters of the patients and half of the relatives appeared satisfied with their lives, relatives manifested depression and anxiety in the later stages increasing to 17% and 14% respectively. In contrast, only 5% of patients developed depression and 4% anxiety.

Patients’ concerns about being cared for at home included .<sup>(58)</sup>

- emotional ability of the family to cope.
- physical ability of the primary caregiver to cope.
- the need to be comfortable and pain free.
- financial pressures and fear of loneliness were expressed by less than 5%.

In Hinton’s article<sup>(34)</sup> on patient admissions to wards from home care, the commonest reasons given for final admission were symptom control, deteriorating medical condition and family respite. There was a statistical link between weakness and impending admission, which possibly highlights the lack of family members as caregivers in today’s society. In addition, the demands of caring could result in strained and unhappy relationships in the remaining time together.

McCusker<sup>(49)</sup> showed that spouses show more preference than patients, in seeking hospital admission in the terminal phase of the disease. Research has shown that relatives have most difficulty tolerating:<sup>(11)</sup>

- incontinence.
- personality disturbances.
- difficulties in walking and getting out of bed unaided.

## **FACTORS INFLUENCING PLACE OF DEATH**

It is understood that home is the preferred place of death for most patients. This is however, not easily achieved. The literature has identified five major factors as predictors of home death :

- The patient's desire for a home death<sup>(9, 27, 28, 48, 50, 65)</sup>
- The caregiver's desire for a home death<sup>(19, 27)</sup>
- Good 24 hour medical back up<sup>(9, 19, 48, 50)</sup>
- Preferably two or more informal caregivers<sup>(9, 19, 27, 50, 67)</sup>
- Adequate finances<sup>(9, 50, 67)</sup>

The last point is of great significance in a developing country where the majority of the population is made up of those in the lower socio-economic bracket.

On the whole, most studies<sup>(7, 28, 34, 44)</sup> show no statistically significant relationship between place of death and age, gender, ethnic origin, degree of mobility and/or symptoms, diagnosis and housing conditions. Some differences that have been highlighted may be specific to those settings, and influenced by other factors such as:

- Patient personality.
- Families/carers coping abilities.
- Course of disease.
- Availability of professional support.
- Cultural differences.
- Absence of specialized palliative care services.

Some of the variables that have been identified in other studies which may influence place of death, but are not always consistent determinants, can be broken down into the following five main categories.

## **1. Place of residence**

It has been recognized for more than 15 years, that the proportion of cancer patients dying at home or in hospital vary between urban and rural areas<sup>(21)</sup>. In an analysis of home cancer deaths in Central London, between 1988 and 1992, an eightfold variation between electoral wards was found. This was inversely related to social deprivation<sup>(32)</sup>.

The prospect of dying at home increases the greater the distance from the hospital. In a Swedish study Axelsson and Christensen<sup>(7)</sup> reported that the proportion of deaths in hospital was higher for persons residing within a 40km radius of the county hospital. McCusker<sup>(49)</sup> also showed that the geographical distance from the hospital influenced the choice. Morris et al<sup>(55)</sup> highlighted this in an abstract on patterns and preferences of death among cancer patients in the Morecambe Bay Health District. In the data collected from 1993 – 2000, the likelihood of patients dying in a hospital or hospice decreased the further the distance from these facilities.

According to the Dartmouth Atlas of Health Care 1998,<sup>(20)</sup> the most significant predictor of place of death was acute bed capacity, that is, the greater the availability of these beds, the greater the likelihood of dying in a hospital.

Distance and availability of transport is a major barrier to choice of place of death. This is a significant problem in South Africa for the socially and economically deprived. Most of this group of patients live in under-privileged areas, in informal settlements and/or on the outskirts of Cape Town, where transport to the hospice/hospitals costs a great deal.

## **2. Age**

The probability of dying in a public hospital diminishes with increasing age as does the probability of dying at home<sup>(15)</sup>. Most elderly patients die in nursing homes indicating diminishing ability to cope, even when living with their spouse<sup>(7)</sup>. A population based

multivariate analysis showed that the probability of home death increased with increasing age and education level<sup>(18)</sup>.

Older surveys have found that patients aged under 45 are more likely to die in a hospital<sup>(11)</sup>, but in a more recent study, it was shown that this group of patients was more likely to die at home<sup>(55)</sup>.

Hinton<sup>(34)</sup> found that age or gender of relatives or patients who had been part of a home care programme made little difference to where patients died. Most studies have shown that in all age groups men are more likely to die at home than women. It appears therefore that age is another factor that is associated with many inconsistencies.

### **3. Home Circumstances /Social Support**

Using data from the National Hospice Study, Mor and Hiris<sup>(54)</sup> found that institutional death was associated with single, divorced or separated patients who lived alone. A St. Christopher's Hospice study<sup>(34)</sup> showed that few patients continued to live at home if other family members were ill, unfit or infirm.

Single patients were more likely to die in nursing homes than patients with a partner, who were more likely to die at home<sup>(5)</sup>. Although a greater proportion of married men died at home, this did not apply to married women<sup>(24, 60)</sup>. There is some evidence that men may be less effective carers than women. Predictive factors for an institutional death for women related mainly to functional dependency, and social support in the elderly, whereas the medical condition only of men was the predictive factor<sup>(38)</sup>.

In an analysis of place of death of 58 patients managed by an Israeli home care programme<sup>(44)</sup>, the relationship of the primary caregiver was the most significant factor influencing the place of death. All patients who died at home had a first-degree relative as the primary caregiver, compared with most of the patients who died in a hospital when the primary caregiver was a second-degree relative. This concurred with the finding of Bass et al in 1984, that dying at home directly correlates with the quality of the relationship between patient and primary care person and staff (cited in Loven et al 1990)<sup>(44)</sup>.

Improved palliative care support services would increase the numbers of patients, with an informal care support system, dying at home<sup>(24)</sup>.

#### **4. Socio-economic Status**

Formal education level attained, occupation and family income are key components of socio-economic status. A socio-economic position can affect a persons education, income, occupation, health options and even life expectancy. House type and residential areas are other important factors that play a role in the relationship between occupation and social status<sup>(51)</sup>. There are numerous scales to assess social status using these above variables.

Occupation has been shown to be the single best predictor of social status. It can be differentiated with respect to the knowledge or skill required to perform the job and to the economic power it can yield<sup>(51)</sup>.

Patients from the upper socio-economic bracket are more likely to die at home than those in the lower socio-economic bracket who died in hospitals<sup>(5, 24, 31)</sup>. Deaths in hospice and nursing homes were evenly distributed across all profiles<sup>(5)</sup>. Roder el al,<sup>(60)</sup> found that patients who lived under more affluent circumstances were more likely to die at home than those who were poorer. The study by Sims el al<sup>(64)</sup> also showed clear associations between place of death and social class. Access to services, understanding of different services and the availability of social support in the different sectors of the community had a role to play in the choice of place of death.

There is no doubt that a high socio-economic status is associated with an increased likelihood of dying at home or in a private nursing home. Affluent people living alone with no family support can afford private nursing services, even if no hospice or palliative care services are available. This is not possible for patients in the middle or lower socio-economic brackets.

Although the supply of services to all social classes is theoretically the same in most parts of the world, different access to these services has been demonstrated according to social

class<sup>(15, 64)</sup>. There is no doubt that there is a huge difference in the two tier health system in South Africa with the non-government organisations trying to bridge the gap.

Social class is not the only factor affecting access to care services and facilities. Individual patient's and family's perceptions and attitudes to service providers and places of death also influence choices. Similarly the perceptions and attitudes of health care professionals influence patients and families choices.

## **5. Diagnosis**

Place of death and diagnosis varies from study to study with most studies showing no statistical significance. In the studies that show differences, the following pattern is found

- Hinton<sup>(34)</sup> – gastric carcinoma favoured a home death whereas breast cancer led to more inpatient deaths, that is hospice.
- McCusker<sup>(49)</sup> and Constanini et al<sup>(18)</sup> – more patients with cancer of the breast, prostate and colorectum died at home than patients with lymphoma and leukaemia.
- Roder et al<sup>(60)</sup> – patients with haematological malignancies tended to die in hospital more frequently than patients with other malignancies.
- Higginson et al (1994)<sup>(30)</sup> – patients with cancer of the lung, colorectum, respiratory organs and head and neck tumours (more than 29%) were more likely to die at home than patients with cancer of the breast (25%) or lymphatic/haematological system (16%).
- Amir et al (1989 – 1996)<sup>(5)</sup> – for all cancer types, hospital was the most common place of death with the exception of colorectal cancer being at home and cancer of the breast at hospice.

Comparison between the data is very difficult as it has been collected from different settings, that is, general population, hospice and palliative care programmes. One fact is consistent - more patients with lymphatic or haematological malignancies die in

hospital. This is probably because these patients tend to be younger with malignancies that respond better to available treatments.

## **6. Interval From First Contact With Oncology Unit**

Functional decline is an important determinant for site of death. In an American study quantifying where people die, Weitzen<sup>(69)</sup> showed that patients who have been functionally impaired for at least a year before death are more likely to die in a nursing home, than patients whose health declined rapidly. The latter group of patients usually died at home. This compares well with surveys that have found that people who have been ill from between three months and two years are more likely to die in hospital than patients who have been ill for longer than two years<sup>(11)</sup>.

Again, this has not been a significant factor in predicting place of death in most studies.

George L Engel's biopsychosocial model of care requires attention to the biological, psychological and social levels of human function including their inter-relationship. Crucial to the social component is the inclusion of the cultural dimension and the patient's religious affiliation. Culture is important, as it influences, mediates and shapes beliefs about many aspects of disease/distress and modes of intervention<sup>(41)</sup>.

The fields of social and cultural anthropology comprise the study of various aspects of society for example, kinship, social exchange, religion in the context of politics, economics, symbolic systems for example, language. Through this, one is able to describe and interpret how the social world is ordered and how it responds to change. Medical anthropology is a subfield of social anthropology and includes the comparative study of healing systems and the social, economic, political and cultural contexts of health and health care<sup>(41)</sup>.

The relevance of anthropological contributions is :

- documentation of particular behaviours and/or disorders in different sociocultural contexts.
- allowing one to respond to these in a culturally appropriate way.
- understanding the social production and course of a behaviour and/or disorder allows one to intervene and possibly improve outcome or avert a crisis.
- allowing the medical fraternity to reflect on medical culture.

Death is a complex interplay of personal and cultural values, physical and medical factors, as well as diverse health care systems. African traditional healing needs to be acknowledged. Religion and cultural beliefs are entwined thereby not only catering for the physical condition, but also the psychological, spiritual and social aspects of individuals, families and communities<sup>(1)</sup>. Caring for the dying is specialized and labour intensive whatever the setting and understanding the trends in place of death, particularly in different ethnic, socio-economic and age groups, is crucial in planning services.

In summary, the individual has a right to choice of place of death, but the place of death is determined by the nature of the disease, kinship and religion. The place of death influences spiritual transformation, and is influenced by religion and ancestral systems<sup>(10)</sup>. At the outset of an illness, the individual has authority over choice of place of death but as the illness progresses and the patient deteriorates the authority shifts, and is influenced by medicine, law in its broader context and culture.

# CHAPTER 3

## METHODS

This is a prospective, descriptive, quantitative study on place of death of new patients referred to St Luke's Hospice, Cape Town, between 1 May 2001 and 30 April 2002. Only the new patients who died within this time frame were analysed. In the time period, there were 1022 new patients of whom a total of 509 died.

A "teleform" (Appendix 1) was designed with the assistance of the Alberta Cancer Board Palliative Care Research Initiative based in Edmonton, Alberta, Canada. The initial data was entered on the form at the first assessment by the home care nursing sister. The date and place of death was entered by the home care nursing co-ordinator. This information was then directly entered into a database for analysis. (Appendix 2)

The place of death was classified into hospital, hospice, nursing home or home. The variables to be analysed with regard to place of death in this study included

- Age
- Gender
- Race
- Social structure which was subdivided into
  - living with friends
  - living with family
  - living in nursing home
  - living alone with help
  - living alone with no help.
- Socio-economic status in this study was measured by formal education level, and family income i.e. whether patient was a
  - state/hospital patient (monthly family income less than R5038 per month), or a
  - private patient (family income more than R5038 per month or on a medical aid).

- The formal education level was subdivided into
  - 0 – 4 years
  - 5 – 8 years
  - 9 – 12 years
  - post graduate.
- Duration of illness - interval from date of diagnosis to date of death
  - less than or equal to 3 months
  - more than 3 months but less than or equal to 24 months
  - more than 24 months.
- Palliative performance scale
  - 0 - 30
  - 40 - 60
  - 70 - 100

Epi-Info 6 (version 6,04b – January 1997), the programme distributed by the Centre for Disease Control, USA and the World Health Organisation, Geneva, was employed for analysis. The associations between place of death and the abovenamed variables were determined using the chi square test. The 0.05 probability standard was used in determining if differences were statistically significant.

A multi-variate analysis was done using factor analysis and varimax rotation. A loading of greater than .700000 was regarded as statistically significant.

# CHAPTER 4

## RESULTS

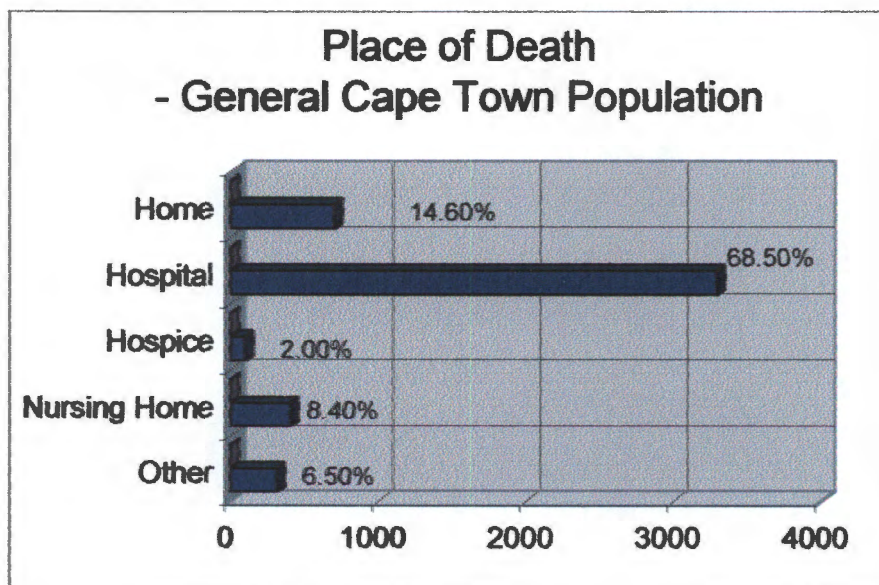
### Place Of Death For The General Population (Estimate)

As there are no official statistics on place of death for the general population of South Africa or Cape Town, unofficial statistics were collated from Goodall and Williams, the largest firm of undertakers in Cape Town.

The area covered by them in the southern suburbs of Cape Town matched the area covered by the St. Luke's Community Sisters. The data was collected by hand from registers covering the same time span as the study period. The registers contained the name of the deceased, site of body removal and despatching, but no diagnosis. Of the 4,802 deaths, 2,402 were from the registers and 2,400 were an estimate from Groote Schuur Hospital. Goodall and Williams had the hospital contract, but the registers were not available. Their working average however is +/- 200 deaths per month.

The total number of deaths was divided into site of death – home, hospice, nursing home, hospital and “other” (“other” being mainly unnatural deaths, or incomplete data). Of the 4,802 deaths, 699 (14,6%) occurred in the home, 95 (2,0%) in the hospice, 3,292 (68,5%) in a hospital, 404 (8,4%) in a nursing home and 312 (6,5%) were “other”. (Figure 2).

FIGURE 2



## **Study Results**

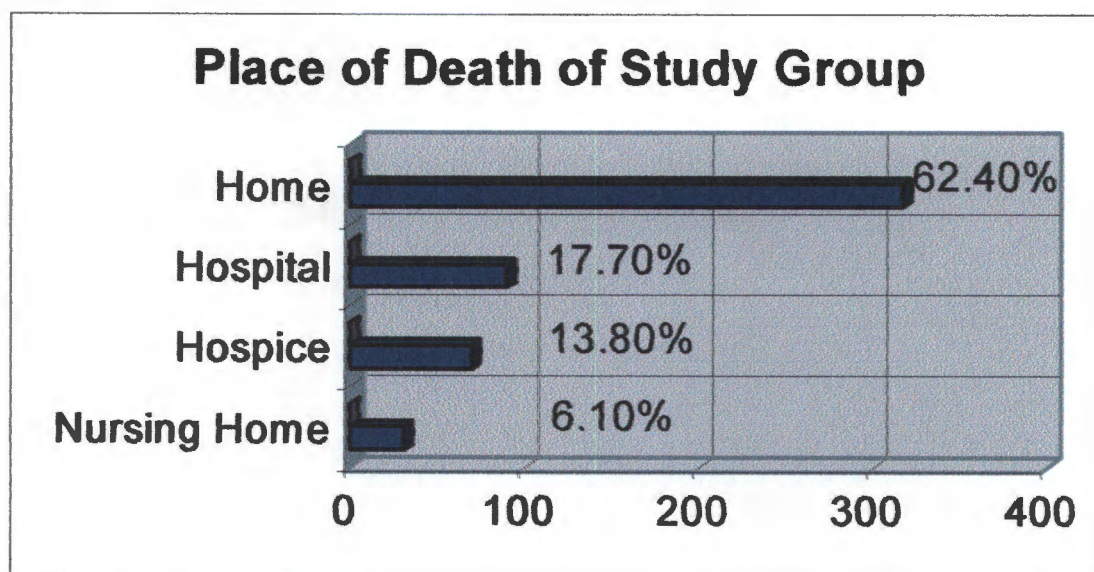
Of the 1022 new patients registered between 1 May 2001 and 30 April 2002, 509 died. Place of death is unknown for one of these patients.

Incomplete data collection was noted among the following variables :

- social structure – only 506 patients details documented.
- formal education level – only noted in 475 patients, was partly due to the sensitivity of the question among certain sectors of the population.
- palliative performance score – recorded in 499 cases, was omitted at initial assessment by the home care sister.
- duration of disease – only 479 patients could be evaluated as date of diagnosis was incomplete, that is only year or month and year of onset was documented.

Of the 508 patients whose place of death was recorded, 317 (62.4%) died at home, 70 (13.8%) in the hospice, 90 (17.7%) in a hospital and 31 (6.1%) in a nursing home (figure 3). Twelve of the 31 patients dying in a nursing home were already resident there.

FIGURE 3

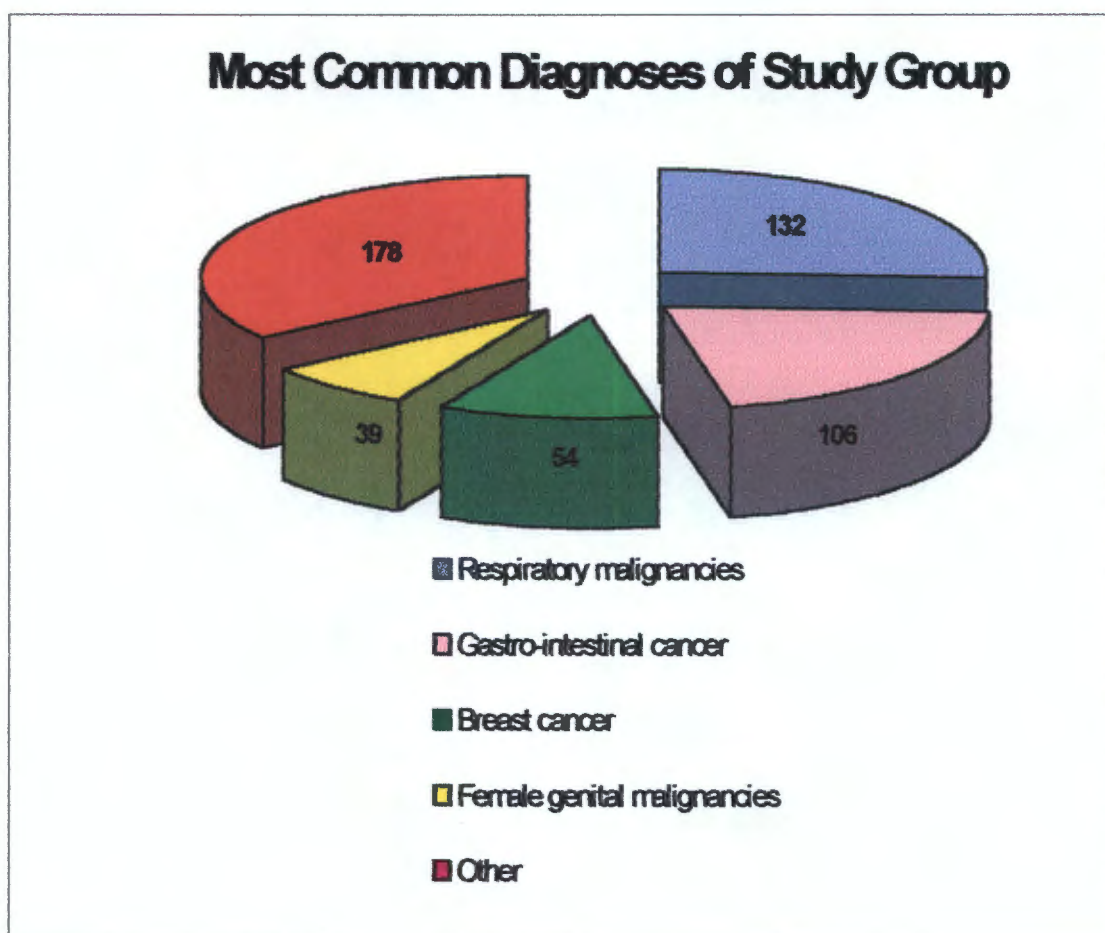


The distribution of the top four diagnoses among the 509 patients was:

Respiratory malignancies	132	(25.9%)
Gastro-intestinal cancer	106	(20.8%)
Breast cancer	54	(10.6%)
Female genital malignancies	39	(7.7%)
Other	178	(35%)

The number of AIDS patients who died was small 11 (2,2%)

FIGURE 4:



## **DEMOGRAPHIC CHARACTERISTICS**

Table 1 (overleaf) shows the demographic characteristics of patients related to place of death.

Characteristics	Place of Death				"p" Value
	Home %	Hospice %	Hospital %	Nursing Home %	
Deaths	317 (62.4)	70 (13.8)	90 (17.7)	31 (6.1)	
TOTAL	509				
Mean age at death (years)	62.8	61.4	61.4	69.1	0.010
Range (std dev.)	15.1	14.0	13.0	16.1	
TOTAL	509				
Age					
▪ < 45	37 (62.7)	8 (13.6)	11 (18.6)	3 (5.1)	0.053
▪ 45 – 64	120 (60.0)	32 (16.0)	42 (21.0)	6 (3.0)	
▪ 65 – 74	92 (68.1)	17 (12.6)	19 (14.1)	7 (5.2)	
▪ 75 – 85	59 (61.5)	11 (11.5)	15 (15.6)	11 (11.5)	
▪ > 85	9 (50.0)	2 (11.1)	3 (16.7)	4 (22.2)	
TOTAL	508				
Gender					
▪ Male	154 (62.9)	29 (11.8)	49 (20.0)	13 (5.3)	0.362
▪ Female	163 (62.0)	41 (15.6)	41 (15.6)	18 (6.8)	
TOTAL	508				
Race					
▪ Black	21 (42.9)	8 (16.3)	17 (34.7)	3 (6.1)	0.000
▪ European	130 (56.8)	27 (11.8)	45 (19.6)	27 (11.8)	
▪ Coloured	166 (72.2)	35 (15.2)	28 (12.2)	1 (0.4)	
▪ Asian	0	0	0	0	
TOTAL	508				
Social Structure					
▪ Living With Friends	9 (47)	4 (21.0)	5 (26.3)	1 (5.3)	0.000
▪ Living With Family	291 (66.7)	58 (13.3)	77 (17.7)	10 (2.3)	
▪ Living in Nursing Home	1 (5.9)	2 (11.8)	2 (11.8)	12 (70.5)	
▪ Living Alone With Help	11 (55.0)	3 (15.0)	1 (5.0)	5 (25.0)	
▪ Living Alone With No Help	3 (23.1)	3 (23.1)	4 (30.7)	3 (23.1)	
TOTAL	505				
Category of Patient					
▪ State	210 (63.3)	53 (16.0)	52 (15.7)	17 (5.1)	0.065
▪ Private	107 (60.8)	17 (9.7)	38 (21.6)	14 (8.0)	
TOTAL	508				
Formal Education Level					
▪ 0-4 yrs	32 (78.0)	3 (7.3)	6 (14.6)	0 (0.0)	0.002
▪ 5-8 yrs	99 (68.8)	19 (13.2)	25 (17.4)	1 (0.7)	
▪ 9-12 yrs	94 (54.7)	32 (18.6)	29 (16.9)	17 (9.9)	
▪ Post grad	74 (62.7)	11 (9.3)	23 (19.5)	10 (8.5)	
TOTAL	475				
PPS					
▪ 0 – 30	97 (66.9)	15 (10.3)	22 (15.2)	11 (7.6)	0.435
▪ 40 – 60	161 (62.2)	39 (15.0)	44 (17.0)	15 (5.8)	
▪ 70 – 100	59 (56.7)	16 (15.4)	24 (23.1)	5 (4.8)	
TOTAL	508				

Table 1: Demographic Characteristics of Patients Referred to St. Luke's Hospice Related to Place of Death between May 2000 and April 2001.

### (i) Age

There was a statistical significance ( $p = 0,010$ ) in terms of mean age at death and place of death. There was no statistical significance in the mean ages at death of patients at home, in a hospital, or in a hospice. The mean age in the nursing home group was higher, which was to be expected, as patients under the age of 60 do not normally qualify for admission to a nursing home. Typically, the age is 65 and older.

Number of deaths by age (years) related to place of death did not reach statistical significance ( $p = 0,053$ ), although a trend to possible significance was shown (table 2). Patients 75 years and older were more likely to die in a nursing home than any other age groups. Those patients older than 85 years, were less likely to die at home than other age groups. The highest percentage of hospital deaths were noted in the patients 64 years or younger. The age group 45 – 64 years showed the highest number of hospice and hospital deaths amongst all age groups.

Table 2 Age and Gender Related to Place of Death

Place of Death	<45		45 – 64		65 – 74		75 – 85		>85		P Value	Total
	Female	Male	Female	Male	Female	Male	Male	Female	Male	Female		
Home	19	18	56	64	47	45	35	24	6	3	0.493	317
Hospice	5	3	16	16	10	7	8	3	2	0	0.502	70
Hospital	6	5	18	24	6	13	8	7	3	0	0.204	90
Nursing Home	2	1	2	4	5	2	5	6	4	0	0.221	31
S/Total	32	27	92	108	68	67	56	40	15	3		508

### (ii) Gender

Of the 508 patients, 245 (48,2%) were male and 263 (51.8%) were female. There was neither statistical significance ( $p = 0.362$ ) between the gender of patient and the place of death, nor was there statistical significance shown when the gender was related to age groups (years) for each individual place of death (table 2).

More females died in a hospice than males, (58.6% vs 41.4%) and the reverse was true for deaths at a hospital (45.6% vs 54.4%). Females were also more likely to die in a nursing home than males (58.1% vs 41.9%). Using the binomial test, the

p values for hospice, hospital and nursing home deaths was  $p = 0.100$ ,  $p = 0.240$  and  $p = 0.240$  respectively. Again this did not reach statistical significance.

### **(iii) Race**

The racial breakdown was : Black 49 (9.6%); White 229 (45.1%) and Coloured 230 (45.3%). There were no Asian patients in this registered study. In addition, the racial variable with regard to place of death did reach statistical significance ( $p = 0.000$ ).

Patients of all racial groups were more likely to die at home. However, Coloureds were more likely to die at home (72.2%) than Whites (56.8%) and almost twice as likely as Blacks (42.9%). Whites were slightly less likely to die in a hospice than the other racial groups, although this was not significant.

Black patients were more likely to die in a hospital (34.7%), which is almost three times the rate of Coloured patients (12.2%); with the rate of White patients being one in five. The majority of nursing home deaths were White patients (87.1%).

### **(iv) Social Structure**

Social structure and place of death showed a statistical significance ( $p = 0.000$ ). This was subdivided into :

Living with friends	(3,8%)
Living with family	(86,3%)
Living in a nursing home	(3,3%)
Living alone with help	(4,0%)
Living alone with no help	(2,6%)

Patients with support – family, friends or other help – were more likely to die at home. Family support significantly increased the likelihood of dying at home (66,7%). In comparing patients with one of the aforementioned support structures, patients living alone with help showed a greater chance of dying in a nursing home following home deaths. Patients living with family or friends were marginally more likely to die in a hospital than a hospice, but this did not reach statistical significance.

Patients resident in a nursing home, were likely to die there (70.5%). Patients living alone with no help showed no specific predilection for place of death.

Of interest, was the statistical significance ( $p = 0.000$ ) shown when comparing social structure to racial groups (table 3). Most of the black patients lived at home supported either by family or by friends, thus re-inforcing their strong community ties. Patients in the coloured population showed a similar trend, with 96,5% of patients being cared for predominantly by family or friends. In the white community, 81,7% of patients were looked after by family or friends. Few lived alone with no help (4,4%), the rest either lived alone with help, or in a nursing home.

Table 3 : Social Structure Related to Race

Social Structure	Race				P-Value
	B (%)	C (%)	W (%)	A (%)	
Lives alone – no help	0 (0.0)	3 (1.3)	10 (4.4)	0 (0.0)	0.00001927
Lives alone – with help	0 (0.0)	3 (1.3)	17 (7.4)	0 (0.0)	
Lives in nursing home	0 (0.0)	2 (0.9)	15 (6.5)	0 (0.0)	
Lives with family	45 (95.7)	215 (93.5)	177 (77.3)	0 (0.0)	
Lives with friends	2 (4.3)	7 (3.0)	10 (4.4)	0 (0.0)	

#### (v) Socio-economic status

In this study, 2 variables were used to determine socio-economic status, namely category of patient – state or private – as defined earlier, and formal education level. Unfortunately occupation of patients was not collected.

##### a) Patient type :

Comparing patient category with place of death was not of statistical significance ( $p = 0.065$ ). Percentage of home deaths was much the same. There was possibly a trend indicating that private patients were more likely to die in a hospital or nursing home than state patients. The incidence of hospice deaths was higher among state patients.

Of statistical significance ( $p = 0.000$ ) was patient category related to race (table 4). 70% of white patients were private patients, while 93,9 % of blacks and coloureds were state patients.

**Table 4 : Category of Patient Related to Race**

Category of Patient	Race				P-Value
	B (%)	C (%)	W (%)	A (%)	
State	46 (93.9)	216 (93.9)	70 (30.4)	0 (0.0)	0.000
Private	3 (6.1)	14 (6.1)	160 (69.6)	0 (0.0)	

**b) Formal education level**

As a demographic variable, formal education level reached statistical significance ( $p = 0.002$ ) (table 1). Although home deaths were by far the majority, the more educated the patient, the less likely he or she was to die at home. This educated group of patients made up 96,4% of nursing home deaths, and showed a tendency to increased hospital deaths.

There was also a significant relationship between formal education and race ( $p=0.000$ ) (table 5). This confirmed what might have been expected in view of South Africa's history, that is, on average whites were more educated than blacks or coloureds.

**Table 5 : Formal Education Level Related to Race**

Education Level	Race				P-Value
	B (%)	C (%)	W (%)	A (%)	
0 – 4 years	7 (19.0)	33 (15.1)	1 (0.5)	0 (0.0)	0.000
5 – 8 years	18 (48.6)	117 (53.4)	9 (4.1)	0 (0.0)	
9 – 12 years	6 (16.2)	62 (28.3)	105 (47.7)	0 (0.0)	
Post Graduate	6 (16.2)	7 (3.2)	105 (47.7)	0 (0.0)	

Table 6 shows that regardless of place of death, all private patients are better and more highly educated than State patients.

Table 6 : Patient Category Breakdown into Formal Education Level Related to Place of Death

Place of Death	Patient Category	FORMAL EDUCATION LEVEL				Total
		0 – 4 years	5 – 8 years	9 – 12 years	Post graduate	
Home	Private	1	4	38	60	103
	State	31	95	56	14	196
Hospice	Private	0	0	10	7	17
	State	3	19	22	4	48
Hospital	Private	1	1	13	20	35
	State	5	24	16	3	48
Nursing Home	Private	0	0	6	7	13
	State	0	1	11	3	15

**(vi) Duration of Disease and Place of Death**

There was no correlation between length of illness and place of death ( $p = 0.883$ ), that is, it was not influenced by whether patients had been ill for less than 3 months, between 3 months and 2 years or more than 2 years. (table 7).

Table 7 Duration of Disease Related to Place of Death

Place of Death	Duration of Disease			P-Value
	< 3/12 (%)	3/12 – 2 Years (%)	> 2 years (%)	
Home	80 (27,1)	149 (50,5)	66 (22,4)	0,883
Hospice	16 (24,2)	36 (54,6)	14 (21,2)	
Hospital	23 (26,4)	47 (54,0)	17 (19,6)	
Nursing Home	5 (16,1)	18 (58,1)	8 (25,8)	
<b>TOTAL</b>	479			

The duration of hospice involvement related to place of death was not evaluated as all patients analysed were newly registered patients and for the purpose of the study died within the same year of assessment. Therefore, for most patients overall hospice involvement was fairly brief.

### (vii) Palliative Performance Scale

The palliative performance scale (Appendix 3) was subdivided into the following 3 main categories:

- 0 - 30            patients totally dependant
- 40 - 60            requiring some form of assistance with daily activities
- 70 - 100            fully independent.

This was again not statistically significant with respect to place of death ( $p = 0.435$ ) (table 1).

### Multivariate Analysis

The multivariate analysis (table 8) provided no further information or enhancement of the factors influencing place of death. Duration of disease was not included as a variable as that data was re-analysed with different software and was incompatible with the one used for the multi-variate analysis.

Table 8: Multivariate Analysis

STAT FACTOR ANALYSIS	Factor Loadings (Varimax)	
	(Marked loadings are $>.700000$ )	
Variable	Factor 1	Factor 2
Age	.024140	.042608
Gender	-.029577	.023059
Patient Type	.070821	.090182
Education	.102633	.010134
PPS	.052640	-.036472
Home	-.898284	.416463
Hospital	.781891	.272528
Hospice	.111098	-.984379
N. Home	.420273	.141297

# CHAPTER 5

## DISCUSSION

Before the scientific and technological advancements of the 20<sup>th</sup> Century, the approach of medical practitioners was to provide comfort and relieve suffering. These advancements however, resulted in a move towards cure and abandonment of the traditional care system. With the advent of the palliative care movement in the UK in the 1960s, there was a rekindling of the care system and this was further promulgated by the World Health Organisation and the health care systems of most industrialised countries.

Outcome measures, including the use of health care services, quality of care and the place of death have been studied to assess the success of palliative care. It is important therefore to determine which factors influence the outcome measures and to determine whether these factors should or could be modified.

The aim of this study is to determine factors which may influence the place of death of patients referred to St. Luke's Hospice. It must be noted that the service offered by St. Luke's Hospice is not standard in South Africa. All hospices differ in their delivery – some have provisions for outpatient clinics only, and others home care only, with or without dayhospice. On the whole, most inpatient units serving as backup to home care, offer a 24-hour service 7 days a week, but there are those that offer an office hours only service. This study has shown that dealing with only socio-demographic factors may underestimate the influence of somatic, psychological and social components of an illness on place of death.

## TRENDS OF PLACE OF DEATH

The unofficial statistics for place of death for the general population of Cape Town, although not cancer specific, are comparable to findings in other studies<sup>(7, 15, 36, 39, 46, 60, 71)</sup>. In Cape Town, 65.5% of deaths occurred in hospital, 14,6% at home, 8,4% in nursing homes, 2,0% in the hospice and 6,5% elsewhere. The Swiss, Swedish and Australian studies as highlighted in Table 9<sup>(61)</sup> (reproduced with permission) compare well with the Cape Town statistics.

Table 9

## Place of Death of Cancer Patients

Reference	Country (year)	No. of patients	Place of death (%)			
			Hospital	Home/nursing home	Hospice	Unknown
3	Italy					
	(1986)	2510	72	28	NM	-
	(1987)	2424	70	30	NM	-
	(1988)	2506	69	31	NM	-
	(1989)	2481	68	32	NM	-
(1990)	2417	67	33	NM	-	
4	Switzerland	317 <sup>a</sup>	51	43/5	NM	1
	(1991-93)	676 <sup>b</sup>	74	11/14	NM	1
5	Sweden	203	64	12/24	NM	-
	(1990)					
6	Australia	1983	61	15/3	8	13
	(1979-81)					
7	Australia					
	(1981)	795	73	14/8	5	-
	(1985)	787	61	14/12	13	-
(1990)	2715	56	14/10	20	-	

<sup>a</sup>Homecare-users; <sup>b</sup>nonhome-care users; NM: not mentioned.

St. Luke's Hospice, a palliative care service with an inpatient unit and home care service, statistics correlate well with death statistics of other palliative home care services (4,18,21,23,50,53). Home deaths were 62,4%, hospital deaths 17,7% and the hospice inpatient unit 13,8%. Despite the fact that South Africa is a "developing country", the number of patients with access to a hospice and palliative home care service show increased home deaths, which is reflected in the statistics in industrialised countries.

The palliative care literature supports the view that people prefer to die at home (11,22,33,43,58,68). Often the choice of place of death is a compromise between the possibilities and the probabilities. The paradox is that although earlier in the disease process most patients want to

die at home, they in fact die in institutions. Allowances need to be made for the fact that patients change their minds as they become sicker. This leads the question – can the factors leading to the admission be dealt with more effectively in order to have an altered outcome? Similarly, it is interesting to note that although most patients spend much of their final year at home, they die in institutions.

Patients' desired place of death is often not recorded as in this study. Better recording of this is needed in order to ensure that such needs are fully met.

### **NATURE OF DISEASE**

The natural history of an illness may also influence place of death. A patient, for example, with a slow growing breast tumour may be more likely to be transferred to a nursing care institution than one with a rapidly progressive tumour<sup>(46)</sup>. Patterns of metastatic disease and symptomatology may also result in patients remaining in hospital.

Patients who die within one month of diagnosis were more likely to die at home<sup>(7)</sup>. Studies have shown that institutional admissions increase as the period of home care lengthens<sup>(8, 34, 44)</sup>. 80% of patients on home care for 6 months or more died in hospital<sup>(44)</sup>. This was similar to an observation reported by Bass et al<sup>(8)</sup>, and Bowling<sup>(11)</sup>, who found this to be due to the emotional and physical strain on the caregiver. A US home hospice programme found that deaths at home were associated with a higher number of nursing visits, whereas a hospital death was associated with a longer period in the hospice program<sup>(8)</sup>. There was no correlation between duration of illness and place of death in this study.

Functional decline is an important clinical determinant for place of death. Patients who were impaired for at least 12 months before death were more likely to die in a nursing home, in contrast to those with a rapid, late decline in condition who died at home<sup>(69)</sup>. On registering with palliative home care teams, the Karnofsky index was significantly lower for those dying at home<sup>(28)</sup>. In this study however, palliative performance scale was not significant.

## **SOCIO-DEMOGRAPHIC VARIABLES**

In this study, variables such as **age, gender, category of patient, palliative performance scale and duration of illness** bore no significant relationship to place of death. The absence of relation to gender and age has been reported in many studies<sup>(7, 23, 28, 46, 49, 54)</sup>.

Some studies, indicate that the probability of dying in a nursing home increases with increasing age, especially if female<sup>(7, 15, 30, 55, 60)</sup>. Patients aged 74 years or younger, are more likely to die at home than those aged 75 – 84 years, and more so if older than 85 years<sup>(30)</sup>. Older people and females are less likely to die at home than younger patients and men<sup>(30, 55)</sup>. Another finding which relates to gender has been that males are more likely to die in a hospital or at home than females, who are more likely to die in a hospice, or nursing home<sup>(5, 15, 46, 55)</sup>. This might be related to the lack of social support. These trends were shown in this study but did not reach statistical significance.

One of the major factors identified as a predictor of a home death, is **social support** in the home, with preferably two or more caregivers<sup>(9, 19, 27, 50, 67)</sup>. In this study, family support significantly increased the likelihood of dying at home (66,7%). The support structure was not broken down into primary and secondary caregivers. Patients with any form of support, that is family, friends or other types of assistance, were more likely to die at home. In a future study, it would be important to identify what type of social support structure either increases or decreases the likelihood of dying at home. There also needs to be more clarification on the definition of a caregiver.

Bass et al<sup>(8)</sup> found that dying at home was directly correlated with the quality of the relationship between patients, primary care person and support staff. Loven et al<sup>(44)</sup> in a small Israeli study, found the degree of the relationship of the primary care person to the patient to be the most significant factor influencing place of death. All patients being cared for by a relative of the first degree died at home. He found, that family members were potentially better caregivers because they have a better understanding of the patients needs, a personal sense of responsibility and a commitment to the care of the patient.

Some authors have stated that married persons are more likely to die at home<sup>(5, 18, 23, 28)</sup> while others have found that marriage made no difference<sup>(7, 46, 49)</sup>. The results from the 48-year data from the Statistics Canada Mortality database, show that married persons had a higher rate of

hospital deaths than unmarried persons<sup>(71)</sup>. The latter may indicate that social support factors other than marriage are of greater importance to patients. It appears that the availability of additional resources is an important factor in enabling patients to remain at home. It is significant if a family member, other than the spouse, is involved in patient care, as well as home carers or private nurses (either full or part time)<sup>(50)</sup>.

Differences were noted in this study when social structure in the different racial groups was compared. Black patients were supported mostly by family (95,7%) or by friends (4,3%). This is probably as a result of the fact that these patients tend to belong to large families or to clan "responsibilities". There is an evident inter-connectedness between the individual, the ancestors, the community, and the environment, and an understanding of not upsetting the ancestors is important<sup>(45)</sup>. Despite this infrastructure only 42,9% of patients died at home. Institutional deaths made up 57,1%, that is hospital 34,7%, hospice 16,3% and nursing home 6,1%. This was surprising because the preferred place of death in the black culture is at home<sup>(45)</sup>. It also nullified the hypothesis that patients from poorer socio-economic groups had more difficulty accessing institutional beds. A contributing factor may also have been the lack of support over weekends by the hospice home care service as black areas were only covered telephonically during these times. However, as the patient numbers were small (n=49) in this group, it was difficult to draw a definitive conclusion.

In the coloured population, 72,2% of patients died at home and 27,8% in institutions. The social support structure was made up predominantly of family (93,5%) and friends (3,0%). Patients in this group tended to come from large extended families and have good community support. All Muslims in this study were part of the coloured population, and they are known to have a good social support system and patients generally prefer to die at home<sup>(43)</sup>. In addition, these patients had no need for a translator, therefore possibly had a better understanding and insight into their illness, and knowledge of how best to utilise the different health care services, both private and state.

56,8% of the white population died at home, with 43,2% institutional deaths. This is probably as a result of smaller extended families with fewer family members available to share the care of the terminally ill. Many patients in this group were financially more secure and able to afford private nursing homes or private home nursing. 87% of the nursing home deaths were from this sector of the population.

Hines showed that there were differences between white patients and patients in the other racial groups in the utilization of health care services, and Colette et al found that non-white patients were less compliant about their treatment regimes (cited by Bass et al)<sup>(8)</sup>. In a study by Higginson and Thompson<sup>(31)</sup>, using data on all cancer deaths registered in England and Wales between 1995 and 1999, hospital was the most common place of death for the Indian subcontinent group. People born in England and Wales were more likely to die at home. There may be several explanations for this, including sub-cultural differences in attitude towards death, influence of race on social experiences, differences in staff and patient racial background.

**Socio-economic status** had great statistical significance related to place of death and this has been confirmed in other studies<sup>(5, 15, 24, 32, 60, 64)</sup>. The 2 variables used to determine socio-economic status were category of patient on a financial basis (monthly income less than or more than R5038.00 per month) and formal education level.

Although patient category compared with place of death was not significant (percentage of home deaths were equal), more private patients tended to die in a hospital or nursing home. Once again this could be due to the fact that they were more affluent and able to afford nursing homes and private care facilities.

Comparing patient category with race, highlighted the differences between the socio-economic groups. 70% of white patients were private, as compared with only 6,1% of the blacks and coloureds. Private patients have easier access to private health care facilities that have far less demand on their services and are better equipped. These facilities include private hospitals, private home nursing and private nursing homes which are accessed by the more affluent white patients.

**Formal education level** related to race confirmed that whites generally had more formal education than blacks or coloureds – a remnant of the past regime. This resulted in greater choice for occupations, and more employment opportunities, with greater prospects and improved income. Although not of statistical significance in this study, institutional deaths were more common among the more educated patient, which can probably be linked to financial status. Despite this, the majority of higher and lower socio-economic patients still died at home. Other studies found that patients in higher socio-economic groups were more

likely to die at home, and those in lower socio-economic groups were more likely to die in a hospital<sup>(5, 15, 32, 60, 64)</sup>.

With regard to resources, various studies have shown that as the distance to the nearest hospital or hospice increases, the likelihood of the patient dying there decreases<sup>(7, 49, 55)</sup>. Grande et al (1988) and Tolle et al (1999) reported that the use and availability of beds in acute care hospitals played a principal role in determining location of death (as cited in Wilson et al 2001)<sup>(71)</sup>.

In summary, this study therefore suggests that place of death for St. Luke's Hospice patients is strongly associated with race, social structure and socio-economic status. This ties in with the literature, on three of the five major factors identified as predictors of a home death namely, the need for 24-hour medical/nursing backup, good social support structures and adequate finances<sup>(9, 19, 27, 48, 50, 67)</sup>. Patients and families desire for a home death was not assessed, but assumed on the basis of their registering with a hospice/home care programme.

### **PSYCHOSOCIAL FACTORS**

Psychosocial factors limit options of dying at home. These factors change with time and circumstances. Copperman<sup>(17)</sup> stated that the attitude and circumstances of the family can make the difference between a patient having to be admitted to hospital, or being cared for at home. Wilkes<sup>(70)</sup> found that the relatives difficulties were more often a cause for hospital admission than those of the patients.

A large proportion of patients admitted to hospital could have been cared for at home if better support had been provided<sup>(3, 68, 70)</sup>. Doyle<sup>(21)</sup> found that admission was necessary in 90% of cases, because of the strain on relatives, nursing demands became excessive, lack of night sitters or absence of equipment. Symptom control accounted for less than 10%.

Patients dying at home appeared to have been more concerned about their family's emotional status than their physical coping abilities. Interestingly enough, their concerns about dying at home were unrelated to the level of awareness of home based palliative care services<sup>(58)</sup>.

An agreement between patient and caregiver about place of death was more important than the individual's preference. Factors influencing the agreement include: <sup>(67)</sup>

- Adequate nursing care.
- Night sitting service.
- Good symptom control.
- Confident and committed medical support.
- Some studies<sup>(9, 18, 50)</sup> indicate physician support as one of the main predictors for a home death. Cantwell et al<sup>(13)</sup> found it not to be a significant predictor. Medical support and back up was not investigated in this study.
- Access to specialist palliative care, that is, such a service should be available to anyone who requires it.
- Effective co-ordination of care.
- Financial support.

## **SERVICE PROVISION**

Hospice or palliative home care participation is a major predictor of death at home <sup>(18, 23, 53)</sup>.

A number of population based studies have reported an association between home care service and an increase in the proportion of home deaths. Katz et al (cited in Constantini et al, 1993)<sup>(18)</sup> reported twice the number of home deaths in a New York county where a home care programme of many years had been operating. Ward (cited in Constantini et al, 1993)<sup>(18)</sup> in a UK study, showed an increase in home deaths only in the districts with a home care service.

A systematic literature review, determining whether specialist palliative care teams provided improved outcomes for patients and their families when compared with conventional services, concluded that these teams improved satisfaction, identified and dealt with more patient and family needs<sup>(29)</sup>. Not all studies showed an improvement, although none showed adverse outcomes. Smeenk et al (cited in Keeley, 2001)<sup>(42)</sup>, reported a systematic review of the effectiveness of home care programmes for patients with a terminal illness – and although positive influences were found in a minority of studies, the overall effectiveness of such programmes remained unclear.

Equally important to note, is that a palliative care service does not necessarily mean a non-medicalised and non-institutionalised death. The availability and the delivery of the service and the resources at its disposal are pertinent to the outcome. This was highlighted in a study by Ida et al<sup>(36)</sup> looking at the current status of hospice patients dying of cancer in Japan, both in their unit and at home. In Japan, between 1995 and 2000, the place of death for the total number of patients dying of cancer averaged 93,1% in institutions and 6,6% at home. 96.7% of these patients who had received hospice care died in the unit, and 3,3% died at home. In this case, although death may not have been medicalised, it was still institutionalised. There might have been many reasons for this, but these were not expanded in the study.

It is important to note the differences in health care systems and provisions for care in industrialised countries such as the USA and the UK. South Africa is a country with unique parameters, and there is a need to develop an infrastructure to deal with the health care needs of the terminally ill, which includes all racial and economic differences. A range of services is required to cope with different combinations of clinical need, personal circumstances, patient and carers choices.

Although theoretically the hospice service is the same for patients from all categories, access to the service is influenced by socio economic factors. Community services are not as well developed in some areas due to distance, high crime rate, poor telecommunication and an inefficient transport system.

No comparative studies exist between the St. Luke's service and other conventional care services in the different suburbs of Cape Town. It is more difficult to assess and appreciate or evaluate an excellent service in an area where there is a good one. It is crucial however to assess and evaluate all categories as to whether or not there are any differences in outcome between the different services. This would highlight the necessity for a needs analysis in order to improve home care support and services for patients and families who wish to die at home.

## SUMMATION

Although apartheid was abolished in South Africa in 1992, the economic and cultural legacy of it still remains. Although the new South Africa is described as the "Rainbow Nation", the transformation of cultural norms will take a long time. It is in the light of the past history that one needs to assess the impact of cultural variability, lack of resources, communication and support services as factors influencing place of death in our society.

Attitudes to death and cultural differences vary from country to country and region to region, and significantly influence place of death. Patients' perception and understanding of hospice or hospital may differ according to their socioeconomic category. In the same way, attitudes towards a home death may also be different. At the present time in South Africa deaths at home may not be appropriate where informal housing, social support networks and/or nursing services are inadequate. It is important therefore to develop scopes of services that are sensitive to the needs of all the people. In South Africa, it is increasingly important to improve the access to the available services for lower socio-economic groups.

Most studies are quantitative and retrospective from statistical data/registers or from deceased records. Factors such as the personality of patients, coping abilities of the patient and family (past and present), course of the disease, symptomatology and availability of professional support, are all important in determining the place of death; yet are rarely commented on.

While certain facts occur regularly in some studies, there are others that yield opposite findings. There could be many reasons for this, for example, different cultures, different setting, different health care services, or small study numbers.

In reviewing the literature in this study, I question the influence of socio-demographic factors and to what extent these factors are key to determining the place of death?

In my opinion, a shortcoming of a study of this nature is that there is too rigid an adherence to the biomedical model. In other words, there is a separation of facts from values, and a priority of facts over values with adherence to the biological which excludes the social and psychological. For example the Home Death Assessment Tool<sup>(13)</sup> (Appendix 4), developed in Edmonton for co-ordinators in planning a home death, is a tick-list focussing mainly on the

five main factors predicting a home death. No assessment is made of social and psychological factors. It seems there is no doubt that this assists in the facilitation of discussion between patient, family and professionals, and brings about an understanding of what is required for successful palliative care delivery at home in that population. Its role however, would be more limited in a multi-cultural society, such as South Africa with great socio-economic variations.

Although the biopsychosocial model is a modification of the biomedical model, with the inclusion of psychological and social elements, it has the potential problem of reducing qualitative accounts to quantitative data. In doing so, it converts insights into meaning, into causal description. Its continuing reliance on scientific principles allows the medical profession to remain in control of medical disease and disorder, and so determine its boundaries<sup>(26)</sup>.

In South Africa, perhaps a biocultural model that does not separate “scientific” and “social” components, but unites them through its human aspect<sup>(26)</sup>, would more successfully evaluate a subject such as place of death, with all its variables. This enormous task would require a major paradigm shift in the medicine and health care system.

In order to improve the care of the terminally ill patients and the quality of life for them and their families, in South Africa, it would be important to know the normal pattern of health care offered to these patients (to date not audited) and to determine with future population based studies issues such as:

- the perspective of patients and families in relation to death at home.
- what support patients and carers need to enable a home death.
- what personality types cope better.
- how and why preferences about place of death change over time.
- what influences health care workers, patients and carers have in deciding location of death.
- the needs of the socially marginalised groups.
- the influence of enculturation and acculturation on place of death.
- what financial resources are required to allow a home death.
- the quality of care provided by home care programmes.

## CHAPTER 6

### CONCLUSION

In the South African context, an important question that needs answering is – is it feasible that more people die at home? If so, how? Studying trends of place of death related to socio-demographic differences in South Africa is one dimension that can help to understand how best to meet the needs of patients who wish to be cared for and to die at home, but it has limitations.

Internationally, the growth of the hospice movement, the development of palliative care, and the expansion of home care services have provided different forms of care for dying patients. This has done much to draw attention to their needs and to help develop methods to assist in meeting these, especially regarding their choice of place of death.

In the wake of the AIDS pandemic in South Africa, health care authorities have placed a greater emphasis on providing care at home, which includes the support of families. The restructuring of health care services, reduction in the number of hospital beds, and increased fiscal pressure, has reinforced the change. State facilities are ill equipped to deal with this juggernaut, and most non-profit organisations, although willing, lack financial resources.

This study suggests that approximately two-thirds of patients with a terminal illness can be supported in their homes by a home care programme, without referral to an institution. However, this result does not necessarily mean that hospices should be developed throughout the country, but rather establishing excellent standardised home support with access to hospitals, hospices, nursing homes and tertiary palliative care units would be more beneficial. The key to this is improving communication, liaison with community services and improved teaching and training of home support teams.

The task that lies ahead for health care planners in South Africa is to decide what kind of palliative care or other service is cost effective, appropriate and optimal to meet the needs of the multicultural society. Outcome measures that explore trends, other than place of death, would be required in the evaluation of such a service. The development of a biocultural model may be a useful tool in this instance.

*“The house of every one is to him as his castle and fortress”.*

Sir Edward Coke (1552 – 1634) <sup>(66)</sup>

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# APPENDIX 1

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**RESEARCH SOCIO-DEMOGRAPHIC  
ST. LUKE'S HOSPITAL**

Form ID

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**LAST NAME**

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**GIVEN NAME**

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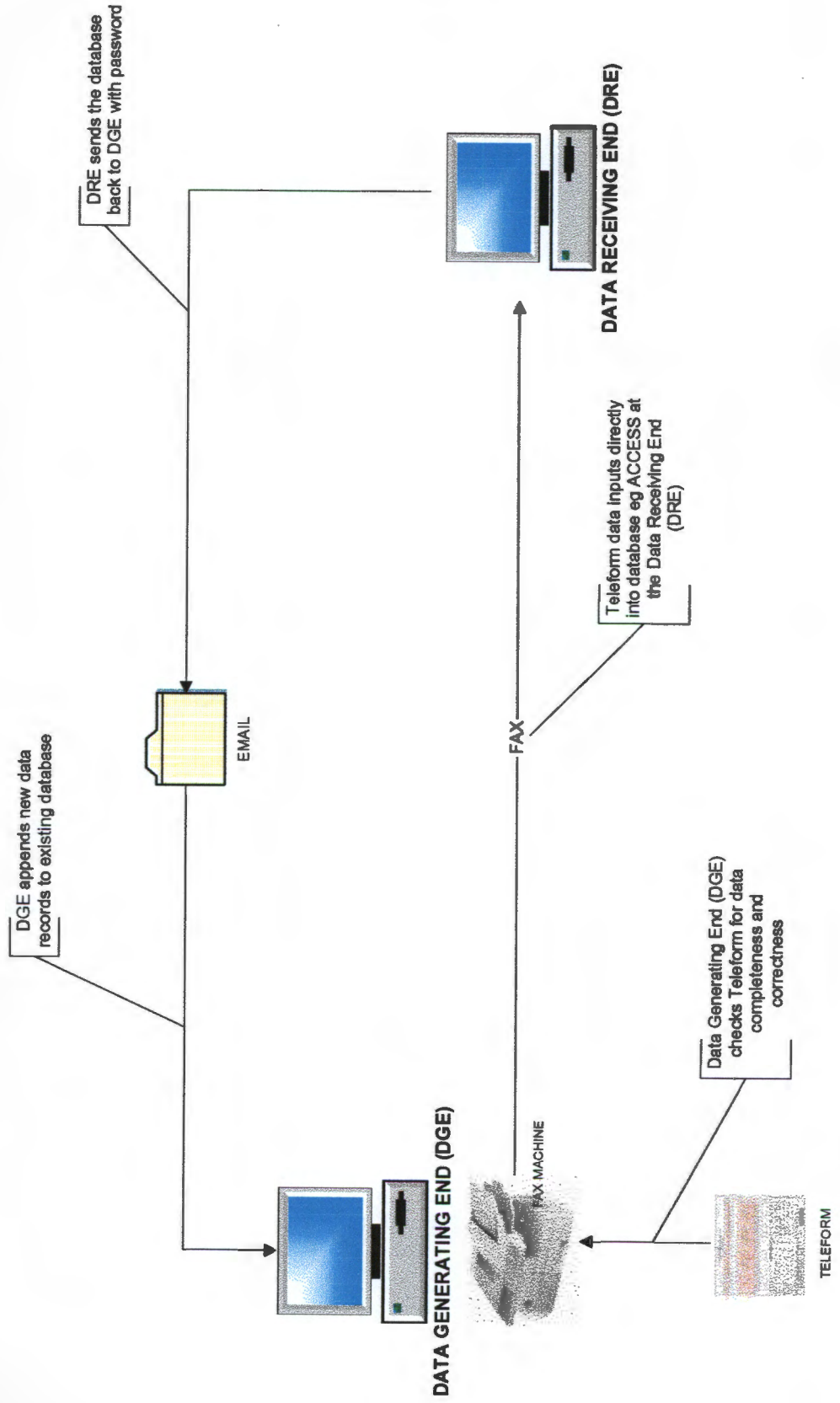
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ASSESSMENT DATE	AGE	SEX	RACE	TYPE OF PATIENT
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SOCIAL	PALLIATIVE PERFORMANCE SCALE	DIAGNOSIS DATE	PLACE OF DEATH	DATE OF DEATH																																																																																																																																				
<input type="checkbox"/> Lives with friends  <input type="checkbox"/> Lives with family  <input type="checkbox"/> Lives in nursing home  <input type="checkbox"/> Lives alone-with help  <input type="checkbox"/> Lives alone-no help	<input type="checkbox"/> 0 <input type="checkbox"/> 40 <input type="checkbox"/> 80  <input type="checkbox"/> 10 <input type="checkbox"/> 50 <input type="checkbox"/> 90  <input type="checkbox"/> 20 <input type="checkbox"/> 60 <input type="checkbox"/> 100  <input type="checkbox"/> 30 <input type="checkbox"/> 70	<table style="width: 100%; text-align: center;"> <tr> <th>M</th><th>M</th><th>D</th><th>D</th><th>Y</th><th>Y</th> </tr> <tr> <td>1</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>2</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>3</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>4</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>5</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>6</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>7</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>8</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>9</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>0</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> </table>	M	M	D	D	Y	Y	1	00	00	00	00	00	2	00	00	00	00	00	3	00	00	00	00	00	4	00	00	00	00	00	5	00	00	00	00	00	6	00	00	00	00	00	7	00	00	00	00	00	8	00	00	00	00	00	9	00	00	00	00	00	0	00	00	00	00	00	<input type="checkbox"/> Home  <input type="checkbox"/> Hospital  <input type="checkbox"/> Hospice  <input type="checkbox"/> Nursing home	<table style="width: 100%; text-align: center;"> <tr> <th>M</th><th>M</th><th>D</th><th>D</th><th>Y</th><th>Y</th> </tr> <tr> <td>1</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>2</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>3</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>4</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>5</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>6</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>7</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>8</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>9</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> <tr> <td>0</td><td>00</td><td>00</td><td>00</td><td>00</td><td>00</td> </tr> </table>	M	M	D	D	Y	Y	1	00	00	00	00	00	2	00	00	00	00	00	3	00	00	00	00	00	4	00	00	00	00	00	5	00	00	00	00	00	6	00	00	00	00	00	7	00	00	00	00	00	8	00	00	00	00	00	9	00	00	00	00	00	0	00	00	00	00	00
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APPENDIX 2



### **APPENDIX 3**

#### **PALLIATIVE PERFORMANCE SCALE (PPS)<sup>(6)</sup>**

<b>%</b>	<b>Ambulation</b>	<b>Activity and Evidence of Disease</b>	<b>Self-Care</b>	<b>Intake</b>	<b>Conscious Level</b>
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Unable Normal Job/Work Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Hobby/House Work Significant Disease	Full	Normal or Reduced	Full
60	Reduced	Unable to Do Any Work Extensive Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	As Above	Considerable Assistance Required	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Normal or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth care Only	Drowsy or Coma
0	Death	-	-	-	-

\* This scale is a modification of the Karnofsky Performance Scale. It takes into account ambulation, activity, self-care, intake and conscious level.

## APPENDIX 4

### REGIONAL PALLIATIVE CARE PROGRAM HOME DEATH ASSESSMENT TOOL

Name: _____
Address: _____
Phone: _____
D.O.B.: _____
PHN: _____

Today's Date: \_\_\_\_\_

Dx: \_\_\_\_\_

Date of PHC Admit: \_\_\_\_\_

1. I would like to receive care at home until I die.  
 Patient – strongly agree 1 2 3 4 5 6 7 strongly disagree
- I would like to provide care at home to my family member until (s)he dies.  
 strongly agree 1 2 3 4 5 6 7 strongly disagree
2. Family Physician Support. Yes No
- |                                    |                          |                          |
|------------------------------------|--------------------------|--------------------------|
| Support Home Death                 | <input type="checkbox"/> | <input type="checkbox"/> |
| Will (s)he Home Visit              | <input type="checkbox"/> | <input type="checkbox"/> |
| Does (s)he have "on call" coverage | <input type="checkbox"/> | <input type="checkbox"/> |
3. Environment/Resources. Yes No
- |   |                          |                          |
|---|--------------------------|--------------------------|
| Accessibility into/out of home                      | <input type="checkbox"/> | <input type="checkbox"/> |
| Accessibility within home                           | <input type="checkbox"/> | <input type="checkbox"/> |
| Family acceptance of medical equipment/home support | <input type="checkbox"/> | <input type="checkbox"/> |
| Supplemental Insurance Coverage                     | <input type="checkbox"/> | <input type="checkbox"/> |
- My/our financial situation will not be a barrier to providing care in the home.  
 strongly agree 1 2 3 4 5 6 7 strongly disagree
4. Identify patient/caregivers' fears/concerns re: death at home.
- Patient \_\_\_\_\_
- Caregivers \_\_\_\_\_

5. Caregivers: None

How many people can help with caregiving and how much are they able to do?

	Age: _____	Relationship: _____
--	------------	---------------------

Actual Availability:  Live In Same House  Live in Same Town  Live Out Of Town

Commitments:  Employed Full Time  Employed Part Time  Not Employed

Dependent Family  School-Full Time  School-Part Time

Other - Specify \_\_\_\_\_

Health/Energy: Excellent | \_\_\_\_\_ | Multiple Health Problems

Willingness to Learn: Very Willing | \_\_\_\_\_ | Very Reluctant

	Age: _____	Relationship: _____
--	------------	---------------------

Actual Availability:  Live In Same House  Live in Same Town  Live Out Of Town

Commitments:  Employed Full Time  Employed Part Time  Not Employed

Dependent Family  School-Full Time  School-Part Time

Other Specify \_\_\_\_\_

Health/Energy: Excellent | \_\_\_\_\_ | Multiple Health Problems

Willingness to Learn: Very Willing | \_\_\_\_\_ | Very Reluctant

Name Other Caregivers: \_\_\_\_\_

Name: _____
Address: _____
Phone: _____
D.O.B.: _____
PHN: _____

Place of Admission: \_\_\_\_\_ Date of Admission: \_\_\_\_\_

Location of Death: \_\_\_\_\_ Date of Death: \_\_\_\_\_

- Reason for Admission to Hospital/LTC:
- Family Exhausted
- Medical Complication  e.g. fracture, DVT, pulmonary embolus, major bleed, M.I., etc.  
 Specify: \_\_\_\_\_
- Symptoms Out of Control  e.g. ↑ pain, uncontrolled emesis, delirium, severe dyspnea, etc.  
 Specify: \_\_\_\_\_
- Did Not Want Home Death  Other  Specify: \_\_\_\_\_