**Evaluation of An Educational Intervention in Palliative Care for Family Doctors in Vietnam**

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# Author’s Declaration

*I declare that the work contained within this document is my own, unless otherwise stated in the body of the text.*

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# Abstract

***Background*** The national strategy for palliative care in Vietnam is to integrate palliative care to cancer care and primary care. In Camau province, 70% of rural family doctors are involved in palliative care provision for cancer patients in rural areas. However, 85% have no palliative care training before or after graduation.

***Objectives***

* To evaluate the outcomes of an educational intervention in palliative care for rural family doctors in terms of perceived knowledge, confidence and practice behaviour.
* To explore and compare views and experiences of hospitalised patients with those receiving palliative care in the community.

***Methodology*** A mixed methods approach was conducted using a pre- and post-workshop design. Doctors completed pre- and post-workshop questionnaires, and patients in two settings (hospital and home) participated in semi-structured interviews. Doctor data was analysed using an independent sample t-test to compare scores of knowledge and confidence before and after the workshop. Thematic analysis was used to analyse patient interviews.

***Findings*** The overall response rate from doctors was 67%. Pain management, fatigue and communication were the most requested topics for the education workshop (85%, 50%, 45%). As a result of the workshop, one-third indicated an increase in morphine prescribing and caseloads in their workplace. There was a statistically significant increase in scores of knowledge (p = 0.004) and confidence (p <0.001) after workshop.

Patients’ choice of place of care was based on their satisfaction with the care, relationship with staff, the severity of symptoms and convenient access. Hospitalised patients claimed that local family doctors lacked expertise and enthusiasm in palliative care provision. The local palliative care service was perceived as acceptable by patients interviewed at home.

***Conclusions*** The multi-faceted intervention improved the knowledge, confidence and behaviour of family doctors. Satisfaction with generalist palliative care from the trained doctors was indicated by patients interviewed in the community.

# Abbreviations

|  |  |
| --- | --- |
| ASEAN | Association of South East Asian Nations |
| CHS | Commune Health Station |
| CME | Continuing Medical Education |
| CPD | Continuing Professional Development |
| DGH | District General Hospital |
| DoH | (Provincial) Department of Health |
| FD | Family Doctor |
| GP | General Practitioner |
| HCMC | Ho Chi Minh City |
| NGPC | National Guidelines for Palliative Care |
| MoH | Ministry of Health (Vietnam) |
| PCP | Primary Care Physician |
| PCU | Palliative Care Unit |
| PEM | Printed Educational Materials |
| PGH | Provincial General Hospital |
| PHR | Patient-Held Record |
| RCT | Randomised Clinical Trial |
| ROP | Regulations of Opioid Prescriptions |
| UICC | Union for International Cancer Control |
| UREC | University Research Ethics Committee (Sheffield) |
| WHO | World Health Organisation |
|  |  |

# Chapter 1 – Introduction

## 1.1 Structure of the thesis

This thesis begins with the introduction chapter, which focuses on the definition of palliative care, the need for a palliative care programme for family doctors, principles of social medicine underpinning for this study and the local context. These leads to research question as well as objectives that the study aimed at in order to answer the question posed. **Chapter 2** consists of two sections. The first one introduces Continuing Medical Education (CME) or Continuing Professional Development (CPD) based on adult learning theory as an educational model suitable for healthcare professionals. The second section is a review of educational interventions in palliative care for family doctors from 2005 to 2012 from around the world. The next chapter is concerned with the structure and financing of Vietnam healthcare system with particular emphasis on the recent establishment and development of palliative care in the country. **Chapter 4** is devoted to issues of methodology such as the theoretical base for employing a parallel mixed methods approach to deal with an evaluation research as well as reasons for adopting the triangulation protocol technique for integrating two data sets. The next two chapters introduce in detail the methods and results of the pretest-posttest surveys with participant family doctors as well as semi-structured interviews with advanced cancer patients. **Chapter 7** presents discussions of the results of each data set, the meaning of these findings for the research population and limitations as well as future work in the next few years of the project. The next chapter deals with the integration of the results from the two data sets reported in the two previous chapters in order to generate a complete picture of the intervention. The final chapter of the thesis, **Chapter 9**, is the summary of main findings from the study in relation with the research question and objectives raised in **Chapter 1**. Finally, the **Appendices** includes a poster and paperwork regarding the research process as well as the **Bibliography**.

## 1.2 Overview

The World Health Organization (WHO, 2007) estimates that cancer is a leading cause of death worldwide with 7.6 million deaths in 2005, and 84 million people predicted to die in the next 10 years. For a majority with cancer, it has been widely recognised that, alongside the disease pathway, treatment goals will evolve from seeking a cure to controlling the disease and its complications while reducing sources of suffering and maintaining quality of life, and ultimately, supporting a peaceful death – ­­­­being free from pain, being at spiritual peace, and being with family (Cherny & Catane, 2010).

According to Rajaponal and Twycross (2010), two-thirds of dying patients in developing countries would benefit from palliative care. However, the models from the USA or the UK are often expensive, and if being adapted into resource­‑limited countries, would merely cover a small percentage of those in need.

Stjernsward and colleagues (2007) suggest that the only way for universal access to be achieved in poor-resource countries is to adopt a public health approach. According to the WHO (2006), in order to plan a programme effectively in low-income countries, it is necessary to understand the context, appreciate past experiences and use limited resources wisely. For example, the WHO developed and disseminated an effective analgesic method for the relief of cancer pain in 1986. This method relies on the availability of opioid analgesics including morphine, codeine and others known as the *Three-Step Analgesic Ladder*. This approach is based on the use of the oral route for its convenience and effectiveness. This approach has been widely disseminated and is widely used around the world (De Lima et al., 2010).

In this introductory chapter, I will present the definitions of palliative care that I have considered; the concepts of social medicine as an underpinning framework for my project; the socio-medical background in which my research question was generated; the aim and objectives of my study; and finally, a brief overview of the subsequent chapters.

## 1.3 Definitions of palliative care

Helping people with cancer live high-quality lives at every stage of their illness is one of the overall goals of palliative care. Despite our best efforts and hard work, cancer treatment sometimes stops working, and a cure or long-term remission is no longer possible, for example when the cancer returns or secondary cancers appear. This stage of cancer is called advanced, terminal, or end-stage cancer. The primary care physician with palliative care skills and knowledge can offer ways to help patients find peace and meaning as they approach the end of their life (Murray, 2004).

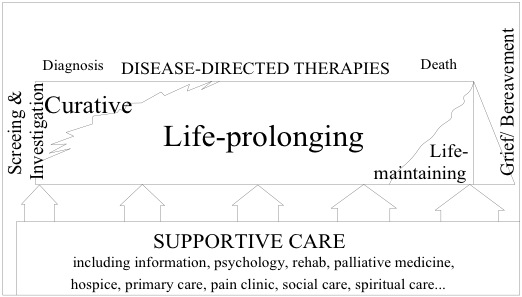
The following definition is derived from the WHO (2002), and often cited in specialised literature – ‘*palliative care*’ is

‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual.’

There are some arguments on the appropriate time for commencing palliative care. (Abu-Saad & Courtens 2001) demonstrated that, according to previous views, life-threatening disease including cancer might be divided into three stages: curative, palliative and terminal. Palliative care is only applied when the patient’s condition is no longer curable or at a terminal stage; and, from this time onwards, caring just focuses on improving patient quality of life as well as end-of-life support.

However, Doyle and colleagues (2005) suggest explicitly that palliative care should *‘start at the time of diagnosis and continue until death*.*’* This point of view is also proposed by a number of other authors (NICE, 2004; Twycross, 2003; WHO, 2007). Recently, the *‘Sheffield model’* of comprehensive supportive care, including supportive, palliative and end-of-life care, seems to be the most appropriate in terms of clinical practice (**Figure 1.1­**). It offers supportive care from a very early stage of disease, even prior to diagnosis, and spans the disease pathway until after the patients’ death, and provides care for both patients and their family (Ahmedzai & Muers 2005; Noble, 2008).

I have adopted this model for this research study. The main reason for my choice is that the *‘Sheffield model’* may enable policy makers and health managers to think about introducing palliative care earlier in the trajectory of illness, often in parallel with disease modifying treatment such as integrating palliative care to cancer care (Krakauer et al., 2007) or primary healthcare system (Murray, 2004).



**Figure 1.1** Sheffield Model of Supportive Care (Ahmedzai & Walsh 2000).

According to Ahmedzai and colleagues (2004), on behalf of the European School of Oncology (ESO), there are two types of palliative care services which reflect the levels at which palliative care can be delivered those are generalist and specialist palliative care, which they define as follows:

‘Basic or generalist palliative care is the level of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their duties to patients with life-limiting disease.’

‘Specialised palliative care is the standard of palliative care provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialist members of the primary or secondary care teams.’ (p.2194)

WHO (2002), ESO (Ahmedzai et al., 2004) and NICE (2004) have been calling for comprehensive coordinated care for patients with cancer. They indicated that the integration of palliative care into the existing primary care infrastructure is of paramount importance. Indeed, this model could make it possible for all members of the primary healthcare team to optimise their performance and deliver the best possible care to their patients in the community.

Noble (2008) presents the consensus amongst APM[[1]](#footnote-1) executive members, who propose that providing good, equitable palliative care to all cancer patients is the responsibility of every physician and his or her care team in any setting. Grunfeld and colleagues (2003) state that family doctors are not only crucial to that team, but are also keen to be team players for their patients with cancer.

The ESMO[[2]](#footnote-2) palliative care training programme recognised that a family doctor or an oncologist does not need to be an expert in all aspects of palliative care at the *skilled level*, for example effective clinical competence or specialist palliative care level, rather even *familiar level,* that is the lowest level of required competence or generalist palliative care level (Clare et al., 2012; Shipman et al., 2008). This refers to familiarity with core concepts to the level of being able to adequately evaluate the patient, initiate basic therapy, and communicate with clinical experts. At the completion of training, one should be familiar with evaluation and management of psychological and existential symptoms of cancer, inter-disciplinary care of patients with advanced cancer, palliative care research principles, ethical issues in the management of patients with cancer and strategies to identify and prevent burnout (Cherny & Catane, 2010; ESMO, 2003). In addition, good collaboration between generalist and specialist palliative care services can offer opportunities for education and clarify the roles and responsibilities of each service (Clare et al., 2012; Shipman et al., 2008).

## 1.4 Palliative care education for family doctors: a need

### 1.4.1 Needs of advanced cancer patients

There is a growing need for palliative care in primary care practice due to many reasons such as terminal stage patients’ preference, the increasing number of old people, high cost of specialist hospital care and so on (Higginson & Costantini 2008). Most cancer patients wish to remain at home and receive care from general practitioners – GPs or family physicians (designated as ‘family doctors’– FDs in this thesis) for their end of life stage (Gomes & Higginson 2006), and even until dying (Ingleton et al. 2009b; Munday et al. 2007). However, in many developed countries with strong hospital sectors, a majority of terminal cancer patients still die in hospitals (Higginson & Costantini 2008; WHO, 2007). According to Aabom and Pfeiffer (2009), the dissatisfaction of people with advanced cancer and their carers with local palliative care services might be one of the causes. The provision of reliable palliative care services in the community by primary care teams is therefore required to meet patients’ needs (Thomas & Noble 2007).

### 1.4.2 Perspectives of family doctors on palliative care in the community

Most family doctors value highly their care in the community. They also express willingnesses to provide palliative care service (Alvarez & Agra, 2006; Lloyd-Williams et al., 2000; Mitchell, 2002). A majority of researchers found that general practitioners identify palliative care as the important and valuable part of primary care (Groot et al., 2005; Lloyd-Williams et al. 2000; Meijler et al., 2005; Mitchell, 2002; Shipman et al., 2001). Most cancer patients want to spend the last months of their life at home under the care of their own general practitioners or family doctors (Bestall et al., 2004; Gomes & Higginson, 2006; Munday & Dale, 2007; Munday et al., 2007). In this case, primary care teams including GPs or family doctors, district nurses, nursing home staff, and others have been recognised as playing an increasingly important role in the provision of palliative care service to patients who are approaching the end of their life (Boyd & Murray, 2008; Munday & Dale , 2007).

Furthermore, when Meijler et al. (2005) and Mitchell (2002) conducted surveys to examine the views of general practitioners on palliative care they found that family doctors reveal a willingness to acquire knowledge, improve skills and adopt attitudes in order to meet a variety of palliative care needs in the community.

However, family doctors in rural areas are often reluctant to provide palliative care for patients due to lack of specialist knowledge and skills or not having adequate information of patients’ diagnosis and treatments from oncologists (Groot et al., 2007; Rhee et al., 2008). In addition, in a study exploring the general practitioner 's perception of educational needs in palliative care, Meijler and colleagues (2005) propose that general practitioners should be trained to become competent in using some psychological techniques and medication prescription.

Therefore, many researchers of the field (Noble et al., 2001; Ingleton et al., 2009a; Liu et al., 2005; Lloyd-Williams et al., 2000) have suggested that family doctors may need a little coaching to help them be more effective in providing palliative care for their patients in the community.

### 1.4.3 Obstacles that prevent family doctors from providing palliative care

As mentioned above, the knowledge barrier is likely the most challenging factor. Some family doctors feel *‘unprepared to deal with what they see as the complex clinical and psychosocial aspects of palliative care’* (Sanderson & Tieman 2010). Long distances from rural areas to metropolitan centres as well as the physical and professional isolations from specialists’ support are considered as other barriers (O'Connor & Lee-Steere 2006; Wakefield et al. 1993). Organisational issues also can lead to some impact on the effectiveness of palliative care practice of family doctors (Groot et al., 2007). Misunderstandings of roles and responsibilities of different health providers, for instance between hospital specialists and local generalists due to a weak collaboration, is another factor which could cause impact on opportunities for education of both parties (Gardiner et al, 2012).

Mitchell (2002) in his systematic review of palliative care delivery by family doctors indicates that more than 70% of family doctors had received no training in palliative care recently. Similarly, in a survey of Lloyd-Williams and colleagues in the UK in 2000, only half of rural GPs reported that they knew the correct prescriptions of morphine and other opioids.

In addition, ever since the publication of the UK’s first End of Life Care Strategy (DoH 2008) the emphasis has been on gaps in providing good end of life care for all: training generalists to address the gaps between palliative care specialists delivering care with those working in non-specialist settings such as care homes, community and other specialties. Education remains the key to good quality care.

### 1.4.4 Continuing professional development (CPD): A suitable educational format to meet the demands

The format of education and training on palliative care for health physicians should be the format of adult learning theory (Ahmedzai et al. 2004; Charlton & Ford 1995; Finlay & Noble 2005). This theory of adult education was developed by the American educator: Malcolm S. Knowles. The Knowles’ theory can be summarised with following assumptions related to motivation of adult learning:

* Need to Know: Adults need to know the reason for learning something.
* Foundation: Adults accumulate experiences (including errors), which provide a rich resource in learning activities.
* Self-concept: Adults need to be responsible for their decisions on education including planning and evaluation
* Readiness: Adults are most interested in learning subjects which they are confronting or topics which are relevant to their work and/or personal lives.
* Orientation: Adult learning is problem-centered rather than content-oriented.
* Motivation: Adults are more motivated to learn by internal drives rather than by external ones.

(Jarvis, 2004; Kaufman, 2003)

In the field of medical education for healthcare professionals, it has been Continuing Medical Education (CME) (Finlay & Noble, 2005), or its synonym, Continuing Professional Development (CPD) (Ahmedzai et al., 2004). These formats will be discussed further in **Chapter 2**.

CME or CPD is considered as effective educational formats to transfer knowledge, and skills of palliative care to physicians. These may result in improvements of competence, confidence and attitudes towards daily practice (Davis et al. 1999; Finlay & Noble 2005; Ahmedzai et al. 2004).

It is important to select the correct educational and training model before planning a training programme for healthcare professionals. The organiser of a training course for these specific learners is aided by family doctors’ motivation to learn. Finlay and Noble (2005) emphasise,

‘Family doctors are more likely to engage in learning as they have some purposes in their mind such as obtaining certain knowledge, getting a specific skill or gaining confidence in dealing with unfamiliar circumstances.’

By getting involved in the process of CPD, as Charlton and Ford (1995) point out, family doctors will acquire new knowledge, develop professional skills and adopt appropriate attitudes towards the provision of comprehensive palliative care.

According to Campbell (2007), in order to undertake successfully an educational and training programme, a basic understanding of the theoretical basis of different educational techniques is required. The **Table 1.1** shows a wide range of educational methods that have been demonstrated effectively in teaching and learning of palliative care to healthcare physicians.

**Table 1.1** Different educational methods in palliative care (Finlay & Noble, 2005).

|  |
| --- |
| Lectures |
| Bedside teaching |
| Reading |
| Case study |
| Audit |
| Reflective practice/ experiential learning through:  Portfolio learning  Small group discussions  Project work  One to one tutorials |
| Interdisciplinary conferences |
| Computer-assisted learning |

In the practical aspect, Finlay and Noble (2005) mention that all of the above methods of learning ‘*may help in training of the family physicians and they should not be used in isolation*’ (p.1160). The authors also suppose that several formats of training such as courses with update lectures, section meetings or the circulations of updates covering common topics, for example morphine prescribing, is likely to play a minor role in increasing the factual knowledge of attendees if they are undertaken separately.

There are many ways to conduct educational programmes for physicians in the community. The most commonly used methods are to organise training classes such as workshops, seminars, role-plays and clinical placements at specialist centres (Boakes et al. 2000; Croager et al. 2010; Hoon et al. 2009). These educational formats are intended to bring up-to-date information of the field to participants. Other formats are those in which GPs receive the contents of educational programme at their work setting. These include sending palliative care specialists to the community (Noble et al. 2003); counselling by telephone or teleconference via the Internet (Mitchell et al. 2008; Tasmuth et al. 2006); or just simply circulating clinical practice guidelines (Davis & Taylor-Vaisey 1997).

Some people believe that the acquaintance with specialised knowledge leads physicians to improve their daily practice in terms of behaviour and performance. In addition to this, it probably brings about positive changes in health professional practice in the workplace, thus improving the outcomes of health care on patients.

In a systematic review by Mitchell (2002), the author indicated that GPs, with adequate palliative care training, can deliver sound and effective care. The findings from the study by Cantillon and Jones (1999), however, were somewhat different. According to them, although the purpose of education is to change the clinical behaviour of general practitioners, only one-third doctors change their behaviour as a result of training. Similarly, Finlay and Noble (2005) also realise that *‘it is much easier to increase knowledge and understanding, or to improve skills and competencies, than to change attitudes and professional behaviours.’* (p.1159)

With regard to organising seminars and workshops, Davis and colleagues in a systematic review study published in 1999 mentioned that these traditional education formats still have utility as useful ways to transfer knowledge, skills, confidence, and competence to attendees. They consist of didactic lectures, audio video presentations, printed materials, and so on. Although didactic interventions in their review had failed to show much success in terms of changing performance or healthcare outcomes, such interventions may *‘ change other elements of competence, such as knowledge, skills, or attitudes, or may act as predisposing elements to change’* (p.870)

Taken together, it could be argued that workshops and seminars are appropriate ways of disseminating the principles of palliative care through providing new knowledge and skills to rural family doctors, who need to become more professionally competent. As a result, this training could lead to improved outcomes of palliative care provision for cancer patients in the rural community.

However, the vast majority of existing evidence in this area comes from developed countries which have a very different cultural and religious context to Vietnam. In fact,

‘Constructing a curriculum is not like using a recipe book to bake a cake. Local needs, tradition, and resources legitimately colour approaches to training. The professional background, extent of prior knowledge, and current clinical responsibility will also legitimately influence the design of the curriculum’ (Buckley & Smyth, 2004:62).

Therefore, taking all local resources and social-medical contexts into account is compulsory prior to planning any educational and training intervention. It is especially the case of the palliative care training project under way in Camau Province, Mekong Delta, Southern Vietnam.

In order to consider the Vietnam context, a social medicine approach will be applied, which will now be outlined in the next section.

## 1.5 Social medicine as the theoretical underpinning for this research study

For the theoretical basis of this research, I have nested my study within the context of social medicine. In this section, I will go through several main concerns of social medicine and explain how they have informed the theoretical underpinnings for my project. These concerns include patients’ satisfaction about healthcare services, the issue of healthcare disparities, physicians’ attitudes to daily practice and the physician- patient relationship. They will be mentioned and discussed more or less depending on the extent to which they relate to the objectives of the project. The organisation and characteristics of healthcare services, in particular the primary healthcare structure and health insurance policies in Vietnam will be presented in Chapter 3. However it is also noted briefly in this section, where relevant. This is because, as Noble (2011) wrote:

‘Diversity of healthcare systems and cultural attitudes to illness and death may produce considerable variation in the way supportive and palliative care needs are addressed around the world.’

### 1.5.1 Development and scope of social medicine.

Social medicine developed in the middle of the nineteenth century. The German physician Rudolf Virchow is seen as one of its founders being one of the first authors to mention the links between society and health and the social origins of illness. When investigating an outbreak of typhus in the Prussian province of Upper Silesia, for example, Rudolf Virchow identified social factors such as poverty and the lack of education and democracy as key elements in the development of the epidemic (Virchow, 2006).

Holtz and colleagues (2006) stated that Virchow had laid the foundation for the practice of social medicine, and advocated that medicine should be reformed on the basis of three principles:

* The health of the people is a matter of direct social concern.
* Social and economic conditions have an important effect on health and diseases, and these relations must be subjected to scientific investigation.
* Measures taken to promote health and to combat disease must be social, as well as medical.

In addition, Virchow also participated in *‘revolutionary’* political action on the streets. Right after that, he helped found the *‘Medical Reform’*, a weekly newspaper that promoted the cause of social medicine under the banners *‘medicine is a social science’* and *‘the physician is the natural attorney of the poor’* (Virchow, 1987). He continued until June 1849, when increasingly reactionary political pressures forced him to suspend publication.

In the USA, the Institute of Human Relations was founded in 1931 under the direction of Milton Winternitz, the dean of the Medical School of Yale University. In Europe, René Sand was appointed as Professor of Social Medicine at Brussels University in 1945, one of the first professors appointed in this discipline. He wanted to integrate medicine’s social role into physician training through the creation of a new academic discipline of social medicine (Porter, 2006). In England in the 1940s, the Committee for Social Medicine was formed by a group of doctors and scientists who wanted to link socio-economic factors with diseases (Cartwright, 1977). The Cuban revolution in the 1960s was inspired by the experiences of Che Guevara – a doctor and political activist. His conceptualisation of *‘revolutionary medicine’* recognised the social origins of illness and the need for social change to improve health conditions. This principle has influenced the training of all healthcare professionals, including physicians. Like campaigners for social justice they have frequently been in direct opposition to major political and economic forces (Porter, 2006).

Social medicine is concerned with the relationships between society, disease, and medicine. It proposes that social and economic conditions impact profoundly on health, disease, and the practice of medicine. In addition, society should promote health through both individual and social means (Eisenberg, 1999). These are more or less similar to *‘Virchow’s principles’*, which were propounded in 1848.

Social medicine has extended to the boundaries of both public health and epidemiology due to the fact that it focuses on the whole of society and recognizes the importance of the relationship between ill, health and social, political and economic factors. In general, public health policies follow a government line with the aim of ensuring a healthy population and tend to divide society into demographic groups according to criteria such as age, sex, ethnicity and so on. They then apply medical initiatives such as sanitary reform, treatment of disease outbreaks, vaccination or screening for diseases to the relevant groups (Stonington & Holmes, 2006).

Over time the term *‘social medicine’* has taken on varied meanings, as it has been adapted to different societies and diverse social conditions. The development of social medicine accompanied and is linked overtly to political programmes of social reform. The interplay between social circumstances and illness created a new social role for medicine in order to engage with epidemiological and social developments in the twentieth century. Therefore, the interdisciplinary relationship between medicine and social science provides medicine with the intellectual skills needed to analyse the social causes of health and illness (Porter, 2006).

To better reflect physicians' current challenges, a report on ‘*Improving Medical Education*’ by the US Institute of Medicine in 2004 identified a need to include a section on behavioral and social sciences to the MCAT (Medical College Admission Test) – a prerequisite for admission to U.S. medical schools. The new test will be applied since 2015 (Kaplan et al., 2012). This revision recognises the major roles of behavioural and social factors not only in health and illness, but also in the interaction with biological factors to influence health outcomes. The effective practice of medicine needs fundamental knowledge about behavioural and social sciences (Lee, 1999).

### 1.5.2. Primary domains of social medicine discipline

#### 1.5.2.1 Cultural and social aspects of interactions between patients and physicians

Social medicine is interested in the interactions between health professionals and patients in relation to patients’ demographics, socio-economical and individuals’ understandings of their situation (Stonington & Holmes, 2006). Although the relationship between patients and doctors is often idealised in terms of universal and timeless principles, it has not been immune from the larger social and cultural forces surrounding it. Socio-economic movement in the past several decades has profoundly shaped this relationship.

According to Bowling (2009) these interactions embrace two main aspects i.e. communication and patients’ evaluations of healthcare. The communication focuses on the verbal and non-verbal interactions between doctors and patients in relation to consultation and treatment. Patients’ understanding of the content of care, recall of information related to disease pathway and satisfactions with the care received are essential for making good decisions and complying with therapy, thus alleviating them from suffering (Stonington & Ratanakul, 2006).

Patients’ evaluations of healthcare services consist of patients’ beliefs about their experiences (Bakdash & Scheper-Hughes, 2006). The care or treatments provided by healthcare professionals, Bowling (2009) argues, could conflict with patients’ desires, thereby influencing the take-up or refusal of services. Today, there is a consensus about the rights of patients to refuse unwanted care; equally strong disagreement persists about patients' rights to demand care (Stonington & Holmes, 2006).

Patients’ evaluations of healthcare include their expectations, preferences, choices and satisfaction about the mode of delivering as well as the outcome of healthcare services. Dictionary definitions attribute the term ‘satisfaction’ to the Latin root ‘satis’, meaning ‘enough’ or ‘fulfilment of one's own expectations.’ According to Crow and colleagues (2002), a feeling of satisfaction with a service does not imply superior service, rather that an adequate or acceptable standard was achieved. Furthermore, satisfaction can be measured only against individuals’ expectations, needs or desires. The relationship between satisfaction and the quality of healthcare provision received is complex and affected by patient, doctor and service factors (McKinley et al., 2002).

The measurement of the evaluation of healthcare services by patients (sometime termed as ‘consumers’ or ‘clients’) is very important for the development of services. There are some problems relating to measuring satisfaction and alternative evaluative approaches. First, patients rate the quality of services by comparing their personal subjective standards with their perception of the care received. The satisfaction they report, therefore, is an attitudinal response to this value judgment, and is a subjective evaluation rather than an objective measure (Coulter & Fitzpatrick, 2003). Second, patients’ evaluations are also more likely to be affected by their emotion and cognition (Bowling, 2009). Finally, according to Crow and colleagues (2002) they reflect users’ knowledge and expectations, rather than the quality of the service and care provided. A number of research studies on patient satisfaction demonstrate that a majority of patients tend to be satisfied overall with the care they experienced (Cartwright, 1992), particularly in relation to the amount of information provided, for example, surveys with questionnaires (Coulter & Fitzpatrick, 2003; Hall & Dornan, 1988).

Patients’ evaluations are often assessed through satisfaction surveys. In palliative care, for instance, these examine patients’ quality of life (Mitchell et al. 2008) as well as the degree of satisfaction of patients and their families with palliative care services (Ingleton et al., 2004). However, this method suffers from several limitations. The form as well as the way of using words in the questionnaire might influence the final results (Fowler, 1995; Oppenheim, 2001). In addition, inherent characteristics of survey research make it impossible to get a high response rate. Finally, time-consuming with face-to-face interviews and reliability issues of a less robust nature of research designs such as lack of randomisation and/or control and blinding are other limitations (Boynton & Greenhalgh, 2004).

Regarding the current project in Camau aims at raising the quality of rural palliative care services through education for primary healthcare professionals, and to a lesser extent, measuring perceived outcomes from patients with advanced cancer. Patients’ reports of their experiences of palliative care received, including satisfaction, also play a role in the evaluation of the effectiveness on the extent to which the project worked.

#### 1.5.2.2 Culture of medicine

Recent studies continue to confirm the impact of culture on the doctor-patient relationship and correspondingly on patient outcomes. According to Stonington and Holmes (2006), understanding the culture of medicine is essential to understanding physicians’ attitudes and behaviour towards illness, patients, and treatments, for example referral or prescription. Kleinman and Benson (2006) name these aspects as the *‘cultural competency’* of healthcare professionals. Physicians play an important role in encouraging their cancer patients to accept themselves as *‘normal’* and make *‘good adjustments’* or accommodate themselves to their situation. This adaptation process is called by Sprangers and Schwartz (1999) a *‘response shift’* that involves changing internal standards, values and the conceptualisation of quality of life. As Stonington and Holmes (2006a) argue:

‘Experiences of and responses to suffering are not confined to the clinical encounter and vary dramatically among different populations. Understanding the specifics of people’s everyday lives is essential to engaging with them and their illnesses.’(p.1661)

Studying culture of medicine applied for people with cancer regarding activities such as self-medication or self-treatment, and discussion of their problem with others within their social network. In addition, patients could seek care outside the mainstream biomedicine system, for instance traditional medicine systems and popular medicine (Quah, 2005). This concept of social medicine was used in this study when exploring cancer patients’ strategies for coping with advanced stages.

In 2005, the Vietnam Ministry of Health (MoH) launched a palliative care initiative. The public health strategy of the World Health Organization (WHO) was used to develop the framework of the national palliative care programme. The intention is to integrate palliative care into existing primary healthcare services that are organised at the rural commune level, normally being called Commune Health Stations (CHSs). Multiple steps were performed to implement this strategy such as a rapid situation analysis in 2005 to explore workload and attitudes of stakeholders regarding palliative care provision in the community (Green et al., 2006), circulation of the National Guidelines for Palliative Care (NGPC) in 2006 and issue of Regulations of Opioids Prescribing (ROP) in 2008 (Krakauer et al., 2010). These actions are likely to help to raise physicians’ awareness about current issues of cancer and palliative care.

#### 1.5.2.3 Social and behavioral determinants of illness

Study of the social determinants of health originated from Virchow’s principles about large-scale forces that shape health (Farmer et al., 2006). According to Bowling (2009), health status varies according to age, gender, culture, racial and/or ethnic status as well as socio-economic factors. In particular, differences amongst socio-economic classes can cause inequalities in health status. It is not only levels of access to health services, but also the degree of access inequalities (Satcher, 2006).

Geographical isolation or disadvantage is another disparity. Catalano and Pickett (2003) argued that the health problems of the poor are likely to be caused by the unequal spatial distribution of hazards, coping resources and tolerance. Inequalities in geographic accessibility of palliative care services as well as that of mean distance or travel time is very important for priority setting to ensure fair access to healthcare facilities for patients as well as obtaining professional education and training for physicians (Evans et al., 2003). Transportation is an additional problem, which might affect the accessibility of professional training for healthcare physicians and healthcare services needed by patients. Even in the USA, unfavourable transportation can cause severely reduced access to medical care, and various problems with health (Freund et al., 2003). In Australia, cancer management follows the overall trend of rural health disparities, with higher incidence rates of preventable cancers and lower survival rates in rural Australia. Five-year relative survival also decreased with increasing remoteness (Hoon et al, 2009).

In Vietnam, because the bulk of the population lives in rural villages, most people die at home rather than in a hospital (Ngoan et al., 2007b). There has been a national programme in palliative care for nearly ten years with the purpose of providing this care to all patients who need it. However, in fact only a small number of cancer patients with palliative care needs have been able to access the service (Krakauer et al., 2010).

### 1.5.3. Concepts and approaches of social medicine discipline

In the respect of research methods, there are some overlaps regarding underpinnings and practices between social medicine and public health. Social medicine has adapted to some extent the methods of epidemiology and public health. Traditionally, these disciplines have favoured using statistical methods to study large groups. However, there is no clear boundary amongst these disciplines today (Tashakkori & Creswell, 2008). This may be an increasing convergence in line with the *‘new public health’*.

In our pluralist society it is perhaps not surprising that explanations about the relation between illness and well-being as the results of the interaction of multiple factors are more acceptable than simple mechanism. Genetic advance and better understanding of social and environmental impacts on health have also improved our knowledge of causation of diseases. For example, Doll and Hill’ s research (1964) linking smoking habits of British doctors with deaths due to lung cancer led to an anti-smoking campaign in Britain. The Framingham studies of heart disease in the middle of the twentieth century in the USA resulted in recommendations for modification of personal habits and the environment that could prevent the development of coronary heart disease (Oppenheimer, 2006). These famous habit-related health studies have inspired effective government propaganda about disease prevention via the media (Porter, 2006). There is now an increase in public and professional understanding of health issues in the social context.

There are a large number of research studies that suit the definition of social medicine as *‘medicine in its social matrix’* such as work related to health inequalities and social disadvantages. Examples include the report (known as *‘the Black Report 1980’*) on significant correlations between social class and health inequalities in the UK (Black et al., 1980) or in India (Subramanian et al., 2006) as well as the inequalities in health related to disparities of ethnicities in the USA (Holmes, 2006; Satcher, 2006).

In Vietnam, social medicine has contributed significantly to the knowledge body of cancer and palliative care services to patients who need it, although there is a paucity of information published regarding palliative care research studies based on the foundations of social medicine. In 2006, Green and colleagues evaluated several aspects of palliative care services in five provinces in Vietnam such as needs, gaps and barriers. One year later, Ngoan and colleagues (2007b) scrutinised and highlighted the different cancer-related rates of deaths between rural and urban communities. And recently, in cooperation with the MoH, Krakauer and colleagues (2007) reported results of a palliative care initiative using the WHO’s public health strategy for developing the national palliative care programme.

### 1.5.4. Concepts of social medicine as underpinning framework for the current project

The prevalence of cancer has increased steadily year by year (WHO, 2007). This is part of what is called by Wilkinson (2004) *‘the epidemiological transition’*, or the shift in the main causes of death, from infectious diseases to cardiovascular diseases and cancers. In resource poor countries, the government often allocates more resources to infectious diseases because of the high morbidity and mortality, for example African and some Southeast Asian countries including Vietnam (WHO, 2002). Attempts to invest more on fighting cancer in developing countries are compromised by the limits of national budget and personnel resources. This conflict between unmet healthcare needs and social policies is at the heart of social medicine concerns.

A social medicine approach to palliative care for people with advanced cancer illustrates the importance of social and economic factors in the continuing increase in prevalence of cancer in population in spite of the enormous reduction in poverty and social inequalities from many developing countries (WHO, 2012).

The reflections of the *‘social matrix’* around palliative care for rural patients with advanced cancer leads to a range of issues for investigation such as the importance of the social context; the acknowledgement of disease burden on patients, their family and healthcare system; the lack of an existing effective paradigm and so on. These naturally lead to an approach to the investigation in the tradition of social medicine with particular emphasis on the alleviation of inequalities regarding healthcare service accessibility for advanced cancer patients in remote areas, through educational intervention on palliative and supportive care for local healthcare professionals.

In Vietnam, due to a long history of war and the small scale of the economy, social medicine research has not been adequately funded. There has been a blurred boundary between social medicine, epidemiology and public health. The Hanoi School of Public Health (HSPH) was founded in 2001 when the government admitted the importance of a relatively new discipline – Public Health(HSPS, 2012).

Although in Vietnam so far there have been a major number of research studies scrutinising illness in relation to the wider social context, most of them do not refer explicitly to the discipline of social medicine. Some of them are described as epidemiology or public health studies (Huong et al., 2006; Khe et al., 2002; Gien et al., 2007; Pham et al., 2009; Thanh et al., 2010). This indistinctness may be because the term *‘social medicine’*, the Vietnamese translation of this phrase is *‘Y Học Xã Hội’*, is not as popular as the terms epidemiology or public health in Vietnam. In addition, as mentioned above, the boundaries amongst these fields are not easy to be recognised. However, from historical and practical perspectives, social medicine is distinguished from traditional public health. Public health tends to define a population as a sum of individuals and classify these individuals into groups based on characteristics such as sex, age, education, income, and ethnicity. Meanwhile, social medicine visualises populations as totalities whose characteristics transcend those of individuals, and therefore, defines problems and seeks solutions with social rather than individual units of analysis (Waitzkin et al., 2001). In this way, the population can be analysed through such categories as social class, economic status and culture, not simply through the characteristics of individuals.

Living and working in remote areas has been considered as a low status for healthcare professionals in terms of accessing educational opportunities. In Vietnam, palliative medicine is not yet considered as a specialism of medicine; and there has not been any official curriculum for teaching palliative care to medical undergraduates or even post-gradates (Krakauer et al. 2007). Therefore, it is understandable that a number of family doctors were not equipped with palliative care knowledge following six years at medical school. Added to this is the lack of training opportunities in the field if they are working in remote or rural areas. One-week basic courses on palliative care have been undertaken to train more than 400 Vietnamese oncologists, healthcare physicians, and family doctors nationwide. These courses were assisted by the Center for Palliative Care of Harvard Medical School, but unfortunately, they were only organised in several large cities of Vietnam such as Hanoi or Ho Chi Minh City (Krakauer et al., 2010).

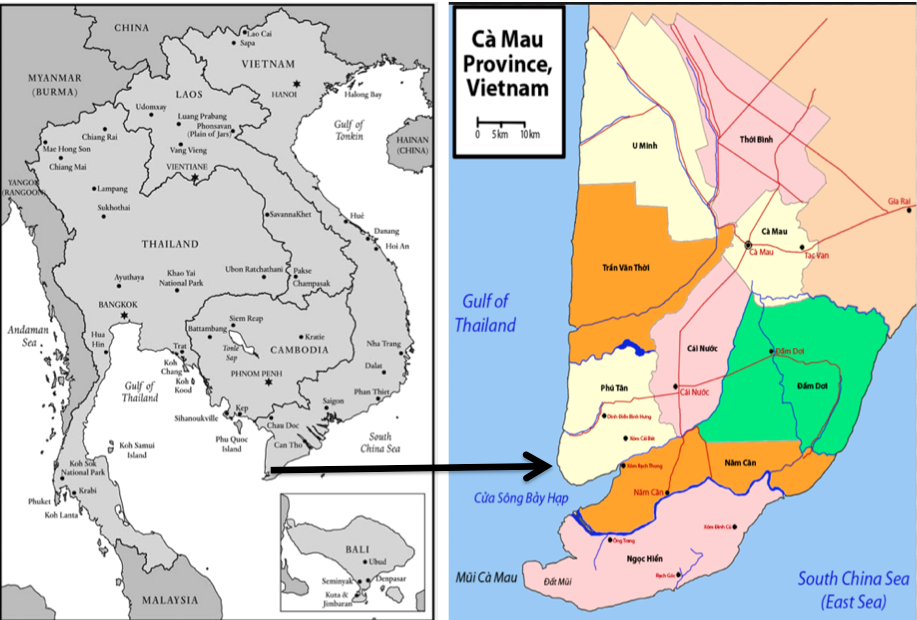
In summary, an investigation of palliative care practices with family doctors and advanced cancer patients’ experiences and opinions in rural area of Camau has to include an understanding of social and political drive to develop palliative care services of all regions of Vietnam and around the world. It must aim at reducing inequalities in terms of access to healthcare services for remote patients as well as providing rural family doctors with professional training opportunities. The approach has to take into account social, economic and political implications of the social medicine discipline developed through the 20th and 21st centuries. It is essential to make sense of cancer, in particular advanced stages, and its impact based on the opinions of patients from the real world context and their real experiences as well as to understand their unmet needs regarding to palliative care service.

## 1.6 Social-medical context of the study

### 1.6.1 National palliative care strategy for people with advanced cancer

Vietnam is a country in the group of ASEAN (Association of South East Asian Nations). It is located on the Eastern edge of the Indochinese Peninsula, bordering China to the north, Laos and Cambodia to the west and South China Sea to the east and south. Its area is about 331,000 square kilometers (**Figure 1.2**). Vietnam has a population of just over 88 million; approximately 60 % of the population lives in rural zones (World Bank 2009).

In Vietnam, approximately 150,000 people with cancer are newly diagnosed each year, with 80 % of this figure in the advanced stages. The number of annual deaths related to cancer is estimated around 75,000 cases (Krakauer et al. 2010). Although there are many advances in cancer treatment, eventually, most of cancer patients will die of their disease or its complications (Ahmedzai et al. 2004). Cancer-related mortality is ranked second with around 75,000 deaths a year, just behind cardio-vascular diseases (MoH, 2012). In a survey in 2002, Khe and colleagues reported that the ratio of average survival more than 1 year of cancer patients in several northern provinces of Vietnam is just in excess of 50%. The corresponding figure in rural communities is much lower, just 21- 25% (Ngoan et al. 2007a).



**Figure 1.2** Maps of Vietnam (*Left*) and Camau Province (*Right*).

It is estimated that at least a half of cancer patients with palliative care needs, approximately 60,000 people, have not received enough symptom control (Green et al., 2006). Specialist palliative care in Vietnam is only delivered in major cancer hospitals, or integrated into tertiary hospitals in a few large cities such as Hanoi, Ho Chi Minh City (previously Saigon) and Hue. There have been only a few PCUs and pain clinics in various parts of Vietnam so far.

The strategy of Vietnam MoH is the integration of palliative care in existing primary healthcare services which is considered to be well-organised in Vietnam (Krakauer et al. 2007). Hence in 2005, Vietnam MoH launched the Palliative Care Initiative, which had adapted the World Health Organization (WHO) public health strategy for planning and developing the national palliative care program. It was the first time the words *‘chăm sóc giảm nhẹ’*, the translation into Vietnamese of the words ‘palliative care’, were officially used in healthcare services. Most palliative care training initiatives for health care physicians have occurred from this point of time onwards. One year later, the National Guidelines on Palliative Care for Cancer and AIDS Patients were put into practice. These official guidelines focus on symptom control for both cancer survivors and AIDS patients. In 2008, the Regulations of Opioid Prescribing (ROP) from Vietnam MoH were circulated to all its subordinates.

### 1.6.2 Characteristics of the Camau healthcare system

Camau is the most Southern province of Vietnam (**Figure 1.2**). It is situated on the peninsula protruding to the Gulf of Thailand and the South China Sea. Camau province has a population of 1.280.000 people with an area of 52.000 km2 .The administrative units of Camau consist of a central city – metropolitan centre of the province and 8 districts surrounding it. The average distances from Camau City to the center of districts range from 30 to 60 kilometres (GSOV, 2012).

According to the figure of cancer registry of Dat and Nghi (2012), the new cases diagnosed in 2011 were approximately 1170 people. According to estimation formula of the WHO (2007), there will be approximately 900 advanced cancer patients living throughout the province needing some degree of palliative care. Unfortunately, most of the existing specialist palliative care services are usually located very far from their residence. Therefore, requests to relieve their symptoms are unlikely to be satisfied.

Theoretically, it may be argued that cancer patients with palliative care needs could receive the services at local primary care team at a commune health station (CHS), often staffed with a family doctor and several nurses. However, there are issues in practice, which make these demands unlikely to be fulfilled. A survey with rural family doctors in 2010 in Camau showed that just 10% of CHSs explored have oral morphine and only half of respondents feel confident in opioids prescription, meanwhile three-quarters of health stations had been involved in palliating to cancer patients (Viet et al., 2011).

In Camau Province, the Provincial General Hospital (PGH) acts as a tertiary centre, the final point of referrals in the province with specialist clinical wards. At the level of districts, district general hospitals (DGH) act as referral points from CHSs in each district. Each CHS is usually staffed by a family doctor (leader), nurses, midwives, and a primary or mid-level pharmacist. There are up to 10 beds for inpatients and normal deliveries. CHSs serve as access points into the health care system, in particular for patients with health insurance coverage. Most CHSs are located in rural or remote areas. They serve a relative small, widely dispersed population. The healthcare professionals working in the system described above are paid by the state budget and managed professionally by the Camau DoH.

People in rural areas must register with a primary healthcare service, commonly CHSs, which is indicated by their residence. In the case of needing a specialist treatment, the patient will be referred by a primary care physician to specialist services such as clinical wards at DGHs or the PGH. As a result, people with critical illnesses usually have to be transported further and wait longer before reaching a specialist centre.

In addition, patients also have the right to choose the level of healthcare service that they prefer; but in this case they have to pay all or 5 to 20 percent of service costs depending on whether they have healthcare insurance or not. There are several levels of co-payment over service cost covered by the national insurance programme. The rural poor or uninsured people including many farmer families who cannot afford private insurance often rely on self-treatments, or in some regions, local services to partially subsidise their care. The healthcare insurance policies in Vietnam are complicated. These will be presented in detail in **Chapter 3** about the structure of healthcare system.

There are several problems for rural patients to access palliative care services. The first one is the lack of emergency medical facilities and essential drugs for palliative care, in particular oral opioids. Access to medicines, including opioids, is one of the major barriers scaling up palliative care in Camau. For decades in Camau, injectable morphine has been the only morphine form available and used merely for inpatient post-operative or cancer-related pain. Oral morphine is not universally available (Viet et al. 2011). Regulations on opioids prescription have also been restrictive. Only a small number of registered doctors are permitted to prescribe limited doses for up to ten days. Second, many CHSs, and even several DGHs, have difficulties in attracting healthcare professionals, in particular doctors to practise in their premises. Therefore, the patients are likely to experience further barriers in order to attain good care. Finally, CHSs normally offer both profit-making and public healthcare services; therefore, with the poor patients, those who are unable to afford the care or not covered by healthcare insurance, often appear at health stations when they are extremely sick, requiring extensive medical attention.

### 1.6.3 Camau Cancer Control Committee (C4) activities

The Camau Cancer Control Committee (C4) was established by the Camau Department of Health (DoH) in April 2010. Its role is to promote the accessibility of palliative care to all cancer patients across the province, particularly in remote areas; encourage the development of good practice amongst healthcare professionals within the province and work closely with them to set up an appropriate network of palliative care services throughout Camau. The National Cancer Control Programme, a state body, has funded C4 worth approximately 500.000.000 VND [[3]](#footnote-3) per year (approximately £15.000) from 2010 onwards. As financial support from the government became available, a project on palliative care for cancer patient was planned; and the first training workshop on cancer control and palliative care for doctors was organised in Camau City in July 2010. This event was considered to be a cornerstone for further collaboration between C4 and rural family doctors in forthcoming years of the project.

In addition, the Oncology Ward of the Provincial General Hospital, in which the principal researcher of this study has been working, plays a major role in all activities of the C4. The Oncology Ward with inpatient Palliative Care Unit (PCU) is also the place that receives cancer patients with palliative care needs referred from DGHs and CHSs all over the province. Feedback has offered us many opportunities to collaborate with local family doctors in order to set up a network for managing cancer patients and training in palliative care within the boundaries of the province.

In 2010, a survey at the first workshop conducted by the C4 with family and hospital doctors in Camau examined the involvement level with palliative care activities and their perspectives on the palliative care provision for cancer patients in the communities of the province (Viet et al., 2011). The primary findings indicate that rural family doctors have been very much involved in palliative care provision for patients with cancer in the community. Over half of family doctors asked indicated that local healthcare services are suitable for patients with advanced cancer. Nevertheless, only around 10% of these doctors had experienced relevant training recently. Therefore, there is a need for further education and training in palliative care for them in order to help them provide palliative care of acceptable quality to rural patients with advanced cancer who need it in the community.

## 1.7 Research questions and hypothesis

The 2010 survey has informed my doctoral study by its implications for planning the strategy and content of the coming research. With the provision of education and training in palliative care for the family doctors of existing healthcare system, a gradual shift in doctors’ behaviour and competence would be likely to occur. This may lead to positive outcomes on palliative and cancer patients of Camau.

For the rural family doctor, as Cherny and Catane (2010) indicated, an enhanced familiarity with palliative medicine can extend the clinician’s therapeutic skills and confidence, diminish the stress of caring for patients with incurable cancer, improve patient outcomes, and provide new avenues for clinical research and reward.

A large number of educational and training programmes in palliative care have been deployed and published from over the world. However, the most effective types of palliative care training have not yet established. In addition, as Ahmedzai and colleagues (2004) admit, the evaluation of palliative care education for participants and the subsequent care of patients have remained either relatively unexplored or under-reported within literature. Research to date has tended to conduct and evaluate the outcomes of training courses on physicians rather than patients. Furthermore, only a few studies have made an evaluation of both groups at the same time. Finally, according to Campbell (2002), findings of many interventions in the field from developed countries, including education programmes, may only be applied internally or locally and will not have much meaning to other providers, stakeholders.

As a consequence, I undertook this research aimed at evaluating the outcomes of a palliative care training workshop with an additional support programme for rural family doctors and to a lesser extent their cancer patients’ views on the care at the same time. This research seeks to address the following question:

*‘How effective, in terms of improvements in knowledge, attitudes and professional practice, is a palliative care training workshop, with additional support activities, for family doctors in remote areas and what are the perspectives of their cancer patients?’*

The hypothesis of the research is that the palliative care training workshop with an additional support programme could lead to some benefit for both family doctors personally and professionally, and for their cancer patients in terms of satisfaction of quality of palliative care service.

## 1.8 Aim and objectives

### 1.8.1 Aim

The aim of this research is to conduct a palliative care training workshop with additional support activities and evaluate their outcomes on both family doctors and their cancer patients, particularly people with advanced cancer in remote areas of Camau Province, Southern Vietnam.

### 1.8.2 Objectives

* To assess the knowledge baseline and confidence of family doctors in practising palliative care in rural communities in Camau.
* To conduct training and dissemination in order to develop supportive and palliative care competence amongst rural family doctors through a workshop, postal information packages and telephone counselling.
* To evaluate the outcomes of the intervention package in terms of doctors’ knowledge, confidence and performance in practising palliative care
* To examine the perspectives on choice of place of care and experiences of care within two groups of cancer patients: those who are admitted to the PCU and those who receive palliative care from the trained doctors in rural areas.

An educational project and support programme on cancer and palliative care for all rural family doctors in Camau Province is likely to be feasible. It may help disseminating the principles of palliative care through providing new knowledge and skills to remote doctors, and consequently, the improvement of palliative care provision for cancer patients in remote areas of the province would be expected.

# Chapter 2 –Literature Review on Palliative Care Education for Healthcare Professionals

## 2.1 Overview

Given the aims of the study and research questions cited above, in this chapter I shall review critically and systematically the current literature in palliative care educational intervention around the world in the last three decades, in particular education and training in palliative care for primary care physicians in rural settings. Such a time frame has been imposed to encompass the most recent debates in the field (Stjernsward et al., 2007).

Before presenting findings from my review on palliative care education and training for primary care professionals, I shall briefly present background literature regarding the adult learning method for healthcare professionals. This includes the principles of adult learning as well as how to approach and evaluate its outcomes, in particular for primary healthcare physicians. They are family physicians / doctors or general practitioners (GPs).

Most of the literature on palliative care education describes interventions happening in developed countries in which most family doctors are taught something about palliative care. In recent years, there has been a growing demand for education and training in palliative care for healthcare physicians, in particular those who are working in remote and rural areas in developing countries (Doyle, 2005). Since the approach to palliative care education in each country, even each region in a country, may be different, it is important to understand models of education, methods and their effectiveness. Insights into recent educational interventions and training programmes in palliative care all over the world were useful for planning the current project. This project aimed at enabling rural family doctors (FDs) to attain the necessary knowledge and skills for practising palliative care in the community, and to ensure that the learners were not away from their work for long. The review, which was conducted systematically to explore what had been reported in the literature regarding educational interventions in palliative care directed towards primary care physicians, shall be presented in **Section 2.3** of this chapter. I shall pay most attention to the evaluation of the impact of different educational methods in terms of improvements in participants’ knowledge, skills and attitudes towards practice as well as changes in professional behaviour and performance in the workplace.

## 2.2 Definitions of Terms

A General Practitioner (GP) – mainly in UK and many European countries – is ‘*a doctor who provides general medical treatment for people who live in a particular area’* (CDO, 2012)*.* In North America he or she will be called either a ‘family doctor’ or ‘family physician’ (Doyle, 2005). According to Webster’s Dictionary a physician is ‘*a person qualified to practice medicine*’. In many Asian countries, including Vietnam, they are also called family doctors or primary care physicians (Goh & Shaw, 2007). These physicians are widely regarded as playing a key role in healthcare teams in the community. In the hierarchy of the healthcare system in Vietnam, a family doctor is normally the leader of primary healthcare team at each commune health station (CHS). In order to make a consensus with the context cited, I prefer using changeably the title ‘family doctor’or ‘GP’ for citations in this chapter, even though in original documents they could be called ‘primary care physician’ or ‘primary care doctor’. There are only a few exceptions in direct quotations where applicable.

A rural area defined in the Cambridge Dictionary is *‘in, of or like the countryside’* and opposite to ‘*urban’* (CDO, 2012). In my research study, the rural areas are located outside the centre of Camau city and eight other administrative districts. The ‘centres’ of Camau city and the other administrative districts have been pre-defined by the administrative authorities. Many of the rural areas are considered as remote regions of the province.

## 2.3 Education and training in palliative care for professionals

### 2.3.1 CME or CPD in palliative care education for professionals

*Continuing Medical Education* (CME) is defined by Davis and colleagues (1999) as *‘any and all the ways by which doctors learn after formal completion of their training.’* Since the early 1950s in the USA, CME has been advocated and supported by the American Medical Association (AMA), medical schools, and various specialist societies to address the gap between available medical knowledge and the individual application of that knowledge in practice (Leong et al., 2010). *Continuing Professional Development* (CPD) or several different terminologies such as *‘Continuing Professional Education’* or *‘Lifelong Learning’* have been used to deal with concerns about the professional or personal development which impact on practice (Ahmedzai et al., 2004). According to Cantillon and Jones (1999) *‘CME is seen as representing a more teacher - based, didactic style; whereas CPD implies a more learner centred and self-directed approach to learning.’* However, in the literature these terms are sometimes used interchangeably. Eraut (1994) argued that one central purpose of CPD is to bring practising professionals into contact with new knowledge and ideas. In addition, it is frequently not only simply keeping up to date, but also requiring an approach to practice (Henwood & McGannan, 2007). CME activities appear, as Davis and colleagues (1999) point out, to be ‘*underpinned by a belief that gains in knowledge lead physicians to improve how they practice and thus improve patient outcomes* (p.867).

The literature on CPD and CME in palliative care is vast. This review will not explore literature relating to formal education in palliative care at the levels of undergraduates and postgraduates because learning and teaching at these levels are beyond the scope of this project. Therefore, in the line with the research questions and the aim of my study, I shall present mainly my current understandings of CPD/CME or informal education in cancer and palliative care for healthcare professionals working in the community, in particular in rural and remote regions. Publications were selected if they are relevant to CME/CPD activities in palliative and cancer care.

It is widely accepted that education and training in the context of healthcare should use principles of adult learning, thus CME or CPD in palliative care. In this context, professionals are expected to continue to learn beyond the point of qualification (Ahmedzai et al., 2004). They are involved in the whole learning process, and learning activities are often required to be interactive (Henwood & McGannan, 2007).

According to Eraut (2004), CPD does not have to be formal, attendance-based activities although it is often perceived to be that. It can be any activities which impact either on individual behaviour in practice or directly on practice. Furthermore, Henwood & McGannan (2007) state that it must link to the work environment. The reason is that without this link to professional activity, as they argue, the activities undertaken are purely personal development, which may be individually valuable, but are not professional development. In this case, CPD activities are for personal gain alone and can show no benefit to the practice setting where the attendee is working (Henwood & McGannan, 2007).

Henwood and McGannan (2007) also point out a flaw in much work written on CPD, that is how to ensure that a CPD programme undertaken is effective. They argue that there are many different views on establishing effectiveness in practice and issues of measurement tools. In fact, most measurements focus on gauging an increase in knowledge and skills after a course, while little or nothing is done to evaluate wider outcomes of the CPD activities, for instance improvements in participants’ competence and behaviour in the long-term.

In this study, the professional characteristics, attitudes and working context of participants were considered as necessary for evaluating the effectiveness of the project.

### 2.3.2 Benefits of educational interventions

There is general agreement that the immediate goal of an educational activity should be to improve knowledge, skills and attitudes (Davis et al., 1999; Harris et al., 2008). Calman (2010) states that the best measure of a successful professional educational intervention is an improvement in patients’ health status due to a change in physician behaviour. Similarly, Buckley and Smyth (2004) argue that the ultimate goal for an educational activity in healthcare is to improve the competence of physicians to manage their patients. They also define *‘competence’* as possessing the ability in terms of knowledge, skills, and attitudes to perform the treatments successfully or efficiently as expected by their organisation. However, as Campbell (2007) admitted, these goals can be difficult to measure and to be subject to many outside influences. Therefore, the practical question of what constitutes the success of an educational programme has led many educators to attempt to find the answers.

#### 2.3.2.1 Development of personal qualities

CPD in palliative care should be aimed at improving knowledge, skills and attitudes (Ahmedzai et al., 2004). These attributes should be guaranteed by ensuring ‘*explicit definition of the expected outcomes of the training programmes in terms of a competency framework’* (Buckley & Myth, 2004:66). Most publications in palliative and cancer care education have indicated that there is an immediate enhancement in the acquisition of knowledge and an improvement in positive attitudes as well as increasing confidence in practising communication and clinical skills (Croager et al., 2010; Davis et al., 1999; Fineberg et al., 2004; Hoon et al., 2009). The acquisition of knowledge, the adaptation of appropriate attitudes, and the development of skills are the cornerstones for GPs providing comprehensive palliative care (Charlton & Ford, 1995).

A literature review by Alvarez and Agra (2006) examined educational interventions in palliative care aiming at primary care physicians published between 1966 and February 2005 and reported improvements in knowledge and attitudes towards palliative care practice as well as satisfaction of the participant physicians in the majority of studies included. The authors also found minimal or no changes in more objective outcome measures in opioids prescribing or pain management, and suboptimal results in the aspects of communication to patients.

Hegarty and Currow (2010) argue that educational objectives include not only the development of knowledge and skills, but also the development of attitudes which they consider to be the most difficult area in which an educational intervention effects change, since it is relatively easy to increase the levels of knowledge and skills, but attitudes are often longer standing and unconscious, and frequently linked with beliefs, values and assumptions. Similarly, a systematic review on medical undergraduate curricula in UK conducted by Lloyd-Williams & MacLeod (2004) showed that changes in terms of attitudes were uncommon. Hegarty and Currow (2010) argue that while the acquisition of new knowledge and skills has few effects on participants’ professional personal lives, attitudinal change has a more profound effect in that it creates a shift in their daily clinical practice. As a result this may bring some positive impact to patients with a life-limiting illness.

However, changes in knowledge and attitudes originating from educational activities are frequently not sustained long enough (Campbell, 2007; Croager et al., 2010). Moreover, the acquisition of knowledge alone does not guarantee that it will be used wisely in practice. Hegarty and Currow (2010) argue that coming to the understanding of a clinical situation and expressing a proper response play an important role in the transition of knowledge from learning to practice.

From the late 1980s, according to Forsetlund and colleagues (2009), questions of how and why some programmes worked better than others were raised, and these questions led researchers to search for potential explanatory factors. The focus also shifted from measuring knowledge, attitudes, or skills to measuring more objective outcomes, for instance physicians’ performance or patients’ health status.

#### 2.3.2.2 Improving competency, behaviour, performance and daily practice

*Competence*

Calman (2010) argue that in addition to level knowledge, skills and attitude, the competence of participants resulting from any education and training programme should be evaluated. According to him, attributes of competence include abilities of problem solving, critical thinking, team working and the continuity of learning.

The recent trend of training in palliative care aims clearly at the competence of healthcare professionals for the purpose of practising palliative care well. However,

*‘Professional competence is a deceptively simple label to describe the complex set of attributes and behaviours required of health professionals who are caring for people with incurable illnesses’* (Buckley & Smyth, 2004: *66*).

Hegarty and Currow (2010) admitted that competency in practice seems to be a more complex process than the acquisition of knowledge. They supposed that this process could be developed and refined over time. The assessment of clinical skills in practice seems to attract a low priority and there are significant weaknesses in the transition from classroom to practice (Larkin, 2007). The success or failure of the transfer of knowledge to practice should not be assessed by objective methods alone, since the best judgement of the impact is the individuals themselves (Larkin, 2007). Training in palliative care is associated with an increased competency in providing palliative care activities. The reason is that, as Farber and colleagues (2004) reason, with increased frequencies of providing palliative care activities, those physicians who provided palliative care to a greater percent of their terminally ill patients also perceived that they performed these activities in a more competent manner.

According to Davis and colleagues (1999), there is a lack of evidence of clinical practice change as a result of new information from informal education through attending specialised conferences, training workshops, or even clinical meetings. However, there has been some evidence demonstrating some degree of effectiveness. For example, a sustainable practice change has been achieved using academic detailing, a technique long used by pharmaceutical company representatives (Hegarty & Currow, 2010). According to Soumerai and Avorn (1990), such detailing consists of key messages generated by evidence-based material, based on key objectives for change in behaviour, an understanding of the participants’ knowledge base and practice and presented in a succinct and friendly way to participants. Furthermore, similar sustained changes in clinical practice in response to educational programmes have occurred in general practitioners’ prescription, clinical ordering and other clinical activities (Clark et al., 2004; Mitchell, 2002; Noble et al., 2003; Shipman et al., 2001). However, how the competence from the learning process is translated into the development of effective practice is still arguable.

*Behaviour and performance*

Leong and colleagues (2006) argue that there are many stages in the development of outcomes from CME training for physicians. The initial stage is the assimilation of new knowledge. The second stage is that physicians are sufficiently convinced by new information to be willing to change their practice. Only with the willingness, the third stage then will be the implementation of the new knowledge or skills; and consequently, improvements in patient care would be achieved. This process helps to improve the knowledge base and evolve clinical practice continually. In addition, it may lead to a reduction in physician ‘burn out’ since the physician feels more competent to address issues in their practice and enriched by understanding the new concepts and techniques.

There is general agreement that the ultimate goal of CPD or CME is to improve outcomes for patients by changing doctors’ practice behaviour. However, Henwood and McGannan (2007) argue that it is questionable whether any clear link is empirically established between CPD activities and an increase in the standards of practice behaviour. Similarly, Elliott and colleagues (2002) rationalised that although in terms of clinical governance, regulatory bodies often require professionals to remain up-to-date in knowledge and skills, in reality an enhancement in knowledge base does not necessarily lead to an improvement in practice performance. One reason can be that changes in practice behaviours require much more effort. Similarly, Finlay and Noble (2004) also realised that *‘it is much easier to increase knowledge and understanding, or to improve skills and competencies, than to change attitudes and professional behaviours.’ (*p.1159)

Until recently, changes in clinical practice behaviour in response to educational interventions have not been observed universally. However, two systematic reviews from the field show conclusive findings. Cantillon and Jones (1999) conducted a review which examined the effects of CME courses on subsequent doctor behaviour and patient outcomes in the UK from 1990-1999, and found that even if the purpose of education is to change the clinical behaviour of general practitioners, only one-third doctors change their behaviour. Additional evidence comes from a review by Alvarez and Agra in 2006, who concluded that intervention programmes in palliative care education, based on prior needs assessment and with a multi-faceted approach, were effective in changing doctors’ behaviours in several of the clinical practice areas explored.

*Practice*

Practice development is a relatively new concept. It encompasses a broad range of approaches that seek to support changes to the provision of health and social care (McCormack et al., 2011). According to Froggatt and Turner (2007), the process of practice development enables changes in health and social care provision to be undertaken in order to improve the quality of care people receive. It brings about changes in both individual behaviour of healthcare professionals and organisational practice. These approaches seek to ensure the best care for patients. In order to make a sustainable practice development, the professionals need to be aware of the following elements: *‘the knowledge they use to base their justification for change; the context within which they seek to bring about change; and the way they bring about the change’* (Froggatt & Turner, 2007).

Practice development is concerned with the ways in which professionals engage with, and create knowledge in order to develop both their understanding and practice of care for patients (Clarke & Wilcockson, 2001). The context for changes in practice should be taken into account that then needs to consider people involved in a practice development initiative, the environment in which the work is being undertaken and the culture of care (Froggatt & Turner, 2007).

The evidence of the effectiveness of CPD on practice is contradictory. Campbell (2007) admitted that there is a lack of evaluation reports and necessary evidence in which education changes knowledge, skills and practice either in the short or long terms. Jordan and colleagues (1999) found little impact of educational intervention on changing participants’ practice. Moreover, evidence from many studies suggests that the outcomes of educational programmes on physicians, in terms of adopting positive attitudes and modifying behaviour and practice, are limited (Croager et al., 2010; Spiegel et al. 2002; Sullivan et al., 2006). They also mentioned that the reduction of feelings of isolation of family doctors working solo in rural area is the most obvious success of such programmes. However, in a systematic review on GPs’ palliative care practice issues conducted by Mitchell in 2002, the author indicated that GPs, who are given adequate palliative care training, demonstrate the ability to deliver sound and effective care for the patients in the community.

#### 2.3.2.3 Outcomes for patients: a need

According to Calman (2010), it is essential for a physician to be constantly updating their base of knowledge, widening a wide range of skills and adopting positive attitudes towards the practice of palliative care in order to meet the patients’ demands and reduce patients’ dissatisfaction with the care services. The reason is that patients usually expect doctors to be fully aware of advances in diagnosis and treatments. Therefore, the primary purpose of an educational or training programme in healthcare is to benefit a targeted patient population, for instance, in the current project in Camau, cancer patients and their family members. Their needs during the disease trajectory, especially in the terminally ill stage, are enormous. There are a great number of needs such as symptom management, psychosocial support, financial and legal issues, and finally, grief and bereavement after the patient has died (Murray et al., 2005; NICE, 2004).

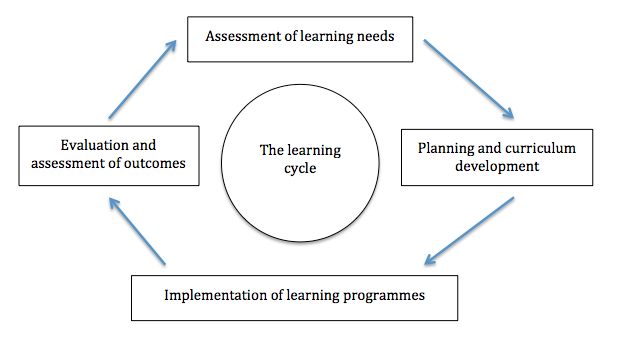
Moreover, as Haugen and Vejlgaard (2008) remarked, user involvement is becoming increasingly popular in healthcare. Palliative care populations have natural limitations in this respect, but palliative medicine is a specialism, which has always been patient-centred. All treatments must be given with patient consent and in accordance with his/her wishes. The patient and his/her family carers, who are often more able to participate in decisions around care, may thus be considered to be members of the extended team, even if the patient does not take part in all team conferences. In addition, Hillier and Wee (2001) believe that patients are powerful teachers because what healthcare professionals could learn from the patients who they are caring for, cannot be learned from books. For example, the professional judgment and response of each doctor to every clinical situation that they encounter may help them improve their palliative care competencies.

### 2.3.3 Approaches in teaching palliative care education

#### 2.3.3.1 Assessing individual and organisational CPD needs

Palliative care education for family doctors whether CME or CPD should follow adult learning principles. Adults learn best when they see the content and learning as is relevant to their practice. Successful adult education is described as *‘ learner-centred, active rather than passive, relevant to the learner's needs, engaging, and reinforcing’* (Knowles 1970, cited in Davis et al., 1999). The organiser, therefore, has to bear this in mind when planning any training course for this specific group of learners (van Onna, 1992). Professional learners are more likely to engage in learning if they have some purpose in their mind such as obtaining certain knowledge, getting a specific skill or gaining confidence in dealing with difficult scenarios (Finlay & Simon, 2005). In addition, in planning provision, it is vital to ensure that a CPD intervention should meet local service needs as well as the personal and professional needs of the individual (Taylor, 2004).

Henwood and McGannan (2007) argue that CPD is unlikely to benefit professionals unless they have the right attitude, and are willing to learn and develop in their own settings. They maintain that *‘a continuous improvement and self-reliance on learning must be motivated and maintained.’* Therefore, assessing the individual CPD needs is essential prior to planning any intervention programme (Buckley & Smyth, 2004). In addition, in planning educational programmes, one learning objective in each activity should be an attitude one to be achieved, for example, reflective feedback such as answers or writing a reflection on participants’ attitudes and beliefs about issues discussed (Finlay & Simon, 2005). **Figure 2.1** shows methods of self-directed learning related to deficiencies in practice or in development of new skills (Calman, 2010).



**Figure 2.1** The learning cycle (Calman, 2010).

Assessing individual and organisational CPD needs is a very crucial task to be considered in planning a training programme. This requires a basic understanding of the theoretical basis of different educational techniques. Buckley and Myth (2004) outline *‘educational theories relevant to training for palliative care’* (*p.66*). They demonstrate several features of this type of educational intervention based on the notion *‘self-directed learning’* which they consider as one of the *‘key principles of adult learning’;* namely, the learners will identify their learning needs, decide the process and context of education interventions, and help the organisers to measure the effectiveness of programmes through feedback (Kaufman, 2003).

In order to enable a CPD programme to be effective, assessing individual and organisational CPD needs in relation to the educational and training content is essential prior to planning any intervention programme, at both individual and organisational level (Buckley & Smyth, 2004). Henwood and McGannan (2007) argue that these assessments are frequently appropriate in the field of cancer and palliative care for both practitioners and nurses because from the point of qualification these needs are not usually addressed. In addition, the larger scale organisational issues can be informed by collating data from individual needs analysis (Henwood & McGannan, 2007).

#### 2.3.3.2 Main formats for organising an educational intervention

The term *‘educational intervention’* covers a wide range of educational formats. Teaching methodologies found to be effective in clinical teaching include the use of multiple teaching approaches, both didactic and experiential (Hegarty & Currow, 2010). A wide range of educational methods has been demonstrated effectively in teaching and learning of palliative care to healthcare professionals. It is summarised and briefly explained in the section below.

*i) Lectures with large groups or experiential workshops, problem-based or small group work in seminars, role-play and so on.*

Educational meetings are one of the most common CME activities. Educational meetings include courses, workshops or seminars in various formats. The nature of educational meetings is highly variable in terms of content, number of participants, degree and type of interaction, length, frequency, and targeted practices (Brown et al., 2002; Davis et al., 1999).

Educational activities in these meetings consist of didactic lectures, audio-visual presentations, and printed materials. It is more likely that didactic lectures – a more traditional format – have been one of the mainstays of CPD (Henwood & McGannan, 2007). Many studies have been found that most health professionals preferred to receive CPD by attending study days (David et al., 1999; Forsetlund et al., 2009).

When selecting the format, it is essential to ensure that the content should suit participants’ specific learning needs. However, as Henwood & McGannan (2007) advised, CPD is not undertaken purely through formal study days or courses. Moreover, they also mention the importance of further collaboration amongst participants, educationalists and organisers in the selection of appropriate programmes. These should ensure that the CPD relates to not only the current position but also the future professional development of the attendees.

*ii) Clinical placements and work-based activities*

It is essential that professional learners are given the opportunity to practise within a specialist clinical unit or centre because this might provide the best learning process through reality and experience (Croager et al., 2010; Hoon et al., 2009)*.* Exposure to other clinical settings can be extremely valuable for enhancing further learners’ knowledge, skills and confidence in practice. In addition, it also helps to develop professional links or networking and to share expertise across settings (Henwood & McGannan, 2007). With the limits of time allocation, resources and local facilities, however, it is often not possible for educational intervention organisers to arrange an afternoon’s tour in a specialist PCU for the participants.

Other formats are CPD based in the workplace in which local GPs receive the contents of educational intervention at their usual work setting. For instance, in the study by Noble and colleagues (2003) GP clinical facilitators were sent to rural healthcare practices aiming at supporting local healthcare teams with knowledge and skills in palliative and cancer care. Another format is the case conference held between GPs and palliative care specialists through telephone calls or face-to-face meetings at the local office or a patient’s home (Mitchell et al., 2008; Shelby-James et al., 2007, van Heest, 2007). In addition, sending printed educational materials (PEM) such as clinical or local guidelines, or specialised journals to the community appear to be the most frequently adopted method for disseminating information to primary healthcare physicians (Farmer et al., 2008).

These models eliminate many of the problems associated with the inequality of access, geographical locations and education providers. They also help to break down some of the traditional barriers between professional groups and to promote the inclusion of other key personnel within service provision (Henwood & McGannan, 2007).

*iii) Telemedicine:*

This type includes Internet or computer-based learning, teleconferencing or group discussion via the Internet, electronic media containing educational data through distance learning packages or distance learning through ‘podcasts’ and so on**.** This format offers several advantages. First, educational information in Internet-based education is delivered directly to the site of clinical activity. In addition, online CME costs little to distribute, is continuously available and easy to access, does not require the expense of travel or lost practice time by the attendee, and can be easily monitored and updated as new findings emerge (Harris et al., 2008).

In palliative care teaching and learning, the Internet provides physicians with crucial ways to enhance specialised knowledge and skills. Its benefits include distance learning courses or interactive websites on some specialised topic. For example, the site *http://www.palliativedrugs.com* makes it easy for remote family doctors to learn from experienced colleagues elsewhere. A number of specialist webpages are valuable sources for updating and downloading a huge amount of useful information (Henwood & McGannan, 2007). Some limitations to web-based education, however, might be recognised, such as how to use the web in an effective way or how to identify the best quality sites (Alvarez & Agra, 2006). In addition, reliable access to the Internet and cost may also be issues in the developing countries, in particular for healthcare professional learners in remote areas.

### 2.3.4 Evaluation in palliative care education

#### 2.3.4.1 Overview

According to the theory of educational evaluation, evaluation can be defined as:

‘The systematic collection of information about the activities, characteristics and outcomes of programme for use by specific people to reduce uncertainties, improve effectiveness and make decisions with regard to what those programmes are doing and effecting’ (Paton 1986, cited in Campbell 2007).

Evaluation research is described as applied research that is designed to answer questions about the impact of services or programmes. It embraces a wide range of the tools and techniques developed in basic research (Ingleton & Davies, 2007). These methodologies are applied to answer the questions of needs and effectiveness based on defining and measuring the objectives and outcomes of healthcare initiatives. In addition to focusing on the extent to which predetermined objectives have been achieved, one possibly needs to identify the existence of any unanticipated or unintended outcomes of a planned intervention (Ingleton & Davies, 2007; Taylor, 2004).

The field of evaluation is extremely wide and varied, since evaluations are carried out for a number of purposes. In the field of palliative care education, evaluations may be needed in different forms and for many different reasons. According to Gale (2007), the effectiveness of implementing a programme may be requested by healthcare organisations. It might also be required by financial funding organisations. Moreover, it is also needed by educators to improve or adapt the teaching and learning methods.

In CME or CPD programmes in palliative care, extending evaluation to other stakeholders besides healthcare professionals is particularly difficult. One reason may be that patients with palliative care needs are often terminally ill and more vulnerable; therefore, staff are frequently reluctant to ask for patient consent. Another reason is that, as Campbell (2007) indicates, collecting data from such patients could give a rise to the Hawthorne effect in which participants alter their behaviour as a result of being part of a study or patients do not want to criticise their professional carers.

While many models of evaluation in higher education have been suggested, Taylor (2004) states that little had been written about evaluating education in palliative care. Therefore, to undertake the evaluation of CME or CPD interventions in this field, evaluators often apply methods that stem from academic education at undergraduate or postgraduate level.

#### 2.3.4.2 Approaches to evaluation

Evaluation can be a formative process which takes place throughout an intervention, describing its nature and exploring how the project is working in relation to its intended outcomes. This type of evaluation is most commonly used to gather data on an ongoing programme and explores the perceived knowledge, skills attainment and satisfaction of participants. Another type is summative evaluation, which undertakes at the end and is concerned with the effectiveness and value of an intervention or programme as a long-term change (Campbell, 2007; Ingleton & Davies, 2007). Summative evaluation aims at the overall effects or impact of a programme. In education, this form of evaluation is concerned with the sustainability of learning outcomes in terms of what has been learned from participating in the educational event and the impact of the learning process on practice beyond the learning activities. There is much debate around definitions of these two kinds of evaluation. However, the distinction between two approaches may not be so clear-cut, since a formative evaluation may have summative elements, and a summative evaluation can have formative effects in the development, implementation and assessment of a programme (Robbins, 1998; Taylor, 2004). According to Campbell (2007), there is usually a mutual relationship between formative and summative evaluation. Consequently, educational programmes often require an examination of both.

*Kirkpatrick's hierarchy* of four levels is often applied as a sequence of ways to evaluate educational and/or training programs (Buckley, 2011). When one proceeds through each of the levels, the evaluation becomes more difficult and requires more time and each additional level provides further information as follows:

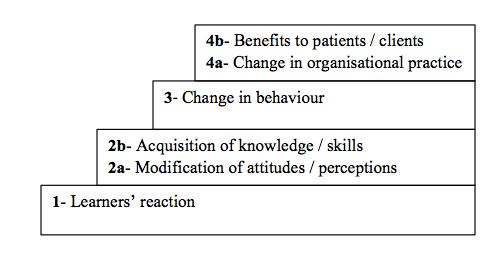
1. *Reaction* – what participants thought and felt about the training.

2. *Learning* – increases in knowledge and/or skills, and change in attitudes.

3. *Behaviour* – the transfer of knowledge, skills and/or attitudes from classroom to the job. These are changes in job behaviour due to the training programme.

4. *Results* – the final performance-based results that occurred because of participation in a training program.

In the field of healthcare education, several authors have suggested the addition of a fifth level of evaluation, which should focus on the impact of the organisation on external clients and outcomes for patients and/or carers. Similarly, a *‘hierarchy of evaluation’* was suggested by Barr and colleagues (1999) (cited in Taylor, 2004) and an *‘education ladder*’ was presented by Campbell (2007). **Figure 2.2** summarises the different levels depending on what kinds of outcomes of a health education programme are targeted. A programme evaluation may include all or just some levels of evaluation.



**Figure 2.2** An evaluation hierarchy (Modified from Kirkpatrick’s four levels)

#### 2.3.4.3 Undertaking the evaluation

*Planning the evaluation*

The evaluation strategy should not be performed as an afterthought, but considered at the programme planning stage (Campbell, 2007). The goals of the training programme must be stated explicitly before commencing the course. The common objectives of an educational and training programme for healthcare professionals are usually improvements in knowledge, skills and attitudes as well as competencies and professional behaviour in daily practice. According to Finlay and Noble (2004), tools for evaluating the improvements above must be tested at right time of planning of any training course or event. Wood (1998), in a systematic literature review, acknowledged the difficulty in identifying appropriate measurement tools for CPD as a standardised tool used for all programmes may not be sufficiently sensitive.

Brown and colleagues (2002) suggested that cost-effectiveness analysis must be applied to studies of educational programmes, in particular those resourced through charity funds. The reasons for undertaking economic analysis in palliative care programmes may be, partly, the scarcity of funding resources and lack of teaching staff with skills in general palliative care. In addition to healthcare professionals, involving other stakeholders also should be considered in the evaluation design when the focus of a programme is to establish whether that programme has any effect on organisational practice (Campbell, 2007).

*Choosing the approach and levels*

Depending on the aims and objectives of the evaluation and the nature of the educational event, it is important to identify whether the evaluation is formative or summative, which level it aims at measuring, who should be involved in the evaluation process, and what methods will be used for collecting data (Campbell, 2007)

There is general agreement that the choice of the most appropriate method for evaluating an intervention is often limited by resource and time costs. Therefore, the approach and level(s) of evaluation will vary depending upon the aims and outcomes of the evaluation as well as whether it is a short or long programme (Bradley et al., 2005; Calman, 2010). For example, as Campbell (2007) suggests, for a study day event or a short programme, for instance 2-5 days, assessing learner satisfaction or knowledge and skills at level one or two of the evaluation hierarchy may be suitable and feasible. These types of evaluation are often formative. While with longer programmes including a number of modules or action learning sets, the level three (behaviour change) or four (effects on patients) evaluation may be appropriate. In these cases, the summative approach may be considered.

*Choosing the methods*

Choosing a methodology to use to investigate a research question in educational evaluation research is similar that in any other type of research. Careful attention must be paid to the aims of evaluation, the validity of the method, tools selected, and the resources available (Hutchinson, 1999; Ingleton & Davies, 2007).

In the field of generic palliative care research, according to Costantini and Higginson (2007), there are four common methods; namely, survey research, epidemiological research, clinical trials and qualitative research. In these methods, an epidemiological approach is probably not appropriate for evaluating an educational intervention. Similarly, experimental methods has been criticised and recognised as failures in the context of evaluation research due to ethics issues in randomisation, lack of harmony between the requirements of the experimental model, and the demands of contextual evaluation (Hanks, 2010; Ingleton & Davies, 2007). In addition, research in palliative care has encountered a number of practical challenges due to the complex nature of this type of care; therefore, in order to evaluate the impact of an intervention and/or the quality of care delivery, researchers often tend to combine both quantitative and qualitative methods of data collection and analysis, that is, a mixed methods approach, into a project (Costantini & Higginson, 2007; O’Cathain et al., 2007).

Amongst most commonly used methods above, survey research, qualitative research and mixed methods approach are more likely to be most appropriate ones to deploy in educational interventions for healthcare professionals in the community setting. As Addington-Hall (2007:45-46) wrote, survey research is a type of study in which researchers

‘Ask people questions and then present or analyse the responses quantitatively, using statistics . . . describe attributes, attitudes and opinions, knowledge and beliefs, or behaviour of a population at a given time point.’

Survey research could be carried out independently as in cross-sectional studies in order to examine relevant characteristics of a population. In palliative care, for instance, these characteristics range from knowledge, attitudes, and behaviours of physicians (Rhee et al., 2008; Noble et al., 2003) to patients’ quality of life (Mitchell et al., 2008) as well as the degree of satisfaction of patients and their family with palliative care services (Ingleton et al., 2004). Surveys are also important components of pretest-posttest design of a great number of research studies. This model is often used to investigate the effectiveness of an intervention; for example, an outreach programme as in the clinical facilitator project conducted by Noble and colleagues in 2003 or the educational programme in palliative care of Croager and colleagues in 2010. The outcomes of a programme are inferred by comparing corresponding characteristics amongst similar surveys carried out before and after the intervention.

It is clear that survey research offers several advantages such as high utility, modest expenditure and relative simplicity (Addington-Hall, 2007; Costantini & Higginson, 2007). By contrast, Depoy and Gitlin (1998) point out several disadvantages of this method. For one thing, the inherent characteristics of survey research make it impossible to get a high-response rate. In addition, the time-consuming nature of face-to-face interviews and reliability issues in the sampling process are also problematic. Lastly, due to these weaknesses, researchers may be unable to deduce the casual relationship between an intervention and its outcomes.

Ideally, the value of an educational programme for health professionals should be evident in terms of clinical outcomes. In general, the goals of palliative care are patient-centred and patient family-centred (NICE, 2004), thus educational programmes target this population. Payne and colleagues (2008) suggested applying an qualitative research approach to examine the points mentioned above through several ways to collect data such as face-to-face interviews (structured, semi-structured and unstructured), participant observations of care provided to the patient, documentary data analysis and narrative inquiry. For example, in the study of Seymour and colleagues (2003) in which they explored the patients’ expectations and experiences in specialist palliative care services, they conclude *‘it is imperative to listen to the experiences of patients and carers as a basis for developing interventions and guidelines for services’* (Seymour et al., 2003:32).

A number of researchers have acknowledged the benefits of multi-method evaluation research due to the complementary nature of the approaches and the ability of exploring more than one dimension of the research phenomena (Campbell, 2007; Bradley et al., 2005; Ingleton & Davies, 2007; Payne, 2007). According to Ingleton and Davies (2007), the basis of this multi-method evaluation, or mixed-methods approach, for evaluation research is ‘*the application of the technique known as triangulation’* (p.197). The technique of triangulation will be present in detail in **Chapter 4 –** Methodology.

*Collecting data*

Depending on the desired learning outcomes, the organiser will be required to design appropriate measurement tools. For example, the improvement of knowledge and facts may be tested by multiple-choice questions or written answers, whereas understandings and skills competencies might be inspected by clinical problem-solving tasks or the practical demonstration of relevant skills (Calman, 2010).

A variety of data collection methods are available including asking participants to complete a scaled response sheet or a questionnaire consisting of multiple choice questions (MCQs) or short questions; writing essays or answering face-to-face interviews; or observing the practice on the day of learning or afterwards (Campbell, 2007). Some of these methods require evaluators to contact participants some weeks or months later to assess whether there has been any effect on practice.

A scaled response sheet or Likert-type rating scale or *‘smile sheet’* is a pragmatic way of collecting level one evaluation data for assessing participant satisfaction and attendance (**Figure 2.2 –** Evaluation Hierarchy). It can generate both quantitative and qualitative data with a focus on providing formative data (Campbell, 2007).

Administration of pre- and post-course questionnaires is frequently employed for level two evaluation which attempts to measure whether the educational outcomes in terms of knowledge, skills and attitudes have been achieved. This might contain some summative component; however, it still focuses more on formative data (Taylor, 2004). This evaluation occurs during the training in the form of either a knowledge demonstration or test. Although it is used commonly in evaluating educational interventions, the pre- and post-test design is considered as a weak tool due to the limitations of perceived or self-report. Another weakness is that the maturation, history and vicarious learning of the trainees, and many others factors may change in the period between the pre- and post-course point, and thus affect the accuracy of conclusions relating to educational outcomes (Costantini & Higginson, 2007).

Performing tasks such as solving problems are increasingly used to assess competence in applying factual knowledge learned to practice. This type of evaluation occurs 3–6 months post training while the trainee is at work. Evaluation usually occurs through observation. In addition to observing clinical work, competence also is evaluated by assessing the ability to demonstrate appropriate professional behaviours (Taylor, 2004). Patients frequently see and experience this type of behaviours. Therefore, in this context, information obtained from patients is likely to be one reasonable way of evaluating the competence of the healthcare professionals (Calman, 2010). These assessments are considered to be mostly summative, at Kirkpatrick’s levels three and four of evaluation. They are usually conducted through interviews, observation and objective measures.

*Reporting the results*

After undertaking evaluations of CPD or CME activity, it is important that feedback is given to the manager and the team involved in the educational activities, in particular feedback pertaining to the potential impact on practice, and how to continue the implementation and development of the programme (Henwood & McGannan, 2007).

### 2.3.5 Summary

I presented different aspects of palliative care education with a greater emphasis on potential benefits for personal professional development as well as the application of the principles of evaluation research to assess the outcomes on the learners and stakeholders.

A wide range of the most commonly used formats of educational intervention were mentioned, from organising workshops or conferences to clinical or work-based educational activities, as well as delivering educational materials through the Internet. Educational meetings are often preferred by healthcare professionals due to the nature of their daily workloads; work-based activities are valuable for enhancing skills and confidence in practice as well as developing professional liaisons between settings; telemedicine has also been useful due to acceptable cost and time-saving as well as the ease of accessing and updating the educational content. The critical issue of choosing formats is their fitness for the purpose of the programme and available resources.

A variety of methods for evaluating educational interventions were also described. It can be seen that a traditional quantitative or qualitative approach alone has appeared to be difficult for evaluating complex educational interventions in palliative care, which often have outcomes for patients and/or other stakeholders. As a result, in recent years, mixed methods approaches in evaluation research have been recognised to be likely to produce the most comprehensive picture of the effects of an intervention or service (Ingleton & Davies, 2007).

Taken together, in the process of planning and undertaking a palliative care educational programme for rural family doctors in Camau, it is essential to acknowledge similar projects from around the world. Therefore, a systematic review of educational interventions in palliative care for primary care physicians is needed. The results of this review will be described in the next section.

## 2.4 A review on education in palliative care for primary healthcare physicians

### 2.4.1 Overview

In terms of systematic reviews of palliative care educational interventions for primary healthcare physicians, I have found only one study, which was published by Alvarez and Agra in 2006. This review scrutinised educational activities in palliative care aimed at primary care physicians all over the world from 1966 to February 2005. They reported that improvements in GPs’ knowledge, skills and confidence had been recognised in the majority of studies; changes in behaviour and practice performance were limited. They concluded that palliative education for primary care physicians was poorly studied in the reviewed period, with the low quality of methodology and little attention had been paid to the assessment of objective measures such as symptom control and the quality of life of the patients.

In recent years, being aware of the weakness of research design in previous studies, many research studies with strong designs such as randomised controlled trials have been deployed in palliative care education. In addition, many of them have focussed more on measuring the outcomes of interventions on patients or family carers that were little reported in the Alvarez and Agra’s review. Therefore, an updated systematic review including recently published studies of the field may be necessary. In my review, I only gathered papers on the educational interventions in palliative care published from March 2005 to December 2012. This can be considered as a continuation of Alvarez and Agra’s work.

This review has used several principles for conducting a systematic review in the medical literature (Khan et al., 2011; Gysels & Higginson, 2007). It addressed the following question: are educational interventions in palliative care directed at primary care physicians, such as workshops, CME courses, sending printed educational materials (PEMs), clinical placements, telemedicine and so on, alone or in combination with other activities, effective in improving professional practice and/or patient health status?

### 2.4.2 Aim

To review systematically the literature describing educational interventions on palliative care for primary healthcare physicians from 1st March 2005 to 31st December 2012.

### 2.4.3 Method

#### 2.4.3.1 Search strategy

For this review, the following sources were searched: MEDLINE, CINAHL, Cochrane and PsychINFO databases. MeSH (Medical Subject Headings) terms were used (**Table 2.1**) in combination with operators such as AND or OR, for example “*evaluation*” AND “*gp*” OR “*physician*” OR “*health professional* ” AND “*education*” OR “*training* ” OR “*outreach*” AND “*palliative*”. In order to filter the search, only papers written in English from 01/03/2005 to 31/12/2012 were selected for the primary preview. A check with the references of reviewed articles was also undertaken. In addition, hand searching of content pages of relevant journals and abstract lists for relevant palliative care conferences was also undertaken. Full texts were retrieved for all included articles.

This search of MEDLINE and all other databases yielded 4256 hits.

Titles and abstracts of articles were read to identify any that fulfilled the inclusion criteria. For those articles whose abstracts indicated that the paper was likely to fulfil the inclusion criteria, the complete paper was read. If an article indicated that other publications reporting aspects of the same study had been published, these were also accessed and considered for inclusion.

**Table 2.1** Search terms

|  |  |
| --- | --- |
| MeSH | Search terms |
| Evaluation | Assessment, effect, effectiveness, impact, outcomes. |
| Palliative care | Supportive care, terminally-ill, end of life, last year of life, palliation, hospice, care home, residential home, nursing home, terminal care, terminal patient, advanced cancer patients, cancer survivors, cancer care. |
| Primary care physician | Family doctor, family physician, general practitioner, GP, healthcare professional, rural, remote. |
| Educational intervention | Conference, workshop, seminar, role-play, didactic, group discussion, small/large group; problem-based, work-based, guidelines, printing educational material or information, patient-held record, audit, placement, hospital, unit, telemedicine, teleconference, computer-based, self-directed learning, distance learning, podcasts, formats, outreach, program (me), project, leader opinion, reminder, training. |

#### 2.4.3.2 Inclusion criteria

*Types of studies* – Studies considered for inclusion were of educational interventions on palliative and cancer care known to be for primary care physicians in terms of CME, CPD, outreach programmes, and so on. Only empirical research studies were considered for inclusion; these were pre-and post-test surveys, interrupted time series analyses or longitudinal cross-sectional studies, cohort studies, case-control studies, RCTs, qualitative studies and mixed methods studies. Eligible studies were published in the time frame from 1st March 2005 to 31st December 2012.

*Types of interventions* – The following types of educational interventions were included: educational meetings such as workshops, seminars, symposia, courses and case conferences; sending printed educational materials such as guidelines or journals; and telemedicine such as Internet- or computer-based learning or counselling/ advice by telephone. These were all related to palliative and cancer care.

*Types of participants* – Studies that involved the participation of qualified primary healthcare physicians such as GPs, family physicians/ doctors were included.

*Types of outcome measures* – Studies that reported objectively measured health professional practice competence and behaviour or patient outcomes in a healthcare setting were included. Studies that measured knowledge or performance in a test situation were not included. Studies using patients’ subjective ratings of health professionals’ performance were also included.

#### 2.4.3.3 Exclusion criteria

Specific exclusions included studies that were single case reports, general descriptions of practice, policy documents or opinions expressed by practitioners or researchers in editorials and review articles. Specific surveys, for instance single cross-sectional studies, were not included since such surveys may not display any potential professional or personal improvement due to the intervention. Studies related to formal palliative education for undergraduates and postgraduates, health professionals in postgraduate training or resident physicians were also excluded from this review since they were beyond the scope of the thesis. Studies published before 2005 or not written in English were also excluded from the review

#### 2.4.3.4 Data collection and analysis of papers

I screened the titles and abstracts identified from the search process and eliminated any obviously irrelevant studies. The remaining studies were retrieved in full-text versions.

Description comprised (1) author(s) and the year of publication and the country where the study had been conducted, (2) the type of research design such as RCTs, pretest-posttest or the mixed methods, (3) type of intervention such as educational meetings, reminders, outreach programmes, Internet or computer-based learning and so on, and (4) outcomes on the competence and behaviour of participant physicians as well as the quality of life of the patient. A specific database was designed to register the aims and methods, response rates, intervention, population and outcomes (**Table 2.2**).

Regarding the analysis of quality of the studies, the quality of randomised and controlled studies was considered as a rigorous standard in the evaluation of outcomes of medical interventions, although one should be aware of its limitations in assessing educational studies (Davis et al., 1999; Pope & Mays, 1993). These are due to difficulties in obtaining a sample large enough for statistically significant quantitative results or managing cross contamination in comparable control groups (Hutchinson, 1999). In non-randomised studies, interrupted time series, and controlled or non-controlled before and after studies, blind assessment of outcome variables and percentage of replies were taken into account. With qualitative and mixed methods studies, the assessment of validity was based on explicit description in the studies regarding methods of data collection and analysis, member checking, deviant case analysis and triangulation process (Mays & Pope, 2000). The outcome variables related to educational interventions in this review were:

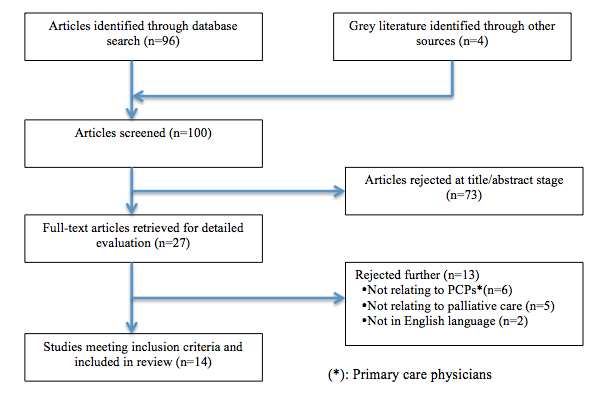
• *Related to the professional* – The response rates and the professional satisfaction with the interventions; measures of changes in knowledge, skills, perceptions and attitudes towards palliative care practice or the learning culture of physicians (interprofessional, self-directed and life-long learning); measures of changes in behaviour and competence of attendees; objective measures of changes in practice such as number of referrals or treatments for symptom control, for instance, the number of opioid prescriptions; communication between patients and/or carers and palliative care specialists.

• *Related to the patients/carers* – Measures of changes in patients and their carers’ outcomes such as levels of symptom control and patient’s quality of life as well as carer satisfaction and carer burden.

Because of the heterogeneity of the studies included, the descriptive analysis approach for summarising the evidence was applied.

### 2.4.4 Results

After eliminating duplicates, the bibliographic search using four database engines produced 96 articles. After checking their references, 4 more articles were obtained. All titles and abstracts of these papers were read to check eligibility, then 27 articles that fulfilled the inclusion criteria were retrieved in full to be examined in more detail. Thirteen papers were then rejected due to not meeting the inclusion criteria. **Figure 2.3** shows the flow chart of this selection process. At the end of the process, 14 articles were selected, which were the basis of this review.



**Figure 2.3** The diagram of included literature.

Of the 14 articles selected, 13 interventions were conducted in developed countries with a long history of palliative care provision such as Australia with 5 studies (Hoon et al., 2009; Mitchell et al., 2008; Mitchell et al., 2005; Reymond et al., 2005; Shelby-James et al., 2007; and the USA with 3 studies (Cox et al., 2012; Harris et al., 2008; Leong et al., 2010). The UK, Canada, Spain, New Zealand and the Netherlands each contributed one study. One study was conducted in Botswana, Africa (Ersek et al., 2010). There were 2 papers, which reported findings from the same project with different participants – GPs (Mitchell et al., 2005) or patients (Mitchell et al., 2008). **Table 2.2** shows the author(s), aims and methods, the format of educational activities, the population and findings of these interventions.

The intervention designs were as follows: 4 randomised controlled trials (Pelayo et al., 2011; Marshall et al., 2008; Mitchell et al., 2008; Shelby-James et al., 2007), 5 pretest-posttest designs (Ersek et al., 2010; Leong et al., 2010; Harris et al., 2008; Reymond et al., 2005; van Heest et al., 2007) including one study which had a control group and randomisation (Harris et al., 2008), 3 mixed methods including survey with questionnaires and semi-structured interviews in the same research (Hoon et al., 2009; Marshall et al., 2008; McKinley & McBain, 2007), and one qualitative study with semi-structured telephone interviews and a focus group (Mitchell et al., 2005).

A needs assessment prior to the interventions in order to develop the programmes of educational activities was mentioned in only two studies (Marshall et al., 2008; Reymond et al., 2005).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Table 2.2** Papers included in the review | | | | |
| Study | Aims and methods | Intervention(s) | Participants | Findings |
| Cox et al., (2012)  United States | • C – Change Cancer Core Competency Initiative  • Explore improvements in knowledge, skills and attitudes  • One of the sites of the programme: Florida | • Didactic lectures, video patient scenarios and an interactive online program on pain management and palliative care for non-oncology health professionals.  • Duration: not described | 120 – Including rural primary care physicians, nurses, social workers, and office staff | • 21% increase in overall level of confidence  • 90% reported improvement in gaining new knowledge and skills to provide better patient care |
| Ersek et al. (2010)  Botswana | • Compare scores on the Palliative Care Self-Evaluation and Brief Test of Palliative Care Knowledge using self-reported questionnaire.  • Pre-& post-workshop | Five-day workshop including lectures, case studies and group discussion on palliative care | 47– Including physicians, nurses, social workers, pharmacists, chaplains and volunteers. | • Overall workshop evaluation was high satisfaction  • Total knowledge and skills scores by the Palliative Care Self-Evaluation tool increased post-workshop (t=6.4, df=2, p<0.001) and also increased for each item.  • The post-workshop scores on Brief Test of Palliative Care Knowledge were significantly higher than the pre-workshop scores (t=4.2, df=33, p<0.001). |
| Harris et al., (2008)  United States | • Changes were measured using the KnowPain-50 tool.  • Pretest–posttest randomised design with surveys baseline, at the end of course and 3 months later. | Two –day CME course.  Chronic pain management was delivered to two intervention groups by expert speakers and online CME programme. The control group received live education on other palliative care topics | 136 physicians | • Ninety-five physicians (70%) completed data  • Satisfaction measures were high: 4-4.72 per 5 point Likert-type scale  • Scores of the KnowPain-50 tool improved immediately following both pain educational programs  - Live group: 138.0→150.6 (p < 0.001)  - Online group: 143.6→150.4 (p = 0.007)  - Controlled group: (139.2→142.5(p > 0.05)  • Effects persisted for at least 3 months in 2 former groups |
| Hoon et al. (2008)  Australia | • Compare the understandings and confidence about chemotherapy and cancer care pre- and post-placement.  Mixed method approach  • Pre- and post-test questionnaires with GPs and their employers  • Semi-structured interviews with GPs, education providers and steering committee. | Five-day clinical placements at metropolitan oncology units | Five rural GPs and 38 nurses | Healthcare professionals  • High levels of overall satisfaction  • Increased in knowledge and confidence in chemotherapy and cancer care such as communication, scoping strategy and emotional needs  • Lack of an opportunity to have practice-based clinical experiences and mentor supervision in the placement sites |
| Leong et al. (2010)  USA | • Explore a willingness to change the practice  • Pre- and post-test in 4 months with self-reported questionnaires | Two- day didactic seminar on pain management | 81 physicians (8 family physicians) representing 17 multiple specialties of medicine | • Response rate: 63%  • 90% of respondents changed their practice based on the CME program in some ways such as more cognitive-behavioral approach, more attention to psycho-spiritual needs of patients, used more narcotic and adjust medications with narcotics and so on.  • Dissatisfaction of several ‘underserved’ topics. |
| McKinley &McBain (2007)  New Zealand | • Evaluation of a funded model of integrated palliative care  • Mixed methods consisted of:  + In-depth, semi-structured interviews and focus groups with stakeholders  +Analysis of routinely collected quantitative data | • Implemented a model of integrated palliative care-the Palliative Care Partnership (PCP).  • Care is delivered by a partnership between palliative care coordinators (augmented by specialist hospice clinicians), GPs, practice nurses, and supported by community district nurses | • 63 stakeholders including GPs, nurses, specialist clinicians, health managers and other hospice staff.  • 585 patients were involved | GPs  • Appreciated the update in symptom control, pharmacology knowledge and information about social and psychological services.  • Felt early entry into the PCP maximised effective palliative care for patients, family and clinicians.  • Felt well supported by the content and manner in which the specialist advice was offered by the specialist hospice staff.  • Reported an increase in confidence and satisfaction  Educational content was seen as valuable and stakeholders were satisfactory with the model of care.  Enhanced skills of primary and specialist clinicians to provide cost effective palliative care.  Patients were very satisfied with care from the PCP.  • They appreciated the skills, human warmth and frequent contact.  Majority of carers were satisfied with PCP care |
| Mannix et al. (2006)  UK | • The Cognitive First Aid Rating Scale (CFARS) were used to evaluate competence through audiotaped sessions with patients  • RCT  • Self-reported, structured clinical interviews to assess the use of 23 different CBT skills in each group at 2 occasions: end of training (randomisation) and end of thee study. | • Brief training course in Cognitive Behaviour Therapy (CBT) techniques, supported by supervision including taught sessions, role-play in 3 days; then weekly half-day sessions in 10 weeks.  • Fortnightly skills-building supervision in 3 months.  • Randomisation at 6 months.  • The intervention group continued under supervision. The control group practiced without supervision | 22 palliative care practitioners and 16 nurses | • Increased in the scores of the CFARS in both groups at 6-month point. The group receiving extended supervision gained the scores further. The remaining group slightly declined in the scores.  • CBT skills revealed no between-group differences in skills utilization at the point of randomization.  • The group receiving extended supervision were reported using more skills of CBT than the group no longer receiving supervision  • Training alone is insufficient to equip health or social care professionals with sustainable skills, and that supervision is necessary to ensure that skills and the confidence to use them are maintained.  • Did not assess patient outcomes |
| Marshall et al. (2008)  Canada | • Improve primary care physicians’ knowledge, skills, and confidence; access; and quality of palliative home care.  • Mixed methods were applied for the evaluation.  + Mailed survey  + Semi-structured  telephone interviews with physicians  + Focus group with nurses using semi-structured interview guide. | • Implement a model of shared care in 15 months through practiced-based educational multi-disciplinary sessions in coordination with multi-professional palliative care specialists ( The Enhanced Palliative Care Teams– EPCT) by office visits, patient home visits and telephone calls to enhance family physicians’ ability to deliver palliative home care in a community-based setting. | 22 family physicians, 36 nurses and other staff | • Physicians felt that the project improved quality, communication, coordination, continuity, and integration of care  • Community nurses were more confident in discussing treatment plans, handling complex issues and making decisions.  • An increase by 40% in referrals.  • 55% of recruited palliative patients died at home, compared with 28% before the project. |
| Mitchell et al. (2008)  Australia | • Whether case conferences improve patients’ quality of life (QoL), and reduce the strain of caring for the primary caregivers  • Multi-centred RCT.  • Primary outcomes on patients were measured using the global QoL scores including the Assessment of QoL at the End of Life (AQEL), the McGill QoL Questionnaire and the Subjective Wellbeing Scale  • Secondary measures included subscale QoL scores and carer burden using the Caregiver Reaction Assessment | • Case conferences between GPs and specialist teams  • GPs participated in by teleconference vs. usual care and communication methods.  • Duration 22 months | 101 GPs  159 patients | Outcomes on patients in case conference arm:  • Improved clinical relationships and care plans at referral  • No difference in global QoL measures from baseline to any time before patients’ death, except some physical and mental health items of the AQEL in the 35 days before patients’ death  • Reduced the strain of caring for patients’ primary carers in two of the five domains, but only in 5-week point.  Outcomes on patients in control arm:  • Higher scores in some physical items when patients approached to death  Overall, the teleconference had inherent weaknesses compared with normal communication methods in the short term.  Case conferences GPs and specialist may improve clinical relationships and care plans at referral when severe symptoms develop. |
| Mitchell et al. (2005)  Australia | • Describe the utility and acceptability to GPs and palliative care staff of case conferences above  • Qualitative research.  + Telephone interviews with all GPs who had participated in a previous case conference using a semi-structured interview guide.  + Focus groups were conducted with palliative care staff | Specialist- GP case conferences through telephoning | 41 GPs and 16 palliative care staff including specialists, nurses, social workers, coordinator and pharmacist | General practitioners  • Being better informed about patient’s progress as an inpatient made discharge planning easier  • Allowed for clear role delineation between the GP and the palliative care service.  • Learnt something new (for example available drugs and treatment modalities)  Specialist palliative care staff  • Built rapport with the GPs  • Helped GPs better understand a team approach to palliative care  • Helped to reduce professional isolation  Both groups thought case conferences could be useful if they were held at critical points in the patient’s illness: at admission to the service, before discharge home, or when there were complex issues to discuss |
| Pelayo et al. (2011)  Spain | • Compare knowledge and attitudes scores on self- administrated questionnaires.  • RCT  + Intervention group: Moodle Platform for online access with tutorship  + Control group: hospital rotation, self-study, clinical session and attendance courses. | A 96-hour online educational model in palliative care for primary care physicians. | 169 primary care physicians | In the intervention group: response rate 73%  • Satisfaction was mostly good and very good.  • Knowledge increased 14- 20% (p = 0.0001)  • Confidence in symptom management increased (p = 0.02)  • Confidence in communication increased (p = 0.038)  In the controlled group: response rate 87%  • Knowledge decreased  • Confidence in symptom management increased |
| Reymond et al. (2005)  Australia | • Pilot and evaluate an intervention aimed at increasing the palliative care capacity of primary health care providers in rural and remote communities  • Pre- & post-workshop, 3 months follow-up questionnaires, 5-point Likert-typed scale.  • Attend one of 14 different workshops run over 6 months | Fourteen 3-h workshops –tailored to participants’ perceived need – consisted of introductory didactic teaching based on participant- nominated topics, small group case management discussions and a session devoted to psychosocial and counselling inputs | 149 health care providers including GPs (20), nurses (68), healthcare workers and others | • Average cost per participant – excluding wages – was $271  • GP response rate 90% (overall, 78%)  • 95% of GPs reported that the workshops had satisfied their educational learning objectives (others: 91.3%)  • GPs reported significant improvements in knowledge, skills and confidence with respect to the management of common palliative symptoms.  • GPs reported that workshop participation had led to increased confidence and better pain management, and obtained an Advanced Health Directive. |
| Shelby-James et al. (2007)  Australia | • Describe and evaluate impact of case conferences including: performance status, symptom control, palliative phases and resource utilisation.  • RCT  • Patients were followed until death or the study end (Nov., 2004)  • 167 patients received case conference, 191 did not receive. | • Case conferences between GPs and specialised palliative care services (SPCS) at patients’ home or through telephone calls.  • Conference minimally includes the patient or their representative, the GP, a palliative care nurse, and a representative from another clinical agency relevant to the person’s care.  • SPCS doctor usually attend | 203 GPs  358 patients | Regarding GPs  • GPs reported satisfaction with the conference organisation.  • GPs participated 99% of conferences  • Inadequate reimbursement was cited as a barrier (43%)  Regarding to patients  • Patients who did not receive a case conference had significantly shorter time from referral to death (p<0.001).  • Deriving the conference agenda directly from patient needs was considered to be a vital aspect of the conference. |
| van Heest et al. (2007)  Netherlands | • Describe a telephone advisory service for GPs caring for patients dying at home  • Pretest and posttest  •Impact of the advice was evaluated by standard questionnaire to the GP after 2–6 weeks. | Organise an programme palliative care advice (multiple topics) through telephone calls for all GPs caring for patients dying at home, run by GPs with a special interest in palliative care (GPwSIs) in 2000–2003 | 947 GPs | • Response rate on evaluation questionnaires was 68%  • Use of subcutaneous infusions at home increased with time from 111 in 2000 to 418 (in three regions) in 2003  • 85% of the cases the advice was followed, and in 11% it was followed in part; 4% did not follow the advice.  • 86% GPs thought the advice was useful.  • 84% of responders felt that the advice had improved the quality of palliative care. However, outcomes at patient level could not be reliably measured. |

There was a wide range of educational formats which included organising single approaches such as workshops or CME courses with didactic lectures or group discussions (Ersek et al., 2010; Leong et al., 2010; Reymond et al., 2005), applying models of care to disseminate palliative care information and education to community health professionals (Marshall et al., 2008; McKinley & McBain, 2007), doing clinical placement at a cosmopolitan specialist centre (Hoon et al., 2008), applying telemedicine principles through case conference telephoning between GPs and specialists (Mitchell et al., 2008, Mitchell et al., 2005, Shelby-James et al., 2007, van Heest et al., 2007) or Internet-based learning (Pelayo et al., 2011). Others combined two formats in a multi-faceted intervention, such as CME courses coupled with interactive on-line programmes (Cox et al., 2012, Harris et al., 2008) or a training course followed by 3-month supervision by specialists (Mannix et al., 2006). A learner-centred methodology was specifically cited in three studies (Cox et al., 2012; Harris et al., 2008; Pelayo et al., 2011), which mentioned using an experiential approach, following the principles of adult learning, where the learner is part of the active educational process.

The duration of each educational activity varied considerably, from a 3-hour training workshop (Reymond et al., 2005)to community-oriented activities over many years (Cox et al., 2012). Participation of stakeholders in the organisational support was mentioned in 3 interventions (Cox et al., 2012; McKinley & McBain, 2007; Reymond et al., 2005). Interventions were directed solely to GPs in only 2 studies (Mitchell et al., 2008; Pelayo et al., 2011), with the remaining directed to a mixed constituency of participant healthcare professionals including primary care professionals, multiple specialists, nurses and allied medical practitioners. Overall, 2212 healthcare professionals were involved in these educational activities. Of the 14 interventions, data for primary healthcare physicians appeared in 6 articles (McKinley & McBain, 2007; Mannix et al., 2006; Pelayo et al., 2011; Reymond et al., 2005; Shelby-James et al., 2007; van Heest et al., 2007); and the remainder reported aggregated data for family physicians and other healthcare members.

Methods used to evaluate the educational interventions were as follows:

• Self-administered questionnaires were used in all studies to measure perceptions of knowledge, attitudes, confidence and behaviour of healthcare participants, except in these reports: McKinley & McBain (2007), Mitchell et al. (2008), Mitchell et al. (2005), and Shelby-James et al. (2007).

• Further interviews with GPs were added following the use of self-report questionnaires in three interventions. In these cases, semi-structured interview guides were used to obtain further qualitative data (Hoon et al., 2009; Mannix et al., 2006; Mitchell et al., 2005). Focus groups were also conducted with other stakeholders, in particular nurses, in the same projects (Mannix et al., 2006; Mitchell et al., 2008).

• Structured interviews based on existing measurement tools were used to assess patients’ quality of life in one intervention (Mitchell et al., 2008), and to measure the satisfaction and burden of family carers in the same project.

Outcomes were evaluated through the following variables:

• Measures of response rates and satisfaction. Response rates were medium to high in the majority of articles, ranging from 63% (Leong et al., 2010) to 78% (Reymond et al., 2005). In half of the papers, the authors did not state the response rate clearly. Participant satisfaction with educational interventions was positive in all cases for entire interventions or across separate topics. The exception was that there were some complaints about specific parts of the programmes, for example not enough time for obtaining practice-based clinical experiences and mentor supervision in the placement sites (Hoon et al., 2009) or for learning on several ‘under-served’ topics of palliative care in addition to pain management (Leong et al., 2010).

• Measures of knowledge, skills and confidence of healthcare professionals after participation. Increases in knowledge and attitude towards topics of palliative and cancer care were observed in the majority of interventions (Cox et al., 2012; Ersek et al., 2010; McKinley & McBain, 2007; Pelayo et al., 2011; Reymond et al., 2005) or in several special topics such as pain management (Harris et al., 2008; Leong et al., 2010), psychological and emotional issues (Mannix et al., 2006), communication with specialists (Marshall et al., 2008; Mitchell et al., 2005, van Heest et al., 2007), patients and carers (Mitchell et al., 2008; Shelby-James et al., 2007).

• Measures of change in the learning culture of physicians. These were conducted in all interventions with multi-professional participation (in particular primary care physicians with specialists) (Harris et al., 2008; Marshall et al., 2008; Mitchell et al., 2008; Mitchell et al., 2005; Shelby-James et al., 2007; van Heest et al., 2007). The high appreciation of the professionals was clearly related to added benefits derived from a greater understanding of one another’s work, personal knowledge, communication facilities, or the design of an overall action plan for the patient and carer.

• Measures of changes in behaviour and performance in practice of health physicians. Five of the 10 interventions reported changes in participant practice following their participation in programmes in some ways, such as more cognitive-behavioral approach, more attention to psycho-spiritual needs of patients (Mannix et al., 2006), use of more narcotics and adjusting medications with narcotics (Leong et al., 2010; Reymond et al., 2005), more subcutaneous infusion at home (van Heest et al., 2007); or an increase in referrals to specialist services (Marshall et al., 2008).

• Measures of outcomes on the patients and/or carers such as the patient performance status or quality of life and carer satisfaction. Patient’s quality of life was noted in one intervention (case conference between GPs and specialists), and showed no difference in global QoL measures from baseline to any time before patients’ death, except for some physical and mental health items (Mitchell et al., 2008). In contrast, another study showed that patients who did not receive a case conference survived for a significantly shorter time from referral to death (Shelby-James et al., 2007). Patients’ preferences for the place of death were explored in Marshall et al. (2008)’s study, in which fifty-five percent of recruited palliative patients had died at home, compared with 28% before the project was implemented. The carers’ quality of life and burden were also measured in Mitchell et al. (2008). The results indicated that there was a reduction in the strain of caring for patients’ primary carers in two of the five domains on the Caregiver Reaction Assessment, but these changes were sustained only in the first five weeks. Similarly, in another study, both patients and family carers were satisfied with the care received from the Palliative Care Partnership (McKinley & McBain, 2007).

### 2.4.5 Discussion

Attention to palliative care education amongst primary healthcare professionals is a recent issue in the literature. Most care for patients at the end of life is provided by doctors working in the community who are normally not specialists in palliative care (Doyle, 2010; Liu et al., 2005). Consequently, there is a move towards a primary care focus in palliative care (Murray et al., 2004; Noble et al., 2003; Thomas & Noble, 2007). In one year, a family doctor can expect to care for between, on average, from four (Lloyd-Williams et al., 2000) to 30 patients (Viet et al., 2011) who are terminally ill.

Prior to this review only one systematic review had been published which summarises the effects of educational interventions in palliative care for primary health care physicians. This review, conducted by Alvarez and Agra and published in 2006, scrutinised the literature from 1966 to February 2005 about educational interventions in palliative care for primary care physicians around the world. Therefore, my review should be considered in the context of continuity with Alvarez and Agra’s paper.

The studies included in my review show that the educational activities and their evaluation were variable. Good results were reported in knowledge, attitude, confidence and satisfaction of the participants. Moderate changes in more objective outcome measures such as physician’s behaviour and performance were observed in other studies, such as using more narcotic and adjust medications with narcotics (Leong et al., 2010) or the increasing number of referrals to specialist services (Marshall et al., 2008). Regarding patients and their carers’ benefits, suboptimal results were also reported. For instance, the quality of life of terminally ill patients and their carers had only been improved at some point of time under the intervention (Mitchell et al., 2008) and the proportion of patients who died in their preferred place of death increased only modestly (Marshall et al., 2008). The two last aspects, however, had been less frequently assessed. These results were in line with those of Alvarez and Agra, who reported that an increase in knowledge and attitudes towards palliative care issues and cancer pain management was documented in 14 out of 18 studies of their review. With regard to patients’ healthcare status and quality of life, as well as carers’ satisfaction, 3 papers in their review showed no significant difference between educational intervention and control groups (Alvarez & Agra, 2006)

The quality of the studies included was acceptable according to the types of the design. For instance, the majority of studies were RCTs or before and after trials with or without control groups and randomisation. The lack of information about the reliability and validity properties of self-administrated questionnaires used to assess outcome variables observed in 11 interventions influenced somewhat the reliability of outcome assessments. The results in this review were somewhat similar to Alvarez and Agra’s in that there were 4 RCT studies, 3 studies in which the participants were all GPs, and 5 studies where sample sizes were larger than 100, although there was only one RCT in the review of Alvarez and Agra. Therefore, the results from this review may be considered as a useful addition to the existing body of knowledge of the field given by Alvarez and Agra’s study.

Evidence from the majority of articles in this review suggests that interactive educational activities that enhance participant activity and provide opportunities to practise skills can lead to changes in professional attributes such as knowledge, skills and attitudes towards practice; in professional behaviour and performance in practice to some degree, and, on occasion, in healthcare outcomes on patients and their carers.

The medium to high rate of responses to completed evaluations, (a range from 63% to 78 % in 9 interventions, with a mean figure of approximately 70%); the low number of objective outcomes that were measured, in particular on patients and carers; and the mixed constituency of participants in the majority of studies suggest that a conclusive statement of the results may be compromised. This is compounded further by the significant heterogeneity of the studies. In addition, professional groups can also differ in their identification of palliative care requirements; physicians in some specialties, for example oncology, are more likely to be aware of palliative care services than others, for instance, cardiologists (Bradley et al., 2000); and there can be differences between hospital doctors and family doctors’ perceptions of the patient’s needs for palliative care (Farquhar et al., 2002; Graham et al., 2010).

A mixed or multi-faceted educational approach was used in 6 of the 14 interventions. Similarly, Alvarez and Agra reported that 10 out of 18 papers in their review had combined in different ways the following educational formats: didactic courses, seminars, distribution of printed educational materials (PEM), hospital rounds, Internet-based educational programmes and so on. The benefits of multi-faceted approaches to change physician practice patterns found in the studies of this review as well as Alvarez and Agra’s were in accordance with those reported in other studies. For example, a systematic review of the impact of CME interventions for healthcare physicians on changes in practise performance by Davis and colleagues in 1999 concluded that didactic education alone was insufficient to change physician behaviour. However, when other approaches were added, they can lead to changes in professional practice

The use of the Internet for educational purposes was included in two studies in this review (Harris et al., 2008; Pelayo et al., 2011) showing significantly favourable results in the intervention groups. The robust design of these research studies (one RCT and one pretest-posttest design with randomisation and a controlled group) and the fact that all participants were healthcare physicians, suggests that the improvements in terms of knowledge, skills and confidence in pain management and other palliative care topics of participants are more likely to be a reliable interpretation. Similarly, a significantly favourable result of using the Internet as an educational facilitator in palliative care was also found in one study in the review by Alvarez and Agra (2006). Benefits of Internet use were described as retrieving information in palliative care to apply to clinical work (Pelayo et al., 2011) or its use as an interactive educational consultation model in pain management (Harris et al., 2008). Other computer-based formats such as using CDs containing educational materials or sending PEMs to local professional learners to help them overcome knowledge barriers in the workplace were not observed in this review.

The Internet provides several advantages over traditional CME. It allows the easy delivery of content, enabling professionals to select the relevant content from regional, national or international experts; to decide the pace and place of learning without needing to move; to use it in an interactive fashion; and to do this easily at the site of clinical activity when they need it (Pelayo et al., 2011). This approach is also consistent with adult learning theory, in which there is a direct relationship between the learner’s level of active involvement in the education activity and the likelihood of changing their behaviour as a result of the learning process (Calman, 2010; Henwood & McGannan, 2007; Jarvis, 2004).

Of the four interventions that mentioned the contact of community-based healthcare teams with palliative care specialist providers, the evidence shows that good communication between local teams and specialists was a key feature of the successful implementation of collaborative working models, for example case conferences held between GPs and specialist palliative care providers (Mitchell et al., 2008; Shelby-James et al., 2007), or shared-care models implemented in the community (McKinley & McBain, 2007; Marshall et al., 2008). GPs in these studies state that they had learnt something new about symptom control and pharmacology updates (Mitchell et al., 2005; McKinley & McBain, 2007) as well as being aware of clear role delineation between the GP and the palliative care service (Mitchell et al., 2005). The findings are in line with the results in the systematic review of Gardiner and colleagues (2012a) on factors supporting good partnership working between generalist and specialist palliative care. In their review they conclude that good collaboration between these two services could offer opportunities for education and clarify the roles and responsibilities of each service. No study in Alvarez and Agra’s review mentioned professional liaison although they admitted that the contact of the GP with a palliative care specialist could provide a key means of informal palliative care education on a case-specific basis (Alvarez & Agra, 2006).

Although two of the included studies evaluated the cost effectiveness of interventions (McKinley & McBain, 2007; Reymond et al., 2005) and reported modest costs, the evidence base does not allow any empirical conclusions to be drawn universally about the economic value of these interventions, due to the heterogeneity nature of study designs. Brown and colleagues (2002) in their review on cost effectiveness of CPD in health care commented that greater attention should be paid to ensuring that methods of evaluation and analysis for cost-effectiveness were of sufficient quality and quantity to allow conclusions to be drawn. They also highlighted that ‘*Continuing Professional Development for healthcare professionals must be cost effective to avoid a waste of resources.’* (p.652)

The training needs of GPs in palliative care have been reported widely in the literature (Meijler et al. 2005; Mitchell (2002). Two of 14 studies mentioned a needs assessment prior to the intervention (Marshall et al., 2008; Reymond et al., 2005). Controlling pain or other symptoms (using analgesics other than opioids and prescribing opioids or controlling nausea and vomiting), management of syringe drivers, breaking bad news, counselling skills, bereavement counselling, and other communication skills deficiencies were perceived as educational needs by primary care professionals across the studies of this review. If the ultimate goal of CPD is to improve outcomes for patients by changing doctors’ practice behaviours, evidence from the systematic reviews of the literature shows that intervention programmes in education, based on prior needs assessment and with a multi-faceted approach, are effective in changing doctors’ behaviours (Davis et al., 1999; Alvarez & Agra, 2006).

### 2.4.6 Limitations

Although comprehensive electronic search, retrieval, and review strategies were used, some studies might have been missed from the searches of this review. This is because the English language was used as a filter on electronic databases. Two studies were excluded because they were written in German although abstracts suggested that they were likely to be appropriate for inclusion. Furthermore, due to time and resource limitations, hand-searches of journals were not completed and experts in the field were not contacted directly. However, it is unlikely that the inclusion of these studies would have changed the results significantly, due to the relatively extensive search, inclusion of a wide range of study designs, and type of educative outcomes, and the range of countries included.

The wide scope of this multiple method study involved a large literature review across many fields and this increased the possibility of missing some important publications. Seeking reference documents from many biomedical electronic databases as well as hand-searching the relevant books and papers from the library could remedy this missing. Admittedly, the small number of similar studies found through the literature search limited the discussion and the generalisability of our findings.

Finally, because the heterogeneity of included studies in terms of methodology and mixed patterns of results as well as time and resource limitations, the quality criteria for assessments of reviewed experimental and observational studies were not comprehensively built. As a result, this review may not be considered as a systematic review in its conventional sense.

### 2.4.7 Summary

From this review, no strong conclusions can be drawn due to the high heterogeneity of the study designs and educational interventions as well as the low consistency of the populations included. However, reviewed evidence suggests a probable benefit of multifaceted approaches in educational interventions in palliative care that have been deployed for primary healthcare physicians. In future, it is essential to develop a collaborative research network to conduct multi-centre, randomised and controlled trials of educational interventions. In addition, the evaluation of effects of interventions should focus more on the assessment of objective measures such as symptom control and the quality of life of the patients.

# Chapter 3 – Healthcare System Structure and Palliative Care Education in Vietnam

## 3.1 Overview

This chapter will present several characteristics of the organisation and development of public healthcare system and healthcare services, in particular primary healthcare, in Vietnam. I will begin with a critical review of the literature in this area. For the theoretical basis of this study, I have nested it within the context of social medicine.

I shall present my understanding of the existing literature, which is based on books, papers and documents published recently in both Vietnamese and English. This chapter refers briefly to contemporary history and its impact on healthcare system, the organisation of current the healthcare system with a focus on primary care, and the development of palliative care in Vietnam. Political arguments concerning modern Vietnamese society are beyond the scope of this thesis. I will include only those pertinent to my subject and the field of social medicine.

To provide a context for this review, I used both English and Vietnamese literature sources. The English sources were searched on MEDLINE and Google Scholar databases; hand-searched from the Star search engine of the Library of the University of Sheffield (UoS) or suggested by my supervisors and senior researchers in the field. There have not been many books and papers regarding healthcare in Vietnam written in English. The Vietnamese literature includes articles published in specialised journals in Vietnam and the ‘grey’ literature such as unpublished studies, hospital or health policy documents in the library of Camau DoH. The majority of these were in Vietnamese.

## 3.2 A brief presentation on the contemporary history of Vietnam

To understand recent changes in healthcare system in Vietnam, it is necessary to have a glance at the key events, which have happened the recent history of Vietnam. There is general agreement that the current healthcare system in Vietnam has been shaped through successive ideological and socio-economic processes taking place during the country’s contemporary history (Ha et al., 2002).

Vietnam has a long history of fighting foreign interventions, from the beginning of French colonial rule in 1884 to World War II. In 1945, Ho Chi Minh led his revolutionary army ousting the French colonial government, and founding the Democratic Republic of Vietnam. The revolutionary government was established in Hanoi (the capital city) in the same year. In 1954, due to external political interference, the country was divided into two territories, the South and North of Vietnam. The North followed a socialist orientation. On the other hand, the South part of the country was controlled by a government supported by the USA.

In the North, the communist ideology called for equity as a country’s top priority. Thus healthcare services were given high priority. Despite experiencing decades of war, the government in the North invested heavily in its primary healthcare system that was centered on commune healthcare centres. In addition, the organisation of healthcare was developed for the purpose of boosting the percentage of the population with access to simple curative and preventive health services (Fritzen, 2007). In order to produce equal access to healthcare for everyone, the government in the North established a very comprehensive healthcare network aimed at *‘bringing medicine to the hamlet [villages]’* and providing free healthcare services to the entire population (Ha et al., 2002).

Subsequent war between the North and the South of Vietnam led to the fall of the government in the South in 1975. Subsequently, the reunification of the two regions established the Socialist Republic of Vietnam (SRVN). After reunification, the government of the SRVN made efforts to continue its principal ambition, namely providing free healthcare for all people nationwide. From 1975, all healthcare services, from basic primary care to specialist treatments in tertiary care hospitals, were provided, at no cost, to all Vietnamese citizens. Unfortunately, the healthcare system in the South during the civil war had been disrupted, as a consequence of the war. Therefore, the country’s limited resources were over stretched. The situation was worsened due to a considerable decrease of international support caused by the weakened socialist bloc, coupled with the isolation from the rest of the world due to the US embargo (Ha et al., 2002). This led to a stretch in Vietnam’s limited public health budget, and exacerbated the squeeze on operational expenses and maintenance that occurred when public finance was constrained during the 1980s (Bloom, 1998). As a result, health facilities deteriorated and there were shortages of drugs, medical equipment and other materials.

In 1986, the government of Vietnam embarked on a multi- sectorial economic policy (known as *‘Đổi Mới’* - renovation), with a view to transforming the country from a planned to a market economy, which was based on price liberalisation and the promotion of the private economic sectors (World Bank, 2009). In the health sector, a series of measures was initiated in 1989 by the Council of Ministers, aiming at further liberalising this sector and mobilising more economic and financial resources.

In 1989, the Ministry of Health introduced major reforms to the health sector. Service and drug fees were applied to the public health service. Facilities at the level of commune health station were also allowed to charge fees. Healthcare facilities could sell medicines to the public at market prices with a mark up of up to 15 per cent. Fees could be retained by the collecting facilities and used to improve the service delivered, including awarding allowances to healthcare workers (Segall et al., 2002). Preventive services and treatment administered under national health programmes, such as tuberculosis, AIDS, leprosy, and so on were to continue to be free of charge. The referral system was liberalised so that patients could attend any facility of their choice (Segall et al., 2002). From the 1990s onwards, the growth of the economy in Vietnam has been rapid and has had a profound impact on healthcare services.

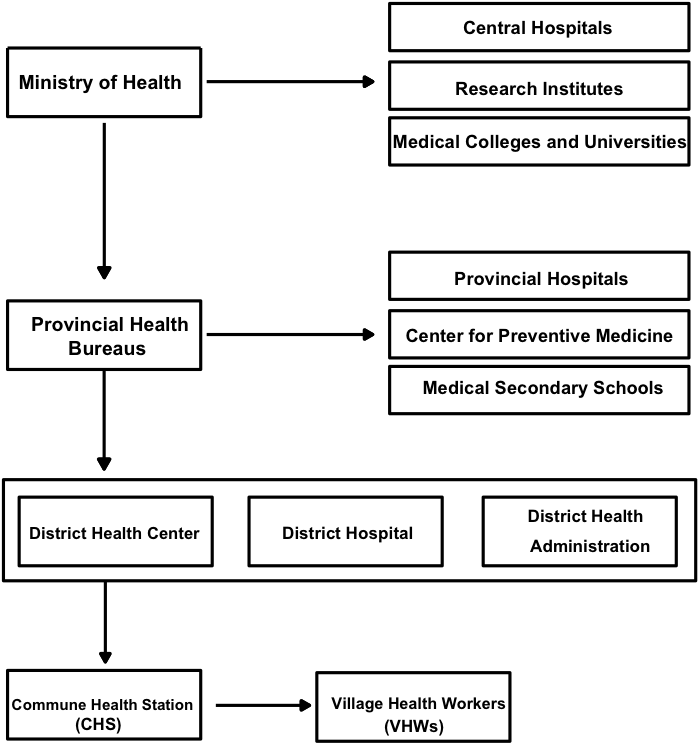
However, the improvement has not been uniform and disparities have widened between urban and rural areas, between different geographical regions of Vietnam and amongst various population groups. The rural poor have not fully benefited from the recent impressive economic growth in Vietnam, following its transition from a centrally planned to an open market economy. As the result, the rural poor have become victims of rapid development. The widening gap between the rich and the poor in Vietnam has led to social issues such as an increase in the number of homeless children, the abuse of child labour and sexual exploitation (Gien et al., 2007).

A brief history reflects the impact of the main historical movements on the healthcare system. The developments and achievements of the healthcare system have accompanied the initiation of economic and social reform programmes. After three decades of liberalisation and development, Vietnam’s healthcare system today represents a complex picture in terms of both structure and activities.

## 3.3 A *‘top-down’* model of healthcare organisation

### 3.3.1 Public healthcare hierarchy - structure and functions of each level

Vietnam established a multi-tiered healthcare system that corresponds to the levels of government. The structure of the state healthcare system comprises 4 levels, which correspond to the levels of government (**Figure 3.1**). The higher levels of government in Vietnam have retained some power over how lower levels use resources. The MoH of SRVN is based in Hanoi, the capital city of Vietnam. It leads 63 municipal and provincial DoHs across the country, and directs their functions. The MoH is also directly in charge of national institutes of health research and specialties, medical and pharmaceutical universities, central pharmaceutical enterprises and central hospitals. The MoH is responsible for formulating and executing health policies and programmes in the healthcare sector for the entire country (Lan, 2009).



**Figure 3.1** The administrative structure of the healthcare system in Vietnam (Tien et al., 2011)

In the public healthcare hierarchy, the higher levels provide specialised referral services and supervise the lower levels. Financially, all the provincial and district governments control public healthcare facilities’ budgets, and must provide minimum levels of funding for preventive programmes and hospital beds for provincial and district hospitals. However, governments of richer provinces or cities can spend additional funds on local health services, if they wish (Bloom, 1998) providing a substantial share of total health expenditure by poor localities in these provinces.

In every province, the Provincial General Hospital (PGH) acts as the tertiary centre, the final point of referrals in the province with several specialist clinical wards. There are approximately 25 out of the 58 PGHs in the country, which have their own oncology ward. There are five public specialist cancer hospitals and several cancer centres built in tertiary hospitals in municipalities (large cities) of Vietnam such as Hanoi, Saigon, Cantho and so on. Each PGH also serves as an education centre for the training of nurses, midwives, and traditional medicine assistant doctors. Administratively, the provincial DoH, which is directed by both the MoH and Provincial People’s Committee, is responsible for the supervision of healthcare services in the province. The functions of the healthcare system at provincial level consist of two main activities – curative and preventive. In addition to the PGH, many provinces have several provincial specialist hospitals such as traditional medicine hospitals, rehabilitation hospitals, obstetrics and paediatrics hospitals or tuberculosis and lung disease hospitals (Oanh et al., 2009).

At the level of districts, as from 2006 (MoH, 2013), there are two governing bodies for the management of health services, namely the District General Hospital (DGH) which acts as a referral points from commune health stations (CHS) in the district, and the District Health Centre (DHC) which deals with preventive and environmental health programmes such as HIV/AIDS, tuberculosis, malaria, and so on. The national preventive programmes have been the most successful aspects of the vertical management system. Each programme formulated guidelines and set targets. These programmes were monitored by local political cadres and by special units of Provincial DoHs as well as Provincial People’s Committees (Bloom, 1998).

The DGH provides inpatient services using basic techniques for the emergency care of patients with common diseases and having several clinical wards such as surgery, internal medicine, OB/GYN and outpatients. If a facility encounters difficult cases beyond their capacity, they refer the cases to a higher level. Each health facility has a notebook that keeps a record of patients referred. If a hospital wants to refer a patient, a summary of the patient’s record with the director’s signature is required. At least one member of healthcare staff accompanies the patient to the referral facility.

The basic level of healthcare is at the commune health level. At this level, commune health stations (CHS) are responsible for delivering all primary healthcare services as well as coordinating the activities of village level and/or Red Cross units in the commune community. Each CHS is staffed by a family doctor and four to six other health professionals including assistant doctors, midwives, primary or mid-level pharmacists, nurses, sometimes with traditional medicine professionals. They are responsible for providing basic curative and preventive health services for a population of 5,000-10,000 people. Functionally, CHSs act as the primary access point for public services in Vietnam (Duong et al., 2004). They are in charge of implementing national health programmes, providing examination and treatment for common diseases, health counselling, and referral services for patients with serious illnesses, prenatal and postnatal care, and common delivery services (MoH, 2006). In addition, CHSs also deliver short-term inpatient services when necessary. Most CHSs have some beds for inpatients in cases of delivery, emergency, or for monitoring patients (Duong et al., 2004). For patients covered by health insurance schemes, CHSs are also the referral point to a higher-level of service, for instance DGHs.

Healthcare professionals working at CHSs are normally employed by the local health authority, and paid by the state. Service fees are paid directly by patients or through the National Health Insurance Agency. Patients pay partly or fully the costs of services depending on whether they are covered by health insurance or not. Although the administration of the healthcare system is the responsibility of provincial governments, funding and legislation regarding healthcare are shared between the central and provincial governments.

Each CHS also manages and coordinates 6-12 health units at a village level, that are staffed by a part-time health worker who receive a short period of training. He or she is paid partly by the commune’s budget. His or her functions are to provide some basic minor healthcare services such as treating minor ailments, to give injections according to doctors’ prescriptions and home care, to coordinate with immunisation or family planning programmes, and to give health education to local households. The government has recently decided to pay the salaries of three to five health workers at each facility in order to ensure at least minimum staffing (MoH, 2006).

Vietnam has a well- developed public healthcare system with extensive rural coverage (Segall et al., 2000). However, the main drawback of the healthcare system in Vietnam, according to Ekman and colleagues (2008), is to favour care at higher levels such as secondary or tertiary health care providers. This has the effect of encouraging patients to seek care at hospital levels, and neglecting primary healthcare services, even though the latter may be more appropriate for patients’ problems.

Several features of the public healthcare system are listed further below:

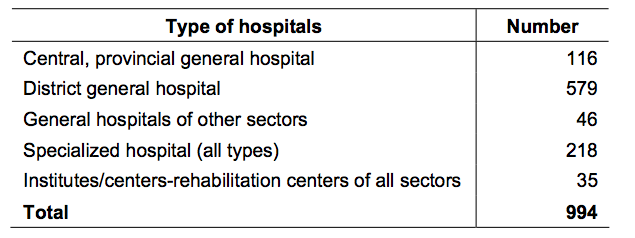
* Few home visits are done by local family doctors and normally only if requested by acquaintances, or sometimes during an end-of-life crisis. Most out-of-hour problems are dealt with in the Resuscitation and Emergency Department of the nearest district hospital, or sometimes at local CHSs.
* The concept of interdisciplinary teams is restricted to the conventional relationship between the more educated doctors and less academically trained nurses. Allied health services such as medical social work and physiotherapy are not developed except acupuncture and traditional medicine in some areas.
* Much of what is considered as an integral part of nursing care in Western countries, such as feeding and cleaning for patients, even serving of medications, is frequently done by family members. This is the norm in a majority of hospital wards and these people are usually designated as family carers.
* Hospices have been almost non-existent at provincial level.

### 3.3.2 Public versus private healthcare sectors

In Vietnam, healthcare services are delivered by both public and private healthcare providers. Most curative care at higher referral levels is provided by public hospitals with relatively few private hospitals operating in urban areas, and most for specialised care. Traditional medicine is a recognised part of the Vietnamese healthcare service system and such providers operate within both the public and the private sectors. In addition, most pharmaceuticals are purchased, with or without a prescription, from private vendors (Ekman et al., 2008).

By July 2005, Vietnam had 1043 *‘hospital-like’* facilities with 136,590 patient beds, of which the public sector accounted for 1000 facilities (96 %) and 133, 345 beds (98%). Three quarters of *‘hospital-like’* facilities are general hospitals (provinces and districts) and one-quarter are specialised, rehabilitation and traditional medicine hospitals in both public and private sectors **(Table 3.1)**. The private hospitals are operated on a small scale and are concentrated in large cities. By July 2005 there were 43 private hospitals totaling 3,245 patient beds (MoH, 2006).

**Table 3.1** Structure of types of public hospitals (MoH, 2006)



The private provision of health services in Vietnam was legalised in 1989 as one of the country's means to mobilise resources and improve efficiency in the healthcare system. These reforms were confirmed in law in 1991 and 1993 and the policy of a public-private mix of health care provision and financing was adopted officially by the Communist Party in 1993 (MoH, 2013). After two decades, the private sector has widely expanded its activities and become an important provider of health services for the Vietnamese people. However, patients with severe illnesses tend to use less private than public care (MoH, 2006). This could be explained partly by the fact of socio-economic health inequalities in which a proportion of poor people cannot afford voluntary healthcare insurance, and they tend to have worse health status than with their rich counterparts.

In general, the private healthcare sector has contributed considerably toward meeting people’s needs for health care and reducing the work overload on higher-level health facilities. The private health sector also facilitates access to service, avoids long waiting times and saves time for patients who can afford to pay. Given the rapid pace of development in Vietnam, private health services (hospitals in particular) have impacted on public facilities by creating competition to attract patients through better quality of care and better health worker attitude in serving patients. Nevertheless, the pace of development in the private sector is relatively slow, which means this sector is unable to compete fully with public hospitals. Moreover, the performance of private facilities needs to be thoroughly reviewed and regulated in terms of quality of care, price of services, overuse of services and diagnostic tests (MoH, 2006).

Private medical practices and pharmacies have become widespread throughout the country, mainly in the form of small clinics and retail drug outlets. Some of the private practitioners are retired doctors and pharmacists from public services, or are still in public employment but engage in *'out of hours'* private practice (Segall et al., 2000). Many healthcare professionals employed in the public sector also see patients in their spare time. *'Out of hours'* private practice is an important source of income for Vietnamese healthcare professionals. Patients who use private services pay total service fees directly to the professionals without any claim for the cost even though they are covered by health insurance.

Private providers are successfully competing with the public health centre system in rural areas but not because they provide cheaper or better services. The quality of private health care services is not controlled and is significantly poorer than public services. Current practice in both systems falls below the national standard, especially for the management of chronic health problems. The low quality of health care services at a community level may help to explain the previously observed phenomena of high levels of self-medicating, low utilisation of CHSs and overutilisation of tertiary health care facilities (MoH, 2006; Tuan et al., 2005)

There are two types of hospitals in the inner cities. First, there are public hospitals (for example the Camau PGH), where most of the poor and insured people come for treatment. These are operated by provincial DoHs. The second type is private or for-profit hospitals. Private hospitals usually refuse to serve patients who cannot pay and refer them to public ones. This increases the time before patients are treated and adds to the burden on public hospitals. In addition, public hospitals frequently lack staff and/or inpatient beds; therefore, there are few places in critical care units such as inpatient PCUs for handling patients with serious conditions. As a result, many patients may have to share a room, or even a bed.

In both public and private healthcare sectors, the distribution of qualified professional staff between hospital levels, provinces, and regions is unbalanced and not commensurate with tasks and functions (MoH, 2006). Highly qualified staff are concentrated mainly at the central, provincial, and township levels. Consequently, many CHSs as well as DGHs have difficulties in attracting physicians to practise in their premises. Therefore, patients are likely to experience further disadvantages in the community compared to those in more urban areas. Staff turnover is also high in CHSs as health workers often change jobs or go into private practice. This has led many skilled personnel to leave poor rural areas, and consequently, exacerbates the existing shortage of manpower at the grassroots level of the healthcare system (Bloom, 1998).

### 3.3.3 Health financing and insurance policies

Health financing policies have been implemented to meet the goals of equity and efficiency for the health sector. The broad orientation of health financing was developed during the 1990s through the development of health insurance, the partial user charge policy, and the Government’s resolution on *‘social mobilisation’* in the areas of education, health, and culture (MoH, 2006). Currently, under the policy of *‘social mobilisation’*, Vietnam’s healthcare sector has been supported financially from many sources including the government budget, health insurance, out-of- pocket spending from patients, and international development assistance (MoH, 2006). These orientations have created a mixed public-private health financing system in Vietnam with two main sources of funds: public funding (including health insurance) and patient out-of-pocket spending on user fees. Nevertheless, partial user fees have created some problems and have led to inequalities.

In common with many countries in the world, Vietnam has a publicly funded healthcare system and its own national healthcare insurance. Public healthcare is free or available with a minimum payment (ranging from 5 to 20 percent of total service cost depending on the patient’s health insurance type), however, public healthcare funding is insufficient to provide adequate health care for all Vietnamese citizens. The healthcare services covered by the health insurance scheme include inpatient care, some forms of outpatient care and several ancillary services. Most healthcare services delivered at patients’ homes, similar to community-based palliative care in the UK, are often provided by the private healthcare sector but not available in the public sector. Patients have to pay for this type of service even though they have health insurance because private provision is not covered. Nursing homes and hospices are scarce in Vietnam (MoH, 2006). Private insurers are excluded from the national healthcare insurance arena. However, private insurance or provincial programs may pay for medication and other services. Hence, access to services, the range of services and cost of medication can vary in different schemes.

Today there are several forms of health insurance for the Vietnamese. Firstly, compulsory health insurance for those in formal employment, which was introduced for government employees and workers in state enterprises in 1993, covers 9% of the population of Vietnam. Secondly, there is voluntary national health insurance, which was introduced in 1994, and covers 11% of the population (Axelson et al., 2009). In addition, the Government has introduced two further programmes: Health Care Funds for the Poor, and free healthcare insurance for children 0–5 years of age, which were established in 1991 (Nguyen et al., 2010). These two programmes cover 18% and 11% of the population, respectively (Lofgren et al., 2008). Today, the national healthcare insurance covers medical care for approximately 60 per cent of the 87.5 million Vietnamese inhabitants (Tien et al., 2011). This means that more than 32 million Vietnamese citizens do not have healthcare insurance coverage and have to pay full healthcare fees in the case of using services (the user fee policy). It appears that the most deprived and vulnerable population groups such as unemployed people, some of the poor and many farming families are yet to be covered fully (Ekman et al., 2008).

People in rural areas must register with a primary healthcare service, designated according to their residence. If in need of specialist treatment, the patient must be referred by a primary care physician to specialist services. Patients also have the right to choose services at higher levels without the need of a referral from the local doctor, but in this case they have to pay all or 50 percent of the service cost depending on whether they have health insurance or not. There are several levels of co-payment of service costs covered by the national insurance scheme, ranging from 5-20% of the service costs. Palliative care service is considered in the same way as other healthcare services and regulated in a similar way.

According to data from the MoH (2006), low-income people with health insurance utilise district hospitals twice as much as those with no health insurance; meanwhile, utilisation at the same service level by middle-income people with health insurance is 1.6 times as much. This indicates that health insurance can help low and middle-income people gain access to health services at the district level. This could be even more beneficial for the poor because the poor tend to seek inpatient care at CHSs, regional polyclinics and district hospitals, whereas the rich are increasingly likely to access provincial or central hospitals (MoH, 2006).

### 3.3.4 Several health statistics

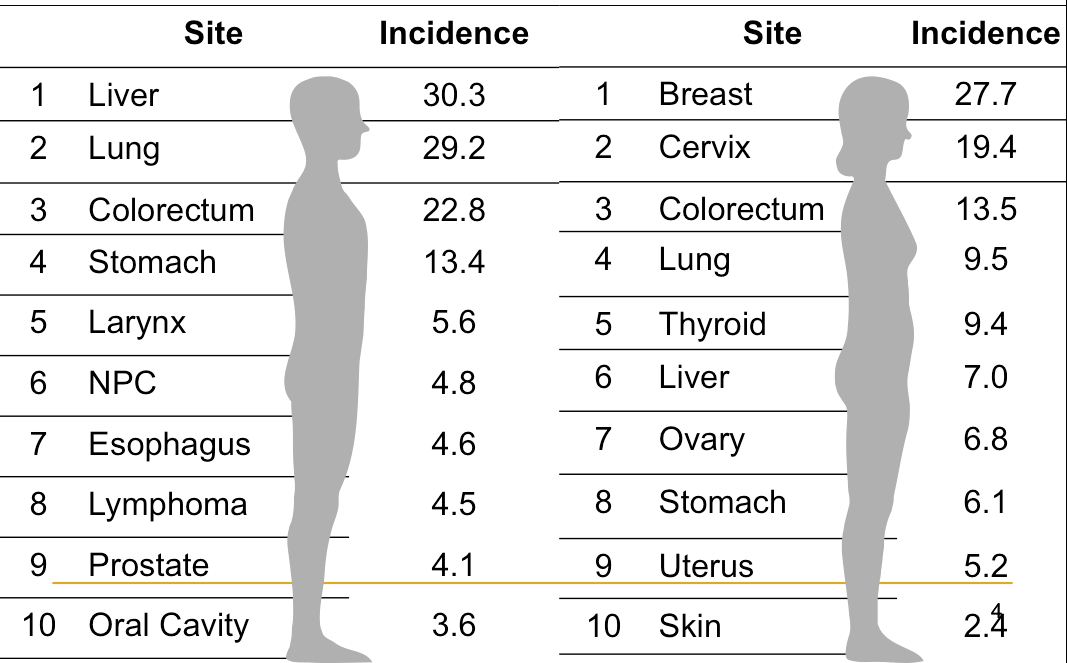
GNI (Gross National Income)per capita is around 1270 USD, placing Vietnam in 120th out of 188 countries on the income level rankings of the World Bank, and as a result, the World Bank has stated that Vietnam is well on the way from a low-income country to a middle-income one (World Bank, 2012). According to the World Bank, poverty rates, a different social indicator, may now be as low as 18% in comparison with around 75% in the mid-1980s (before undertaking reform policies). However, the Vietnam Health Report 2006 indicates that there are some income-related inequalities in access to and utilisation of healthcare services as well as in health outcomes amongst geographical areas, the ethnic minorities and low-income people (MoH, 2006).

The national expanded programme on immunisation (EPI) provides free vaccinations against seven common diseases in children. These include tuberculosis, diphtheria, whooping cough, tetanus, polio, measles and hepatitis B. The rate of children who receive full vaccination against all seven diseases is about 95 percent (Oanh et al., 2009).

Life expectancy at birth is 75 years. This puts Vietnam in one of the highest positions amongst countries that have a similar income. The number of cancer cases diagnosed newly every year is approximately 150,000 with about 80% in late stages (stage III or IV according to the classification of the Union for International Cancer Control (UICC). Deaths from cancer are approximately 70,000 per year, accounting for 12 % of annual total deaths in the country. This ranks cancer at at second position amongst leading causes of mortality, after cardiovascular disease (MoH, 2011). In a survey by Huong and colleagues in 2006, the average survival of more than one year for cancer patients in several Northern provinces of Vietnam is just in excess of 50%.

The most common cancers in men are liver, lung, colorectum, gastric and nasopharyngeal carcinoma (NPC). In women, they are breast, cervix, colorectum, thyroid and lung (**Table 3.2**)

**Table 3.2** Ten most common sites of cancers in both sexes in Vietnam (Le et al., 2012)



*(Proportions per 100,000)*

### 3.3.5 Household perspectives on healthcare

Many factors can affect the quality of health services. They include physical facilities, equipment, drugs, health service management, and especially human resources (such as knowledge, competence, attitudes, and professional ethics). Patients often assess the quality of care mainly based on their impressions about the type of health facility or the personal qualities of the healthcare professionals who treated them. Usually, people in Vietnam perceive that higher-level facilities provide a higher quality of care than lower level services do (MoH, 2006). The level of education of the patients significantly affects healthcare decisions. According to Thuan and colleagues (2008) patients with higher education tend to choose healthcare providers rather than self-treatment. Therefore, community level care is often bypassed, and patients often present directly to higher levels. This leads to overloaded services at central hospitals, in particular neurosurgery, oncology, orthopedics and cardiovascular diseases (MoH, 2006).

The introduction of a new economic policy in 1986 increased out-of-pocket health expenditures [[4]](#footnote-4) as a proportion of total health expenditures (Thuan et al. 2008). In the current system, households can choose between the public health service on the one hand, and the purchase of drugs over the counter (OTC) and private healthcare consultations on the other. Within the public sector they can choose between consultations at CHSs and, if they can afford it, self-referral for much more expensive hospital treatment. This increases choices for patients, but at the cost of skyrocketing household healthcare expenses, it also adds a burden on households, which is especially heavy for the poor (Segall et al., 2000).

Thuan and colleagues (2008) examined patients’ choice of medical providers and household healthcare expenditure for different providers in a rural district of Vietnam, they stated that the use of private health providers and self-treatment are quite common, and patients often use private healthcare services before public ones. In addition, the poor tend to use self-treatment more frequently than wealthier members of the community. As a result, they tend to appear at the health stations when they are extremely sick, requiring extensive medical attention. According to the MoH (2006), the poor usually have most contact with grassroots health services (CHSs and DGHs) and rarely contact a level of care higher than the district level such as provincial or central hospitals. Finally, geographical conditions greatly affect access to health services. Geographical factors not only affect the poor, but also affect all other income groups in Vietnam. This effect, however, is most marked among the poor (MoH, 2006).

The government of Vietnam has been committed to promoting and securing equity in access to health care for all citizens. The current rapid changes towards a market economy challenge the government’s wish to maintain equity, especially for low income and vulnerable groups in society. In the current transition phase, with changes in healthcare financing, the government has put great emphasis on partial payment by individuals. This could bring additional funding for the healthcare sector but the danger is that many people who are unable to pay even small amounts could be deterred or excluded from obtaining healthcare (Khe et al., 2002).

### 3.3.6 Opioids availability and use

Vietnam is a signatory to the Single Convention on Narcotic Drugs of 1961 (signed November, 1997), and thus, part of the International Narcotics Control Board – INCB (Green et al., 2006). Opioid use for pain relief is still far below the recommendations of World Health Organization at 9 mg per inhabitant per year (WHO, 2000). According to the INCB, Vietnam’s per capita morphine consumption in 2004 was 0.1 mg (compared with 115.7 mg in Austria), and Vietnam ranked 122nd in morphine consumption out of 155 countries reporting to the INCB (Krakauer et al., 2007). The INCB (2013a) has called attention to this striking disparity and has urged governments to improve pain relief by ensuring opioid availability for medical purposes and identifying the barriers to adequate opioid availability, particularly in low- and middle-income countries (LMICs). In the INCB’s report, positive changes have occurred when countries adopted policies that foster a healthcare infrastructure for pain and palliative care that facilitates appropriate distribution of medications and lessens heavy legal or regulatory restrictions (INCB, 2013b). Such improvements are possible only with full cooperation between healthcare experts and government officials. The INCB points out that working with palliative care experts, the Vietnamese government recently amended regulations to repeal a daily maximum dose limit and expand the range of patients permitted to receive an opioid prescription. This is only one of many countries that have achieved similar change (INCB, 2013b).

Many of the medicines regarded as essential for palliative care in a developed country may be unavailable in Vietnam, and even when they are, may be too expensive for the majority of Vietnamese patients to be able to afford. Slow-release morphine preparations are not popular, but immediate-release morphine preparations are domestically manufactured and commonly used at some tertiary institutions. Transdermal fentanyl is also available but its use is restricted by high prices. Methadone is available exclusively on hospital prescription for withdrawing drug users and hydromorphone and oxycodone have not been available officially in Vietnam.

Although the National Guidelines for Palliative Care (NGPC) were issued in 2006 (Xuyen, 2006) and the Regulations of Opioids Prescription (ROP) from the MoH were brought into effect in 2008, the accessibility of strong pain-relieving medicines remains problematic in Vietnam (Green et al., 2006; Krakauer et al., 2007). Opioids are classified as schedule A controlled medicines, and access to them is very limited. Oral morphine, while legal, is not widely available within most hospitals throughout Viet Nam. Parenteral morphine is more widely available in most healthcare facilities at all levels, but the quantity permitted for prescription at CHSs is often limited. The lack of oral morphine in the hospital environment may be because hospital managers are often not well informed or trained in morphine use and pain control as well as not clear on what the law regarding opioid prescriptions entails. Therefore, they may fear legal repercussions for providing opioid analgesia. Because of these perceptions, doctors are not inclined to ask about pain or to prescribe morphine to patients in severe pain.

Although morphine in both oral and injectable forms was recently made available and significant training and regulations have been given, clinicians are still hesitant in using it. Only ten per cent of family doctors in a provincial survey state that they feel confident enough to prescribe morphine for their cancer patients in the community (Viet et al., 2011). The reason may be partly due to the fact that oral opioids, if available, can only be obtained from the pharmacies of tertiary referral or specialist hospitals. In addition, oral opioids can only be prescribed for a limited period of 10 days, for a maximum of 3 consecutive prescriptions, and with a legal ceiling on the dose permitted.

Analgesic combinations, which include the weak opioids codeine or tramadol with NSAIDs or paracetamol, are available for inpatient use and for sale in private pharmacies. Codeine is considered as a very effective and inexpensive medicine in controlling moderate pain (Green et al., 2007). However, codeine alone is not legally available and is not listed in the Vietnam Essential Drugs List. Only the combinations of codeine with paracetamol or ibuprofen are authorised for production and use in Viet Nam. This limits the palliative care use of codeine because no more than 4g of paracetamol or 3g of ibuprofen can be taken in a 24-hour period.

The availability of other palliative care medicines is also highly limited. Certain anti-depressants essential for management of neuropathic pain and depression are difficult to find and often expensive. Medicines to manage breathlessness and anxiety are also not available universally at CHSs although they are legal and available for provincial and district hospitals to order from pharmaceutical companies (Oanh et al., 1999).

### 3.3.7 Influences of social, cultural and political factors on healthcare services

Traditionally, doctors have tended to avoid disclosure of cancer and/or terminal illness to patients. In addition, family members often attempt to protect patients from grave diagnoses. This situation is tending to change to more open communication between physicians and their patients. This probably mirrors changes in patient-physician communication that have occurred in the developed world. However, open disclosure of diagnosis and prognosis may be culturally sensitive. It is a cultural norm that the family usually take a more prominent role than the patient in making decisions regarding treatments and care options to patients with cancer, in particular patients at the terminally ill stage.

Inequalities in income and in access to health services have been increasing in Vietnam (MoH, 2006). There are considerable inter-regional differences, and most poor households live in the economically slow-growing regions. Health expenditure is increasing most rapidly in urban areas. Geographical inequalities in access to health services have also been observed. The government allocates a disproportionate share of its health expenditure to urban hospitals and most private practitioners tend to be based in the cities. Given the low coverage of health insurance in rural sector occupations such as farming and amongst the self- employed, the majority of people covered by compulsory health insurance (the work-related health insurance which pays health facilities on a fee-for-service basis) are urban dwellers. Consequently, this will encourage further divergence between urban and rural health services (Tien et al., 2011).

There are several problems for rural patients in accessing healthcare services. First, most CHSs in rural areas serve a widely dispersed population where transportation is difficult. Moreover, CHSs normally offer both profitable and public healthcare services. Because of charges for healthcare services at CHSs, the rural poor (including many farmer families) without insurance health coverage or who cannot afford private care or voluntary health insurance often use self-treatment first. As a result, they usually present at health facilities with critical illnesses, sometimes need to be transported further or wait longer before being referred to a specialist centre.

Out-of-pocket payments or service-user fees continue to be the most important means of financing healthcare in Vietnam. However, large and unpredictable health payments for care and/or medication could expose households to substantial financial risk and, at their most extreme, could result in impoverishment (van Doorslaer et al., 2006). Another concern is the widespread practice of self-medication in Vietnam, exacerbated by the limited access to health services in poor and rural societies that are constrained by income and distance (MoH, 2006). Impoverishment is all the more disturbing when it arises from spending on self-prescribed medicines that have little or no positive effect. Out-of-pocket health payments, therefore, worsen the poverty problem further for vulnerable people.

As in most of lower and middle-income countries in the region, palliative care and hospice services in Vietnam are negligible or still rudimentary and sporadic, caring for only a small proportion of patients with cancer or AIDS that need care. Palliative care is still not available for people with other chronic illnesses such as heart failure, dementia, COPD[[5]](#footnote-5) and so on. Even in some provinces in Central Highlands or in the Mekong Delta in the South, there is still very little awareness of palliative care amongst healthcare workers. In addition, the lack of universally accredited training programmes is an important obstacle in educating healthcare professionals in palliative care. There is a lack of trained staff in palliative care services, even at the level of tertiary hospitals, as well as a lack of national specialist lecturers for teaching on palliative care (Krakauer et al., 2007).

Unfortunately, at the present time, in most places across the province, only a minority of patients is able to access specialist palliative care services. One way to improve the effectiveness of palliative care could be to develop basic palliative care packages to be administered by local primary care professionals, thereby ensuring increased patient and family access. However, according to Bruera and Sweeney (2002), effectiveness of different interventions as demonstrated by research or pilot programmes is one thing. Such interventions may require adaptation in other contexts.

The socioeconomic realities of low-income regions make it essential that palliative care programmes should deliver acceptable and affordable services to patients and families. It is impossible to expect the great majority of the population to pay or even to be able to travel to areas where the care is delivered. Difficult geography and lack of facilities and resources for transportation make the need for palliative care services in the community greater in the developing than in the developed world (Clemens et al., 2007).

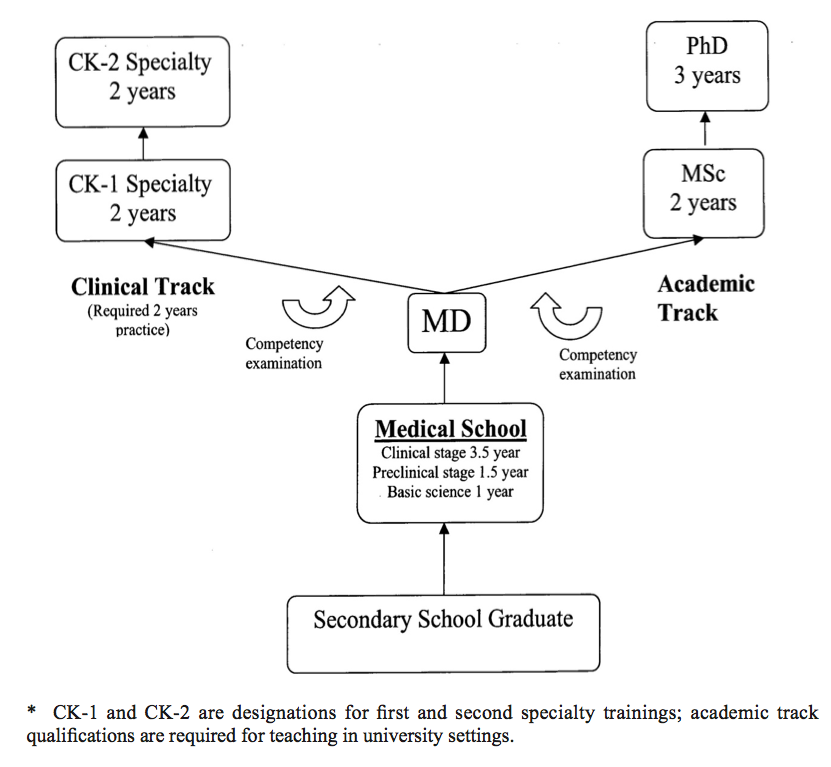
## 3.4 Palliative care education and development in Vietnam

### 3.4.1 Formal medical education in Vietnam

Formal education takes 6 years for a general medical doctor and 9 years for a specialised medical doctor, 5 years for a pharmacist, and 4 years for other professions. The healthcare sector still has a type of doctor training that takes 4 years, where assistant doctors with a certain number of working years have the opportunity to study 4 years further to become a qualified family doctor. These doctors often work at the grassroots level (MoH, 2006). Candidates are eligible to enter 6 years of medical school directly after high school. Medical training consists of traditional classroom teaching, followed by rotations within the hospital. Little time is spent in outpatient care. Two years of postgraduate training is required for the first-degree specialties, which include internal medicine, paediatrics, surgery, obstetrics and gynaecology, and recently, family medicine. Following this certification and 2 to 3 years of practice, a first-degree specialist may then be eligible for additional training as a second-degree specialist. This certification of advanced training is needed for a physician to become a subspecialist within his or her discipline **(Figure 3.2**).

At present, the MoH administers a network of 10,000 CHSs developed in the 1950s. Vietnamese general practitioners or family doctors graduate from medical school to enter directly into practice in the grassroots healthcare system. Upon entering practice, they have had no training in palliative medicine and in their workplace there are limited opportunities for organised CME or CPD (Krakauer et al., 2007).

In Vietnam, family doctors at CHSs make the initial assessment, order simple investigations, and decide whether or not to refer the patient to a district hospital for further sophisticated investigations and specialist care. This includes specialist advice and diagnostic services such as x-ray, bacteriology, and biochemical tests. In many areas, there is low utilisation of the primary healthcare teams, probably due to the population’s lack of confidence in those teams. The result for the healthcare system is increasing numbers of expensive and often mismanaged patient self-referrals to a limited supply of specialists in urban areas (Montegut et al., 2004)



**Figure 3.2** Training Pathways in Medical Education in Vietnam (Montegut et al., 2007).

Palliative medicine is not currently included in the undergraduate curriculum in medical schools and it also has not been accredited as a medical subspecialty. It is sometimes combined in lectures at post-graduate level in the specialist training of related medical specialties, or as part of a short training course for family doctors and oncologists after graduation. It is expected to be recognised as a subspecialty at the HCMC (Ho Chi Minh City) School of Medicine in 2013.

In many countries, the provision of CME is mandated by professional or regulatory bodies or is promoted by incentives (Peck, 2000), which contribute greatly to the increase in these activities. In Vietnam, however, CME or CPD is not considered mandatory for all health professionals in all areas of medical practice (MoH, 2006).

### 3.4.2 Palliative care – a young subspecialty in Vietnam ­– education and practice

Many experts from the USA, Australia and Singapore have visited and taught palliative care in Vietnam since the mid-1990s (Goh & Shaw, 2007). The first palliative care unit was launched in the National Cancer Hospital in Hanoi (the capital city) in 2001. This 35-bed unit was considered as an official recognition of the importance of palliative care in Vietnam (Krakauer et al., 2007). From this time onwards, many smaller palliative care units have been established in tertiary hospitals in large cities of Vietnam such as Hanoi, Ho Chi Minh City (formerly Saigon), Hue (Centre of Vietnam) and so on. These units are often integrated into cancer hospitals and provide mainly inpatient services.

In the past two decades, non-profit groups and international organisations have begun introducing palliative care to Vietnam. In 2002, Dr. Erick Krakauer received funding from the U.S. Centre for Disease Control and Prevention to come to Vietnam to teach HIV–AIDS treatment and palliative care to Vietnam’s nurses and doctors. Krakauer’s efforts to promote palliative care in Vietnam were greatly strengthened when Vietnam became the 15th country to receive PEPFAR[[6]](#footnote-6) funding in 2004 (Crane, 2012). At the request of Vietnam’s MoH, a palliative care working group was convened in 2005. This was chaired by the Director of the Ministry’s Therapy Department and included PEPFAR officials, physicians from Vietnam’s national cancer and infectious disease hospitals, and experts in palliative care, community-based care, and health care policy (Krakauer et al., 2007). Through funding palliative care initiatives and helping the establishment of a national palliative care strategy as well as the creation of the National Guidelines for Palliative Care, the PEPFAR has made the most significant recent contribution to palliative care education in Vietnam (Hunt, 2007; Krakauer et al., 2007).

As a result of those developments, Krakauer began to collaborate further with Vietnam’s MoH to produce the National Palliative Care Strategy (**Section 3.4.3**). The NGPC was issued in 2006. Krakauer’s training programmes, funded by the Harvard University, has helped train hundreds of physicians in palliative care, and palliative care training recently became a required part of training at the HCMC Cancer Hospital.

The first home care programme for patients with advanced cancer was launched in HCMC in 2011, with some positive results (HMS CPC, 2013). This is an important initiative because home-based care is the most common mode of delivery of palliative care for patients with advanced cancer in developed countries. However, in Vietnam, these patients are often looked after by family carers, in common with other resource-poor countries (Hunt, 2007). As discussed above, there are some palliative care units in hospitals in large cities; however, there is still a lack of community programmes providing home care.

The main issues affecting palliative care development in Vietnam are the lack of palliative care education for healthcare professionals, the lack of drug availability such as opioids, and cultural and ethical sensibility. These sensibilities include strong taboos around talking about death and cancer as well as *‘opiophobia’* from both healthcare professionals and patients (Krakauer, 2007; Viet et al., 2007). Pervasive misunderstandings and fears of opioids have deep roots in Vietnamese history. Crane (2010) found that in countries where opium dependency was part of colonial control, such as China and Vietnam, resistance to opiates could be quite strong. The battle against the fear of opioids has involved many strategies. First, training in pain relief and palliative care have been scaled up to reach all national and provincial healthcare leaders and many more clinicians. Second, many national and provincial campaigns for pain relief on television and in other mass media have been performed to educate the public about opioids and about palliative care as a human right. Finally, the MoH has worked with domestic pharmaceutical companies to scale up local production of oral and parenteral morphine and import essential medications which cannot be domestically produced in order to meet the rising demand for opioids (Krakauer et al., 2010).

### 3.4.3 Driving forces in palliative care education and practice

In the initial stages, funding for most palliative care programmes was derived mainly from overseas foundations. As services became more established, they began to attract government funding, in particular when the government realised that home care, and, to a lesser extent, outpatient services could result in savings in healthcare costs through reducing hospital length and investigations.

The Asia Pacific Hospice Palliative Care Network (APHN), a regional network of organisations and individuals working in palliative care in the region, was established in 2001 and now has more than 860 members in 28 countries. Since 2005, APHN has supported a three-year Training of Trainers programme in palliative care consisting of two sessions per year providing one-week intensive didactic lectures and bedside training (Goh & Shaw, 2007).

With respect to palliative care training and certification, extensive nationwide training in palliative care is being planned. In spring 2007, the MoH and National Institute for Infectious and Tropical Disease held palliative care *‘train-the-trainers’* conferences for physician-leaders in HIV/AIDS and cancer in partnership with the National Cancer Institute and palliative care experts from the the Harvard Medical School Center for Palliative Care. All participants were trained not only to provide palliative care following the new national guidelines but also to use the Vietnamese curriculum to train others in their home institutions and provinces. The curriculum was designed in the format of a concise clinical manual (Krakauer, 2010).

Three training curricula in palliative medicine were developed with assistance from the Harvard Medical School Center for Palliative Care (HMS CPC). The one-week basic curriculum has been used to train more than 400 Vietnamese oncologists, HIV physicians, and general doctors, 100 of whom also completed the two-day advanced and refresher course after that (HMS CPC, 2013). In 2008, The MoH launched three-month, full-time fellowship programmes in palliative care to begin training specialists in the field for both nurses and physicians. This Fellowship and Certification Program in Palliative Medicine provided intensive training in palliative care leading to nationally recognised certification in palliative care (Krakauer, 2010). In addition, the MoH organised two-day workshops on the NGPC and Regulations of Opioids Prescribing (ROP) for more than 1,000 health care managers, pharmacists, and physicians across the country. The four Vietnamese palliative medicine fellows who received advanced training at the San Diego Institute of Palliative Medicine have been mentored to gradually assume responsibility for teaching the three curricula. In addition, the National Curriculum in Palliative Medicine has been compiled by the MoH, and will be introduced in all medical schools in Vietnam.

In August 2005, the MoH appointed a Project Committee on the Development of National Guidelines for Palliative Care (NGPC). Funding and technical assistance for developing the guidelines was provided by PEPFAR. Care was taken to ensure that the guidelines were relevant to local needs and culture and consistent with current or expected medication availability. The NGPC were then issued in September 2006 (Xuyen, 2006). The Guidelines consist of chapters about basic medical and ethical principles of palliative care including practical approaches to, and treatments for both AIDS and cancer patients, in medical facilities or at home; palliative care for cancer patients who are receiving radiation therapy, chemotherapy or cancer surgery; pediatric palliative care; psychosocial support; and finally, care for the actively dying patient and bereavement counselling. The largest chapter covers pain and other symptoms. The WHO’s three-step pain ladder is also included. Proper dosing and possible side effects of non-opioids, opioids, and adjuvant analgesics are presented in table format.

In terms of the national opioid policies, Vietnam’s MoH recognised the need to increase the availability of oral and parenteral morphine to treat pain and of methadone for substitution therapy for patients with a history of opioid dependence or misuse. In summer 2006, all laws and regulations relevant to opioid availability were reviewed carefully and ways to increase opioid availability for medical use while minimising the risk of diversion were sought with financial and technical support from the Pain and Policies Group (Carbone Cancer Center, University of Wisconsin, USA). Revisions aimed at achieving a coherent national opioid policy safely and responsibly, and improving opioid availability. The Workshop on Opioid Policy was held in 2007 in Hanoi with representatives from the relevant ministries, the United Nations Office of Drugs and Crime, and the WHO. One year later, the MoH issued Regulations of Opioid Prescribing (ROP) that reflect international standards (Krakauer, 2010).

The national strategy for palliative care in Vietnam is to integrate palliative care into the mainstream primary healthcare system (NGPC, 2006). The WHO’s public health strategy for national palliative care programme development was adopted. In Vietnam, the *‘top-down’* model of healthcare service structure makes it possible for the Vietnam’s MoH to easily extend its new policies to lower levels such as CHSs, DGHs or PGHs. In addition, a majority of professional education and training for healthcare staff is often provided by experts within the MoH or other statutory bodies. Therefore, the MoH needs to develop educational plans that fit the workforce’s educational needs and availability.

### 3.4.4 Challenges in palliative care education and training in Vietnam

Although there are national policies and some resources for palliative care provided by the MoH, the implementation and progress of the training programmes in palliative care to local healthcare teams has been still low in Vietnam. Several causes have been identified in similar countries. According to Bruera and Sweeney (2002), important issues related to palliative care in developing countries include poverty, insufficient knowledge of healthcare professionals,  patients and families receiving inadequate information about diagnosis or prognosis, drug scarcities and lack of models for delivery of palliative care. In addition, it has been observed that the most significant barrier in the development of training programmes is an inflexible, hierarchical, organisational structure with limited input from the grassroots levels of the healthcare system (Clemens et al., 2007).

Another challenge for the development of palliative care in some countries of the ASEAN (including Vietnam), as Goh and Shaw (2007) mention, is a language barrier. It is because most nurses, or even family doctors in the region are not fluent in spoken and/or written English. Unfortunately, most of the specialised textbooks and journals available are presented in this language. The solution for this issue is, therefore, the translations of foreign guidelines or texts into local languages, for example Vietnamese.

Despite a rapid development of palliative care in recent years, Vietnam does not yet have a long-term strategy. Such a strategy is necessary to encourage the scaling-up of sustainable palliative care education and integration throughout the healthcare system, in particular at the primary level in the community. In addition, there also is not yet a national palliative care organisation that could provide continuing education for its members as well as promoting palliative care research.

Finally, according to Krakauer and colleagues (2010), a lack of collaboration among international financial and technical supporters has detracted from some parts of Vietnam’s palliative care initiatives.

### 3.4.5 Approaches to palliative care education in Camau

Most people with advanced cancer in Camau have had some contact with local health professionals during the course of their disease. Therefore, all health professionals should have some education in palliative care. Clearly, the responsibility to develop and deliver palliative care education and training lies with specialists such as ourselves who are working at a teaching hospital as the Camau PGH. Indeed, under sponsorship from the National Cancer Control Programmes, the C4 has developed a long-term strategy for disseminating palliative care training to all primary care professionals, in particular family doctors and nurses working at CHSs across the province. In my view, the most pressing issues are how to start and sustain palliative care services, how to make essential drugs available, and how to find funding to organise classes in remote areas.

Training courses normally last two to five days at tertiary institutions in large cities such as HCMC or Hanoi, and provide a good basis for the practice of palliative care in the workplace. However, many healthcare professionals who participate in do not have the same academic background, and so cannot benefit fully from these courses. The content of these courses might also not be optimal for this diverse group of participants. Furthermore, different regions may have different educational needs.

Fortunately, to date, Camau has a number of trained palliative care trainers and clinicians. The next five-year plan of C4 is to continue educational workshops and support programmes in palliative care to local family doctors. The palliative care training curricula developed by the MoH will be delivered to other local healthcare staff such as assistant doctors (similar to nurse practitioners) and nurses. A palliative care clinical and training unit could be established at the PGH. This unit could provide clinical training in palliative care for some clinicians and family doctors from the province. In addition, it may foster research in the field.

## 3.5 Summary

The current Vietnam healthcare system has been built and developed, with accompanying social and economic policies, during the length of its contemporary history. Four levels and the function of each level were described. The government policies regarding healthcare, particularly palliative care, were also included. The official medical education programme and the lack of palliative medicine content in the programme were presented as a gap, which needs to be filled by CME or CPD activities for qualified health professionals. Facilitators and challenges for deploying palliative care at the provincial level were considered. These factors played an important role for the C4 choosing a suitable educational model for the integration of palliative care in the provincial healthcare system, in particular at community level. In the next chapter, I shall present rationales for adopting the mixed methods approach for evaluating the impact of current educational intervention and support programme in palliative care to rural family doctors in Camau province.

# Chapter 4 – Methodology: A Mixed Methods Approach for An Evaluation Research Study

## 4.1 Overview

Previous chapters have identified the need for this evaluation research study and presented the research questions, which need to be answered in the next chapters. I have attempted to set the study within the context of social medicine, the field of CME or CPD for healthcare professionals, palliative care and evaluation research.

This chapter will focus on the methodological theoretical framework and the development of the study design. The theoretical underpinnings of research design, and relevant methodological theory were used to inform the methods and design of this study. In designing any research study the most important issue for researchers is that the research strategy and methods used are appropriate to answer the research question (DePoy & Gitlin, 1998; Kelly & Stone, 2007; Robbins, 1998). This statement is also applicable to the design of an evaluation research study in that the chosen methods must be appropriate in order to generate answers to the evaluation questions asked. In this study, the aims are to evaluate the impact of an educational intervention in palliative care to rural family doctors and their advanced cancer patients.

Evaluation is a key component of health services research. It aims to describe and record change and what has led to change, establish whether there are linkages between theory and practice, generate new knowledge and/or enable application of knowledge to other contexts (Ingleton & Davis, 2007; McKinley& McBain, 2007). Cronbach (1982) states that *‘evaluation is an art’* and *‘there is no single best plan for an evaluation, not even for an inquiry into a particular programme, at a particular time, with a particular budge*t.’(Cronbach, 1982; cited in Robbins, 1998). Robbins continued *‘there is little room for methodological dogmatism in the field of evaluation.’*

The choice of an appropriate study design will depend on what is already known about the particular question to be investigated. With the recent emphasis on evidence-based medicine, there has been much debate within the field of palliative care research on the need for RCTs and whether the RCT is the *‘gold standard’* and the most robust method for evaluating new treatments (Bennett, 2007). The RCT is considered as the most robust method due to features including a strict process of randomisation, the use of control groups, and blinding of participants and researchers (Bennett, 2007).

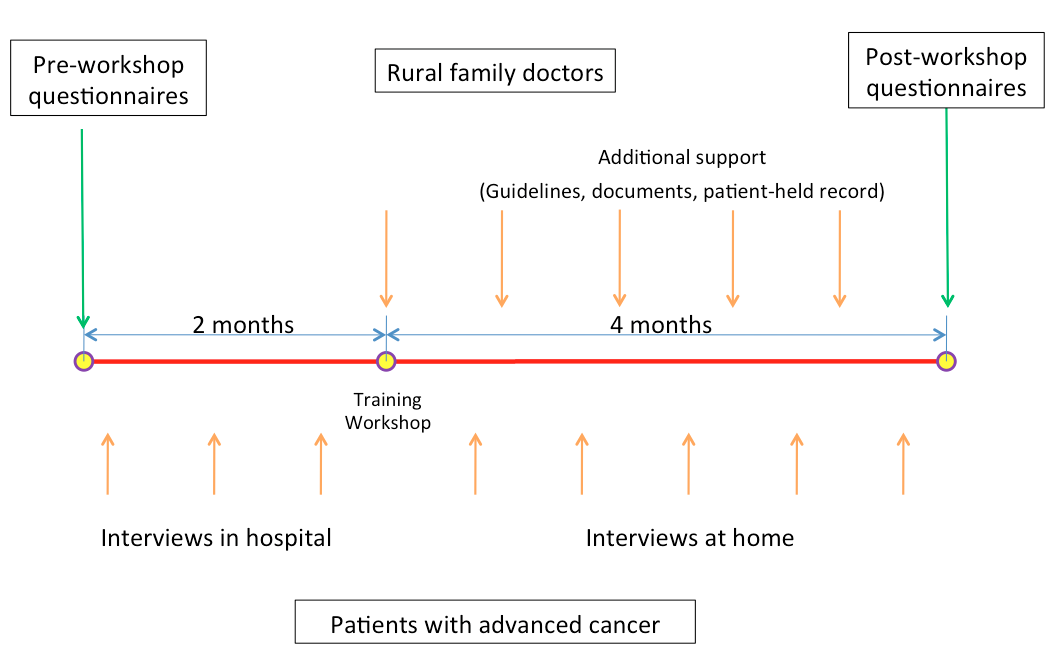
However, in palliative care research RCTs are usually concerned with interventions for controlling the symptoms of advanced diseases such as pain, fatigue, nausea, breathlessness and psychological distress (Bennett, 2007). An RCT is a test to explain the causal relationship between two or more variables, for example, if giving a certain drug to nauseated patients cause patient symptoms to improve greatly. In addition, many research questions do not need to be answered in an experimental study (Courtens, 2001; Depoy & Gitlin, 1998). All research seeks to address one or more specific research questions or hypotheses. Quantitative research in general, RCTs in particular, normally deals with ‘ how many/much or how often’ questions. However, if the research questions begin with the words‘what, who, when, why and how’then qualitative methods of enquiry may be appropriate (Payne, 2007; Pope & Mays, 1993).

Next, many strict requirements regarding controls, randomisations, blinding and, often, long-term research processes required in order to make an experiment valid are usually not met in a palliative care research design (Grande & Todd, 2000). First, RCTs in palliative care research can be especially challenging given that patients are often characterised by old age, multi-system disease, and generally severe illness with many symptoms, a progressive clinical condition, and limited survival time (Hanks et al., 2010). These features make it particularly difficult to perform prospective randomised controlled studies to perform, because there are major problems such as attrition and missing data from this population which may impact on the interpretations of trial results (McWhinney et al., 1994). Second, with respect to form control groups, allocating vulnerable patients to less than optimal care is often contentious. This is because there is reason to prefer one treatment to another; patients assigned to some group are at disadvantage (Reyna et al., 2007). Third, patients may have difficulty in completing standardised questionnaires; therefore investigators sometimes rely on assessment by carers, proxy or retrospective accounts to collect sufficient data (Grande & Todd, 2000). However, these informal views do not necessarily reflex those of patients (Reyna et al., 2007). Finally, when attempting to design a randomised study, a lack of sufficient descriptive data may make it difficult to decide upon a study design, on a valid sample size calculation or on projecting appropriate outcomes (Bennett, 2007). Taken together, it may be well recognised that RCTs are not frequently applied for studies in the context of palliative care.

In the field of palliative care research, a wide range of research methods have been used, some of which may offer more value than others. There is a general agreement that experimental methods have been harder to apply at the service level (Costantini & Higginson, 2007). However, cross-sectional, retrospective surveys of satisfaction have been found to be useful for service planning (Robbins, 1998). It has also been suggested that important requirements for a palliative care evaluation are *‘setting appropriate outcome indicators, adopting appropriate research design and making feasible comparisons’*. Ingleton & Davies (2007) argue that quantitative research methods provide only superficial information and may fail to take account of the variability in response to a programme or intervention. In addition, they continue, qualitative methods, which incorporate the views of different stakeholders, give a more comprehensive picture.

All suggested approaches to evaluation research have strengths and limitations. The most appropriate research design to be used in an evaluation will depend on the research question being asked. The approach generating the answer then will be determined by the particular focus of the evaluation, the financial and personnel resources available; and the main interests of those involved (Ingleton & Davies, 2007; Robbins, 1998).

## 4.2 Study design



**Figure 4.1** Study design.

A Gantt diagram illustrating key milestones of the research process is presented in ***Appendix 5 – Key Milestones of the Research Process.***

This study has a mixed methods design. The quantitative component was a pre-test and post-test survey design; and the qualitative component was a series of semi-structured interviews. **Figure 4.1** presents the research design, which reflected my approach to answer the research questions.

As discussed in **Chapter 2**, Buckley (2011), Calman (2010) and Taylor (2004) suggested a hierarchy for evaluating the outcomes of an educational intervention. This hierarchy consists of 4 levels: learner reactions, changes in knowledge and attitudes, changes in behaviour, and benefits to clients or patients. They provide a simple model, which relates to the levels of evaluation. It was chosen as a starting point because of its simplicity. This model does not take into account the context of the study, what sort of data is collected or the role of other stakeholders. Nevertheless, using that ladder as a template enabled some clarification as to where to start in designing this evaluation research study. For example, one purpose of the study was to find out whether differences in terms of experiences and perspectives on palliative care services exist between patients with advanced cancer in the inpatient PCU, and their counterparts who were palliated by a trained family doctor. This then favoured the qualitative approach because the qualitative research is more appropriate to deal with research questions relating to people experiences and views (Payne, 2007). Moreover, the lack of existing information on this patient population of the province made it impossible for us to apply a quantitative research. Alternatively, with the question how effective in terms of improvements in knowledge, confidence and professional practice of rural family doctors after participating the workshop, a pre-test and post-test design was employed after taking into account local resources, research experience and allocated time frame.

The issues of who the research participants were, how they were selected for this study (including informed consent), and how ethical issues regarding to confidentiality and anonymity were achieved will be described in detail in **Chapter 5** and **Chapter 6**.

### 4.2.1 A mixed methods approach for evaluation research

#### 4.2.1.1 Definition of mixed methods research

In this section I shall present how the mixed methods approach was employed to evaluate our intervention and explain the rationale behind this choice. Recently, social medicine and healthcare researchers have tended to employ a multi-method approach, for instance a combination of qualitative and quantitative research into a study in order to deal with complex research questions (Craig et al., 2008; Ingleton & Davies, 2007; NICE, 2004; Taylor, 2004). It is clear that the approach provides them with multiple perspectives to contribute to an overall picture.

This approach, or ‘*the mixed methods approach’* as it is termed in recent publications, often combines quantitative and qualitative methods into a project (Creswell & Clark, 2011; O’Cathain et al., 2007; Teddlie & Tashakkori, 2009). Tashakkori and Creswell (2007) define mixed methods as follows:

‘Research in which the investigator collects and analyses the data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry.’ *(p.4)*

The needs of patients and the interventions required to address them are complex. Therefore, additional qualitative approaches such as the combination between quantitative and qualitative ones should be considered (Grande & Ingleton, 2007; NICE, 2004). Each method may capture something that may not be captured by the other (Ingleton & Davies, 2007). Qualitative approaches are valuable in capturing patient experiences, their illness journey as well as their contexts (Payne, 2007), while quantitative ones are valuable in exploring the prevalence, trends and relationships amongst factors or patterns. It is essential for palliative care researchers to understand the contribution of each method and combine research skills and perspectives to answer effectively research questions posed (Grande & Ingleton, 2007).

In their introduction to qualitative methods in health and health service research, Pope and Mays (1993) point out that *‘Methodological pluralism is vital in an applied subject like health services research’.* Furthermore, the 2008 Guidelines of Medical Research Council (MRC) in the UK (Craig et al., 2008) recognised a number of limitations of the previous version, published in 2000. One of the limitations is a lack of attention to the social, political or geographical context in which interventions take place. Mixed methods inquiry as a new research paradigm has been advocated by the MRC (Craig et al., 2008) and NICE (2004) to address the limitations recognised by the MRC. The MRC in the UK have now issued guidelines for conducting rigorous multi-method investigations. These guidelines recommended that investigators should be specific about how their methods will be combined and how the findings will be integrated.

#### 4.2.1.2 Components of mixed methods research

There are three essential components of a mixed methods study. They include quantitative data, qualitative data and a method for interpreting and integrating two types of data together to draw final conclusions. Greene (2007) suggests that both components also may be treated equally (the methods are intended to be of relatively equal weight in a research study) or prioritised on one. However, it is common in a mixed methods approach that there is a ‘dominant-less dominant design.’ It means one paradigm and its methods are dominant, while a smaller component of the overall study is drawn from an alternative design (Creswell & Clark, 2011; Kristjanson & Coyle, 2005). The research questions of this study are complex and multifaceted because they were relevant to multi-level evaluations of an educational intervention on participant doctors, and to a lesser extent, patient satisfaction. As a result, a complementarity mixed methods study could be appropriate for the study since the findings from patient interviews would serve to enhance the inferences and interpretations from the doctor surveys. Together, two sets of data provide a more comprehensive and complete account of both intended and unintended outcomes of the intervention.

Different methods tend to use different types of instruments for data collection. For example, experiments typically use some kind of devices or facilities, surveys use questionnaires, and case studies frequently use field protocols or unstructured interviews. Mixed methods research use both quantitative and qualitative instruments. Although there are differences, various instruments could contain similar variables. The more these variables overlap or complement each other; the more the mixed methods can be part of a single study. Conversely, greater divergence can lead to multiple studies (Yin, 2006).

#### 4.2.1.3 Rigour of mixed methods research

Five criteria to be considered when evaluating the rigour of a mixed methods research study, according to Creswell and colleagues (2004) are:

1. Identifying the reasons for mixing quantitative and qualitative data.
2. The types of data collected and analysed.
3. The priority given to quantitative or qualitative research in a given study.
4. The implementation sequence (concurrent or sequential).
5. The phase of research in which the integration or relationship between quantitative and qualitative data collection and analysis occurred.

Teddlie and Tashakkori (2009) argue that a study becomes more rigorous when a rationale for mixing methods is presented. They identify 3 various categories of reasons for conducting mixed methods research: personal, societal and reasons associated with advancing knowledge. These reasons then lead to develop research objectives followed by the development of research question(s) and hypotheses. Alternatively, the typology of Greene and colleagues (2007) suggests five options for determining the purpose for mixing approaches. They are triangulation, complementarity, development, expansion and initiation. According to Creswell and colleagues (2004), the quantitative outlier or extreme results can be better understood through qualitative data collection. Quantitative results might also help researchers select qualitative cases so they can examine the results in greater depth (Greene, 2008).

The rigour of a mixed methods study is also determined by the priority given to its quantitative or qualitative component. This priority is determined by the researchers, who place an emphasis on quantitative data, qualitative data, or an equal priority shared between the two forms of data (Creswell et al., 2004). Such priority is detected at the beginning of the study by noting the relative emphasis given to frame the research problem (for example, intent to test a theory, study variables, or explore constructs) or the subservient use of one form of data to the other (for example, qualitative data helps to build an instrument). Alternatively, in some studies, investigators might give equal emphasis and status by providing both detailed quantitative and qualitative data collection and data analysis.

The concurrent or sequential implementation sequence plays another role in assessing the reliability of a mixed methods study. This concerns the sequence or order in which the qualitative and quantitative data are used. The sequence refers to whether the quantitative and qualitative data are collected and analysed sequentially or concurrently (Creswell et al., 2004). A mixed methods approach involves the use of qualitative and quantitative analytical techniques that are implemented either concurrently (at the same time or in a relatively close time frame) or sequentially (one form is conducted first and it informs the other type). Interpretations then may be made in a parallel or an integrative manner (Onwuegbuzie & Collin, 2007).

The integration phase refers to the point of research process in which the integration or relationship between quantitative and qualitative data collection and analysis occurred (Teddlie & Tashakkori, 2009). There are two stages in the process where integration is possible: when data analysis leads to further data collection decisions, and when results are reported. According to Creswell and colleagues (2004), the issue of integrated stage in the research process illustrates the complexity of mixed methods research and the need to be explicit about the model of inquiry being used.

#### 4.2.1.4 Mixed methods for evaluation research

According to Robbins (1998), evaluation is a form of applied research, which is designed to answer questions about the impact of programmes, services or policies. Although a wide range of models and methods have been identified in the literature of evaluation research in palliative care, there is general agreement that the combination of quantitative and qualitative methods in a study produces the most comprehensive picture of the effects of an intervention or service (Ingleton & Davies, 2007; Pope & Mays, 1995; Robbins, 1998). This is because it draws on the strengths of different methods and counterbalances their respective weakness. Ingleton & Davies (2007) argued:

‘ Given the complex nature of palliative care . . . a systematic evaluation of either the effectiveness of palliative care interventions or the quality of care delivery often requires the use of both quantitative and qualitative methods of data collection and analysis.*’(p.191)*

In the field of palliative care education, according to Taylor (2004), goal-oriented and responsive approaches to evaluation are most commonly used. The former aims to investigate the success of a programme or an intervention in terms of meeting specific goals and objectives that have been set. The latter attempts to understand an issue from as many different viewpoints as possible using naturalistic methods, which are mainly observation and interviewing.

#### 4.2.1.5 Reflections of mixed methods principles on the study

This evaluation research followed the tradition of social medicine in emphasising the social context of illness and health, and in which the mixed methods approach is more likely to be most appropriate. This is because, according to Greene (2007), the core meaning of mixed methods in social inquiry involves a plurality of philosophical paradigms, theoretical assumptions, methodological traditions, data collection and analysis techniques as well as personalised understandings to examine the research phenomena. In my study, the evaluations were conducted to explore more in-depth contextual factors from the different viewpoints of those who were related to the current project. These people were mainly rural family doctors and advanced cancer patients with palliative care needs. As discussed in the introduction chapter, both types of data from the surveys with family doctors and semi-structured interviews with advanced cancer patients were important to my study aim because these data help to assess various dimensions of the research question. The rationale for mixing two approaches is that qualitative data would help support statistical results from doctor surveys. Gathering both forms of data may contribute to a comprehensive and complete understanding of the results.

The survey data of this study were collected by structured instruments. They are self-completed questionnaires built on existing measurement tools with several more open-ended questions. The qualitative data were collected using semi-structured interviews with patients. The qualitative data were analysed using thematic analysis and grouped into codes, themes, and categories. Adherence to these collection methods enables me to collect strategically multiple forms of evidence, such that the combination of methods presents convergent and divergent evidence, subsequently strengthening the findings of the mixed methods study.

The first step in our research design process was to select a principal data collection method which is a pre- and post-workshop survey design with self-complete questionnaires. This method is recognised having strengths in terms of fulfilling the evaluation project’s goals (Abu-Saad & Gitline, 2003, Costantini & Higginson, 2007). The next step was to choose a complementary qualitative method, which offered a set of additional strengths to the overall ability of research design in order to meet the project’s objectives.

In this approach, because of the use of parallel mixed methods design, quantitative and qualitative data were collected at nearly the same time and were brought together in the results and interpretation of the results. During the process of parallel sampling, the quantitative sampling technique was used to. In addition, given time limitations of joint location research regarding both palliative and primary care, this approach was more practical than a sequential approach because this enabled me to collect multiple forms of data at one period of time.

### 4.2.2 Quantitative component of the mixed methods: a research survey

A one-group pretest-posttest design was used. This design was chosen in order to answer the question of whether an educational intervention could bring any improvement in family doctors’ knowledge, confidence, attitudes and behaviour in palliative care. The approach included a pre-workshop survey two months before the main intervention (which is the palliative care workshop) and a post-workshop survey four months after the workshop.

A descriptive survey is an appropriate design to explore the frequency or prevalence of particular attributes and the relationships between them in a population (Addington-Hall, 2007a; Floyd & Fowler, 1995; Oppenheim, 2001). The scope of survey exploration includes attributes, knowledge, attitudes, views, beliefs and behaviours of a population at a given time point (Addington-Hall, 2007a). My research question was concerned with personal and professional attributes, knowledge, belief and behaviour of rural family doctors therefore using surveys with questionnaires is the way to answer this type of question (McColl et al., 2001; Boynton & Greenhalgh, 2004). By classifying, counting and scoring doctors’ answers to pre-test and post-test surveys, meaningful numbers and characteristics of the respondents can be produced (Burns et al., 2008). According to Addington-Hall (2007a), surveys may be considered as a research model in which they *‘ ask people questions, and then present and analyse responses quantitatively, using statistics’* (p. 45).

There are three key components that a researcher should pay attention to when conducting a survey. These are (1) the development of questions (questionnaire design), (2) the selection of those to whom the questionnaire will be administered (sampling), and (3) the choice of the most appropriate way for gathering data (data collection method) (Addington-Hall, 2007a; Boynton & Greenhalgh, 2004; Burns et al., 2008; Floyd & Fowler, 1995; Oppenheim, 2001). Addington-Hall (2007a) argues further that surveys are

‘Not simply to describe the views of the people who complete the questionnaire, but rather to draw valid, reliable and unbiased conclusions about the population from which these people are drawn.’ (p.46)

The first step of good survey research is to produce the right questionnaire in terms of making decisions on what is to be measured in the survey, whether the questions mean the same to every participant or create confusion, how consideration must be given to sensitive or threatening topics are presented to participants, and what constitutes an right answer (Addington-Hall, 2007b; Boynton, 2004). Attention should be paid in designing good questions for a survey instrument in terms of reliability and validity. Addington-Hall, (2007b) explained that being reliable means that two participants in the same situation will answer the question in the same way, and being valid means that the instrument *‘measures what it is intended to measure.’* (p.73). The development of the questionnaire in this study will be presented in the next chapter relating to pre- and post workshop surveys with family doctors.

A wide range of sampling strategies can be used in survey research. These are systematic or complete (Addington-Hall, 2007a), statistical probability and non-probability sampling procedures (Addington-Hall, 2007a; Burns et al., 2008; Floyd & Fowler, 1995; Oppenheim, 2001). A systematic sampling is a sampling procedure in which the sample includes all members of the research population. In probability sampling procedures, the data collection is normally drawn from a defined population based on statistical probability theory in order to obtain comparability across the whole sample, and then the results are summarised and analysed statistically (Oppenheim, 2001). Non-probability sampling procedures include ‘quota’ and ‘snowballing’ sampling. In quota sampling, researchers target a specific number of respondents with particular qualities, for example women aged less than 50 and having children under the age of 10. Snowballing sampling is particular useful in approaching members of hard-to-reach populations (Addington-Hall, 2007a), as these individuals in turn help to identify other potential respondents meeting the same criteria (Burns et al., 2008). In this study, systematic or population sampling was used to reach all rural family doctors working at CHSs across the province. Therefore, the likelihood of systematic differences between the respondent doctors and the population of rural family doctors in the province would be inconsiderable if the response rate was sufficiently high.

In addition to sampling procedure, another factor that may affect the ability to draw inferences accurately from the sample to the population is the response rate. Non-respondents may differ from the respondents in ways that are relevant to the survey objectives. If this is the case, non-response errors are more likely to be introduced into the survey (Addington-Hall, 2007a). There is general agreement that a response rate of 70 percent or higher is deemed to be adequate for drawing acceptable inferences; thus non-response bias in this case might be considered as negligible or insignificant. However, the response rate should be as high as possible (Floyd & Fowler, 1995; Oppenheim, 2001). If it is lower than 50 percent, the response rate is probably unacceptable and not representative of the population because the respondents in such surveys are usually self-selected. In this case, the ability to make accurate inferences will be severely compromised; but the association amongst variables may still be examined in order to generate hypotheses (Addington-Hall, 2007a).

The third fundamental component of any survey is methods of data collection. These can include a personal or telephone interview or a self-complete questionnaire, which may be sent to the respondent by post or e-mail or accessed over the Internet (Oppenheim, 2001). Each method has strengths and weaknesses. The choice of appropriate data collection method plays an important role in the success or failure of a survey. Many factors may affect the choice of data collection methods such as the population characteristics, the study topic, and the data complexity as well as the availability of financial and staffing resources (Addington-Hall, 2007b). In comparison with personal and telephone interviews, Addington-Hall (2007b) noted that surveys with postal questionnaires are less expensive and require fewer staff and facilities. In addition, they are easier to administered when sampling populations in which the respondents are widely geographically dispersed. In terms of the respondents, they could read and re-read the questions, look up necessary information for the answers, respond in a more comprehensive way, and feel less hesitant about personal or sensitive questions provided the questionnaires are designed on an anonymous basis. However, the absence of an interviewer to clarify questions, the difficulties of obtaining an accurate address list, and higher levels of missing data are considered as the drawbacks of this method.

In this study, the postal self-completed questionnaire method was chosen for collecting data from rural family doctors for several reasons. First, the anonymous nature of the study prevented it from conducting interviews with the participants. Second, the workplace of doctor participants spread widely across the province, therefore, mailed surveys are the suitable choice in terms of convenience as well as financial and personnel resources. Finally, some questions concerning professional or organisational characteristics may need time to find the exact answers.

Many tactics are used in order to obtain a high response rate from postal questionnaires. A systematic review on ways of improving the response rate concluded that using a monetary incentive more than doubled the number of questionnaires being returned, though the increase of response rates was not proportional with that of the amount of money (Edwards, 2002). Using non-monetary incentives, for example a pen with the questionnaire, may also increase the response rate (Sharp et al., 2006). A user-friendly design or number of words in the questionnaire may have some impact on the rate of response. A shorter questionnaire probably results in a higher response rate (Nakash et al., 2006). Moreover, coloured ink on possibly coloured paper might be used to obtain a high response rate (Edwards et al., 2002). With respect to submitting questionnaires, recorded delivery should be used rather than standard post. In addition, stamped return envelopes for returning questionnaires should be included. These strategies may double the response rate, as Edwards and colleagues (2002) realised. Using reminder letters enclosing a questionnaire and/or telephone reminders also make it possible for researchers to increase the number of questionnaires returned (Nakash et al., 2006). However, the effectiveness of these tactics varied significantly among published studies (Addington-Hall, 2007a). Several tactics used for this study will be presented in the survey research chapter.

There is general agreement that surveys are not able to establish causal relationships amongst examined variables (Addington-Hall, 2007a), however, longitudinal surveys or one-group pre-test and post-test design or before and after study, which follow the same population over time, are better able to analyse these relationships than cross-sectional surveys alone (Costantini & Higginson, 2007). This is because these approaches provide some information on the nature of the association between intervention and outcomes of interest although other factors, which happen at the same time, might contribute to the observed results. In this study, pre-workshop and post-workshop surveys were used with the same group of participant doctors. The findings from these surveys probably helped us assess the relationship between our intervention and the obtained outcomes. Arguments for this relationship will be presented in **Chapter 7**.

### 4.2.3 Qualitative component of the mixed methods

The qualitative component comprised semi-structured interviews with advanced cancer patients being cared for in hospital and in the community under the care received from trained family doctors in order to explore their experiences and perceptions of current palliative care services as well as their views on choice of place of care.

Payne (2007) states that interviews are a suitable method of eliciting data in the context of palliative care. This type of experiential qualitative research is best known in palliative care. It is based on assumptions that it is possible to make inferences about people’s experiences and personal understanding, how people think, feel and behave from their verbal accounts (Payne, 2007). Qualitative research is not a single method. It can be considered as a ‘*toolkit of methods’* consisting of a wide range of fundamental approaches that are based on the principles of epistemology (Clark, 1997; Payne, 2007).

During interviews, the task of the interviewer is to make sense of what is said, and how it is said by paying intense attention to the narrative and also to non-verbal communication. He or she also needs skills that encourage patients to feel comfortable, relaxed, and able to talk freely (Payne, 2007). Interview accounts reflect the way in which people tell and retell significant life stories. These stories are built on the experience of both patients and professionals in terms of previous clinical interviews, and patients are generally pleased at having the opportunity to talk with an attentive interviewer in a face-to-face situation (Payne, 2007). These stories can be viewed as a resource in which narratives may be a potent way to develop meaning. Interviews with patients may have a therapeutic effect in helping to soothe distress. In addition, research interviews may have an altruistic value as they may be seen as potentially helping future patients. In fact, they may be regarded as a way of making a new and positive contribution by patients who are facing the terminal stage of their disease.

The research question of this study about the differences and similarities amongst patients with advanced cancer in terms of experiences of palliative care services and perspectives on place of care existing between two settings (the PCU and in the community) was likely be answered appropriately by a qualitative approach. This is because, as Pope and Mays (1995) emphasised, the exploration of the meanings, experiences, and views of participants in a social setting are best elicited through qualitative research. In addition, the C4 (Camau Cancer Control Committee), which funded the project, and the Camau DoH – the health management body – want to know about patients’ views on palliative and primary care services in the province. The exploration of patients’ evaluations of their satisfaction and healthcare services in the project in Camau is more likely provide information about both the results of the current palliative care service and the mode of delivering that service. It is not possible to obtain this information without an understanding about people’s beliefs and expectations about health and illness.

I chose to interview patients with an advanced cancer stage in order to best explore their *‘lived world’* experience and meaning. I decided to conduct semi-structured interviews in an attempt to focus on the main issues. This format pre-determines to some extent the interview agenda, but also gives patients some freedom to present their views, and thus for the researcher to obtain insights. Participating in the interviews only requires the ability to talk and understand the questions, and may be less demanding for patients than completing a questionnaire or trying to write. Indeed, with patients who were very ill, short of breath or in severe pain, in particular those hospitalised, I tried to avoid over-lengthy sessions. Face-to-face interviews are likely to generate a higher response rate than other methods, and may result in less missing data than in questionnaires. As a clinical doctor, my daily work involves in listening to patients and their relatives’ stories. This makes it easier for me with the interview method, which relies on the development of rapport between the researcher and the interviewees. An interview guide was used in order to ensure that key areas were covered. The design and content of this guide will be presented in **Chapter 6**.

Qualitative research typically, although not exclusively, employs non-probability sampling techniques such as purposive sampling (Mays & Pope, 1995; Murphy et al., 1998). Purposive sampling is a procedure in which individuals are selected because they meet specific criteria (Burns et al., 2008), for example in this study they were advanced cancer patients with palliative care needs. This approach to sampling allows the researchers to include deliberately a wide range of types of informants and also to select key informants with access to important sources of knowledge (Mason, 2002). It is not usually intended that the findings of a particular study using purposive sampling will be generalisable rather than applied only to the specific population under investigation (Mays & Pope, 1995). Therefore the sample size is determined by a desire to investigate completely the chosen topic and provide fully information-rich data – the data saturation. The sampling process is complete when theoretical saturation is reached, and at that condition no new emergent themes or concepts are generated (Mason, 2002).

In this study, the size of interview sample was determined by purposive sampling and practical issues. The number of interviews needed to be sufficient to allow the saturation of patient data reached in both settings as well as a manageable number for me as a single researcher. Therefore, the sample was opportunistic, depending on recruitment, and purposive. The original research proposal which was submitted to the Research Review Committee (it belongs to the Camau DoH) for clearance proposed up to 10 interviews in each setting: the PCU in the PGH and at patients’ homes. Eventually, however, I was satisfied that the total 10 interviews in the hospital and 7 with patients at home provided rich data saturation and fulfilled the need of understanding the patients’ views.

Regarding data analysis, I chose the method of thematic analysis for capturing the themes, which emerged in the interview data in order to answer my research question. According to Boyatzis (1998), this method involves the identification of patterns of similarity in the text, which are relevant to the research question. There are 5 stages of the thematic framework analysis as follows:

1. Reading and re-reading transcripts for familiarisation.

2. Identifying recurring and important themes to develop a thematic framework

3. Coding or indexing each emergent theme into a label code

4. Charting by examining and lifting data from each transcript into themes.

5. Mapping as well as interpreting by striving to establish comprehensively the meanings, concepts and explanations of the data.

(Boyatzis, 1998; van Cleemput, 2011)

In fact, thematic analysis aims at identifying and grouping similar descriptive accounts across individuals (Payne, 2007). Coding of themes focused on the manifestation of content, for example *‘satisfaction with the care’* or may include identification of latent content such as coding segments of text making references to the fulfillment of the patient’s expectations even when the actual phrase is not included. This method is popular in qualitative palliative care research because, as Payne (2007) states, it appears to *‘capture the subtlety and complexity of qualitative data and present it in intuitively coherent accounts.’* (p.155)

After several first interviews, the large volume of data collected quickly overwhelmed me. I undertook all transcriptions myself. This process was very labour-intensive, but made it possible for me to become aware of the level of analysis and gave an insight into the ongoing work. I usually listened to the audio files and checked through all the transcriptions twice for errors and omissions. This is also in the line with the remarks of Payne (2007) in which the transformation of spoken language to written text should be regarded as the first stage in the interpretative process. I also received training in using the Nvivo software package. However, in my opinion, it was probably useful for indexing and managing data, but could not replace a deep engagement with the data through the process of coding and interpretation.

This study collected patient transcripts and survey data from family doctors. To prevent the study from breaking into two isolated studies, the interviews cover deliberately some of the same questions as those in the survey, for example about the ability and willingness of family doctors to provide palliative care. Similarly, the survey questions asked doctors about issues of applying new knowledge to their patients, for example mentions of an increased caseload or morphine prescription. In other words, this ensures each resulting data set could reach into the domain of the other in order to produce a single mixed methods study.

### 4.2.4 Data integration

Mixed methods investigations involve integrating quantitative and qualitative data collection and analysis in a single study or a programme of inquiry (Collins & O’Cathain, 2009; Ingleton & Davies, 2007; Mays & Pope, 1995; Teddlie &Tashakkori, 2009). Johnson and colleagues (2007) point out components that could be mixed or combined such as *‘quantitative and qualitative research techniques, methods, approaches, concepts, or language into a single study’* (p. 117). Mixed methods approach is more than simply collecting and analysing both quantitative and qualitative data. It indicates that data will be integrated, related, mixed or triangulated at some stage of the research process. The notion of integration or triangulation is that neither quantitative nor qualitative components are sufficient in themselves to achieve the more complete picture of the research situation (O’Cathain et al., 2010). When used in combination, both quantitative and qualitative data yield a more complete analysis, and they complement each other (Creswell et al., 2004).

Yin (2006) supposes that without integrating to some degree quantitative and qualitative data, different methods merely *‘sit in parallel, potentially leading to multiple studies, and not the desired “mixing” of methods’* which is usually implicit in the nature of mixed methods research. Similarly, Bazeley (2009) remarks ‘*all mixed methods research involves, as a minimum, integrating conclusions that are drawn from various strands in the research*.’ These remarks indicate the importance of integrating quantitative and qualitative research in a single study or programme of inquiry.

Although blending quantitative and qualitative data constitutes the heart of integrative mixed methods inquiry, Greene (2007) notes that the interaction challenge within various elements of integrated designs is under-theorised and understudied. This challenge can be reduced by utilising sampling designs that help researchers to make meta-inferences such as combining both sets of inferences into a coherent whole (Tashakkori & Teddlie, 2009). This combination will represent both the quantitative and qualitative findings and allows conceptualising appropriate findings from both sets of data (Collins et al., 2007).

The integration of mixed methods research calls for the collection of quantitative and qualitative data concurrently, or in parallel, or gathering information sequentially (O’Cathain et al., 2010; Payne, 2007; Teddlie &Tashakkori, 2010). According to Teddlie and Tashakkori (2009):

* Parallel/ concurrent mixed designs refer to quantitative and qualitative phases of a mixed methods project occur in a parallel manner, either simultaneously or with some time lapse. Both address related aspects of the same research phenomenon.
* Sequential mixed methods designs refer to mixed methods study where the phases occur in a chronological order with one phase emerging from or following the other. The research question for one depends on the previous one (p.143)

Many researchers argue that triangulation, and the use of multiple methods to study a given issue provides a better basis for drawing conclusions than would any single method. The term triangulation comes from navigation: an accurate way to determine the position of a fixed point is by calculation the angle to it from two fixed points that are a known distance apart. Because each method has its own strengths and weaknesses, the use of different methods will help the strength of one method to compensate for the weakness of another, and vice versa (Ingleton & Davies, 2007; Manstead, 2008; O’Cathain et al., 2010).

The primary aim of this study required the collection of data from both healthcare professionals and cancer patients with palliative care needs, in relation to an education programme. In such a programme, according to (Robbins, 1998), in addition to evaluating effectiveness against pre-determined objectives, measurement of the unintended impact of an intervention with various stakeholders should be attempted. A number of investigators (Ingleton & Davies, 2007; Robbins, 1998) have described an approach based on embodying the principles of triangulation in an evaluation design.

Woolley (2009) outlines triangulation as follows:

‘Quantitative and qualitative components can be considered *‘‘integrated’’* to the extent that these components are explicitly related to each other within a single study and in such a way as to be mutually illuminating, thereby producing findings that are greater than the sum of the parts.’ (p. 7)

Triangulation also refers to the point in the process of research procedures at which the researcher mixes or integrates the quantitative and qualitative data collection and analysis (Creswell et al., 2004; Teddlie & Tashakkori, 2009). In the field of health services research, there are two stages in the process where integration is possible (1) when data analysis leads to further data collection decisions and (2) when results are reported (O’Cathain et al., 2007; Collins et al., 2007). If qualitative and quantitative data are not integrated during data collection or analysis, the findings may be integrated at the stage of interpretation and conclusion (Bazeley, 2009; Creswell et al., 2004; O’Cathain et al., 2010; Teddlie &Tashakkori, 2009).

The design and conduct of a single study involves a wide range of procedures such as the identification of the research questions being addressed, the definition of the units of analyses, the structure of the samples being studied, the instrumentation and data collected, and the strategies of analysis. ‘*The more that two (or more!) methods have been integrated into each of these procedures, the stronger the “mix” of methods*’ (Yin, 2006). However, many difficulties may arise from trying to ‘*fit’* qualitative data into a quantitative framework and vice versa. They include differences in theoretical stance possibly leading to conflict in the research design, lack of researcher expertise in either method, difficulty in meshing numerical and narrative data to understand the research phenomenon, and an increase in expense and effort of multi-method research (Thurmond, 2001).

Although in some textbooks, several techniques have been described for integrating findings (Teddlie & Tashakkori, 2009; Creswell & Clark, 2011), discussions about criteria, and examples, are limited in recent social, health and behavioural science literature (Ostlund et al., 2011). Some scholars describe an exhaustive process of reading, re-reading, and checking transcribed text to arrive at a series of themes and subthemes, often then used to elaborate items already gathered through a questionnaire and, much less often, sorted to compare the views of different subgroups (Bazeley, 2009; Baskerville et al., 2001: McVea et al., 1996). This process, named ‘triangulation protocol’, is described in more detail in the paper of Farmer and colleagues published in 1996 in which the findings from each data set of their study was firstly listed on the same page of paper or as they named it as the ‘convergence coding matrix’ (**Table 4.1)** (Farmer et al., 2006). Applying this technique probably makes it easy for investigators to examine where findings from each method show agreements or partial agreements in interpretations (convergence), offer complementary information on the same theme (complementarity), or appear to contradict each other (discrepancy or dissonance) (Creswell et al., 2004; Collins & O’Cathain, 2009, Farmer et al., 2006; Teddlie &Tashakkori, 2009).

Seeking disagreements between findings from two data sources is also an important part of this process. Disagreement is not a sign that something is wrong with a study, according to O’Cathain and colleagues (2010). This exploration may lead to a better understanding of the research question, particularly in terms of unintended outcomes. Moreover, O’Cathain et al. (2010) and Farmer et al. (2006) also include a ‘silence’ sign, which they describe as a theme or finding arising from one data set and not in another. According to them, silence might be expected because the mixed methods approach examines different aspects of a phenomenon, the presence of ‘silences’ might therefore increase the understanding of research issues or lead to further investigations.

In addition to the *Triangulation Protocol,* O’Cathain and colleagues (2010) described two other techniques, in which the integration of the findings from the qualitative and quantitative components of a mixed methods study takes place at the analysis stage of the research process, instead of interpretation stage as the *Triangulation Protocol*. These are *Mixed Methods Matrix* and *Following A Thread.* The former is often concerned with in‐depth interviews carried out with a sample of survey respondents in order to create a subset of cases for which there is both a completed questionnaire and a transcript (O’ Cathain et al., 2008; O’ Cathain et al., 2010). In the latter, researchers select a question or theme from one component and follow it across the other components — this theme is called a thread (Morgan-Ellis et al., 2006; O’Cathain et al., 2010). **Table 4.1** summarises the triangulation protocol stages.

**Table 4.1** Steps to conduct a triangulation protocol (Farmer et al., 2006).

|  |  |  |
| --- | --- | --- |
|  | Step | Activities |
| 1. | Sorting | Sort findings from each data source or method into similarly categorised segments that address the research question(s) of interest to determine areas of content overlap and divergence. |
| 2. | Convergence coding | Identify the themes from each data source. Compare the findings to determine the degree of convergence of themes.  Characterise the degree and type of convergence using the following typifications of concurrence (or nonconcurrence) within theme areas. |
|  | Convergence coding scheme | |
|  | Agreement | There is full agreement between the sets of results on both elements of comparison. |
|  | Partial agreement | There is agreement on one but not both components. |
|  | Silence | One set of results covers the theme or example, whereas the other set of results is silent on the theme or example. |
|  | Dissonance | There is disagreement between the sets of results on both elements of comparison. |
| 3. | Convergence assessment | Review all compared segments to provide a global assessment of the level of convergence. Document when and where researchers have different perspectives on convergence or dissonance of findings. |
| 4. | Completeness assessment | Compare the nature and scope of the unique topic areas for each data source or method to enhance the completeness of the united set of findings and identify key differences in scope and/or coverage. |
| 5. | Researcher comparison | Compare the assessments of convergence or dissonance and completeness of the united set of findings among multiple researchers to (a) clarify interpretations of the findings and (b) determine degree of agreement among researchers on triangulated findings. Plan for how disagreements will be handled and how final decisions on interpretations will be made. |
| 6. | Feedback | Feedback of triangulated results to research team and/or stakeholders for review and clarification. |

With regards to the integration of quantitative and qualitative in my study, I adopted the Triangulation Protocoltechnique (Farmer et al., 2006), which is developed from the *Triangulation Design Model* (Creswell et al., 2004). In my view, given time limitations for primary care research, concurrent approaches that enable the collection of multiple forms of data at one time might be more practical than a sequential approach (Creswell et al., 2004). In addition to this, the most important reason is that my study design was well suited to this model. The typical examples which they describe as best fit for this approach are those in which the researchers use quantitative methods such as surveys or experimental trials to assess the effectiveness of an healthcare intervention, and then semi-structured interviews with patients or other stakeholders to consider the way in which the intervention has impact in the real world (Creswell et al., 2004; O’Cathain et al., 2010). The intent of this model is to triangulate or gather both quantitative and qualitative data at the same time, and to integrate the two forms of data sets to best understand the research problem (Creswell et al., 2004).

In my study — evaluation research on an educational intervention to aim at improving the delivery and quality of healthcare services — the main purpose of combining methods in the study was complementarity (methods used to address different aspects of the intervention). The integration of the doctor and patient data sets help to obtain a comprehensive picture of the impact, ensuring that the views of parties related to the intervention are heard, and increasing the confidence in the interpretation of findings (O’Cathain et al., 2007). In addition, the confirmation of intervention effectiveness based on two data sets in which the results of two methods converge was also, to some extent, the purpose of data mixing in this study.

Furthermore, as a component in this study, I used a qualitative approach to explore the experiences and experiences of advanced caner patients with the current palliative care service. I conducted semi-structured interviews with 17 patients in both generalist and specialist palliative care settings, and tried to find the silences in these interviews and the dissonances with findings from family doctor surveys in order to understand more fully patient views about our current palliative care services.

A typical structure for reporting a triangulation study is typically to have separate sections on quantitative data collection and qualitative data collection, as well as separate sections on quantitative data analysis and qualitative data analysis. The investigators then provide a results, discussion, or conclusion section in which they discuss the results of both analyses (Creswell et al., 2004). For examples, researchers presented the two forms of results as supporting or conflicting evidence in the results section (Baskerville et al. 2001; McVea et al., 1996). In contrast, they might transform one type of data into another form, for instance quantitatively count the codes from qualitative results in order to to converge results with the quantitative themes.

Within each of the two previously mentioned methods, one examining the patient experience and the other assessing the doctors work, the items in the various data sets were probably combined. Some of these items were numeric such as using interview transcripts to enumerate the number of patients with advanced cancer receiving and being satisfied with the service from the trained family doctors in the community, and having the same item asked in the survey *(‘How many people with cancer per month do you currently provide palliative care in your workplace*?). Other items needed to be more conceptual and qualitative (for example, using interviews to define the ‘*facilitators of using a patient – held record (PHR)*’ of patients at home, and using multiple choice questions (MCQs) in the survey questionnaire survey to explore the same ‘*facilitators of using PHRs*’ concepts from the participant doctors’ perspective. Although the measures were not exactly the same within each data set, I deliberately tried to create directly comparable items at the design phase of the study, to assure the desired common scopes of data collection and variables. By comprehending and comparing between them at analysis phase, I realised many non-overlapping items. At the same time, the data sets were not limited to their common ground.

## 4.3 Ethical issues

Adhering to research governance, ethical approvals for this study were required. Ethics clearance was firstly obtained from the Camau DoH – the authorised body at the research site. This is because the whole project has been conducted in Camau Province, Vietnam. The Ethics Approval had to be endorsed by the Local Ethics Committee of the Camau DoH. In addition to this, the research study was a joint location research under the supervision of the University of Sheffield hence it also needed to be approved by the UREC (University Research Ethics Committee).

The Declaration of Helsinki, developed by the World Medical Association in 1964 (amended in 1975 and 1983), was a response to the need for ethical framework on human experimentation, which would be applicable to all countries and most ethical social interactions that a researcher engaged with (Hanks et al., 2010). Its key points are respect for the participants, the assurance of confidentiality or anonymity, the prevention of harm and the maintenance of privacy (Sheldon & Sergeant, 2007).

### 4.3.1 Consideration for doctor participants

Respect for the participants was demonstrated by the professional manner, in how I liaised with doctors and provided them with information about the study before, during and after the workshop. This was established by how I as well as members of the research team presented ourselves with them in all actions of the intervention, particularly when asking them to respond. Data collected in the study was provided voluntarily by participants, and remained unchanged from the original. Respecting and valuing participants was also an inherent way in which the researcher ensured ethical principles were adhered to.

With regard to the prevention of harm, I took into account potential physical or emotional risks that may affect doctors due to being involved in this study. However, I believe that there were no or little inherent physical risks for them. Possible discomforts may have included spending time completing and returning the questionnaires. Emotional risks, in my opinion, centred mainly on the reminders of timely feedback of questionnaires. A post reminder was usually submitted one month after sending the questionnaires out. In addition, a telephone call also was sometimes applied after that. Doing these reminders could potentially cause family doctors some annoyance and they could have felt pressured to return the questionnaires. In order to ease these issues, the written and verbal reminders were conducted in the most considerate way by the research team as well as showing our appreciation of the participants’ contributions to the success of the programme.

The doctor participants in this study were provided a written informed consent form, and their participation to the project was voluntary. In addition, they were free to withdraw from the study. The confidential and anonymous nature of the study were described explicitly in the information sheet and consent form which were included in the postal package accompanied with the questionnaires. The personal details of doctor participants were protected by not revealing their location and name. The questionnaires were also designed on an anonymous basis. When mails were retuned, one member of the research team took the questionnaire out and kept the envelopes separately. Another was responsible for inputting the data from the questionnaire into the SPSS software (the Statistical Package for the Social Sciences). Information on anonymisation and storage were described on the participant information sheet (**Appendix 4.1**). As part of the research process, discussions within the research team and my supervisory team as well as publications or presentations at conferences were only based on the coded data. All steps were taken in order to ensure that participants' confidentiality and privacy was not breached. Although anonymity was guaranteed, the names of the CHSs receiving postal questionnaires remained known only to the members of the research team.

### 4.3.2 Consideration for patient participants

Similarly, conducting research with advanced cancer patients needing palliative care presents particular ethical issues such as taking time from them and their family carers when time is sometime short and precious. Patients’ vulnerability and reliance on others may make it difficult for them to refuse to take part. Cognitive impairment is not uncommon. Therefore, some may not understand the implications of research fully before agreeing. They are unlikely to benefit personally from the results of the research and the research may intrude on sensitive territory causing them distress (Addington-Hall, 2002). These issues were related directly to this study.

To ensure that patient fatigue was kept to a minimum, the interviews were usually short, merely in a maximum of 30 minutes. Interviews in hospital were undertaken at a time suitable to the patient in a quiet room in order to avoid disruption as far as possible. Patients who were too ill to be interviewed were not approached. Judgments on patients’ health performance were made by reviewing the patient's hospital record and discussing with their doctors. My status could potentially make patients feel unable to refuse to be interviewed. Because I acted both roles as a ward doctor and a researcher at my own work setting, this could lead to a sense of compromise (Sheldon & Sargeant, 2007). To prevent this I was careful to stress that I was conducting the interview as a researcher rather than a ward clinician, and highlighting the voluntary nature of the interview. It was similar when I conducted interviews at patients’ homes. I also prepared for the situation of terminating the interview early if the patient felt distressed. However, no interview was stopped due to this. All interviews were audio-recorded, and then transcribed by myself. Confidentiality and anonymisation was maintained by ensuring the audio files and transcripts were kept secure and potential identifiers were removed from the data (Mason, 2002).

Informed consent was obtained in a usual way: through using an information sheet, spending time explaining to the patient the aims of the study, answering their questions and obtaining signed consent. Whilst most patients approached were very keen to recount their story and seemed to have no difficulty with understanding the purpose of the study, the initial information sheet, although brief (two sides of an A4 sheet), was too long for some patients to read (**Appendix 3.1**). It seemed to be paradoxical that the part of the study which seemed to cause the most distress was the consent process, which had followed closely UREC guidelines.

## 4.4 Methodological issues

### 4.4.1 Recruitment issues

Recruitment to any palliative care research has been known to be difficult. It can be particularly problematic in interviews with patients with advanced cancer in hospital because they usually present at the terminally ill stage. This was observed with hospitalised patients in my study (the median KPS score [[7]](#footnote-7) was 50). Patients at home usually had a higher KPS score (the median was 70), and most of them usually lived in the remote areas of the province. From my experiences for caring people with advanced cancer I recognised that alongside medical investigations and interventions, patients may also be involved in time-consuming and stressful legal procedures, which may possibly also reduce the chances of recruitment.

Several of earlier interviews with patients in hospital were short. This is because the patient often felt uncomfortable with the procedure of informing them about the research purpose and informed consent, as well as the presence of a recorder during conversation. They answered the interview questions briefly. Therefore, the interview sometimes did not last very long, and I obtained only limited depth of information. In addition, in the first few interviews I followed strictly the order of the interview guide, therefore the flow of conversations sometimes seemed to be unnatural.

The recruitment with patients in the PCU occurred in a timely manner. However, with patients at home, the recruitment was slow at the beginning. It took me 3 months to recruit the first three patients in their residence, although I did not experience any gate-keeping barrier as often described in the literature (Addington-Hall, 2002). The main trouble was the long distance from my workplace to patients’ homes, from 40 to 100 kilometres on average. The transportation was sometimes challenging. There were two interviews on which I had to take a speedy-boat in order to be able to arrive patient residences. Another limiting factor was the medical condition of patients was deteriorating and unpredictable. One daughter cancelled an interview that her father had consented verbally. When I telephoned to make an appointment she said that her father was unwell at that point of time and she did not want him to be interviewed, and he died two weeks after.

With respect to family doctors, an ethical considerartion might be some stress and discomfort with receiving mail and phone call reminders as I described above.

### 4.4.2 Limitations of this research design

The one-group pre-test and post-test design provides weak information on the nature of the association between the intervention and outcome. Furthermore, due to the lack of an external control, this approach did not allow us to draw an inference whether other factors, which happened at the same time, might be contributing to any observed changes in knowledge, confidence, performance and behaviours of the trained family doctors in their workplace (Costantini & Higginson, 2007). Although these changes may have been caused by their participation to the project, the nature of the study design is too weak to draw these conclusions.

The qualitative approach through semi-structured interviews with patients probably introduced some selection bias to the data. Some patients may not want to be interviewed, in particular concerning sensitive topics. Therefore, this may lead to a bias towards the sample. As a result, only those who were prepared to be interviewed would agree to participate. In addition, patients with advanced cancer may be too ill, too distressed or busy with medical interventions to be interviewed; or relatives could be worried about putting the extra burden on the patients. These challenges may lead to a limited number of patients recruited. As a result, the views of such a small group may not be representative of the population of people with advanced cancer in Camau. In addition, conducting the same interview with patients of different age groups or different health status scores may show that patient views on their care probably vary.

As discussed above, the dual role of a researcher and a clinician as in this study may cause further impact on the process of data collection (Addington-Hall, 2002; Sheldon & Sergeant, 2007). When conducting interviews with patients with advanced cancer, different subjectivities in my own life history related to to my professional work probably drew my focus to different aspects of the context and informed the question pursued. By making these biases, values and prior knowledge explicit (Sheldon & Sergeant, 2007) as well as being impartial on the process of data collection and interpretation (Patton, 1999) helped to obtain to some extent greater transparency. The issue of reflexivity in this research is presented in the next section.

Mixed methods approach is frequently a goal-oriented paradigm. The depth of qualitative research makes it difficult to reproduce or replicate in the exact same form. Therefore, its findings may not be applicable to other services elsewhere. According to Kristjanson and Coyle (2010), the nature of the methods means that the interaction between the researcher and participants may not be something that another researcher could attain in the same depth, detail or scope. Consequently, the evaluation may not seek to produce generalisation (Robbins, 1998).

The process of integration two data sources is another difficulty. The challenge in using mixed methods arises because different methods favour different units of analysis. This may lead to a threat to the integrity of a single study (Yin, 2006). My understanding on the technique of triangulation was limited, and was exacerbated by a scarcity of the literature explaining practical steps on how triangulation process should be undertaken. In addition, there might be incompatible between the unit of analysis and theoretical paradigms, as a result, the process of triangulation might amplify sources of error and bias in each data source (Farmer et al., 2006)

## 4.5 Issue of reflexivity in this research

The dual role of a researcher and a clinician as in this study may cause further impact on the process of data collection (Addington-Hall, 2002; Sheldon & Sergeant, 2007) and to a lesser extent, data analysis. In order to control this impact, the effect of the personality or professional characteristics of the researcher on investigated issues, or reflexivity process, was taken into account. According to May and Pope (2000), reflexivity means sensitivity to the ways in which the researcher and the research process have shaped the collected data. Reflexivity is an important component of qualitative inquiry. It involves constant attention to the researcher's perspective, background and influence on the research process and the effects this has on the researcher, which may affect the research. They include the role of prior personal assumptions and experience or professional status such as doctors or nurses. These factors can influence in any inductive inquiries (Sheldon & Sergeant, 2007). The potential for research participants was seen as beneficial. However, the interview process could lead to risk of exploiting participants as well as cause conflict between my roles as clinician and researcher.

As a clinician I have interviewed patients in the course of my work. This type of interviewing aims at exploring the patient's medical history as well as their symptoms and concerns to achieve a clinical diagnosis, to understand the patient's preferences for management and to assess the effect of treatment. This familiarity provided both advantages and disadvantages in this study. Firstly, it enabled me to select suitable patients for interviews. Secondly, I had experience in putting patients at ease and looking out for signs of fatigue or distress. Thirdly, it provided me with communication skills, including noticing verbal and non-verbal cues and finally experience in interviewing, listening and taking note simultaneously. However, undertaking this study challenged my previous scientific training which reinforced the concept of data collection by an 'objective' observer as the normative conditions for rigorous inquiry. Understanding that the researcher brings an influence on and becomes part of the data was a challenging concept to learn in a deep sense. Second, when conducting interviews with patients with advanced cancer, different subjectivities in my own life history related to my professional work probably drew my focus to different aspects of the context and informed the question pursued. Finally, it is acknowledged that my identity as a doctor might have influenced my interactions. The reason is that clinical encounters are predominantly doctor led, whilst research interviews should be patient led. Therefore, I may unwillingly have dominated the interviews due to my role as doctor. There was a potential conflict although I always put interviewed patients at easy and encouraged the patients talking freely and friendly

As a researcher I focused mainly on performance and efficiency of the research process. Therefore, the role of empathy and reciprocity in the researcher-participant relationship (both patients with advanced cancer and their family doctors) were highlighted. Reflexivity also involved exploration of the emotional impact of doing the research and implications of the research setting (Sheldon & Sergeant, 2007).

Reflexivity was a prominent thread throughout this study, involving professional and personal aspects. First, personal and professional biases were discussed, recognised and made plain at the beginning of this research amongst members of the local research team. By making these biases, values and prior knowledge explicit (Sheldon & Sergeant, 2007) as well as being impartial on the process of data collection and interpretation (Patton, 1999) helped me obtain to some extent greater transparency. Second, professional dominance and/or biases might be reduced through openness and mutual respect through engaging in ethical research practice and ensuring consent as informed as described in **Section 4.3 Ethical Issues**. Last but not least, having experienced research supervisors were other vital requirements for obtaining academic feedback from being reflexive on interviewing style during interviews as well as data analysis.

## 4.6 Conclusion

The design and conduct of mixed methods research study regarding a wide range of procedures were presented. They consist of the research patterns (the quantitative and qualitative paradigm adopted to address the research questions), the research population in which the samples were drawn, the instruments were used to collect data, the definition of the units of analyse as well as the techniques for integration data. The more methods are integrated into each of these procedures, the stronger the ‘mix’ of methods’ results are produced (Yin, 2006). Regarding the processes of this research, Ethics governance, recruitment issues and rigour also were presented. In the next two chapters, I shall present in detail the methods and results from each quantitative and qualitative component of this mixed methods study: the pre- and post-workshop surveys with family doctors and the semi-structured interviews with advanced cancer patients.

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# Chapter 5 – Evaluations of Family Doctors: Methods and Results

## 5.1 Introduction

The intention of this chapter is to present in detail the palliative care educational intervention and the additional support programme as well as the methods used to evaluate of its impact on rural family doctors. This is a key component of the parallel mixed methods study as discussed in **Chapter 4** – Methodology.

Evidence from the developed world suggests optimum palliative care could be integrated with cancer and primary care system. Current challenges for central government and provincial health management bodies include identifying efficient and effective strategies for raising competence in palliative care for members of local primary healthcare teams who provide care to patients in the community. Family doctors’ competence in the delivery of palliative and supportive care is important to facilitate effective patient follow-up at commune health stations (CHS).

Worldwide, the high prevalence of advanced cancer patients who need palliative care suggests that each primary healthcare service would benefit from at least one professional with palliative care expertise (Cherny & Catane, 2010). In Vietnam, cancer patients are often cared for by oncologists as long as there is potential benefit in disease-modifying treatment. When it is clear that there is no further benefit to be derived from this treatment, the responsibility for the patient’s ongoing care is transferred to the palliative care service. However, Vietnam so far has insufficient doctors and nurses qualified in palliative care and lacks models for community and home-based palliative care at the national level (Krakauer et al., 2010). Therefore, patients with advanced cancer living in rural and remote areas are likely to be disadvantaged with respect to palliative care (Xuyen, 2006). According to Green and colleagues (2007), approximately 75% of Vietnamese patients with advanced cancer in the community have unmet palliative care needs at the terminal stage. As a result, they are likely to experience a poor quality of life, uncontrolled distress or suffering. Care is often provided to these patients by local healthcare professionals, although a majority of them have had little or no formal training in palliative care (Viet et al., 2011).

A number of studies have been conducted to examine general practitioners’ perspectives on palliative care. The healthcare physicians in these studies revealed a willingness to acquire knowledge, improve skills and adopt attitudes in order to meet a variety of patients’ needs in the community (Meijler et al., 2005; Mitchell, 2002; Noble et al., 2001). Some authors found that GPs consider palliative care as the most important and valuable part of primary care services (Meijler et al., 2005; Groot et al., 2005).

The use of educational and training models in palliative care can help local healthcare professionals to improve specialised knowledge, skills and confidence in practice in the workplace (Croager et al., 2010; Hoon et al., 2009; Meijler et al., 2005). For instance, with basic training about applying the WHO’s Pain Relief Ladder – ‘*using the right drugs, at the right dose, at the right time’* – family physicians can treat pain effectively in 80-90% of cases (WHO, 1986).

A considerable number of research studies have been directed towards identifying and supporting the needs of healthcare professionals who deliver palliative care services to patients in the community. Some strategies, which have been deployed include:

* Effective palliative education programmes tailored to local environments (Boakes et al., 2000; Shipman et al., 2001).
* Organising educational workshops in palliative care (Ersek et al., 2010; Reymond et al., 2005; Spiegel et al., 2002).
* Support from palliative care specialists for treatment guidance for local healthcare teams (Noble et al., 2001)
* Integration of palliative care to existing primary healthcare services (Thomas & Noble, 2007; Krakauer et al., 2010).
* Strategies that facilitate communication between specialists and primary healthcare providers (Marshall et al., 2008; Tasmuth et al., 2006).
* Regular clinical support either by teleconference or sending specialised documents and/or guidelines to local physicians (McConigley et al., 2001; Mitchell et al., 2008; Zitzelsberger et al., 2004).

However, none of the programmes listed have demonstrated effective outcomes in all settings or for all providers. The reasons may be that there are many differences amongst settings studied, such as social and cultural features, health system structures and policies, financial and personnel resources and many other factors (Newell-Jones, 2007; Doyle, 2005). Besides, the most appropriate methods for measuring outcomes of educational interventions on health care professionals still have not been entirely agreed (Higginson & Harding, 2007). Therefore, different approaches should be adopted for different settings. The purposes of a programme and the characteristics of subjects involved are likely to be key factors in choosing an appropriate educational format. In addition, the availability of financial and personnel resources must be considered.

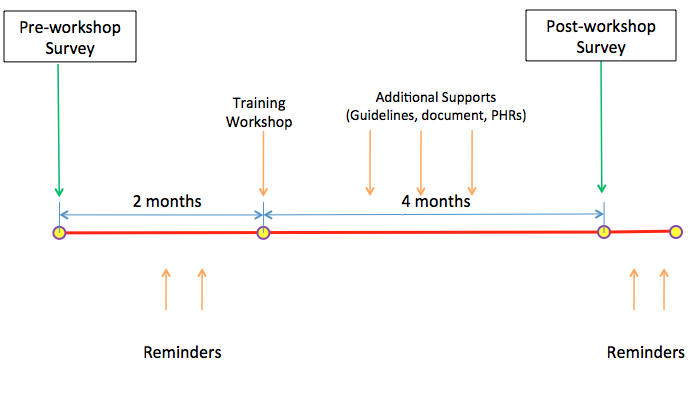
This study was undertook in order to evaluate the effectiveness of an educational workshop and additional support programmes in palliative care for rural family doctors in Camau. Three objectives of this research phase are:

* To assess the knowledge baseline and confidence of family doctors in practising palliative care in rural communities in Camau.
* To conduct training and dissemination in order to develop supportive and palliative care competence amongst rural family doctors through a workshop, postal information packages and telephone counselling.
* To evaluate the outcomes of the intervention package in terms of doctors’ knowledge, confidence and performance in practising palliative care.

## 5.2 Methods

### 5.2.1 Study design and procedure

A pretest-posttest survey design was used to evaluate family doctors’ improvement and changes in terms of knowledge, confidence, and attitudes and to some extent, their behaviour. The approach was a pre-workshop and post-workshop design in which questionnaires were submitted to participant doctors two months before and four months after the workshop (**Figure** 5.**1**). A descriptive survey is an appropriate design to explore the frequency or prevalence of particular attributes and the relationships between them in a population (Addington-Hall, 2007a; Oppenheim, 2001).



**•** PHRs: Patient-Held Records

**Figure 5.1** The pre-workshop and post-workshop design.

In early August 2011, the self-complete questionnaires were posted to 85 family doctors who were working at CHSs and were responsible for delivering primary healthcare services in the community throughout the province. A copy of these questionnaires will be presented in **Appendix 2.1 and Appendix 2.2**

Each questionnaire consisted of three sections, 40 questions altogether. The first section consisted of 12 questions aimed at asking family doctors for several demographic and professional characteristics, daily practice in the workplace and what topics of palliative medicine they would like to be taught at the upcoming workshop.

The second section was 20 true-false questions of the Palliative Care Knowledge Test (PCKT). This tool had been designed, tested and applied broadly in Japan by Nakazawa and colleagues since 2009. It measures a wide palliative care knowledge base, such as philosophy, pain control, symptom management, and so on. Each right answer is given a score of 1, an incorrect scores zero. The validity and reliability of this instrument has been established already (Nakazawa et al., 2009). The principal author (Y. Nakazawa) permitted using this test for this evaluation research through an approval email.

The last section was the Confidence Rating Scale with 8 Likert-type questions. This scale was employed to rate doctors’ confidence about practising palliative care. It had been extracted from the booklet of Help the Hospice – ‘*Palliative Care Toolkit-Improving care from the roots up in resource-limited settings*’ (Bond et al., 2008). It includes 8 questions asking about confidence level in palliative care practice from 0 to 10 points. Zero points represents ‘ not confident at all’, and ten ‘absolutely confident’. Each question is given a corresponding score according to where the answer is placed on the scale. No permission was required for using this scale for non-commercial studies, according to the booklet.

The post-workshop questionnaire (**Appendix 2.2**) was identical except for the first section which was modified to capture possible changes in the performance of trained doctors, such as whether there was an increase in the number of palliative patients or the amount of morphine prescribing in their workplace.

In an attempt to evaluate qualitatively practical outcomes, there were several intentional spaces for free text within each questionnaire, in order that doctors could express their attitudes in practice or their own comments to solve matters raised. The content of these free text responses were analysed using qualitative methods, with main themes identified.

A knowledge score for every participant was calculated by summing all right answers on questions of the PCKT. Similarly, a confidence score was calculated from the 8 rated scores on the confidence scale. A total score for each questionnaire was calculated and summed for making a comparison between pre- workshop and post-workshop.

The main intervention, a 2-day training workshop in palliative care, was held in Camau City two months after submitting the pre-workshop questionnaires. The educational intervention design was informed by theory and practice relating to previous initiatives in rural family practice as well as the topics requested by family doctors in the pre-workshop questionnaires. According to Henwood & McGannan (2007), in order to organise an effective CPD activity, learners must be involved in planning it, in particular the curriculum content.

The idea for this workshop (in 2011) was evolved from a previous workshop. That workshop had been organised in Camau city in 2010 and focused mainly on cancer prevention, diagnosis and management coupled with a brief presentation about palliative care principles. Planning for the workshop began in July 2011 when I was aware that Dr. Collin Wozencraft – the consultant of the Center for Palliative Care, Harvard Medical School (HMS CPC), and also the Co-Director of the Vietnam Fellowship Program in Palliative Medicine – the cooperative programme between the HMS CPC and the Vietnam MoH – would be in Vietnam in 6 months for a training the trainers course. Through email and telephone contacts, he agreed to teach at the workshop in Camau City at the end of September 2011 accompanied by Dr. Quach Thanh Khanh – a fellow in palliative care who qualified from the San Diego Institute of Palliative Medicine, USA.

A meeting of C4’s members was then held in order to assess the learning needs of family doctors, the financial and personnel resources available, target audiences and the dates of the workshop. Adult learning theory was used for planning and implementing the workshop (Jarvis, 2004; Kaufman, 2003). The scope of content and educational activities were built depending partly on the desired topics, which were indicated by family doctors in the pre-workshop questionnaires, as well as the contextual issues raised by C4’s members. These ensured the workshop would be relevant, interactive and clinically applicable. Although the planning team recognised the potential benefit of including clinical observational experiences at the workshop, pragmatic considerations forced the abandonment of this idea. All PowerPoint presentations and accompanying texts were sent to the organisers of the workshop to form the workshop booklet. The workshop programme consisted of didactic lectures, expert-led group discussions on clinical situations and specific issues, post-workshop support programme and so on. The programme also included an invitation to attend a post-workshop dinner to encourage local networking.

Core lectures covered most main aspects of palliative care (**Table 5.1**). Every attendee was given a workshop bag at the registration desk. Each bag included a workshop booklet, a copy of the NGPC, several palliative care readings and pharmaceutical products. The workshop room had a moderate capacity to ensure the workshop retained an interactive atmosphere for attendees.

**Table 5.1** Lectures and seminars at the workshop

|  |  |
| --- | --- |
| Topics | Lecturer |
| Palliative care principles | Dr. Colin Wozencraft |
| Pain management | Dr. Colin Wozencraft |
| Communication – Breaking the bad news | Dr. Quach Thanh Khanh |
| Palliative care management of common symptoms | Dr. Colin Wozencraft |
| Opioids policies | Dr. Quach Thanh Khanh |
| Local guidance and trends | Dr.To Minh Nghi |
| Local palliative facilities and drugs available | Dr. To Minh Nghi |

Two qualified specialist trainers in palliative medicine (Dr. Collin Wozencraft and Dr. Quach Thanh Khanh) were responsible for teaching and leading discussion sessions at the workshop. The workshop schedule was set up including several 1-hour didactic lectures on main aspects of palliative care such as principles of palliative care, pain and symptom management, delivery of bad news and so on. Then one-hour expert-led sessions were held aimed at responding to issues raised by participants and discuss further if necessary. I myself acted as a mentor providing information regarding local healthcare and palliative care policies, clarifying main points of the NGPC and giving information on essential drugs available in the list of the Camau DoH. Participants were also taught about common side effects of cancer treatments and the ways to control them.

Many topics that sparked considerable debate were similar to those reported by Ersek and colleagues (2010). These include obstacles to providing palliative care such as the shortage of healthcare professionals, lack of effective interdisciplinary communication, inadequate knowledge, stigma of getting cancer, scarcity of opioids as well as the fear of addiction or hastening death by using opioids. There was also a wide range of topics outside the main programme raised by participants during the workshop such as death and the dying process or using complementary alternative medicine (CAM). However, there was only a little time for the discussions of spiritual issues as well as advanced clinical skills.

The additional support activities following the workshop included the following:

1. First, guidelines about palliative care and specialised papers were posted monthly to family doctors at the end of every month for the succeeding four months. These documents emphasised practical aspects of palliative care at the level of primary healthcare, and encouraged local health professionals to collaborate well with the project.
2. Second, a counselling phone line to the PCU at the Camau Provincial General Hospital (PGH) was set up on the basis of 24/7 access. This was designed to provide immediate discussions and consultation for difficult or unfamiliar clinical situations that family doctors would encounter in their workplace. The main contents of discussions were documented. Any event that occurred with high frequency was then reported to the research team for analysing later.
3. Finally, cancer patients who were discharged from the Oncology Ward of the PGH, including the PCU, were accompanied by a patient-held record (PHR). This summarises the diagnosis, disease stages, and oncology treatments, and so on. Moreover, the record and verbal guidance from staff also suggested that the first place patients need to visit for possible troubles related to their disease is the local health stations which are staffed with family doctors who had received training and collaborated within the project.

### 5.2.2 Participant inclusion and exclusion criteria

*Inclusion criteria*

* Family doctors who had been working at commune health stations (CHSs) in the administrative boundaries of Camau Province.
* Family doctors who agreed to participate in the research. The evidence of this was the return of the signed consent form and the completion of pre-workshop and post-workshop questionnaires.
* Attendance at the workshop.

*Exclusion criteria*

* Family doctors who did not agree to engage in the research
* Family doctors who did not attend the training workshop
* Family doctors who did not return the pre-workshop or post-workshop questionnaire after one postal reminder and one telephone call.

### 5.2.3 Recruitment

At the beginning of this research (8/2011), 2 months before the planned training workshop, family doctors’ contact details were extracted from the registration list of the Camau Department of Health. All family doctors identified were submitted a pre-workshop package by post.

This postal package included a questionnaire, an information sheet and a consent form accompanied by two stamped, addressed return envelopes – one for the completed questionnaire and one for the signed consent form. In the case of not receiving a response after 4 weeks, a second mail was submitted. A phone call was also considered later. These aimed at ensuring whether the packages had arrived at the right places, and also to encourage doctors’ participation. According to Harrison and Cock (2004), such letters and/or telephone reminders can lead to an increase in response rate.

The invitation to attend the palliative care workshop was posted and faxed to all family doctors throughout the province. During the four months after the workshop, additional support activities occurred as described in the earlier section of this chapter.

The second questionnaire for evaluating changes in knowledge, confidence, performance and behaviour towards practice palliative care was submitted to participant doctors four months after the workshop. The package and the reminders were similar to the pre-workshop ones.

In order to achieve a response rate as high as possible, several tactics were employed:

* A pen and stamped return envelopes were included in each package (Edwards et al., 2002; Sharp et al., 2006).
* Questionnaires were short with approximately 850 words arranged neatly on 2 sheets of A4-sized paper of with user-friendly design (Nakash et al., 2006).
* A reminder letter accompanied by a questionnaire would be posted coupled with a telephone reminder if return questionnaires were still not received.

Confidentiality protected by not revealing of participating doctors, such as location and name. The questionnaires were designed on an anonymous basis. Information on anonymisation and storage were described on a participant information sheet. This was given to potential participants to read as part of the recruitment process, and before consent for the study was taken.

The English translation of the questionnaire, the information sheet and the consent form used in the surveys with family doctors are attached in **Appendix 4.1 & 4.2**.

### 5.2.4 Variables and statistical analysis

The main outcome measures were changes in family doctors’ knowledge and confidence in providing palliative care to patients with advanced cancer in the community, the degree to which participants made accommodations in daily practices in the workplace to manage better care for patients at home, and doctors’ satisfaction levels with the intervention.

The independent variables were participant demographics, organisational and professional factors, caseloads, and so on. The dependent variables were the doctors’ mean scores on the Palliative Care Knowledge Test and the Confidence Rating Scale before and after the workshop.

Data management and analysis were performed using SPSS version 19.

A descriptive analysis with frequency distribution was used to describe the demographic characteristics, organisational and professional factors, workload and participants’ opinions on the content of the workshop.

The independent sample t-test was used to compare the mean scores of knowledge and confidence scales of the attendees before and after workshop with statistical significance set at p ≤ 0.05. Multiple linear regression analysis was used to explore the relationships between changes in self-reported knowledge and confidence scores in palliative care practice. Associations between these scores and family doctors’ reports of having previous palliative care training, showing an improvement in performance and changes in behaviour as well as demographic and professional characteristics were also tested statistical significance using the independence t-test.

It was assumed that for this intervention to be considered successful it needed to achieve some educational outcomes such as an increase in knowledge and confidence scores as well as positive practical behaviour changes in morphine prescription and referral patterns.

### 5.2.5 Ethical considerations

The purpose of the research, possible discomforts, for instance spending time completing and sending back the questionnaires, the freedom of subjects to withdraw from the study, the confidentiality and anonymity and so on were described explicitly in the information sheet and consent form that were included in the postal package which accompanied the questionnaires. Because of local sensitivities related to daily practice and personal opinions of the professional participants, an anonymised approach had been discussed and obtained agreement amongst members of the local research team as well as with my first supervisor (Dr. Bill Noble). It was agreed that doctors return questionnaires must be entirely anonymous. This led to an unavoidable limitation of the study, which was using a pre and posttest design. The reason was that the anonymity precludes analysis of the before and after training data at an individual level. In order to explore possible effects of the programme, analysis of the group data was undertaken to detect changes within the group. With regard to conducting anonymous data collection from participant doctors, consent forms and data were returned under separate cover.

Ethics approvals were obtained from the Camau DoH and the UREC (University Research Ethics Committee). This is because the whole project has been conducted in Camau Province, Vietnam. Therefore, the ethical clearance had to be endorsed by the Research Review Committee of the Camau DoH. The application to this committee was submitted in October 2009. The approval was granted in December 2009 after my presentation about the project in a meeting with members of the committee. One of them asked about whether sufficient information would be obtained from the 20 patients in both settings (referring to the original intention to recruit 10 patients for interviewing in each setting). After clarifying about the mixed methods approach (and some other areas of concenrs), in particular the qualitative research, no amendment was required to the original protocol. The Higher Degree Review Scheme from the Medical School of the University of Sheffield was then also signed by the Director of Camau DoH for the application for a place in the University of Sheffield for the year 2010.

In addition, this study was a joint location research under the supervision of the University of Sheffield hence it also needed to be approved by the University Research Ethics Committee UREC. The research ethics application had not been straightforward. The first application, submitted in April 2011, the Ethics Research Administrator of the UoS emailed me informing that the Vietnamese Department of Health's ethics approval system had not met the University's robust process for approval. Therefore, I had been required to submit all samples of questionnaire, information sheets and informed consent forms (related to both targeted family doctors and patients) to the UREC. After three weeks, I received an informing letter stated that a number of compulsory amendments which needs to be addressed before ethics approval could be granted. These requested information mainly related to the clarity of the English-translated versions of the above samples and several suggestions for process of anonymity and confidentiality. The last application was resubmitted after revising as requested by the ethics research reviewers of the Medical School. Finally, the School’s Ethics Reviewers approved for the research at the end of May 2011. During this process of applying for the ethics approval I had learnt that there are a number of compulsory amendments which needs to be addressed before the committees could grant ethics approval. The request from the UREC seemed more challenging in comparison with that from the LREC.

A copy of approval letter from the UREC with the reference code - SMBRER187 will be attached in **Appendix 7**.

## 5.3 Results

Of 85 pre-workshop questionnaires posted to all rural family doctors at the beginning, 61 questionnaires were completed and returned to the research team. The pre-workshop response rate was 72% (**Figure** 5.**2**). For the purpose of the research, only doctors who both attended the workshop and returned the post-workshop questionnaires were counted in the post-workshop response rate. There were 44 family doctors who met these criteria therefore the post-test response rate was 67%.

Qs\*: Questionnaires

**Figure 5.2** Summary of recruitment

A total of 122 delegates attended the workshop. They consisted of family doctors, clinicians, nurses, health managers, and probably many family doctors who had not returned the pre-workshop questionnaires.

The majority of doctors surveyed before the workshop were men (51/61). Two-thirds of respondents (65%) had been working in their current setting for up to ten years after they qualified as a family doctors (**Table** **5**.**2**). Lack of data on the non-participating doctors eligible for the survey precludes comments on how representative our sample is.

Sixty percent of respondents (36/61) reported that they had not attended any previous educational event regarding palliative care in the previous 2 years. Twenty-five doctors (40%) had attended the first workshop on cancer and palliative care held by the C4 in July 2010 in Camau. The survey on this occasion was published (Viet et al., 2011).

Palliative care provision for cancer patients in the community was provided by two-thirds of respondents (65%) in the pre-workshop group. In this group, 36 out of 61 respondents (59%) reported that 1 to 3 cancer patients with palliative care needs visited their workplace per month. On the other hand, one-third (35%) of family doctors indicated that they had not provided care for any cancer patients during the previous 6 months. Regarding the reasons for not being involved in palliative care for cancer patients, 14/61 doctors (23%) stated that they had not encountered any palliative patients, 5/61 (9%) respondents indicated that they did not want to treat cancer-related symptoms at their office.

**Table 5.2** Doctors’ personal and professional characteristics, pre-workshop (n=61).

|  |  |  |
| --- | --- | --- |
|  | n | % |
| Gender |  |  |
| Female | 10 | 17 |
| Male | 51 | 83 |
| Years in practice |  |  |
| 0-5 | 23 | 38 |
| 6-10 | 17 | 28 |
| > 10 | 21 | 34 |
| Previous participation to palliative care training |  |  |
| Yes | 25 | 41 |
| No | 36 | 59 |
| Number of cancer patients per month |  |  |
| 0 | 21 | 35 |
| 1-3 | 36 | 59 |
| 4-5 | 4 | 6 |
| > 6 | 0 | 0 |
| Reasons for not having patients | 21 | 35 |
| Not encountered | 14 | 23 |
| Do not want to treat cancer-related symptoms | 5 | 9 |
| Others | 2 | 3 |
| Documents consulted in daily practice |  |  |
| National Guidelines for Palliative Care | 27 | 44 |
| Regulations on Opioid Prescribing | 41 | 67 |
| Places for making a referral |  |  |
| General District Hospitals | 19 | 31 |
| Camau Provincial General Hospital | 30 | 49 |
| Cancer Specialist Hospitals | 12 | 20 |

With the question regarding the pre-workshop reference to specialised documents in practice, the proportion of doctors indicating that they had been referring to the National Guidelines for Palliative Care (NGPC) and the Regulations on Opioid Prescribing (ROP) were 44% (27/61) and 67 % (41/61), respectively. In the case of making a referral, the Camau Provincial General Hospital was the most preferred place (49 %), followed by district general hospitals (DGHs) (31%) and cancer specialist hospitals (20%) (**Table 5.2).**

Three-quarters of respondents 75 % (46/61) stated that workshop attendance was their preferred educational format, while the format of sending guidelines and specialised documents was the preferred option for 16% (10/61) of respondents. Amongst palliative care items listed, pain management, fatigue and communication were the most requested topics (85%, 51%, 45%) (**Table 5.3**).

**Table 5.3** Preferred educational formats and topics by family doctors (n=61)

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | n | % |
| Preferred educational formats | |  |  |
|  | Workshop/seminar | 46 | 75 |
|  | Documents by post | 10 | 16 |
|  | Internet-based | 8 | 13 |
|  | Telephone counselling | 7 | 11 |
|  | Hospital placement | 5 | 8 |
|  | Others | 1 | 2 |
| Preferred topics | |  |  |
|  | Pain management | 52 | 85 |
|  | Dyspnea | 17 | 28 |
|  | Gastrointestinal symptoms | 22 | 36 |
|  | Fatigue/ Anorexia | 31 | 51 |
|  | Communication | 27 | 45 |
|  | Psychiatry | 5 | 8 |
|  | Others | 2 | 3 |

**Table 5.4** Practice characteristics of family doctors and their satisfaction levels with the activities of the programme 4 months after workshop (n=44).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  |  | n | % |
| Number of cancer patients per month | | |  |  |
|  | 0 |  | 13 | 29 |
|  | 1 to 3 |  | 25 | 58 |
|  | 4 to 5 |  | 5 | 11 |
|  | 6 |  | 1 | 2 |
| Hospitals for making referrals | | |  |  |
|  | The PGH |  | 18 | 41 |
|  | DGHs |  | 17 | 39 |
|  | Cancer Specialist Hospitals | | 9 | 20 |
| Reasons for not prescribing opioids | | |  |  |
|  | Complicated regulations | | 27 | 61 |
|  | Unavailability of oral morphine | | 18 | 41 |
|  | Afraid of misuse | | 15 | 34 |
| Using counselling telephone line | | | 8 | 18 |
|  | Consultation about clinical situations | | 3 | 7 |
|  | Questions related to PHRs | | 3 | 7 |
|  | Ask about local services & guidance | | 2 | 4 |
| Levels of satisfaction with the workshop | | |  |  |
|  | Very satisfied | | 10 | 23 |
|  | Satisfied | | 24 | 54 |
|  | Neither | | 7 | 16 |
|  | Unsatisfied | | 3 | 7 |

Regarding the post-workshop survey, of 44 rural family doctors who responded to post-workshop questionnaires, 70% (31/44) had provided palliative care to cancer patients in their workplace. Amongst this group, more than a half (58%) had 1 – 3 patients per month, although only one-third (30%) mentioned an increase in caseloads since the pre-workshop survey (**Table 5.4**). Thirteen doctors (30%) reported an increase in morphine prescription in their workplace since the workshop. The largest number of morphine ampoules prescribed was 30 ampoules per month; however, the mean figure was just 4 ampoules monthly. On the contrary, 19 (43%) doctors had not prescribed morphine since the workshop. The reasons stated as preventing doctors from prescribing opioids stated include complicated regulations (27/44), unavailability of oral morphine (18/44) and being afraid of misusing the drugs (15/44). More than a half of respondents (24/44) indicated that they did not experience any trouble with the supply of morphine. However, fentanyl patches or oral morphine were only used by 11% (5/44) CHSs surveyed. Potential indicators for changes in practice performance after the workshops may be the quantity of palliative patients visited and the number of ampoules of morphine prescribed.

Interestingly, after 4 months, almost all rural family doctors (42/44) admitted that they had referred the NGPC in practising palliative care. In the case of making a referral, the Camau PGH and DGHs were each preferred by approximately 40% of doctors. Three-quarters of doctors (77%) were satisfied or very satisfied with the programme of the workshop (**Table 5.4**).

In relation to the additional support programme from the project after the workshop, 18% (8/44) rural family doctors reported using the counselling phone line. Questions asked were related to clinical situations which they were facing, information on patient-held records, current services at the PCU and the local guidance on palliative and cancer care which had been posted monthly to them (**Table 5.4**). In addition, 27% (12/44) doctors indicated they had used and been interested in these documents. The benefit of the patient-held record was agreed on by only 3/44 responses (7%) (**Figure 5.3**).

Most popular themes presented, in the descending order of satisfaction, were WHO’s ladder-based pain management 84% (37/44), communication and palliative care principles 61% (27/44), management of common cancer-related symptoms 25% (11/44) (**Figure 5.3**). Other activities of the programme such as circulating guidelines and documents monthly, the counselling telephone service call and accompanying discharged patients by their PHR received satisfaction ratings of 27% (12/44), 16% (8/44) and 7% (3/44) (**Figure 5.3**).

**Figure 5.3** Satisfaction about palliative care topics and activities (n = 44).

With regard to the educational outcomes of the intervention, the mean total score on the Palliative Care Knowledge Test (PCKT) and the Confidence Rating Scale (CRS) as well as the mean scores for every aspect obtained by participants before and after attending the workshop are shown in **Table 5.5.**

An independent sample t- test was conducted to compare the PCKT scores between pre- and post-workshop. There was a statistically significant increase in scores of knowledge before (M= 10.1, SD= 1.9) and 4 months later (M= 13.3, SD=2.6; t (103) =2.9, p = 0.004, two-tailed). The magnitude of the difference in the means (mean difference = 5.07, 95% CI: 1.6 to 8.5) was moderately large (eta squared = 0.09).

Similarly, there was a statistically significant increase in scores of confidence with the same test on two occasions, pre-workshop (M= 35.9 SD= 15) and post-workshop (M=52, SD= 13.2; t (101) = 6, p <0.001, two-tailed). The magnitude of the difference in the means (mean difference = 16, 95% CI: 10.8 to 21.3) was considerably large (eta squared = 0.25).

**Table 5.5** Comparisons of knowledge and confidence scores of family doctors before and after participation in the workshop.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Pre-workshop | | Post-workshop | | P-value |
| Mean | SD | Mean | SD |
| ***Knowledge*** | ***10.1*** | ***1.9*** | ***13.3*** | ***2.6*** | ***0.004*** |
| 1. Philosophy | *1.3* | 0.8 | *1.8* | 0.4 | 0.002 |
| 2. Pain management | *3.1* | 0.7 | *3.9* | 0.9 | <0.001 |
| 3.Dyspnoea management | *1.5* | 0.8 | *2.3* | 1.2 | 0.002 |
| 4.Psychiatric problems | *2.5* | 0.9 | *3.1* | 0.7 | 0.009 |
| 5. Gastrointestinal issues | *1.6* | 1 | *2.2* | 0.9 | 0.008 |
| ***Confidence*** | ***35.9*** | ***15*** | ***52*** | ***13.2*** | ***<0.001*** |
| 1. Pain management | *14.8* | 5.1 | *20.3* | 5.9 | <0.001 |
| 2. Palliative principles | *6.9* | 4.7 | *11.5* | 4.0 | <0.001 |
| 3. Communication | *14.3* | 7.8 | *20.1* | 5.6 | 0.001 |

Linear regression analysis was used to investigate associations between self- reported knowledge and confidence scores. Moreover, the relationships between dependent variables (knowledge and confidence scores) and independent variables (increases in caseloads or number of patients, professional and personal characteristics and so on) were tested using the independence sample t-test.

There was a weak correlation between scores of knowledge and scores of confidence (r = 0.27, n = 44). In addition, doctors who reported an increase in morphine prescription had a higher mean score on the PCKT (t-test, p =0.009); and who mentioned increased caseloads had a higher mean score on the CRS (t-test, p = 0.05).

Finally, 7/ 22 (32%) comments in the blank box at the end of the post-workshop questionnaires suggested that the procedures for the supply and prescription of morphine should be simplified.

## 5.4 Summary

This chapter reported the evaluation of the impact of the educational workshop in palliative care and additional support activities on the knowledge and confidence of rural family doctors in Camau. The national strategy for palliative care in Vietnam is to integrate palliative care to the existing cancer and primary care system. The primary healthcare teams at CHSs are the mainstay of healthcare provision for patients with advanced cancer with palliative care needs in the community. In Camau, 70% of rural family doctors are involved in palliative care provision for cancer patients. However, 85% of them had no palliative care training before or after graduation (Viet et al., 2011). Recognising their central role, the C4 commissioned a provincial palliative care education intervention because post-qualification education had been limited.

The main activity of the intervention included a 2-day workshop held in Camau City, followed by additional support in subsequent 4 months, such as circulating local clinical guidance, setting up a counselling telephone line and accompanying a discharged patient by a PHR. The evaluation was conducted between August 2011 and February 2012, through pre- and post-workshop questionnaires based on a parallel mixed methods approach. In the pre-workshop phase, 85 rural family doctors from 85 CHSs were selected anonymously to receive questionnaires and were invited to participate in the workshop 2 months later. Sixty-one amongst them participated the workshop and were subject to receive additional support and post-workshop questionnaires.

The overall response rate was 67 % and three-quarters of participant doctors were satisfied or very satisfied with the content and activities of the programme. Approximately one-third indicated an increase in morphine prescription and caseloads in their workplace. There were statistically significant increases in scores of knowledge from 10.1 to 13.3 and confidence from 35.9 to 52 observed from the participants pre-and post-workshop. There was a weak correlation between scores of knowledge and scores of confidence. Moreover, doctors who reported an increase in morphine prescribing had a higher mean score on the PCKT, and who mentioned increased caseloads had a higher mean score on the CRS.

The workshop increased the knowledge, confidence, and to a lesser extent, changed behaviour of participants. The clinical outcomes of this educational intervention with advanced cancer patients who need palliative care at primary healthcare level will be partly evaluated partly in the next chapter by interviewing patients who were receiving care at CHSs from the doctors who were trained on the project.

# Chapter 6 – Choices of Patients with Advanced Cancer on Two Palliative Care Settings: Method and Findings

## 6.1 Introduction

In this chapter I will present interviews with cancer patients who had been admitted to the inpatient PCU as well as those had been under the care of the family doctors who received training during the project. I conducted interviews with them to explore the reasons for choosing place of care, their views on the current service and experiences during their disease trajectory. The similarities and differences between two groups of patients will also be discussed.

Evidence suggest cancer patients want to have their voices heard in decisions about their treatment and care, and they may contribute to planning, evaluation and delivery of palliative care services provided their voices are heard (NICE, 2004). According to Richardson and colleagues (2007), listening and responding to the views of service users is now considered as a cornerstone of patient-centred care. Healthcare professionals and policy makers recognise that listening to patients and their carers’ voices is an important way to develop sound and appropriate palliative care services (Conner et al., 2008; Seymour et al., 2003).

Most cancer patients wish to remain at home and receive care from GPs or family doctors for their end of life stage (Gomes & Higginson 2006), and even until dying (Ingleton et al. 2009b, Munday et al. 2007). However, even in many developed countries with a strong hospital sector, a majority of terminal cancer patients still die in hospitals (Higginson & Costantini 2008, WHO 2007). There is complex interaction of many factors which influence place of death. They are illness-related, individual and environmental factors (Higginson & Costantini 2008). According to Aabom and Pfeiffer (2009), the dissatisfaction of the patients and their carers with local palliative care services might be one of the factors.

Patients’ preferences impacting on the process of making decisions on the choice of health services is the result of a complex series of psychological and social processes (Bowling, 2009). Preferences are affected by patient perceptions and previous experiences of care available at home, in a hospice or hospital. Preferences are also shaped by fears about possible loss of dignity or fears of becoming a burden (Noble, 2011). Being in a preferred place of care is important as well as several other factors that contribute to patient satisfaction.

In Vietnam, Green and colleagues (2006) interviewed 39 patients with cancer and found that the majority of patients prefer to receive care in hospital. In addition, three-quarters of them experienced severe symptoms such as fatigue, pain, weight loss, anorexia, insomnia and so on. To my knowledge, this is likely to be the only research in Vietnam examining the preferences of advanced cancer patients on place of care, so provides important data. However, it was conducted in large cities of Vietnam in which inpatient palliative care services were more comprehensive than those of other provinces, so the findings may not be transferable to other cities or to rural areas.

According to Entwistle and colleagues (2002),

‘Research into people’s experiences of living with cancer, of treating and being treated for cancer, and of caring for someone with cancer or being cared for as someone with cancer, has a crucial role to play. The knowledge it generates can inform the development of treatments and services, help people who have cancer to develop their self-understanding and shape their identities, and contribute to wider understandings of the “problems” of cancer and cancer care.’

There are a considerable number of satisfaction surveys on cancer patients’ experiences and views on the quality of palliative care services that they receive. In surveys, researchers usually collect self-reported data. Surveys with questionnaires have been prominent in must of the research into experiences of cancer (Aspinal et al., 2003; Philip et al., 2009). These frequently apply a questionnaire format with closed-questions to examine patients’ views on relevant issues (Dougall et al., 2000). However, Seymour and colleagues (2003) argue that these measures only assess very specific aspects of overall care quality, and they may not allow patients to raise issues which are important to them. Therefore, surveys with a closed format questionnaire might not provide an insight into the real life of patients with palliative care needs. These patients may wish to express their feelings and thoughts about service provision from a holistic viewpoint and without being constrained by closed format questions (Aspinal et al., 2003). Moreover, in research studies related to palliative care, as Reyna and colleagues (2007) argue, patients are usually too ill or too distressed to complete a questionnaire or family carers do not want their loved one to suffer further from irrelevant work.

In contrast, qualitative research methods ask open questions to allow broader and deeper exploration and can be appropriate to research the complexity and individual nature of events and issues that are significant for patients, such as the doctor-patient relationship or experiences of cancer sufferers (Pope & Mays, 1995; Silverman, 2010). Similarly, Britten (1995) points out that this type of research may allow one to ‘ *ask people to explain why they had behaved in a certain way, to explore the decision making processes or to enquire about underlying factors.*’

The theoretical underpinnings for this study were based in the theory about interactions between health professionals and patients, a foundation of social medicine (Bowling, 2009; Cockerham, 2005). This theory has been extensively applied in studies about patients’ evaluations of healthcare services in addition to the communication between patients and physicians. It deals with the expectations, preferences and satisfaction of patients with healthcare providers, as well as how these factors influence patients’ choices of health services (Bowling, 2007). The key concept that guided this study is that experiences, expectations and satisfaction form facilitators to decision-making on preferred place of care.

Many factors may influence patient choices of care setting. First, patients’ views and beliefs about a potential setting play an important role (Koedoot et al., 2003; McCall & Rice). In addition, a number of additional factors can impact on a patients’ choice of place of care such as severity of illness; referral procedures; cost of services, for instance specialist versus generalist; geography and transportation issues; and so on (Higginson & Sen-Gupta, 2000; Koedoot, 2003; McCall & Rice, 2005; MoH, 2006). Values of patients may play an important role (Corner, 2010). Knowledge of the factors upon which patients’ preferences or the patients’ actual choice are based is necessary in guiding the patient through the decision-making process (Koedoot, 2003). Several studies in the literature have been performed on the nature and background of preferred place of care (Higginson & Sen-Gupta, 2000; McCall & Rice, 2005). According to them, the patient’s preference for place of care is seen and used as an indication for their actual care choice. However, patients’ actual care setting and their intended choice or care preference are sometimes not necessarily the same, since the preference on place of care is usually affected by many contextual factors, in particular when patients are facing an unexpected situation (McCall & Rice, 2005). In addition, preferences may have different meanings for different patients, and preferences were also influenced by the change in the choices that the patient and family made with the progression of disease, passing of time and the quality of the service delivered (Higginson & Sen-Gupta, 2000).

## 6.2 Research question raised from the research setting

Advanced cancer patients with palliative care needs in Camau can receive care from primary healthcare teams at their residence; from the inpatient PCU in the Provincial General Hospital (PGH); or even by travelling further to specialist cancer hospitals, which are frequently located in large cities outside Camau Province. The inpatient PCU provides specialist care for cancer patients with palliative care needs. These patients are frequently admitted in crisis and are normally referred from District General Hospitals (DGH) and Commune Health Stations (CHS) throughout the province.

In 2010, the Camau Cancer Control Committee (C4) launched a 5-year educational project on cancer and palliative care for healthcare physicians across the province. Its targets are to promote accessible and affordable palliative care to patients with cancer, in particular those who are living in remote areas of the province. However, there has been a lack of evidence on the preferences and perspectives of patients with advanced cancer on palliative care services. In Vietnam, because of the nature of healthcare and the health insurance system, patients have some choices on the place from which they wish to receive care. With regards to hospitalisation, for example, patients could choose services at any level of the healthcare system provided that they could afford to pay partly or totally the service costs (**Section 3.3.4**).

Green and colleagues (2006) found most patients with advanced cancer prefer to be cared for in hospital. This finding is probably the only available empirical evidence on the topic of choice of place of care, and the most reliable source of evidence on this subject in Vietnam. However, issues such as how cancer patients experiencing distressing symptoms indicate their preferences and wishes, and how these influence their views about the care they are receiving are unknown. This therefore has driven me to explore the issue of preferred place of care further.

The research question of this study was *‘What differences and similarities in terms of experiences of palliative care services and perspectives on place of care exist between patients with advanced cancer in the PCU, and their counterparts who were palliated by a trained family doctor in the community*.*’*

Therefore, this study aimed at exploring the experiences and the views of patients with advanced cancer on generalist palliative care provided by trained rural family doctors, and the specialist palliative care team in the hospital setting.

Two primary objectives were:

* To explore the experiences and perceptions of healthcare services as well as views on choice of place of care of patients with advanced cancer being cared for in hospital and in the community.
* To compare views and experiences of hospitalised patients with those being cared for in the community.

## 6.3 Methodology

A qualitative research approach with semi-structured interviews was employed to explore the experiences and views of patients with cancer on palliative care services in both hospital and community settings. The interviews aimed at gaining patient’s perspectives on existing services and sought to understand patients’ experiences, which may influence the process of making decisions on choosing the place of care. This method was chosen to enable the participants to speak about events and issues that are significant for them, such as the doctor-patient relationship and suffering from cancer-related symptoms (Aspinal et al., 2003; Pope & Mays, 1995).

### 6.3.1 Sample

A purposive sampling strategy was chosen to obtain a wide range of views about the choices of place of care. Patients relevant to the research questions were sought and invited to participate in the research (Mason, 2002; Bissell, 2011). The sample included hospitalised patients who were asked about the reasons for their admission, their experience with the disease as well as why they had not chosen to be cared for at primary healthcare services. Similarly, people with advanced cancer at home were interviewed to examine why they had chosen to be under the care from their current primary healthcare team and whether or not they were satisfied with the care. In total, 10 advanced cancer patients in the PCU and 7 at home were recruited. The recruitment was stopped when the data appeared to have reached saturation, with no themes or information within themes emerging.

### 6.3.2 Inclusion criteria

* People with advanced cancer (stage III or IV according to the staging of the UICC – Union for International Cancer Control) and over 18 years of age.
* Patients who were being cared for at the inpatient PCU in the Camau PGH or by trained family doctors at CHSs or at home.
* Patients who, in the estimation of the interviewer, were able to participate without carers’ help.

### 6.3.3 Exclusion criteria

* Patients with apparent cognitive impairment. This was ascertained by myself asking several simple questions regarding personal details, time or place.
* Patients who were unable to understand the research information either from the information sheet or verbal description.

### 6.3.4 Recruitment

Patients with advanced cancer, who were being treated at the inpatient PCU and were interested in the research, were invited by the research team to take part in an interview. The interviewer then contacted the patients to arrange a time and location convenient for an interview. Interviews were most frequently conducted in a quiet hospital room.

Similarly, patients who were currently receiving palliative care from trained family doctors in the community were invited by local healthcare professionals to participate in the study. If the patient agreed to participate, a member of the research team then contacted the patient to arrange an interview at home at a convenient time. The interviewer always came to patients’ homes with a local nurse who would be consulted if the patient felt distressed. All patients were asked to sign a written informed consent form before beginning an interview. A sample of this is presented in **Appendix 3.1**.

### 6.3.5 The Interview Guide

In order to tackle the research objectives, the original semi-structured interview script addressed the following issues:

1. The physical symptoms and psychosocial issues that the patient was experiencing. These were highly likely to influence patients’ decision on choosing the place of care: local health settings versus an acute hospital setting.
2. Who were the decision makers? How were decisions made?
3. Patient’s views on the healthcare professionals’ work, especially family doctors, and contexts in which the care was delivered.
4. Patient’s views on how services should develop in order to respond to patient’s choices.

As needed, the interviewer probed areas that emerged from the interviews that were relevant to the study aims. The interview guide was tailored to the flow of the patients’ story. Questions were re-ordered as necessary to create a flow that would allow patients to reflect on their responses to questions. A English – translated version of an interview with a patient with cancer is presented in **Appendix 5**

### 6.3.6 Data collection and analysis

Interviews often lasted from 15 to 30 minutes. These interviews took place from August 2011 to January 2012. Several demographic data were also collected (**Table 6.1**). This is because the author’s assumptions that these might have some impact on patients’ choice on place of care.

The author, who was not involved in current care, interviewed all participants. The interviews were recorded using a Sony ICD-PX312 recorder and transcribed verbatim. Field notes also were documented during the interview process. This ensured the provision of contextual data for the analysis of transcripts.

Each transcript was given a code number, the names of patients interviewed were coded by assigning different letters, and any identifiable information was removed. These steps guaranteed the anonymous basis of the data.

The method of thematic framework analysis was applied to identify themes related to patients’ views and experiences. The coding framework was developed partly from the author’s preconceptions based on the research questions together with further emerging concepts during the interview process and the familiarisation stage using a data-driven technique. This useful technique is described meticulously by Boyatzis (1998) in the book entitled ‘*Transformation Qualitative Information – Thematic Analysis & Code Development*’. The principal investigator reviewed the transcribed interviews and coding reports to identify themes, overarching constructs represented in the data. The unit of analysis included phrases or sentences that conveyed one specific idea. Additional emerging themes were identified inductively from the interviews. Divergent perspectives between participants at home and in hospital were noted. The themes raised by patients from the interviews then were grouped together to develop the core themes (Boyatzis, 1998; Pope et al., 2000; Van Cleemput, 2011).

The software package NVivo (version 8) was used to aid in the management of text data and organise sub-themes identified as well as core themes. Analysis on the Vietnamese versions of the transcripts was performed by the author. To address the issues of rigour and trustworthiness, the interrater reliability of the analysis of the coding was performed with a Vietnamese colleague who has experience in qualitative analysis. We firstly noted down themes independently through reading all Vietnamese transcripts. Any discrepancies then were resolved by consensus.

My second supervisor – Dr. Clare Gardiner – then assessed the quality of analysis based on coded core themes, sub-themes and direct quotations which were translated into English.

### 6.3.7 Ethical approval

This study was approved by the Camau Department of Health – the authorised body at the research site – and the University Research Ethics Committee of the University of Sheffield (UREC) where the researcher was studying.

## 6.4 Findings

There were 36 sub-themes, which emerged during the analysis process. They were grouped into six main themes. Some themes that related to opinions appeared somewhat contrasting, and as the analysis progressed further exploration occurred within and across themes. For example for two themes (dissatisfaction and negative views) it became apparent that patients in two settings expressed opposing views on the nature of ideal care. In order to answer the main research question about the similarities and differences in terms of patients’ experiences and views in the PCU and at home, themes will be presented in the form of divergent views where appropriate. Direct quotations have been selected to illustrate the themes raised by participant patients.

### 6.4.1. Descriptive features

**Table 6.1** shows several demographics and characteristics of patients with cancer interviewed in both settings. Ten patients in the PCU and seven at home were interviewed including six female and eleven male. A wide range of cancer diagnoses included liver, breast, lung, colon/rectum, stomach, prostate and so on. The patients’ age range was 40 –78 years and all patients were resident in rural areas.

Most interviewees complained about some degree of fatigue. The three next most common complaints reported were pain (14/17), anorexia (10/17) and dyspnea (4/17) in both settings. However, pain and dyspnea were the chief complaints of patients seeking inpatient care.

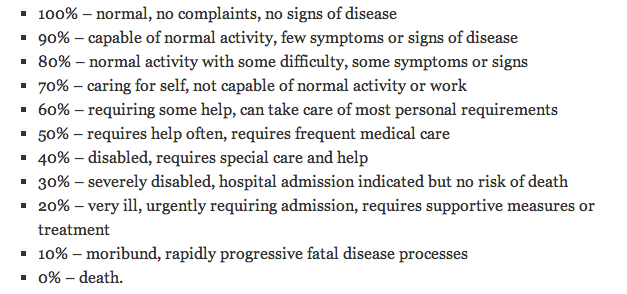
**Table 6.1** Several demographic characteristics of interviewees (n =17).

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | Number of patients | % |
| Age Mean =67 | Range = 40-78 |  |  |
| Gender | Female | 6 | 35 |
|  | Male | 11 | 65 |
| Primary malignant site | Liver | 4 | 23 |
|  | Lung | 3 | 18 |
|  | Colon / Rectum | 3 | 18 |
|  | Breast | 2 | 12 |
|  | Others | 5 | 29 |
| Health Insurance coverage | Yes | 15 | 88 |
|  | No | 2 | 12 |
| KPS\* scores | Median (min-max) | | |
| Inpatients | 50 (30-70) | | |
| Outpatients | 70 (30-80) | | |

(\*) KPS: Karnofsky Performance Status.

Although reported by both hospitalised and home patients, the degrees of distress and debilitation appeared to be more severe amongst the former. The median KPS score (Karnofsky Performance Status Scores – **Table 6.2**) of the ten patients at PCU was 50 in comparison with 70 for their counterparts at home. This indicates that the patients in the PCU had a greater level of need and worse performance scores than those at home.

With the question related to who had made the decision on the choice of the current place of care, almost all patients stated that they had made their own decision, except two patients at the PCU who had been admitted in emergency crisis by their family members’ decision.

**Table 6.2** Karnofsky Performance Status Score (Hanks et al., 2010)

### 6.4.2. Previous experiences of the disease

*Onset of disease, denial and suspicion*

Patients had their own ideas about their initial symptoms. Patients’ initial symptoms at the onset of disease corresponded with the classic warning signs of cancer, but they were not severe enough for the patients to seek medical advice immediately. Most patients recalled that they initially considered their first symptoms as signs of common illnesses such as cold, back pain, or blood in feces thought to be caused by hemorrhoids. They often attributed these troubles to getting older or working hard.

This denial transforms fear into feelings that are less threatening and easy to overcome. The following quote is from a patient with lung cancer in PCU:

‘I didn’t suffer much at the beginning, only a little short of breathe and cough. I persuaded myself that it wasn’t serious and just got on with my life . . . so I ignored it, after a few weeks it was still persistent, then I realised how serious the situation was.’

Many patients appeared reluctant to seek help until they suffered from very distressing symptoms that did not respond to self-medication and/or treatments at local healthcare services. Patients also appeared reluctant to express their distress, perhaps as a strategy to avoid additional emotional distress or anxiety for themselves as well as for their relatives.

Most patients recalled that they were informed of the diagnosis of suspected cancer at the first imaging investigation. Some patients still remembered their reactions to the diagnosis, many were shocked initially, and this was often followed by a stoical response to destiny.

‘ When he [oncologist] said to me, after having the result of my endoscopy, there was possibly a malignancy with my belly which I needed to get it cut off. I was shocked completely and could not remember anything after that. After taking time to get things sorted out, I remembered my cousin’s case, he had been living with his stomach cancer more than five years anyway.’

*The burden of conventional cancer therapies*

A majority of patients visited or were referred to the HCMC Cancer Hospital – the best of few specialist cancer hospitals in the South of Vietnam – for the confirmation of cancer diagnosis and for some specialist treatments such as surgery, chemotherapy and irradiation therapy. Patients’ experiences varied considerably. For some patients the investigations and interventions were to some extent unpleasant and distressing; others seemed to tolerate these procedures well.

Ten of the seventeen patients reported that they had received oncology treatments. Surgery seemed to be less likely to cause memorable discomfort compared to other interventions. Similarly, irradiation therapy alone did not seem to cause significant distress. Conversely, most patients had negative experiences with adjuvant chemotherapy related to vomiting, anorexia and hair loss. However, the most considerable treatment burdens were the physical demands of multiple hospital appointments, a long distance travelling to get treatments and the overcrowded conditions in specialist cancer hospitals. A patient with advanced breast caner reported:

‘ I travelled to there [cancer hospital] dozens of times for chemotherapy . . . in the period of radiation therapy, I had to rent a flat near hospital for more than a month . . . it was really terrible. I had to wait ages to my turn because there is always a very long queue of patients at there.’

*Recognition of the incurable stage of the disease.*

From the interviews, it was clear that all patients knew that there was no likelihood of a cure at the current stage of their disease. They often redefined the meaning of their symptoms as their disease developed and initial hopes of the disease being ‘curable’ altered as it reached to advanced stages. For some patients the acceptance of a new situation appeared to empower them. They felt easier talking with friends and neighbours about their illness. It was also easier for them to make decisions around choosing a preferred place of care in the case of symptom recurrence. In all interviews, patients appeared to have made a conscious decision about choosing where they would prefer to be cared for at that moment. One patient at home with advanced liver cancer who was predicted an expectancy of life of no more than 6 months expressed his thoughts:

‘ It may be better as you know that it is no longer curable [incurable stage] . . . No need to travel a lot . . .No need to waste lots of money . . .and time. Sometimes, I’ve thought that I’m still lucky because . . .at least I’m also aware of how much time I have been given to live . . .’

### 6.4.3 Physical and psychosocial impact of disease progression and treatment

Patients’ stories revealed the direct impact of their disease stage on their current health status. Most of the symptoms and problems described were physical or psychosocial ones. For example, patients reported physical suffering, which was often related to their previous cancer, such as lung or spinal metastasis or local recurrence from primary cancer sites. A patient in the PCU with a breast cancer recurrence after eight years described the physical impact of this:

‘ Because . . . unfortunately, the lump in my chest returned and spread out to my liver . . . It has made me very, very painful and tired most of the time.’

Patients also described the negative effects of previous cancer treatments given to ameliorate disease symptoms. As a result of physical limitations due to the illness, patients reported that they were not able to do the things they wanted to do. This experience was frequently followed by feelings of frustration, and sometimes a sense of anger, directed at their illness or themselves. As one patient in the PCU complained bitterly of his condition:

‘I cannot look after for myself any more . . . I cannot even stand up without help . . . I am almost bedridden . . . my life is so miserable now.’

Similarly, but to a lesser degree, one patient at home was frequently experiencing a treatment-related trouble, that is abdominal colic pain and defecation incontinence because of total colectomy due to cancerous colonic polyposis. The patient described the impact of this trouble on his psychosocial functioning and dignity:

‘ . . . You know from the last operation, I cannot attend any meeting at my place . . . the only reason is that . . .It is so embarrassing . . . I admit that I cannot control the time of having a shit, often just a little . . . So my solution was wearing a nappy all time . . . like I do now.’

In comparison with their counterparts in hospital, patients with advanced cancer at home had a higher median KPS score (70 versus 50). Only one patient with end-stage colonic cancer at home was bedridden with a KPS score of 40. The six remaining patients were able to care for themselves and do some daily activities. Patients described ways in which they maintained the ability to look after themselves and carry out a normal role in their families, particularly in relation to day-to-day activities. One patient with breast cancer reported:

‘ I’ve been doing most stuff . . . for example washing my clothes, cleaning my room or watering the garden . . . most of the things myself but a bit slower . . . ‘

### 6.4.4 Patients’ adaptations and strategies for coping with the disease

All participants showed some acknowledgment about their current disease, and the poor prognosis. Most of them had experienced a long disease trajectory along with illness-related suffering, and they developed a gradual acceptance. Statements below provide examples of the participants acknowledging the fatal nature of their disease.

‘I was told that the cancer had spread to my lung. I know until now doctors have done whatever they can . . . and there is nothing more they can do for me at the moment.’

‘ I was told that the cancer that I’m suffering was incurable and I had to suffer it as an unexpected companion . . . when you get to accept its existence, it’s easier than for you to think about some things to fight it.’

Patients described broad coping efforts to fight the impact of the disease and not let it take over their lives. They often attempted to keep a balance between their knowledge about the incurable nature of the disease, with several solutions they used to attempt to stay as healthy as possible. Spirituality was highlighted as a fundamental component of coping with, and adapting to, the disease process. The spiritual solution used most was the reliance on religious faith, for example belief in Buddha or God. Although many participants acknowledged initial fear upon hearing the diagnosis of advanced cancer, spirituality served as a source of comfort, enhanced confidence, and lessened fears. In particular, patients noted that their faith and the direction of Buddha or God over the doctors could alleviate their misery and discomfort.

‘God is the one to give us life. He is the one to take our life. Every one has her or his fate . . . If you trust to God then he would give you a miracle . . . through, for example your doctors or someone else.’

A large proportion of patients did not feel nervous, or fearful of impending death or dying. They talked about their impending death at the time of the interview even though these subjects were not broached directly because of the potential for causing distress. They had come to terms with their situation by peaceful thinking and they all had accepted that they had been inevitable, far or close, to reach to the prospect of incoming death. This was a typical sentiment expressed by all patients interviewed. One hospitalised patient with a terminal lung cancer talked about his death as being close and inevitable.

‘I do understand that my disease [end-stage of lung cancer] cannot be cured . . . I have been prepared for it [death] . . . I am not worried about it [death] much. It could happen to anyone . . . even though without this cancer . . . at anytime . . .’

Another coping strategy was seeking and using complementary and alternative medicine (CAM) and/or traditional or folk remedies. Two main reasons for using these solutions were identified. One was the awareness of the incurable disease stage and the failure of the current conventional treatments. One patient with a relapsed breast cancer recalled her oncologist’s phrase at that point of time:

‘He said to me that . . .the fact is that there's no need for any more treatment for me. They had done all necessary treatments for me . . . It's now better as it is ... and I would not have to visit there [the cancer specialist hospital] for any additional treatment . . .I could use any traditional remedies at home provided that I find it OK for me.’

Another reason was a belief in additional benefits of CAM for their problems. One patient having acupuncture for a severe back pain stated:

‘ I was very impressed when having acupuncture done at the health station. I usually feel more comfortable with it [back pain] for a couple of days until the next session. Besides, he [acupuncture therapist] was always listening to me and giving me lots of useful information.’

Another patient even resumed social and charity work in which she had got involved before her disease appeared.

Although potentially linked to the coping strategy of resignation, patients do not seem to be passively disengaging from their stressors but rather going through a process of accommodating realistically impact of their disease. One patient with a recurrent breast cancer recalled:

‘After being in very low spirits for several months, I started to hope that I could survive this terrible disease. This happened when I was going home for the Tet [traditional holidays in Vietnam] before the next sessions of chemotherapy. Even though I could not eat anything at that time, I was convinced that I still had a good life to look forward to.’

Two patients at home were quite positive and optimistic and they expressed their feelings with the same old saying: *‘things that should come, will come’*, and one continued:

‘ . . . Although like it [his cancer] or not . . . it’s happened to you and the good things you should do is . . . to get on with it.’

### 6.4.5 Positive factors influencing patients’ choice

A considerable number of patients in both settings showed general satisfaction with the work done by healthcare professionals. In their stories they expressed a variety of positive feelings. It seems likely that this satisfaction, stated by 7 out of 10 patients in PCU interviewed, was the main reason for patients with cancer-related symptoms to choose to be cared for care in hospital.

Patients in hospital expressed satisfaction because they received effective and specialist treatments. In the views of hospitalised patients, their symptoms might be controlled more effectively if they were under the care of clinical doctors at the PCU. This may be because, as they explained, these doctors are already familiar with patients' problems since the patients had been admitted to the hospital many times for cancer treatments and/or palliative care. In addition, the staff in the PCU were believed to be more competent in terms of dealing with acute symptoms in addition to the availability of drugs and ancillary facilities in the PGH. Two patients in the inpatient PCU made clear comments on the issue of symptom management:

‘ I am getting very good treatment. My pain has disappeared rapidly. I can sleep like a baby now which I hardly could get if I was not here [the PCU].’

‘ I always get in here [the PCU] every time I get short of breath . . .because I think that there are many cancer specialists here . . .they used to treat my trouble a couple of times . . . also you know drugs are always available and medical devices are modernised . . .’

Similarly, a majority (6/7) of patients being under the care of local family doctors in rural area highly appreciated the ability of local healthcare professionals to meet their practical, physical and psychosocial needs. One of them described a positive experience with the primary healthcare team:

‘ They [local HCPs] are very kind to me. They helped with daily practical care every time I came to see them. They seem to be there to help patients. Generally speaking, the care I had was great.’

Another factor, which impacted on patients’ choice of care setting, was geographical convenience. This is often one of the main reasons for patients to choose being cared for in the local healthcare setting, as reported by 6 of the patients living with cancer at home, ‘ *It just takes a couples of minutes to get there [CHS]* ‘ or *‘ I could get medication injected and infused at home, because she [a nurse] is near here’*. On the contrary, only two amongst hospitalised patients obtained a pleasant feeling from travelling short distances to access to hospital services. One patient in hospital reported:

‘ …You know, it just took me half an hour to get here [PCU] . . . instead of more than one hour to go to the commune health station.’

The physician-patient relationship was another factor, which was likely to influence patients’ choice about place of care. There were 12 out of 17 patients in both settings who admitted that they had a reasonably close relationship with healthcare professionals, or that a professional was even a relative of theirs. One patient at home said:

‘He [a local healthcare professional] is my young acquaintance, so it is a little bit easy to talk to him about my trouble [pain caused by liver cancer] . . . or even request him something special such as a home visit or transfusion . . . for me which would be quite difficult with hospital doctors.’

Several patients in PCU also had a close and long-term acquaintance with the ward staff because they had been admitted to the Oncology Ward many times for episodes of cancer treatment or previous crises regarding acute symptoms.

‘ I am most acquainted with staff here. They seem to regconise immediately what problem I am suffering from every time I am referred to.’

Beside several similar positive factors, some patients who decided to be cared for by local family doctors pointed out further reasons for choosing their preferred place of care. First, patients at home appreciated the plurality of health services available because it met their palliative care needs. In fact, CHSs were frequently able to provide a wide range of healthcare services such as outpatient, out-of-hours, or even home care.

‘ If I was able to walk, I got there by myself. If my pain got worse, I probably got my injections done out-of-hours by them [local healthcare team].’

Another facilitator which was revealed in patients’ stories in rural setting is that it was easy for them to receive support and help that they needed from family and friends, and they were greatly appreciative of this:

‘You know everyone is just around and ready to help me. Their support and empathy for me have been extremely great …it makes me have a feeling of my troubles being shared so much. ’

‘ . . . Sometimes I think that it meant more to me [family support] than the professional care from nurses and doctors.’

Another expressed it in this way:

‘The contact with my family and friends was very important and helped my faith and helped me to lift up my spirit . . .. I really needed some one to talk about it over and over.’

The stories made it clear how much social relations mean to the patients. The need for togetherness and nearness and to talk repeatedly about their situation was a common feature in interviewees’ stories. Struggling through illness without the support of the family was difficult for the patients with advanced cancer. One male patient spoke of feeling grateful for his family members’ support:

‘I used to think I would get care at nursing home when I would get old . . . but as I ‘ve got this disease [metastased lung cancer], I feel less able to do daily stuff . . .I mean . . . such as getting to the loo . . . I tried to sort myself...but I couldn’t...They [his family carers] are always around and looking after me . . . said to me that I don’t have to be worried about everything . . . I really owed them so much for all their doings.’

The family assisted in various ways, but no matter how much assistance was given, it was of immense importance to their loved one.

Another facilitator for choosing being cared for with local healthcare team was a decrease of family carers’ efforts and financial burden in comparison with the case of hospitalisation. In the majority of the interviews in both settings, there was a sense that patients considered themselves as a burden to those supporting them.

‘Everything now, in fact that everything I want to do, my wife has to do it for me or help me overall. So sometimes I feel a bit guilty . . . a bit annoyed and unpleasant. You know that she is taking on a lot of responsibility looking after me since the beginning of my illness.’

Finally, two patients at home felt that the patient-held record (PHR) had been helpful and offered some benefit to them. One patient with breast cancer at home admitted that keeping her PHR made her feel more in control and better prepared for meetings with healthcare staff. She said:

‘ I can take information more from it [her PHR] . . .and be aware of my illness more . . . It has been helpful with my age . . . I sometimes have forgotten the information which I’ve been told about . . . whenever I go to the health station if they [healthcare professionals] ask me my illness pathway, I just show it to them . . .’

Examples of similar positive factors in both settings, which potentially influenced patients’ choice, are summarised and exemplified in **Table 6.3**. Three main themes were satisfaction with the care**,** close relationship with healthcare professionals and geographical convenience. In addition to these, patients at home gave three additional reasons, which are a wide range of local healthcare services, patients’ social interactions, and a reduction of family carers’ burden.

**Table 6.3** Summary of factors influencing choice of place of care in both settings

|  |  |
| --- | --- |
| Facilitators | Examples |
| Satisfaction with the care | *‘I am getting a very good treatment.’ \**  *‘Generally speaking, the care I had was great.’ \*\** |
| Close relationship with healthcare professionals | *‘I am acquainted with staff here.’ \**  *‘He [local professional] is my young acquaintance.’ \*\** |
| Geographical convenience | *‘It just took me a half of hour to get here.’ \**  *‘It just takes me a couples of minutes to get there.’ \*\** |
| Socio-psychological aspects (only related to patients being care for at home) | Wide range of local healthcare services  Social interactions  Reduction in family carers’ burden |

(\*): Patients in the inpatient PCU. (\*\*): Patients at home.

### 6.4.6 Negative factors influencing patients’ choice

*Patients in the inpatient PCU*

Patients with advanced cancer in hospital expressed some degree of dissatisfaction with care received in the local healthcare setting. Some of them stated that they wanted to be cared for in the PCU because they had encountered significant barriers to accessing local healthcare services. Four patients had felt that local family doctors staff were unwilling or reluctant to provide care to them, or even worse, behaved in a disrespectful manner to them. One said:

‘ He [CHS doctor] seems to lack enthusiasm in providing the patients with the care. He normally makes a superficial examination on me, gives me injections and some medication every time I come and says the same “ no need to worry”. Then I go back home and still live with my problem.’

In this theme, several additional reasons were also listed by patients to explain why they had chosen to be admitted to the inpatient PCU. **Table 6.4** provides example quotes for the sources of dissatisfaction including: local healthcare professionals who were not familiar enough with caring for cancer-related symptoms (3 patients), or did not acknowledge the cancer patients' condition (2 patients), and there was a lack of drugs and facilities at CHSs (2 patients). Below are some phrases from their stories:

‘ I do not think they [local professionals] could control my pain . . .I know they only have a few kinds of regular painkillers. Even at here [PCU] with lots of morphine and patches . . . it has taken ages to relieve my pain.’

‘ . . . How could they treat me while they didn’t know anything about my disease except my current pain.’

The next theme that emerged was difficulties in access and navigation through the healthcare system. Four participants made a total of eight statements regarding this theme. Participants stated that they had experienced long delays and excessive paperwork when they had asked to be referred to DGHs or the Camau PGH. They talked about insulted or offended feelings and described complicated processes such as navigating from the local setting to the hospital setting. They wished for more guidance or a clearer and faster way to navigate referral procedures, as one complained:

‘ I have been waiting a long time . . . around 3 hours just for all the paperwork stuff [referral document authenticating a valid health insurance coverage] regarding my case for the district hospital. Then I was treated one day there before being referred to here [PCU].’

Lack of time with doctors was reported by three patients in the PCU. One patient complained:

‘I could understand why they [doctors] didn’t have enough time for me . . .because they were physicians and it was like they were always busy and . . . they seem to focus so much on the treatment rather than on the state of mind of the patient . . . I don’t think he [the doctor] paid any mind to what I was feeling.’

*Patients at home*

In contrast, advanced cancer patients in rural healthcare settings discussed several problematic aspects of getting care in hospitals. Most of them were dissatisfied about the amount of time, which doctors devoted to them on each visit. This was frequently related to issues with poor communication, and insufficient time for patient-physician discussions. A patient at home told about his previous hospital doctor:

‘He [a hospital doctor] does what he has to do for a patient in the scope of his responsibility such as going through patients’ rooms, asking every patient a couple of questions, recommending something on nurses’ work, and going out . . .every patient, say, just up to five minutes. That’s all . . . I know he has a lot of patients he needs to visit . . . it would be better if he spent just a little bit more of time chatting to his patients.’

In addition, various unpleasant experiences in the past when patients had been admitted to hospital appeared to impact on patients’ choice to be cared for by local healthcare professionals. These include difficulties in getting access to inpatient services, such as complicated and bureaucratic referral procedure and difficulties progressing through the system together with having to travel considerable distances from their home in order to get specialist palliative care. Moreover, some patients felt separated from their social networks and family support. Overcrowded conditions in inpatient rooms and further burdens on family carers were also mentioned as a source of unpleasant experiences. For example, many patients had to share a hospital room, and their family carers even were allowed to stay in the room at night. One patient recalled:

‘ It was really terrible on my recent hospitalisation, you know . . . eight patients had to share an inpatients room coupled with carers, visitors . . . particularly in the evening, the room was overwhelmed by people and people . . . it was really exhausting.’

### 6.4.7 Patients’ wishes

In response to the question about patients’ suggestions for current palliative and cancer care service, or patients’ views on how services should develop in order to enable them to have a real choice, most patients wanted local healthcare teams to be more competent and enthusiastic about specialised care for patients’ problems. They also wanted there to be sufficient essential drugs and facilities at CHS as well as hospital level.

**Table 6.4** below summaries the sources of dissatisfaction for the patients both in hospital and at home.

**Table 6.4** Summary of sources of dissatisfaction in both settings

|  |  |  |
| --- | --- | --- |
| Sources of dissatisfaction | Patients at home | Patients in hospital |
| Alleged limitations at CHSs  Not being treated right  Lack of focus on individuals  Ineffective treatments  Lack of drugs and facilities |  | ✔ |
| Difficult access to inpatient services  Bureaucratic factors: delays in referrals  Transportation and/or long distance | ✔ | ✔ |
| Lack of family & friend sentiment/support |  | ✔ |
| Discomfort with hospital environment |  | ✔ |
| Increasing family carers’ burden |  | ✔ |
| Lack of time spent with patients | ✔ | ✔ |

## 6.5 Summary

This chapter presented the factors, which influence decisions around choosing the place of care for cancer patients with advanced stages in rural areas in Camau province, Vietnam. This exploration was conducted by comparing patients’ perspectives on the preferred place of care in two setting: in hospital and in the community. This was a descriptive, explorative, qualitative study using recorded semi-structured interviews, with a purposive sample of seven terminally ill cancer patients at the inpatient PCU and ten at home under the care of primary healthcare team. Thematic analysis was used to generate final findings.

The main determinants for desired place of care in both settings were organised into two main themes: past satisfactory experiences with the services and close relationships with healthcare staff. Regarding patients in hospital, two other factors were identified: a lower KPS score and negative attitudes with local services. Patients who chose the care with primary healthcare teams tended to have higher KPS scores, had taken into account family resources and support as well as social interactions, and also highlighted geographical convenience.

This study provides evidence that there are many important factors influencing patients’ place of care such as severity of patients’ symptoms, relationships with healthcare staff, family support, geographical locations and so on. In addition, the personal choice of patients also plays an important role. They often made their own decision on their preferred place of care based partly on their evaluation of the quality of palliative care services. Therefore, the challenge to those who work with cancer patients at terminal stages is to develop effective interventions in order to be able to provide an acceptable quality of healthcare service to facilitate the patients’ desires around place of care, and thereafter, where possible, to response to patients’ preferences.

In the next chapter, the improvements in competence and behaviour affecting palliative care practice of trained rural family doctors and satisfaction levels of advanced cancer patients with palliative care services will be discussed in detail by examining two data sources: surveys with the doctors and interviews with the patients.

# Chapter 7 – Discussion

## 7.1 Overview

This provincial educational intervention and support programme should be seen in the context of the initial steps of a five-year educational project in palliative care for the rural family doctors in Camau. The overarching aim of this project was to integrate palliative care for cancer patients with the existing primary healthcare services through, partly, raising the standards of generalist palliative care. So far, I have found few published studies of this type in Vietnam. In addition, this chapter focuses on the situation in the Camau province of Vietnam, and it is acknowledged that there would be similarities and differences to other provinces and countries, particularly ones with a long history of palliative care development.

The study of the effectiveness of the intervention in relation to rural family doctors’ knowledge and confidence can be regarded as both formative and summative evaluation. This is because the focus was on assessing the outcomes after a fixed length of time in relation to the stated objectives. Moreover, the evaluation of patient satisfaction with the care can be considered to be a summative element, since the main purpose was to examine satisfaction with the quality of care from the perspectives of the patients, and to provide feedback for planning the next steps of the programme.

As discussed in the methodology chapter, a trend to conduct separate analysis on quantitative and qualitative data is found frequently in the majority of mixed methods healthcare studies, including in palliative care research (O’Cathain et al., 2007). Even if the qualitative and quantitative data are not integrated during data collection or analysis, the findings may be integrated at the stage of interpretation and conclusion (Ostlund et al., 2011). As such, I will first discuss the findings of the two empirical chapters separately, before integrating the findings using a triangulation protocol in **Chapter 8**.

This educational intervention and the support programme followed several of the important principles of adult learning theory (Jarvis, 2004). First, the educational intervention was context-based and required the active involvement of participating family doctors. Second, the educational input was tailored and specific to doctors’ learning needs in terms of content and format, depending on their preferred learning style. Third, the learners had some personal autonomy and control over the learning process (Calman, 2010). Finally, learning support was sent in a timely manner to facilitate optimal management of the patient’s care (Davis et al., 1999).

In addition to the above, the intervention was clearly defined at the beginning, and the outcomes were measured by changes in physician competence and behaviour. In general, the findings demonstrate high satisfaction with the workshop and considerable improvement of perceived knowledge, skills and confidence in palliative care practice by participants.

There has long been awareness that the effectiveness of CME can be measured at different levels: competence (perceived knowledge and confidence), performance, and patient health status (Calman, 2010; Campbell, 2007) and that the impact declines in that order (Forsetlund et al., 2009). However, there is general agreement that measuring the outcomes of an intervention on the population of palliative patients is usually difficult. Normal measures of clinical success, such as reduction in mortality or crisis emergency rates, can be replaced with symptom control, but these do not always capture important changes in psychosocial distress. In order to evaluate the impact on patients convincingly, a RCT or a controlled experimental research design might be suitable. However, data for building a tool for measuring the quality of life of patients with advanced cancer did not exist. In addition, using existing tools to assess physical, functional, psychosocial and spiritual dimensions of patients’ lives such as the AQEL (Assessment of Quality of Life at the End of Life) is considered to be complicated (Mitchell et al., 2008) and might be inappropriate to the local context. Therefore, in order to address to some extent the C4’s question about the impact of the intervention on targeted patients, a qualitative research approach was used additionally to explore the perspectives of patients under the care of trained rural family doctors on the quality of palliative care service in comparison with that from their counterparts in the PCU. This approach was undertaken to collect valuable experiential data from patients, in the absence of a methodology that would allow an assessment of the direct impact of the intervention on patients.

The following sections will present discussions on findings achieved from the intervention following the format of an educational evaluation research report.

## 7.2 Outcomes of the Intervention to rural family doctors

### 7.2.1 Response rate

The response rate was 61/ 85 for the pre-workshop and 44/61 for the post-workshop survey (more than 70% each). Partly completed questionnaires were counted as a response, not as a refusal, if less than 10% of the items were omitted. According to Addington-Hall (2007a), a response rate needs to be high enough (possibly, in excess of 70%) in order to make a valid inference about a surveyed population. The response rate of this study was somewhat higher than that of some previously published studies (Liu et al., 2005; Lloyd-Williams et al., 2000; Noble et al., 2001). It may partly be due to the fact that the questionnaire was relatively short (Nakash et al., 2006). There were only 40 self-completed questions on two sides of two sheets of A4 for each questionnaire. Another reason may be that the surveys related to day-to-day practice that was, therefore, more likely to be of particular interest to many doctors. Although a moderate response rate limits the strength of conclusions, it is likely to reflect the context of current palliative practice as well as doctors’ perspectives on that practice. In addition to this, it probably provides some useful information for the whole project. However, as the final response rate was just 44 /85 rural family doctors of the province; caution should be exercised when making any inference. This is due to the fact that non-responders might differ systematically from the responders. Addington-Hall (2007a) explains that ‘*when response rates are low, respondents are essentially self-selected and are not representative of the population ... then non-response error is introduced to the survey.’* As I was unfortunately unable to collect data about the non-respondents, the extent to which the responding population is representative is unknown.

Therefore, the information from respondents in this study is, to some extent, not considered as a sufficient source for the assessment of the rural palliative care services of the province.

It is not apparent why the post-workshop response rate was low, though several tactics were used in order to increase the responses. Similarly, Noble and colleagues (2003) mentioned that a reminder does not lead to a further significant response.

### 7.2.2 Personal and professional characteristics

Family doctors working at health stations in Vietnam need to spend six years studying in order to get the corresponding qualification at medical schools. Until recently, however, there has not been any official curriculum about palliative medicine at undergraduate or postgraduate levels (Green et al. 2006). Teaching courses and workshops such as CME or CPD in pain management and palliative care are not still available universally to healthcare professionals at all levels (Krakauer et al., 2007). Therefore, the fact that only 41 % of pre-workshop doctors had experienced some palliative care training in the previous two years is entirely understandable. This figure is lower than that from several countries with a long history of palliative care specialism (Barclay et al. 1997, Groot et al. 2005).

Two-thirds of surveyed rural family doctors had been working at CHSs for up to ten years since being qualifying. In Vietnam, it normally takes 6 years in medical school for an undergraduate to become a general practitioner. Since staff shortages have been frequently observed at the CHS level for many years in Vietnam, many newly graduated family doctors are able to apply for a job as a family doctor at the CHS level (similar to GPs at surgeries in the UK) without any other professional training being required. Findings from our study showed no relationship between the years in practice of family doctors with the scores on the knowledge or confidence tests.

There are several specific organisational and personal factors, which may affect the learning approach both positively and negatively. According to Delva and colleagues (2002), a feeling of being overwhelmed at work is often associated with a superficial and disorganised learning approach. In their study, they observed that young rural family physicians might be most vulnerable in terms of feeling overworked and adopting less effective approaches to learning in comparison with their older colleagues. In contrast, physicians with feelings of right choice, independence and support at work will have internal motivation, take a deep approach to learning and use independent learning methods (Henwood & McGannan, 2007).

The main role of family doctors in remote areas of Camau province is to provide primary healthcare services to all inhabitants in the community. They sometimes provide palliative care to advanced cancer patients with palliative care needs as well. In the pre-workshop survey, 65 % of family doctors reported that a monthly number of 1-3 palliative patients visited their office. This figure was similar to that of a similar survey in 2010 in Camau (Viet et al., 2011). In the survey of Lloyd-William and colleagues (2000) in the UK, the corresponding figure was 4 patients with advanced cancer per year on average. The higher number reported in the survey in Camau is likely due to the fact that in traditional Vietnamese families, cancer patients at the terminal stage are often willing to be cared for and die at home. For instance, the number of cancer-related deaths in the PCU is approximately 20 (3%) out of 600 cancer patients with a terminal stage hospitalised per year (Tai, 2010). In contrast, about three-quarters of cancer patients eventually die in hospitals in developed countries, although a majority of them want to die at home (Aabom & Pfeiffer 2009, Gomes & Higginson 2006).

In Camau, every CHS serves as an access point into the healthcare system, particularly for patients with health insurance coverage. It is also responsible for providing primary healthcare services for a population of approximately 10,000 inhabitants. Therefore, family doctors are more likely to encounter cancer patients with palliative care needs in their area. This was confirmed by approximately two-third family doctors pre-workshop stating that they had experienced caring for advanced cancer patients. The corresponding proportions from the surveys of other authors are somewhat different; for example, Liu and colleagues (2005) in Taiwan reported 32.9%, Rhee and colleagues (2008) in Australia 25.2%. Involvement in palliative care makes it possible for these doctors to gain more relevant experiences and knowledge. As Groot and colleagues (2007) point out, doctors who have a larger number of palliative patients will have less perceived obstacles in obtaining new knowledge and expertise as well as delivering primary palliative care in the community.

It is evident in the body of the literature that some knowledge gained from educational programmes may be retained for between 6 weeks and 6 months (Bullock et al., 1999; Campbell, 2007; Fineberg et al., 2004). In this study, the 4-month period post-workshop was a compromise between allowing enough time for participants to encounter new palliative care patients and to optimise chances of receiving the post-workshop additional educational support. This also accords with the remarks of Ersek et al. (2010) and Leong et al. (2010). They suggest that four months is necessary to assess the long-term impact of an increase in knowledge and commitment to palliative care of participant doctors.

### 7.2.3 Educational reach with respect to perceived knowledge, skills and confidence

The educational outcomes of the intervention with participant doctors were evaluated mainly by quantitative analyses. The significant achievement of learning objectives was demonstrated on self-evaluation scores of the Palliative Care Knowledge test (PCKT), the Confidence Rating Scale (CRS), some changes in practice, workshop attendance and participants’ satisfaction levels. Scores of knowledge, skills and confidence in practice related to all topics increased four months after attending the workshop. These increases were statistically significant. According to Kenny (2001), self-reporting of changes in practice and the commitment of participants in terms of practice innovations either at an individual or organisational level may be considered as direct outcomes of attending education activities. In this study, however, a weak correlation between scores of knowledge and scores of confidence was also observed. It is acknowledged that this is not easy to explain due to the complicated nature of these attributes, and may be beyond the scope of this study.

The improvements in knowledge and confidence scores in doctors from our study are also in line with the findings of the study by Harris and colleagues in 2008 on the effects of pain management programmes on the competence of healthcare physicians. In the pretest-posttest study with randomisation and a control group, they found that physicians who participated in either of the two educational programmes in pain management experienced an immediate improvement in their scores on the KnowPain-50 scale; and this improvement persisted for at least 3 months. Based on data from the control group, they reasoned that these changes were most consistent with a conclusion that other environmental effects were unlikely to contribute to such changes due to the full magnitude and pattern of the changes which had been observed in their results. Similarly, in a systematic review of educational interventions in palliative care for primary care physicians from 1966 to 2005 around the world, Alvarez and Agra (2006) regconised that an improvement in knowledge had been seen in all studies reviewed.

Educational formats such as single section meetings or day courses with update lectures covering common topics, for instance morphine prescribing or management of some symptoms, in the view of Finlay and Simon (2005), may do little to increase the factual knowledge of attendees. In contrast, through didactic presentations, case studies and interactive discussions, participants gained knowledge and skills to improve their practice and influence the system in which they were working (Leong et al., 2010). In addition, Davis and colleagues (1999), in a systematic review of 64 studies from 1993 to 1999 examining the impact of formal CME such as conferences, workshops, rounds, and other traditional continuing education activities on changes of physician behaviour or healthcare outcomes, stated that although didactic interventions fail to achieve success in changing performance or healthcare, ‘*such interventions may change other elements of competence, such as knowledge, skills, or attitudes, or may act as predisposing elements to change.’* (p.870)

In respect to doctors’ educational outcomes, although the mean scores of most topics increased in the post-workshop survey, some items such as psychiatry and gastrointestinal symptoms had lower scores. This is partly because of time constraints for the workshop, which made it impossible for lecturers to expand on these themes. In addition, although workshop content was prepared depending on participants’ interest and needs, there were an additional number of concerns raised by delegates during the workshop. As a result, several presentations in the agenda had been changed. This inevitably led to time constraints on other topics.

Furthermore, according to Hegarty and Currow (2010), adopting the above approaches in undertaking educational interventions and programmes may have benefits in producing targeted, quantifiable changes in clinical practice. However, sustaining change in more complex knowledge or skills, for example the development of communication skills, is best achieved through clinical supervision following teaching sessions. This is may be because the communication skills learned in the training environment are not always transferred back into the clinical setting. The potential role of clinical supervision could be considered as one way of enhancing the clinical effectiveness of communication skills training programmes (Heaven et al., 2006). Because of time limitations, clinical supervision was not considered in this study.

Hutchinson (1999) argued that it is difficult to establish the extent to which an increase in knowledge could lead to a change of behaviours and an improvement in practice. Similarly, Finlay and Noble (2005) state that it is easier to improve knowledge, skills and competencies than to change professional behaviours. In contrast, some studies suggest that the acquaintance with specialised knowledge leads physicians to improve their daily practice in terms of behaviour and performance (Davis et al., 1999), which could improve the outcomes of health care on their patients.

Over the last two decades, according to Forsetlund and colleagues (2009), questions of how and why some educational programmes worked better than others have been raised and investigators have tried to find potential explanatory factors. Their focus has shifted from measuring knowledge, skills, or attitudes to measuring the performance and behaviours of physicians as well as the health status of patients.

### 7.2.4 Performance improvements and behavioural changes

The clinical and practical outcomes of this study were evaluated quantitatively. Four months after attendance at the workshop, one-third (13/44) of doctors mentioned an increase in caseloads related to palliation for patients with cancer. This evidence, taken alongside the improved scores in knowledge and confidence, may indicate that doctors felt more confident in managing common palliative issues and therefore, did not refer their patients to secondary or tertiary hospitals. In addition, many different facilitators may impact on the effectiveness of this educational intervention such as having suitable participants, the relevance of the programme to practice and the adequacies of the practice milieu (Calman, 2010). Nevertheless, Campbell (2007) argues that many potential factors which happen at the same time might contribute to the observed changes, and prevent one from concluding that perceived knowledge is gained mainly from the educational programme.

With regard to the question of whether or not the workshop and additional support have lead to behavioural and practice changes, this study found that one-third of doctors reported an increase in cancer-related caseloads and morphine prescription. In addition, the proportion of doctors who referred to the National Guidelines for Palliative Care (NGPC) in practice four months after the workshop was 95%, in comparison with 44% pre-workshop. These findings are also in agreement with those of the Cantillon and Jones’ systematic review in 1999. They reviewed 69 papers which described the effects of educational interventions with GPs occurring after completion of general practice vocational training on subsequent doctor behaviour or patient outcomes. The results showed that one-third of these papers documented changes in doctor behaviours. Moreover, in a systematic review conducted by Mitchell (2002), the author found that with adequate palliative care training, GPs were able to deliver sound and effective care.

The findings indicate that workshop participation may have been responsible for positive behavioural changes, such as improvements in rural family doctors’ performance regarding morphine prescription and the number of palliative patients treated. These improvements were probably relevant to significant increases in knowledge and confidence scores of the participant doctors after workshop. The results from this study showed that doctors who reported an increase in morphine prescription had a higher mean score on the PCKT, and those who mentioned increased caseloads had a higher mean score on the CRS. These associations might be explained partly by the fact that trained family doctors probably decreased the number of referrals for patients with palliative care needs to specialist services because they gained knowledge and felt more confident about the management of common palliative issues. Other facilitators may be the impact of additional support activities for participating doctors after the workshop. These includes information on the availability and provision of oral morphine at the province level that was disseminated monthly; a counselling telephone line for doctors; and, the patients with advanced cancer who were discharged from the PCU were frequently accompanied by their patient-held record (PHR). However, it is possible that many potential factors could also have contributed to cause the above changes. Therefore, whether the increase in the number of patients and the increases in prescribed morphine occurred as a result of our educational intervention may not be proved convincingly in this study because the nature of pretest – posttest design does not allow us to explore such causal relationship.

These changes in morphine prescription behaviour were modest but important for the local context because inadequate access to pain-relieving medication as well as drugs for controlling other symptoms remains one of the chief barriers to global palliative care development (WHO, 2007). Since 1986, the three step analgesic ladder of the WHO has provided a simple framework for the treatment of malignant pain. However, two-thirds of advanced cancer patients in the community in Vietnam still suffer from pain (Green et al., 2007). Graham and colleagues (2010) stated that reluctance on the part of physicians to prescribe strong opioids and fears amongst healthcare professionals and the public about opioids addiction and abuse might be some of the causes. Concerns about giving high doses and having insufficient training in opioid use amongst primary care physicians are additional causes (Gardiner et al., 2012b).

Finally, many authors state that the ultimate aim of any education intervention with healthcare professionals is to improve the quality of healthcare services for targeted patients. For example, Grunfeld (2008) argue that, apart from outcome measures related to professional participants, a matter of further concern is whether positive indicators of knowledge, confidence, and satisfaction actually lead to better patient care and, subsequently, improved patient outcomes. According to him, such a relationship is neither apparent nor evident. While the outcomes on the knowledge, confidence and satisfaction of participants may or may not be necessary, he reasons, they are certainly not sufficient to ensure improvements in patient care. A vital issue, therefore, should be to measure the effectiveness of the intervention on patient outcomes such as the scores for symptom relief, the quantity of unscheduled or emergency room visits to cancer specialists as well as patient satisfaction.

### 7.2.5 Evaluating the effects of additional support to the workshop

Only one-quarter of doctors showed interest in mailings of specialised documents and local guidance. Sending printed educational materials (PEMs) in this study was considered as an integral component of the workshop and not as an additional independent intervention. The reason for the low satisfaction with this activity is not clear. This finding is consistent with remarks of Finlay and Noble (2005), who argue that the circulation of updates covering common palliative care topics probably plays a minor role in increasing the factual knowledge of physicians. The evidence on the effects of using PEMs in changing physician behaviours is contradictory. With the exception of circulating local guidelines, the provision of PEMs was reported to have little or no effect on professional behaviour by the review of Grimshaw and colleagues in 2001. However, this finding has been contested in a recent review on the effects of PEMs on professional practice and healthcare outcomes (Farmer et al., 2008). These authors found that PEMs when used alone may have a beneficial effect on professional practice, but not on patient outcomes. Although the benefit of PEMs from my study appeared small, given the relatively low cost of PEMs and potentially wide coverage, they could be considered as useful reminders to reinforce benefits obtained from the workshop. In addition to this, although the consistency and quality of locally produced guidelines may not be effectively regulated and measured (Henwood & McGannan, 2007), in my view it could bring additional learning opportunities for healthcare professionals to enrich knowledge as well as reducing the feeling of being abandoned after the programme was finished.

The proportion of doctors using the counselling phone line was low, only a minority of respondents (17%) indicated that they used this service. However, this result was significant in at least two aspects. For one thing, it was possibly beneficial for several local doctors, to some extent, in making an instant decision on clinical encounters. In addition, by helping to clarify local guidelines, specialised documents and some content in the patient-held record (PHR) that patients had presented to them, the use of this counselling line was more likely to add further useful information to what the local doctors received and supplement partly the information which they need from the specialists (Grunfeld, 2008). Therefore, my point of view is that telephone counselling may be useful for the training in palliative care for rural family doctors in the province.

The impact of the PHR on the overall improvement in terms of participants’ knowledge and behaviour was not apparent. In my project, the PHR was designed to be small enough for the patient to take to health stations and hospital appointments. However, it also has enough room for the insertion of salient facts about the patient treatment pathway, medications prescribed and the results of important investigations. It also includes sections on symptoms that may develop as the illness progresses and the likelihood of possible treatments to control these symptoms at the level of primary healthcare services.

The PHR in this study acts as means to a smooth transition of care from the hospital to community-based services. As in other countries, family doctors are typically responsible for the primary care relating to the major medical problems faced by the patient in the community. By maintaining continuity in care, the palliative care-trained oncologists may ensure that cancer-related issues might be adequately addressed by local healthcare professionals when palliative care is given at their local health station. In a study by Williams and colleagues (2001) evaluating the use of PHRs for the continuing care of patients with cancer, the authors identified its advantages including helping patients to remember what had been said to them; facilitating communication amongst professionals; and facilitating communication with patients. In contrast, in their systematic review of six studies regarding to the use of PHRs with oncology patients, Ko and colleagues (2010) found no clear impact of using a PHR on professional practice. However, they admitted that the outcome measures of using PHRs on healthcare professionals had not been noted properly and all six studies had likely experienced a high risk of bias.

With regards to patients, the record may decrease concerns about abandonment and discontinuity of care after being discharged that could magnify patient and family distress. According to Cherny and Catane (2010), abandonment and discontinuity of care are a cause of great distress to cancer patients; therefore, it must be ensured that all patients should have an ongoing and adequate care plan. This is extremely important as the role of cancer-specific therapies diminishes and the patient approaches the end of life. The outcomes of holding a PHR will be discussed further in **Chapter 8**.

It is well documented in the literature that there remains a wide gap between the information that primary care professionals need and the information they receive from cancer specialists (Grunfeld, 2003). Consequently, the purpose of all above activities in the support programme was aimed at improving the deficiency in communication between oncologists or palliative care specialists and rural family doctors in the province. Shipman and colleagues (2001) found that increased difficulty in accessing information is associated with reduced confidence in symptom control. In contrast, improving and facilitating communication between primary care physicians and oncology care specialists may increase the formers’ confidence in providing care for cancer patients (Grunfeld, 2003). Therefore, any mechanism that helps to narrow the communication gap would be a valuable contribution to cancer patient care. In addition, as Zitzelsberger and colleagues (2004) state, activities such as the provision of cancer-specific information in formats tailored for the needs of primary care physicians and delivered in appropriate timeframes to care for particular patients are ‘coaching’ strategies that can help improve the performance of these physicians.

### 7.2.6 Philosophy of the approach in this research

The overarching target of the current project in Camau is to integrate palliative care to the existing primary care system through educational intervention and training for rural family doctors. Therefore, the application of adult learning theory with CPD or CME formats would be the most suitable educational model with considerations to the local context. We have to be pragmatic. In addition this, the methods for assessments of formal education are still often used for evaluating informal educational interventions with professional learners. Until 2010, as Hegarty and Currow wrote in the Oxford Textbook of Palliative Medicine:

‘Evaluation of palliative care of postgraduate education is largely ad hoc and still in its early stage . . . Most published evaluations of individual courses rely on student self-assessment and report self-rated increases in confidence, knowledge, and skill competence in the short term, with some reporting sustained improvement over slightly longer periods.’

Practising palliative care in rural and remote settings in Camau appears to be difficult in respect to getting training in specialised knowledge and skills (Viet et al., 2011). In this educational context, the teachers are often international or national visiting experts or busy clinicians whose teaching activities are extra to their ‘day job’. For example, our teaching team included some specialists of the Oncology Ward and myself. Equally, professional learners are usually busy healthcare professionals who are trying to learn while juggling their daily clinical responsibilities (Wee & Hughes, 2007). However, they estimate palliative care to be an important and valuable part of the primary care field (Meijler et al., 2005; Groot et al., 2005) and show a wish to learn about palliative care (Mitchell, 2002; Viet et al., 2011).

Healthcare employers in Camau, for instance the Camau DoH, have undertaken some steps in order to achieve palliative care integration. The establishment of the C4 aims at promoting this process. One of the responsibities of the C4 is to develop palliative and cancer care services at all healthcare service levels within the province. This may be achieved partly through the development of effective CPD programmes for rural healthcare professionals. Such educational actions may enable equitable access to CPD for professional learners and enhance both individual and service quality.

Palliative care services, like any other healthcare services, should be locally appropriate, acceptable in terms of methods and technology, and affordable (Graham et al., 2010). It cannot be assumed that Western models of hospice and palliative care should be applied universally, and be effective in other healthcare systems. This concept is particularly important because the improvement and extension of palliative care in some regions requires a combination of socio-economic, cultural and medical solutions. Graham and colleagues (2010) argue that palliative care initiatives, particularly those in resource-poor regions, should take account of these essential matters.

Many educational models in palliative care are readily available across the world. I tried to resist the temptation to take an existing model and apply it wholesale to the project. Although it might be simpler to deploy an existing content list on how to organise a palliative project, the key to success of any programme, as Gale (2007) state, is to look closely at the local particular context and needs, which are then likely to influence decision-making in the planning and delivery of palliative care education. A characteristic educational intervention, therefore, was built to fit best with the local context including financial and personnel resources.

Many authors have suggested that palliative care programmes should be integrated into public healthcare policies, with ongoing evaluation of coverage, equity, and accessibility while developing a comprehensive programme (Admedzai et al., 2004; Herrera et al., 2007; Krakauer et al., 2007; Stjernsward et al., 2007). In order to implement these policies in Camau, in my view, training in palliative care for family doctors plays a valuable role in reducing inequalities in receiving continuing education between remote and cosmopolitan areas.

In the planning and conduct of educational interventions for professional adult learners, the organisers must respect the prior learning and experiences of the learners. One should also bear in mind, as Calman (2020) commented that every learner comes with her or his abilities, experiences and expectations. Moreover, Fraser (2004) argues that learning will not occur unless the learner sees the relevance of the knowledge and skills being acquired to their professional or personal needs. In addition, different teaching methods will target different aspects of the learning process as well as professional development for family doctors. Therefore, a mixture of methods is required in planning and conducting an educational or training project. Didactic lectures may lead to an increase of knowledge and understanding, role-play and multimedia-based formats help to improve communication skills and competencies, posting documents and local guidance play a role in updating knowledge and reinforcing the confidence as well as positive attitudes towards the practice of palliative care in the community (Davies et al., 1999; Finlay & Noble, 2004; Taylor, 2004).

Regarding the choice of statistical tests for this study, a statistician with skills and expertise in several areas of clinical research was consulted for his advice. Of the 61 participants those who returned the pre-workshop questionnaires and the 44 who replied to the follow-up questionnaires were voluntary and anonymous; therefore, the post-workshop responses could not be paired with the pre-workshop responses. In this case, according to Action and colleagues (2009) as well as Pallant (2010), the use of the paired sample t-test or the Wilcoxon Signed Ranks test would not be appropriate. For the purposes and strictness of statistical analysis, the differences between pre-workshop and post-workshop scores on the knowledge and confidence scales, therefore, must be tested statistically using the independent samples t-test.

Taken together, it could be argued that organising a workshop in our context is likely to be an appropriate format for disseminating the principles of palliative care through providing new knowledge, skills and confidence in practice to the rural family doctors who need it to become more professionally competent. As a result, it could improve the outcomes of palliative care provision to cancer patients in rural communities. The potential impact of the intervention on advanced cancer patients with palliative care needs in the community will be presented in the next section.

## 7.3 Views of advanced cancer patients on the choice of care settings

This study was conducted with a broad range of patients with advanced cancer in hospital and at home in Camau Province, Vietnam. The sample included patients with many types of cancers in advanced stages. The sample was also diverse in age, gender and residence, therefore, this could help to gain a maximum variation of experiences.

The use of qualitative methods provided a rational approach to examine systematically the key aspects of patients’ experiences and views on the supportive and palliative care services, in particular the expression of patients’ dissatisfaction and satisfaction, and factors affecting choice about care setting. The key themes which probably influenced to patients’ choice about care settings are summarised in **Table 7.1**. The differences between the two groups were mostly reflected in their perspectives about the care received, whereas the aspects of satisfaction and dissatisfaction were somewhat contrasting across participants from each group.

**Table 7.1** Summary of core themes influencing patients’ choice about care settings

|  |  |
| --- | --- |
| Core themes | Sub-themes |
| Satisfaction with care | Meeting practical, physical and psychological needs |
| Relationship with staff | Acquaintances or relatives |
| Convenient access | In terms of geography and transportation |
| Current suffering | The acuteness and severity of symptoms, KPS scores |
| Past experiences | Related to previous periods of hospitalisation |

The interviews generated a wide range of data around patients’ experiences and attitudes towards their illness. From these, areas of agreement and divergence between participants within two settings were identified. The semi-structured interview format allowed for an exploration of the views of a wide range of participants, and allowed discussion on more private matters, for instance troubles and embarrassment regarding a colostomy. Use of the constant comparison method ensured that early emerging themes could be tested and compared as the recruitment continued. All patients in this study had received care from specialists and/or family doctors in the province, therefore, patients’ perspectives might be interpreted as the reflections of patients with advanced cancer with palliative care needs on provincial healthcare services.

Most patients in both settings admitted that they ignored first symptoms and did not seek medical counselling at the beginning of the disease. These findings are in line with previous qualitative reports elsewhere (Bain et al., 2002; Missel & Burkelund 2011). This is also agreement with previous studies in Vietnam, approximately three-quarters of new cancer patients diagnosed annually are in advanced stages (Green et al., 2006; Krakauer et al., 2010). The later stage presentation means poorer survival duration.

It is noticeable that all patients interviewed in this study experienced some degree of suffering from their disease. However, the severity of symptoms and the level of their impact on daily activities of patients in the PCU tended to be greater than those of patients at home. In the view of hospitalised patients, their symptoms seem to be managed more effectively in the inpatient setting. This was probably an important reason for patients choosing the care in hospital setting although they could encounter several disadvantages such as being away from home and family support, experiencing delays in bureaucratic referral procedures and accepting with overcrowded inpatient rooms.

With advanced cancer patients who chose to be under the care of local family doctors, the data suggests that proximity of physical or emotional support, which is provided predominantly by family and friends, might play a crucial role in the choice of their care setting (in the context of their less serious disease status in comparison with that of their counterparts in the hospital setting). Feelings of loneliness were common in advanced cancer patients, therefore, relationships with family and friends could play an important role for patients to fight against the stigma of a cancer diagnosis and the fears about death (Murray et al., 2007). All patients appreciated the local nature of being cared for by local healthcare professionals. It means that friends and relatives could visit them easily. In contrast, in the PCU, where friends and relatives had to take a long journey to the hospital, the long distance meant people were less likely to visit the patients.

Most participants with advanced stage of cancer seemed to make their own decision regarding place of care. Their spouses and offspring seemed to have a limited role in this process. However, the personal choice was not the only factor that is important in influencing place of care. When making decision patients took into consideration various factors such as the physical burden of symptoms, past experiences related to hospitalisation, the overall care burden on family carers and the ease of access to services in terms of geographical locations and referral procedures. They often perceived themselves as a burden and wanted to make that decision based on their own judgments about their situation. Given and colleagues (2001) acknowledged the important role which family members play in keeping people with advanced cancer at home. However, there is little evidence in this study regarding their role in making decisions on choosing the place of care for their loved one, although patients are frequently dependent on family carers for support and physical help.

Most patients in this study in both settings (15/17) were covered by health insurance in comparison with only approximately 60% in the Vietnamese population (Tien et al., 2011). This may be because with a long disease trajectory, the patients have sufficient time to register for health insurance. The issue of hospital costs, therefore, was less likely to influence patients’ decision-making about place of care amongst patients recruited in this study.

The importance of the patient-professional relationship in choosing preferred care settings has been identified in other research with cancer patients with palliative care needs (Aabom &Pfeiffer, 2009; Philip et al., 2009). This was supported in my findings with a considerable number of participants in both two settings mentioning the patient-physician relationship as one of the reasons for choosing a particular place of care.

There was much evidence in the interviews that patients managed suffering in a variety of ways such as lifting up their spirit by beliefs in God or accepting the disease. In a study in Scotland with terminally cancer patients, Johnston and colleagues (2011) found that when patients reached acceptance, they were able to cope better and to manage their illness more effectively. Moreover, patients often found their own ways of managing distressing symptoms in which they used orthodox treatments in combination with complimentary and alternative medicines (CAM) as well as traditional remedies. These solutions made them feel more accepted and comfortable, less of a burden on their families and also helped maintain their dignity. Freund and colleagues (2003) explained that the people’s belief systems shape how they combine various approaches to alleviate their symptoms. Patients with stages of advanced disease might believe that the real causes of their suffering were spiritual, hence the orthodox modern medicine along with medical doctors were not necessarily the best source of help for their problems. The use of native or folk practices amongst participants might be considered as related to a similar underlying belief system. Several similar adaptation strategies that patients use to cope with their troubles have been reported elsewhere (Corner et al., 2008; Koithan et al., 2007).

The results of this study indicate that the notable satisfaction of patients with the quality of current service was an important factor in choosing their preferred setting. According to Beck and colleagues (2010), patients’ satisfaction is congruent with expectations of care and perceptions of the care received. High satisfaction with care is considered a desired outcome and may influence decisions to seek care, change providers or medical plans, or adhere to prescribed treatment plans.

Finally, a wide range of negative views on health services in the opposing setting was more likely to impact on patients’ choice to be cared for in the current setting. These include alleged limitations at CHSs expressed by patients in hospital. However, patients who chose to be under the care of local healthcare teams indicated that difficulties in getting access to inpatient services, necessities of social and family connectedness, and unpleasant past experiences with hospitalisation were underlay their choice.

## 7.4 Limitations of the approach

### 7.4.1 Limitations of the pre- and post-workshop surveys

The research surveys were limited in several ways. First of all, the numbers reported here are small and not all family doctors in the province responded to the surveys. The number of respondents to the post-workshop survey four months later was lower. However, the percentage of respondents (approximately 70%) is consistent with other studies of this type. The overall dropout rate of 30% limits the reliability of the study relating to remote healthcare services. This is because the non-respondents may have different views on surveyed themes, which could introduce some bias into the results. Nevertheless, a large discrepancy would not be expected as the study had an overall response rate of approximately 70%. Consequently, a number of the findings obtained were comparable with those in the literature of the field. However, how representative the sample is of Camau or Vietnamese doctors is not known, as a result, the generalisability of the findings is uncertain.

Next, this study was based on self-report by doctors, involving recall of events, which in some cases are likely to have happened several years previously, therefore, it will be likely to contain certain biases. Moreover, no attempts were made to assess the actual behaviours of respondents in providing palliative care to patients. Thus, doctors might have reported that they engaged in such behaviours more than they actually did.

Furthermore, Sands and colleagues (2010) remarked that the palliative care literature has evolved largely in the absence of standardised data points. According to them, across local and national border studies, instruments for data collection, subjective or observer-related reports and population vary. Although for each intervention a number of studies can be identified, the heterogeneous target populations and the lack of clarity in characteristics for defining populations, make it very difficult to compare studies or to pool data in meta-analysis. Therefore, the findings of this educational intervention might only be applied internally or locally, and perhaps, would not have much meaning for other providers or stakeholders.

Another limitation is the anonymous feature of the surveys. Therefore, the pairing of the responses before and after the workshop could not be performed. Consequently, the final results could not help the organisers determine whether those who had the increased scores of evaluation tests and/or changed in their practice post-workshop were the same one who returned the pre-workshop questionnaires previously.

Finally, trainers from a different socio-economic and cultural background, though well experience in clinical specialism, could sometimes convey incorrect messages to the trainees (Kumar, 2004). Whenever possible, the author suggests, the policy should be to ensure active involvement of the local trainers along with the trainers from abroad. While appreciating the dedication of the external speaker, the efforts that he took and the personal sacrifices he had made in coming over to teach in Camau, it was not guaranteed that the educational contents that were offered to the participants were likely to be culturally appropriate and transferable to the community.

### 7.4.2 Limitations of the interviews with patients

First, this study lacks an exploration of issues of race and/or ethnicity as well as socio-economic classes of the participants. The majority of researchers in the field of social medicine agree that these social determinants are likely to have an impact on health status as well as individuals’ satisfaction and perspectives. In addition, issues related to end-of-life care or preparing for death and dying were not discussed, although some patients were faced with an imminent death. This is due to this being out of the scope of this study, in addition to the awareness of cultural taboos.

Second, it is recognised that there are some potential weak points in the research design. For instance selection bias might have been introduced to the study due to patient participants were identified by local healthcare professionals. In addition, the issue of translating of transcripts of the interviews might have impacted the nuance of stories. I did, however, make every effort to apply rigour to the research process and to check and test the findings appropriately by purposive sampling, strict inter-reliability checking, trying to make translation of quotations from Vietnamese into English as accurate as possible and so on.

Third, this mixed methods study employed the model of parallel data analysis in which the different analyses on the quantitative and qualitative components were undertaken separately. As a result, the findings which emerged from each data set were not compared or consolidated or integrated until the full analysis of both data sets had been completed and presented. Onwuegbuzie and Leech (2005) suggest that if the data are correlated in earlier phases of the research process in a mixed methods design, a more complete picture of research phenomena may be produced. I acknowledge this limitation in the analysis. The reasons are that the nature of a parallel mixed methods study design was planned at the beginning of the project as well as the local research team lacked experience and expertise in conducting complex healthcare research.

Finally, during the six-month period of the data collection phase for the study in Camau Province, Vietnam, I was not able to identify ‘deviant cases’for patient research data. To my knowledge, these cases could be advanced cancer patients with palliative care needs who had been receiving the care from rural family doctors who had not participated in our project. Analysing and discussing potential data from these patients might help us to identify further themes in the data that contradict, or seem to contradict our explanation based on our data and presumptions. If I had encountered opportunities to interview such patients, it would have been easier for me to discuss some themes which emerged under study more convincingly. Such ‘deviant case’analysis, according to Mays and Pope (2000), helps refine the analysis until it can explain all or the vast majority of the cases under scrutiny.

## 7.5 Practical difficulties

With the choice of an evaluation research approach in attempting to evaluate this education programme we certainly faced a number of challenges. First, the negotiation with family doctors in order to obtain research data from them and their patients proved difficult. This may be partly because some family doctors felt threatened by the project, which was built to explore and evaluate a part of their practice. This may be particularly true, according to Ingleton and Davies (2007), *‘if the doctor holds a firm belief that their particular practice works.’* Another challenge encountered was around setting the priorities for the objectives of the intervention. At the beginning, we intended to evaluate the effectiveness of the intervention with both doctors and patients using objective measurement instruments. After taking financial and personnel resources as well as research capability into account, however, the impact on doctors was prioritised in this research study. The measurable impact on cancer patients will be evaluated quantitatively in the next few years when the project is under way.

Applying a qualitative approach presented further practical challenges in terms of how to manage large amounts of complex data and how to conceptualise the rich, in-depth stories from patients into categories and themes in such a way as to retain the poignancy and context of patients’ experiences. The techniques of analysis are particular skills required for ensuring an acceptable quality of the qualitative research that may be challenging to learn without experienced research consultation. Spending time learning how to use the software package Nvivo was fundamental so that it could serve as a useful tool for data management. This software programme was particularly helpful in handling large amounts of data, quickly confirming coding decisions, facilitating re-coding of data, and simplifying the analysis process (Kristjanson & Coyle, 2010).

Difficulties in convincing the funder – the C4 as well as the Research Review Board of Camau DoH – about the appropriate research paradigm (parallel mixed methods) for the outcome evaluation of the programme presented another challenge. The main reason was that they were unfamiliar with the philosophical underpinnings, language and methods of this research paradigm. The approach of a mixed methods study was considered considerably different from traditional methods.

During study time in my institution in Vietnam, in addition to being a single researcher organising all aspects of the intervention and evaluations, I was in charge as the chief of the Oncology Ward with the responsibility of managing a 35-bed department including the 8-bed, inpatient PCU. My weekly workload consisted of doing two ward-rounds with junior doctors, undertaking 2 – 4 major elective operations, signing admission records and discharge certifications, giving advice to family doctors in and out-of-hours as well as liaising with C4 members and local primary healthcare teams at CHSs. This continued throughout the study, therefore, it meant some inconvenience and considerable overwork while I was engaged in the research.

In order to help doing some auxiliary work of the project, a local research team was built from some staff of the oncology ward in order to share some activities and paperwork with the principal researcher. There were four members of the local research team: a junior doctor, 2 nurses and myself. The doctor assisted the research with helping to contact with several patients in both settings for the interviews. He also was asked for his opinions on some themes which emerged during analysis process of research data which were performed by the principal researcher. Two nurses were in charge of doing research paperwork (printing, submitting and receiving the pre- and post-workshop packages as well as inputting data to the SPSS). All interviews, transcriptions and data analysis were performed by myself. In addition, I acted myself as the role of administration and supervision the research activities of above members.

## 7.6 Single novice researcher

The mixed methods approach, organizing the workshop, managing many activities, and interviewing patients across my province was an ambitious undertaking for me as an inexperienced single researcher. Although I was keen on conducting qualitative research – for the first time in my job – I sometimes felt overwhelmed with the huge amount of data collected. When writing up the study I was frequently challenged by the task of trying to translate exactly my ideas into English, and make them as understandable as possible. In addition, handling many study activities spread out over a large area in six months required very careful organisation as well as the mental challenge of ordering arrangement for recruitment, data management and other practical problems. If time had allowed it would have been easier to extend the duration of some patient interviews at home instead as it had been planned originally.

Writing academic poster and papers for professional conferences and having them proofread by my supervisors were valuable experiences and eased considerably the writing-up process for this thesis. Two papers related to the project (Vietnamese version) were published in the Journal of Vietnamese Society of Cancer. The English versions of these two articles were accepted for poster presentation at the 9th Palliative Care Congress in Newcastle, UK and the 19th International Congress 2012 in Montreal, Canada in 2012.

Researching in palliative medicine is likely to have some emotional impact on the researcher, and this was certainly true in my case. While not encountering any particular trouble in conducting the surveys with doctors, I found the interviews with cancer patients at an advanced stage distressing. Much of this feeling was likely to be related to the difficulties of being away from my professional and geographical ‘comfort zone’. These included contacting local healthcare team members acting as gate-keepers, finding the patients’ homes, arranging a suitable time for the interviews, and not realising how difficult transportation was in remote areas of the province. In addition, the fact that I had no medical role of influence in the localities made me feel somewhat professionally vulnerable when interviewing patients at home. Finally, the acceptance of my inability to help these patients further, being away from regular contact with clinical colleagues and missing the ability to discuss some of the troubling aspects of the study probably contributed to occasionally overwhelming feelings of melancholy.

It was during these interviews that clinico-social problems were encountered, and the decision making process involved in seeking care and the subsequent events which led to the patient's decisions could be explored in depth. These semi-structured interviews, therefore, form an important part of the project to investigate patients’ experiences in healthcare services, reasons for choosing place of care and providing complementary interpretations for issues identified in the surveys with family doctors. The interviews and the survey also answered questions regarding the role of healthcare professionals involved with these patients both in the community and the hospital. Two data sets collected from this study will be explored and interpreted further with a triangulation technique in order to provide the whole picture of the intervention. These will be presented in the next chapter about data integration.

# Chapter 8 – Integration of Survey and Interview Data

## 8.1 Overview

As presented in **Chapter 1**- **Introduction**, this study is underpinned by the principles of social medicine. This discipline is interested in the interactions between health professionals and patients in relation to patients’ demographics and socio-economic characteristics as well as individuals’ understandings of their situation (Stonington & Holmes, 2006). According to Bowling (2007), these interactions embrace two main aspects: communication in consultation or treatment and patients’ evaluations of healthcare. Patients’ evaluations about healthcare services include the expectations, preferences, choices and satisfaction on the mode of delivering as well as the outcome of healthcare services (Bakdash & Scheper-Hughes, 2006). The relationship between satisfaction and the quality of healthcare provision received is complex and affected by patient, doctor and many service factors (McKinley et al., 2002). Furthermore, Bowling (2007) argues that the care or treatments provided by healthcare professionals could conflict with patients’ desires. Accordingly, the measurement of evaluation of healthcare services of patients (sometimes termed ‘consumers’ or ‘clients’) is very important for the development of services. Recent studies have continued to confirm the impact of culture on the doctor-patient relationship and correspondingly on patient outcomes (Bowling, 2007; Kleinman & Benson, 2006). According to Stonington and Holmes (2006), understanding the culture of medicine is essential to understand physicians’ bahaviour and attitudes towards illness, patients and treatments, such as referral, prescription and so on.

The research question is *‘How effective, in terms of improvements in knowledge, attitudes and professional practice, is a palliative care training workshop, with additional support activities, for family doctors in remote areas and what are the perspectives of their cancer patients?’* In order to answer this research question, a parallel mixed methods design and analysis were employed. The qualitative and quantitative data were collected and evaluated separately and managed in a traditional manner, as described in the methodological considerations section in **Chapter 4** – Methodology. Statistical analysis procedures for the quantitative data were used to draw descriptions and inferences for corresponding variables from the doctor surveys (**Chapter 5** – Surveys with family doctors). A thematic analysis technique was used for qualitative data analysis (**Chapter 6** – Interviews with patients).

At the start of the project, the aim of the C4 was to improve the quality of palliative care services for people with advanced cancer who need palliative care in Camau province. According to Yin (2006), every study applying a mixed methods approach should have an implicit, if not explicit, unit of analysis. Therefore, the notion of the ‘*quality’* of palliative care provision could be regarded as the unit of analysis. The purpose of determining a unit of analysis is to hold theoretically different studies together in a mixed methods research design (Teddlie & Tashakkori, 2009; Yin, 2006). This is because the quantitative and qualitative components of this parallel mixed design answered separate research questions, and applied different data collection methods and analysis procedures. This made it challenging to integrate the two data sources because different methods favour inherently different units of analysis, thus leading to a threat to the integrity of a single study (Yin, 2006).

In a parallel mixed design, two data sets are collected concurrently and analysed separately to produce two sets of findings (O’Cathain et al., 2010; Teddlie & Tashakkori, 2009). According to Creswell and colleagues (2004), this model typically gives equal priority to quantitative and qualitative data and analysis, and the two components are often found in separate sections of the report. The process of integrating the findings from both quantitative and qualitative data then may take place at the result or interpretation (O’Cathain et al., 2010), or conclusion phase (Creswell et al., 2004). The parallel analysis of quantitative and qualitative data from different sources can lead to either convergent or divergent results (Greene, 2007; Teddlie & Tashakkori, 2009).

In fact, as I presented in **Chapter 4**– **Methodology**, this parallel mixed design study employed two types of triangulation. The first one is methodological triangulation, including quantitative and qualitative components. This combined of two methods of data collection: surveys with self-complete questionnaires and a qualitative method with semi-structured interviews, into a single study. The two data sets then were analysed separately in order to create their own results and interpretations respectively. The other type is a data source triangulation from different respondent populations: the survey data from family doctors and interview data from patients with advanced stage cancer. In the triangulation procedure, results were collated between the two data sets. These results included a wide range of perspectives represented in the interview analysis with patients in two settings (specialist palliative care service in the PGH versus generalist one in the community), and a number of numeric results were drawn from statistical analysis of the surveys (the response rate, satisfaction proportions, increases in knowledge and confidence scores and so on).

There are several similar designs from the literature (Baskerville et al., 2001; Farmer et al., 2006; Hoon et al., 2008; McVea et al., 1997; Mitchell et al., 2005, 2008), the majority of which employed parallel data analysis in which the different analyses were not compared or consolidated until the full analysis of both data sets was completed. Although the two sets of analysis are independent, each provides an understanding of the research phenomenon from a different conceptual angle (Teddlie & Tashakkori, 2009; Wendler, 2001). A trend to conduct separate analysis on quantitative and qualitative data is apparent in mixed methods healthcare studies (O’Cathain et al., 2010), despite the fact that if the data are linked at the analysis phase, a more complete picture of the research phenomenon may be produced (Onwuegbuzie & Leech, 2005).

Before undertaking the triangulation process for this study, however, it is acknowledged that there are some inherent limitations of this process due to the different methods of the two components for gathering data: the interviews collected data following a priori research question, and the survey data set included content on some, but not all, the research question. With regards to our study, the understandings that we wanted to grasp were related to the quality of palliative care, in particular the impact of the educational intervention and additional support programme on both family doctors and the perspectives of patients with advanced cancer. In the literature, however, there has been a lack of pragmatic guidance on how to combine qualitative and quantitative approaches and how to integrate qualitative and quantitative findings (Ostlund, 2011).

## 8.2 Triangulation protocol technique for data integration – analysis and findings

As discussed in **Chapter 4** – **Methodology**, this mixed methods study integrated two data sources at the result and interpretation phase by applying the *triangulation protocol* technique (O’Cathain et al., 2010; Farmer et al., 2006). Given the study’s dual data sets and the need to generate an integrated set of findings, the aim of employing triangulation was to test convergence and/or dissonance of associations and themes.

The triangulation process focused on a specific objective of our intervention: to examine contextual factors related to the research processes, affecting patient satisfaction and dissatisfaction or their evaluation of the quality of health services. The triangulation protocol involved two sources of data: qualitative from semi-structured interviews with patients and quantitative data from the descriptive analysis of the questionnaires returned from participant family doctors.

I adapted the detailed guidance on the triangulation technique using the six steps suggested by Farmer and his colleagues published in 2006 **(Table 4.1**). This protocol was chosen in order to use a reproducible method for triangulation, which is important for development of mixed methods research in palliative care. However, Step 5 – Researcher Comparison was not followed because there was a single researcher in this study. Instead of undertaking researcher comparison, I discussed main categories from the survey data, relevant themes from the interview data and the integrated findings with my supervisory team, and consensus was obtained. Testing of the triangulation protocol in this study focused on the following question: what contextual factors were relevant to the impact of the intervention on quality of palliative care services, from the perspectives of family doctor participants and their advanced cancer patients? With respect to rural family doctors, the unit of analysis was likely to be willing to change their practice. Regarding advanced cancer patients with palliative care needs in the community, it could be perceived as satisfaction with the health services that these patients were receiving.

Step 1- Sorting

Findings related to contextual factors and quality of palliative care services from each data set were sorted and separated from the rest of the data into two files: survey analysis findings and interview analysis findings*.* The contents of both files were then reviewed to identify key themes discussed in each set of data. This process aimed at creating a unified list of themes for the comparison of importance or meaning, frequency and illustrative examples and quotes. These themes would form the rows of the convergence-coding matrix used to summarise similarities and differences between the two sets of data **(Table 8.1).**

Eventually, two files containing themes from the interviews and survey data were formed. The themes from these two files then were spread out in the working interface of the Excel programme of the MS Office software package. This programme is easy to use and widely recognised as the most useful tool for mixed methods tasks involving synthesis of varied forms of data from a range of sources (Bazeley, 2009; Creswell et al., 2004; Ostlund et al., 2009). The contents of both files were then reviewed to identify the key meanings discussed in each data set, which described or belonged to a general theme that reflected somewhat the quality of the palliative care services. This step of the triangulation protocol enabled me to move from thinking about the themes related to each data source to what Farmer and colleagues (2006) call ‘*meta-themes’* or *‘meta-inferences’* by Teddlie and Tashakkori (2009) that cut across the themes from the different data sets.

Step 2– Convergence coding

The two files of findings then were compared with respect to the importance of themes, the frequency of themes (for example, number of surveyed doctors and interviewed patients related explicitly or implicitly to a theme), and specific quotes and examples to support or explain a particular theme (for example, number of doctors in the survey data set or patient interviewees who had made explicit reference to, or implied a theme).

The Convergence Coding Scheme was then applied as described in **Table 4.1**. This scheme was used for two purposes: (1) to determine convergence between two sets of results on the essence of the importance and frequency of themes presented, (2) to identify the convergence in terms of coverage, specific examples or quotes provided in relation to each theme in each data set. The resulting convergence coding matrix of themes from doctor data and quotes which exemplified the relevant themes from patient interviews are presented in **Table 8.1.** The next paragraphs are discussions on the instances of agreement, partial agreement, silence, and dissonance codes along with illustrative quotes of the various contextual factors revealed across the two data sets.

**Table 8.1** Frequencies and quotes in relation to contextual factors and the quality of palliative care services.

|  |  |  |  |
| --- | --- | --- | --- |
| Doctors themes | Number of mentions in the surveys & interviews | | Quotes and themes from patient interviews |
| Survey | Interview |
| Before workshop | |  | |
| Negative attitudes and behaviour of local family doctors on palliative care provision | 7/61 | 7/10 | *‘He [CHS doctor] seemed to lack enthusiasm in providing care to patients. He normally made a superficial examination on me, gave me injections and some medication and said “ no need to worry” every time I came. Then I went back home and still lived with my problem’ (*A patient in the inpatient PCU). |
| No previous training in palliative care | 36/61 | 3/10 | *‘ . . . How could they treat me while they didn’t know anything about my disease except my current pain?’* (A patient in the PCU). |
| N/A |  | 4/10 | Long delays in making referrals from CHSs due to bureaucratic and complex procedures (Patients in the PCU) |
| After workshop | |  | |
| Knowledge and confidence improvement | Majority of doctors | 6/7 | *‘ They [local HCPs] were very kind to me. They helped with daily practical care every occasion I came to see them. They seemed to be there to help patients. Generally speaking, the care I had was great.’* (A patient at home) |
| Favouring patient-held records (PHR) | 3/44 | 2/7 | *‘ I could take information more from it [her PHR] . . .and be aware of my illness more . . . It has been helpful with my age . . . I sometimes have forgotten the information which I’ve been told about . . . whenever I go to the health station if they [healthcare professionals] ask me about my illness pathway, I just show it to them . . .’* (A patient at home). |
| Performance and behaviour improvement | 13/44 | 6/7 | *‘ They [local HCPs] were very kind to me. They helped with daily practical care every occasion I came to see them. They seemed to be there to help patients. Generally speaking, the care I had was great.’* (A patient at home). |
| Using the counselling telephone line | 8/44 | N/A |  |
| Referring NGPC and ROP in practice | 42/44 | N/A |  |
| Suggestions and comments to the programme | 22/44 | 6/7 | Local healthcare teams to be more competent and enthusiastic.  Sufficient essential drugs and facilities at the local health services.  (Patients at home) |
| Satisfaction with monthly PEMs | 12/44 | N/A |  |
| N/A: Not available |  |  |  |

(a) Agreement

In this case, according to Farmer and colleagues (2006), there is a full agreement between two sets of findings on both elements of the comparison. Across the findings, there was only one instance in which there was agreement in both meaning and frequency in the doctor survey data and patient interview quotes. The theme area related to the increase in knowledge and confidence scores of trained doctors four months after the workshop as a key impact of the programme. This outcome was generalised as the *knowledge and confidence improvement* or perceived *competence improvement*. This finding focused primarily on the positive impact of improved knowledge and confidence in practice. As a result, these positive changes may act as facilitators for better quality of palliative care service in the community, which then might play a role in fulfilling the expectation of cancer patients with palliative care needs who receive the local healthcare service from the trained family doctors. This outcome was ranked the most frequently identified factor in both data sets. In terms of meaning and interpretation, this positive impact was presented importantly in both data sets. In addition, the level of prominence observed was also similar in both data sets. With regards to the interview data, the majority of patients under the care of local family doctors in rural areas highly rated the ability of the local healthcare professionals in terms of meeting their practical, physical and psychosocial needs. Alternatively, increases in mean total scores as well as mean scores of every aspect on the PCKT and the CRS of doctor participants were demonstrated by the majority of trained doctors in the post-workshop survey.

(b) Partial Agreement

There is an agreement on one but not both elements of the comparison in this interpretation (Farmer et al., 2006). An instance of partial agreement was the theme relating to negative attitudes and behaviour of family doctors in palliative care provision for patients with advanced cancer when the programme had not been deployed yet. With respect to this theme, there was an agreement regarding the importance of the theme, but there was a lack of agreement in terms of frequency between the survey and interview data regarding doctors’ attitudes before the programme. The importance or meaning of this theme in the relationship with quality of local palliative care service in both data sets was somewhat similar. However, its frequency in each data set was different, in fact it was mentioned by a minority of surveyed family doctors (7/61). In contrast, the majority of interviewed patients (7/10) who had chosen the care in the PCU because they had felt a lack of engagement and enthusiasm in care deliver the services and a lack of enthusiasm in delivering of the care from local healthcare teams.

Another example of partial agreement was observed in the theme related to the ‘*benefits of PHRs.’* The PHR in our study acted as an information source for both advanced cancer patients and their local healthcare professionals. The importance of the theme in both data sets was similar in terms of providing necessary information for the communication between the patients and local healthcare team as well as, to some extent, between generalists and specialists. The frequency of this theme in each data set was also similar. It was ranked a middle-to-low frequency in each data set. In the survey data, there were three family doctors who had been satisfied with this type of support. In the interviews, however, two cancer patients at home supposed that the PHR made them feel more prepared for meetings with healthcare staff. Therefore, this theme was coded as a partial agreement in both data sets.

A similar situation was observed with the finding related to the category *‘no previous palliative care training’* observed in the pre-workshop survey with doctors. The importance of this theme in both data sets was similar. It was perceived as a contextual factor influencing the quality of local palliative care services by both doctors and patients. The frequency of this theme was considered to be in the middle of both data sets. In the interview data, the theme was demonstrated by three patients who had a feeling that their local family doctors had not been adequately familiar with providing palliative care in the community. Otherwise, 36/61 rural family doctors reported no previous training in palliative care in the pre-workshop survey. Therefore, this theme also was coded as a partial agreement in both data sets.

In addition, the theme on behaviour and performance improvement of the trained doctors after workshop was also coded as a partial agreement because the importance of this theme in relation with the unit of analysis (quality of palliative care services) was similar the agreement code above. However, the frequency of this category was lowly ranked in the survey analysis. On the other hand, in the patient data file this theme was recognised by the majority of patient participants through their positive evaluation of the palliative care service from the trained family doctors.

(c) Dissonance/ disagreement

Through both inductive and deductive approaches based on the triangulation question, results from both data sets as well as discussion and feedback with my supervisors (Bill Noble and Clare Gardiner), I did not find any instance in which there was a full disagreement on theme importance or prominence of the survey file and themes or any quote from the interview data set.

(d) Silence

Silence occurs when one set of findings covers a theme, whereas the other set is silent on that theme in terms of both importance and coverage of the themes (Farmer et al., 2006). In the analysis of the survey data, the role of referring clinical guidelines (indicated by 95% of post-workshop responses) was realised as relevant to practice. The action of consulting guidelines could be considered within a theme of *‘the willingness of family doctors to change their practice’*, which could result in an improvement in the quality of local palliative care services. However, this theme (actions of willingness to improve practice) was coded as silent in the interview results. This may be because at the beginning phase of this study, the nature and purposes of conducting surveys with family doctor and semi-structured interviews with advanced cancer patients were different since they aimed at answering different research questions. Moreover, patients were unlikely to comment on the use of guidelines and CPD, as their knowledge of these processes was probably limited. In this instance, many themes revealed in the survey data were less likely to be explored in the interviews and vice versa.

Another instance of silence was observed in the theme regarding *‘use of counselling telephone line’*. This theme was ranked as low frequency in the survey data set (18% doctors after workshop). The use of the counselling telephone line was related to clinical situation, information regarding the PHRs or local guidance. These aspects might be seen to some extent as a desire to change practice, and thus, the quality of healthcare service. In terms of the meaning or interpretation, this theme played an important role for some doctors in practice. Therefore, it was coded as a partial agreement in the survey data set. However, this theme was coded as silent in the interview data set of patients because the content and coverage of this theme was not within the interview guide and patients were unlikely to comment on the use of this line.

Step 3: Convergence Assessment

This step reviewed all themes compared in order to provide a global assessment of the level of assessment. Taking into account the importance, frequency and coverage of themes as well as specific quotes provided to support the findings, the majority of themes and quote areas between the two data sets showed either partial or full agreement (**Table 8.2**). In addition, no instance of disagreement in the comparison between the two data sets was identified. However, there were two instances in which findings in doctor were present in the survey data set and silent or absent in theme areas of the patient interview data. These themes were the use of clinical guidelines and counselling telephone line. According to Farmer and colleagues (2006), such silences are likely to be related to differences in the focus, scope and nature of the two data sets.

Step 4: Completeness Comparison

Comparisons between the two sets of results were then performed to emphasise both similar and unique contributions to the integration question. This process finally created a summary of unified findings of the two data sets. In this step, the range of findings relevant to the research question was broadened to ensure completeness in perspective and in the ways in which a theme was characterised (Farmer et al., 2006). Based on the convergence assessment, it is evident that there are many theme areas and quotes in which the two data sets agreed and confirmed core findings. The patient interview data generally added contextual factors to the integrated findings, which were not explored in the doctor surveys. For example, the slow process of making a referral from local family doctors or long delays as processing through the system was identified in the patient interviews, but not documented in the survey data. This is partly because the surveys did not aim at these organisational issues due to the limited length of the questionnaires, and probably these issues are not easy to quantify.

Another contextual factor revealed in the interviews was patients’ perspectives on the desired quality of local palliative care service. They wanted local healthcare teams to become more competent and enthusiastic about care provision. In addition, supplies of essential drugs and facilities at CHS level become more sufficient. With regards to doctors’ views, 7/ 22 comments from the post-workshop questionnaires with local family doctors suggested a simplicity of the procedures for the supply and prescribing of morphine. Analysed together, the interviews and surveys confirm the overall willingness in both parties for a more comprehensive palliative care service in the community. Thus, each data set on its own provides part of the story for the research question. However, taken together, they contribute to a higher level of analysis and a broader understanding of the research question. The contextual factors identified in the doctor data were improvements in knowledge and confidence in practice palliative care in their workplace, referring more often to clinical guidance and willingness to reduce in complicated procedures requested for prescribing morphine. In the interview data, these factors were the patients’ satisfaction with the care from trained family doctors and their desires for better quality in local palliative care services at CHSs.

**Table 8.2** Convergence coding matrix for contextual factors.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Integrated Findings | Convergence Code | | | | | | | | |
| Themes of Doctor Data | | | |  | Themes of Patient Data | | | |
| AG | PA | S | DA |  | AG | PA | S | DA |
| Negative factors |  |  |  |  |  |  |  |  |  |
| Negative attitudes and behaviour of local family doctors |  | • |  |  |  | • |  |  |  |
| No previous training in palliative care |  | • |  |  |  |  | • |  |  |
| Positive factors |  |  |  |  |  |  |  |  |  |
| Increase in knowledge and confidence scores in practice | • |  |  |  |  | • |  |  |  |
| Performance and behaviour |  | • |  |  |  | • |  |  |  |
| Referring the NGPC and ROP | • |  |  |  |  |  |  | • |  |
| Using counselling telephone line |  | • |  |  |  |  |  | • |  |
| Benefits of keeping PHRs |  | • |  |  |  |  | • |  |  |
| Satisfaction with monthly PEMs |  | • |  |  |  |  |  | • |  |
| Suggestions to improve the services |  | • |  |  |  |  | • |  |  |
| Totals | 2 | 7 | 0 | 0 |  | 3 | 3 | 3 |  |

Note: AG: Agreement; PA: Partial agreement; S: Silence; DA: Dissonance

Step 5: Feedback/reports

Farmer and colleagues (2006) recommended that a further step in the triangulation process that would be helpful is to share the triangulated result with research team members for comments or discussions of any issues of significant disagreement. The reason is that co-operation within the research team may help to enhance the data interpretation. In fact, in the situation of my study, member checking was performed with my supervisors in order to reinforce the validity of my research findings. The level of agreement between us with respect to the definition of the unit of analysis, the identification of contextual factors and the degree of convergence between the two data sets (in both meaning and prominence of themes) were discussed and we obtained through many supervisory meetings. Furthermore, at an appropriate point of time, a summary of triangulated key findings will be distributed to provincial health managers for their review and feedback. Feedback of findings to stakeholders is an important part of the triangulation process, as it can confirm the accuracy of findings and help to determine the presence and source of different results (Farmer et al., 2006).

## 8.3 Limitations

Similar to any analytical approach, there are some limitations associated with adopting a multi-method approach to a research study. First, there might be incompatibility between theoretical paradigms (purposes, targeted populations, and modes of data collection and analysis). Consequently, the two data sets may be different in aspects such as their content areas, units of analysis or focus. In addition to this, the process of triangulation might amplify sources of errors and bias in each data set. Therefore, it could compromise the validity of integrated interpretations. As a result, the findings from the data integration process might not be completely convincing. To increase the validity of this process, the research question for the purpose of data integration included a unit of analysis (quality of rural palliative care service) which was defined clearly. The themes across the two data sets only were collated with the considerations of their relationship with the unit of analysis. Therefore, this reduced some inherent differences in terms of the content and coverage of themes or specific examples of different data sets as well as methods of data collection.

Second, it is acknowledged that little pragmatic guidance on conducting data integration in mixed methods has been found in the relevant literature. Therefore, my understandings of the triangulation process were limited by a scarcity of the literature regarding how this technique should be conducted. Fortunately, a worked example of a pragmatic approach for the data integration process (Farmer et al., 2006; O’Cathain et al., 2010) was found and adapted; and was then shown to be useful for us to complete this process.

Finally, although the collection and analysis of both quantitative and qualitative data were intended from the start, the two particular data sources might not have been considered a powerful research design for the data integration, which is a central principle of mixed methods designs in social sciences. This coding convergence template for analysis, which was adapted from a public health study (Farmer et al., 2006), might need to be modified further to address better nuances of mixed methods investigations in palliative care. I have been carefully ensured that the mixed methods design I have employed is entirely reproducible in future work.

## 8.4 Further work and implications

The improvements in knowledge, confidence and behaviour observed in this study are more likely to be educationally relevant to our intervention, while there has been little information in the medical education literature that provides a useful point of reference. However, the causal relationship between the educational intervention and participants’ achievements in this study has not been proved convincingly. Therefore, further studies will be helpful to define which interventions are effective under which circumstances, as well as what tools are appropriate to objectively measure the outcomes of an educational intervention on professional practice and patients’ health status.

A matter of further concern is whether these results (improvements in knowledge and confidence in palliative care practice) will be sustained over time and actually lead to better patient care and, subsequently, improve patient outcomes. Such a relationship, as Grunfeld (2008) points out, is difficult to make clear. While the outcomes of rural family doctors’ knowledge, confidence and satisfaction may be measured in this study, they may not be sufficient to ensure improvements in patient care. Leong and colleagues (2010) suggest that further studies to evaluate the patient care outcomes by performing chart audits of individual or groups of physicians may be indicated to determine whether self-report changes reflect changes in practice accurately. Therefore, a vital next stage of this project will be the assessment of effectiveness on patient outcomes such as symptom management and patient satisfaction in objective instruments. With respects to doctors, appropriate measures will include the number of referrals to specialist services and the amount of morphine prescription.

Because of the inherent nature of the methodology, findings from qualitative research are not usually generalisable. However, this study provides some useful data for policy makers of the C4 and the provincial DoH as well as local healthcare professionals working with patients who wish to remain at home for their palliative care. The transferability of findings to other patient populations, including those with non-malignant end-stage diseases warrants future work. In addition, while there is no reason to believe that these family doctors in Camau are more or less receptive to palliative education than any other group of doctors in Vietnam, it also would be useful to confirm findings from this study in different physician populations.

The primary targets of this project have tended to concentrate on people with a diagnosis of advanced cancer. However, it could have some impact on other populations requiring palliative care in the community such as people with AIDS, heart failure, dementia and so on. The reason is that the scope of palliative care services is wide. Therefore, indications for palliative care are also wide. The question of how many people within a community or in an area needing palliative care services over a period of time is difficult to answer. Therefore, the unintended outcomes of this project regarding other patients with palliative care needs will probably be examined further in the coming years.

# Chapter 9 – Conclusions

The present mixed methods study was designed to evaluate the outcomes of an educational intervention in palliative care for rural family doctors in terms of perceived knowledge, confidence and practice behaviours. In addition, it also aimed at exploring and comparing views and experiences of advanced cancer patients in the inpatient palliative care unit (PCU) with those receiving palliative care from the trained family doctors in the community.

The most obvious finding to emerge from this study is that the educational objectives of the project have largely been achieved. Positive educational and professional outcomes were measured and demonstrated through statistical means. Rural family doctors who participated in the project had a statistically significant increase in scores for knowledge and confidence in practice after participating in the project.

In addition, there were also post-workshop increases in cancer-related caseloads and the amount of morphine prescribing in their workplace. The majority of doctor participants also indicated that the National Guideline for Palliative Care (NGPC) was referred to more frequently after the workshop than before. These findings demonstrate that following the intervention, palliative care has obtained considerable importance at the primary healthcare level in the province, which can be seen as preliminary evidence of the impact of the project. However, conclusions on these findings should be treated with caution because of the single of the study and its uncontrolled design.

The study also identified factors which influenced patient choices of preferred place of care. These included satisfaction with the quality of palliative care services, relationships with healthcare professionals in the different settings, convenience of access and experiences of similar care in the past. In addition, hospitalised patients tended to have low KPS scores (Karnofsky Performance Status) and to be somewhat less satisfied with the quality of local palliative care services. These patients reported that local family doctors lacked enthusiasm, specialised expertise and essential drugs for palliative care in the community.

Undertaking triangulation (data sources, methods) identified different areas of priority from the perspectives of patients and family doctors on local palliative care services. A minority of doctors were not willing to provide palliative care at commune health stations (CHS) for various reasons. This refusal was perceived by most hospitalised patients as evidence of a lack of enthusiasm and expertise on the part local healthcare teams. However, convergent findings from the two sets of data showed commonalities between the two groups of participants. In fact, a majority of family doctors displayed their willingness to improve the quality of local health services through participating in the project, improving their competence and adapting positive behaviours in practice. These changes were perceived as positive by patients who were interviewed. Indeed, advanced cancer patients with palliative care needs being treated in the community highly appreciated the health services which they were receiving from family doctors who had been trained during the project. In addition, both of the two parties desired to improve the quality of services further through their comments on the programme.

This study confirms previous findings by Alvarez and Agra (2006) and contributes additional evidence that suggests that educational interventions and support programmes may be appropriate ways of disseminating the principles of palliative care through providing new knowledge, skills and confidence in practice to rural family physicians, enabling them to become more professionally competent. As a result, it could improve the outcomes of palliative care provision for cancer patients in rural communities, by better meeting their needs and preferences.

The study was limited in several ways. First, the pre- and post-workshop surveys with doctors based on self-report and the recall of events. Therefore, it was unlikely to eliminate all biases. Second, the moderate response rate of rural family doctors may compromise the generalisability of the survey results. Third, because of the anonymity of the surveys, pairings of responses before and after the workshop were not possible. Consequently, the final results may not help the organisers determine those who need more support from the programme. Finally, there are also weaknesses with the pre-test/post-test design. Differences before and after the intervention might not necessarily be attributable to the intervention but also to many different potential factors. The only reliable way to test this type of intervention is with a randomised controlled trial of an educational intervention.

With regards to qualitative research with advanced cancer patients, potential social factors impacting individuals’ health status and views, such as race, ethnicity and socio-economic classes of the participants were not examined. Furthermore, ‘deviant cases’ were not encountered at the recruitment stage. Therefore, the comprehensiveness of the findings for local palliative care services might be compromised. Finally, the fact that the original transcripts were in Vietnamese made it difficult for the researcher to obtain supervisors’ advice during the analysis stage, which may have some impact on the reliability of the findings.

Like any analytical approach, the data integration process might not be completely convincing due to incompatibility between theoretical paradigms for collecting and analysing. In addition to this, the process of triangulation might amplify sources of error and bias in each data set. The integration technique for analysis, adapted from a public health study (Farmer et al., 2006), might need to be modified further to address better nuances of mixed methods investigations in palliative care.

The findings from this evaluation of a provincial educational programme for rural family doctors in palliative care have important implications for those in Vietnam and developing countries who are seeking to improve the quality of care for people with advanced cancer living at home.

*Implications for palliative care practice*

First, the findings provide preliminary evidence that locally organised educational provision, based on healthcare professionals’ educational needs, can be effective in improving perceived knowledge, confidence and behaviour in practice for the participants. This programme probably needs to be continued locally, in order to reinforce these improvements. The development of a national educational programme in palliative care is also indicated, so that the benefits of locally organised programmes can be standardised and implemented across Vietnam. In addition, family doctors need to be encouraged further to translate educational contents into their ongoing work and to commit to making actual changes in palliative care practice. This will require ongoing coordination and facilitation

The results of this study indicate that satisfaction of patients with the quality of current healthcare service was an important factor in choosing their preferred setting. A majority of patients under the care of family doctors in rural areas highly rated the ability of the local healthcare teams highly in terms of meeting their practical, physical and psychosocial needs. These findings suggest that cancer patients with palliative care needs would choose to be cared for by local healthcare professionals as long as they do not suffer from severe or life-threatening symptoms and local palliative care services are still able meet their demands. This provides further support for palliative care education for family doctors, as our evidence suggests many patients would prefer to be cared for in the community setting, by family doctors who can meet their palliative care needs.

*Implications for palliative care policy*

The findings show that some family doctors can be identified as highly competent in palliative care. These doctors could be recruited as local facilitators, and their expertise could benefit the educational programme in palliative care as it develops in the coming years, through standardising elements of the programme and promoting national engagement in palliative care education.

Given the centrality of primary healthcare teams to rural healthcare services as well as evidence of the impact of our programme on actual practice, our findings suggest that educational programmes in palliative care for these teams should be an integral part of strategies to improve this type of healthcare services in the community at both provincial and national scales.

Policy-makers in the field can standardise parts of this approach such as contents, support activities, timeframe and costs in order to create an educational model in palliative care (based on this study) for family doctors which would be then deployed in other provinces in Vietnam or similar regions in developing countries. Policymakers should also consider the importance of educational interventions in palliative care when developing national policy on the integration of palliative care into primary care across Vietnam. As Vietnam’s health services improve alongside the expanding economy, it will be important to recognise the importance of palliative care at a national policy level. The country may seek to follow examples from other countries (for example, the Gold Standards Framework in the UK or the UK End of Life Care Strategy) in developing national policy specific to palliative care, which should emphasise the importance of education.

*Implications for palliative care research and education*

This study provides some evidence about what types of educational provision may be particularly effective, especially when coupled with organisational changes and current policies on the integration of palliative care into the primary healthcare system.

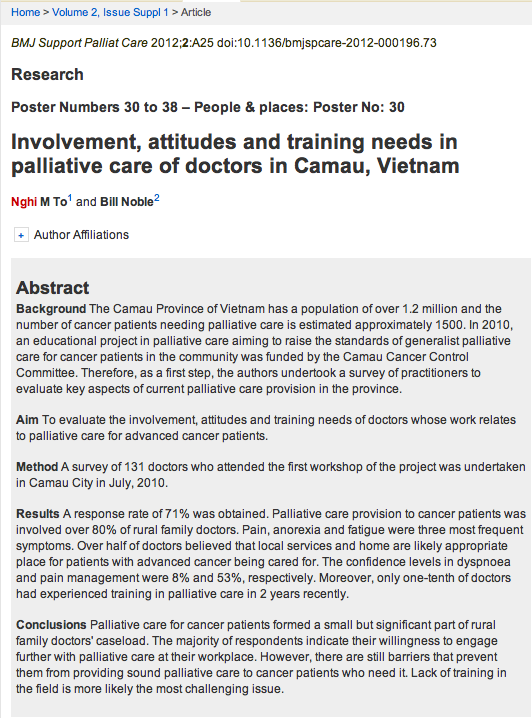
In addition, improvements in knowledge and confidence in palliative care practice amongst rural family doctors could be of some benefits to other patient communities who need this care at home such as people with AIDS, heart failure, dementia and other conditions requiring palliative care. These unexpected benefits from this project suggest that training and education in palliative care for family doctors could be an integral part of strategies to improve generalist palliative care for all patients with palliative care needs in the community

The mixed methods design and the triangulation protocol for integrating data in palliative care which I have employed in this evaluation research is entirely reproducible, not only for future research work of this project but also for similar research studies in the field from different regions in Vietnam as well as in other developing countries. However, the use of triangulation protocols for integrating data in mixed methods studies in palliative care requires further research attention. Methodological evaluation of the process and outcomes of integrating data would help in evaluating the appropriateness of this method for future palliative care studies.

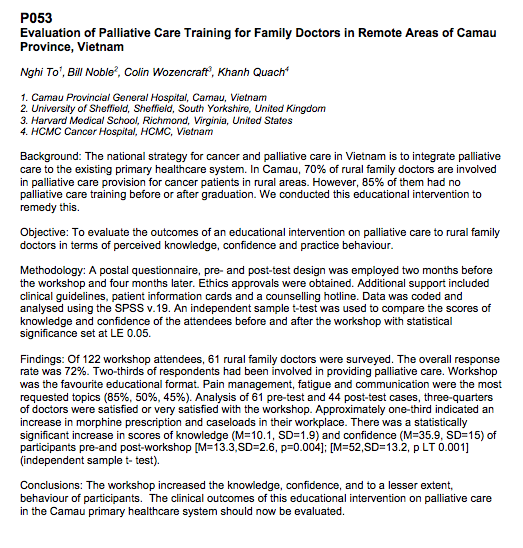
Further work needs to be done to ensure that the evaluations of outcomes of educational interventions for healthcare professionals focus more on quantitative data related to quality indicators, such as the number of patients who received palliative care at each CHS or the quantity of morphine prescribed per month. The identification of additional outcome measures may also be beneficial in assessing the impact of educational interventions. With regards to the evaluation of clinical outcomes for patients, patient-reported outcome measures (PROMs) should be used to assess the levels of symptom control, quality of life, satisfaction with care and so on. Future studies should use measures such as these to explore the direct effect of the educational intervention on patient outcomes. Moreover, it would be necessary to develop a national collaborative research network to conduct multi-centred educational interventions with cluster randomised and controlled trials, if they are to be evaluated rigorously before establishing definitive national policy in this area.

# Appendices

## Appendix 1.1 – Abstract of Poster Presentation at the 9th Palliative Care Congress – The Sage, Gateshead, Newcastle, UK. 14th–16th March 2012.



## Appendix 1.2 – Abstract of Poster Presentation at the 19th International Congress on Palliative Care–Palais des Congrès, Montréal, Canada. 9th - 12nd October 2012.

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## Appendix 2.1 – Pre-workshop Questionnaire (English version)

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**University of Sheffield**

**Camau Cancer Control Committee**

**Questionnaire I**

Please tick the appropriate box

|  |  |  |  |
| --- | --- | --- | --- |
| 1 | Your gender | Female……………………… | ❑ |
| Male………………………… | ❑ |

|  |  |  |  |
| --- | --- | --- | --- |
| 2 | Your workplace is situated on | Urban | ❑ |
|  |  | Sub-urban | ❑ |
|  |  | Rural | ❑ |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 3 | Number of years in practice | 0 - 5 years ………………….. | ❑ |  |
| 6 – 10 years ………………... | ❑ |  |
| 11 – 20 years ………………. | ❑ |  |
| > 20 years ………………….. | ❑ |  |

|  |  |  |  |
| --- | --- | --- | --- |
| 4 | Have you attended any training class on palliative care in 2 years recently? | Yes………………………….. | ❑ |
| No…………………………… | ❑ |

|  |  |  |
| --- | --- | --- |
|  | If yes, please describe course(s) and year attended | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 5 | Did you read any palliative care papers and/or books last year? | Yes………………………….. No ………………………….. | ❑❑ |
|  | If yes, please elaborate what kind(s) | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |  |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 6 | Have you provided palliative care to people with cancer in your workplace in the recent 6 months? | | Yes …………………………. No .......................................... | | ❑❑ |  |
|  | If you do not provide palliative care, please indicate the reason: | | I do not want to treat symptoms related to cancer…………….. | | ❑ |  |
| I did not encounter any patient with cancer………………….. | | ❑ |  |
|  |  | | Lack of financial incentives… | | ❑ |  |
|  |  | | Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |  |  |
| 7 | How many cancer patients with palliative care needs (on average) do you treat every month? | | 0 patients………………… . . . | | ❑ |  |
|  | 1 - 3 patients …………………. | | ❑ |  |
|  | 4 - 5 patients …………………. | | ❑ |  |
|  | > 6 patients ………………….. | | ❑ |  |
| 8 | Do you use the National Guidance for Palliative Care in practising daily? |  | Yes ………………………… | ❑ | | |
|  | No …………………………. | ❑ | | |
| 9 | Do you have the regulations of the Ministry of Health on prescribing opioids in your workplace? |  | Yes ……………………….. | ❑ | | |
|  | No ………………………… | ❑ | | |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 10 | Where do you usually refer a cancer patient with palliative care needs? | District General Hospital …….. | ❑ |  |
| Provincial General Hospital …. | ❑ |  |
|  |  | Tertiary Cancer Hospital …….. | ❑ |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 11 | In your view, what are the appropriate formats for learning palliative care? | Training workshop …………… | ❑ |  |
| Printed documents by post …… | ❑ |  |
|  |  | Telephone counselling ……….. | ❑ |  |
|  |  | Through the Internet …………. | ❑ |  |
|  |  | Hospital placement …………… | ❑ |  |
|  |  | Others………………………… |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 12 | What topics of palliative care do you want to be covered at the incoming workshop? | Pain management …………….. | ❑ |  |
| Dyspnea ………………………. | ❑ |  |
|  | | Gastrointestinal symptoms …… | ❑ |  |
| Communication ………………. | ❑ |  |
|  | | Anorexia / weight loss | ❑ |  |
|  | | Fatigue . . . . . . . . . . . . . . . . . . .  Psychiatry . . . . . . . . . . . .. . . Others (please elaborate ). . . . . . | ❑❑ |  |

**Questionnaire II** **Palliative Care Knowledge Test (1)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Please tick (✓) | True | False |
| 13 | Palliative care should only be provided for patients who have no curative treatments available | ❑ | ❑ |
| 14 | Palliative care should not be provided along with anti-cancer treatments | ❑ | ❑ |
| 15 | One of the goals of pain management is to get a good night’s sleep | ❑ | ❑ |
| 16 | When cancer pain is mild, opioids should be used more often than a mixture of paracetamol and codein phosphate. | ❑ | ❑ |
| 17 | When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used | ❑ | ❑ |
| 18 | The effects of morphine may decrease if using a fixed dose over time | ❑ | ❑ |
| 19 | Long-term use of opioids can often induce addiction | ❑ | ❑ |
| 20 | Use of opioids does not influence survival time | ❑ | ❑ |
| 21 | Morphine should be used to relieve dyspnoea in cancer patients | ❑ | ❑ |
| 22 | When opioids are taken on a regular basis, respiratory depression will be common | ❑ | ❑ |
| 23 | Oxygen saturation levels are correlated with dyspnoea | ❑ | ❑ |
| 24 | Anti-cholinergic drugs or scopolamine hydro bromide are effective for alleviating bronchial secretions of dying patients | ❑ | ❑ |
| 25 | During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort | ❑ | ❑ |
| 26 | Benzodiazepines should be effective for controlling delirium | ❑ | ❑ |
| 27 | Some dying patients will require continuous sedation to alleviate suffering | ❑ | ❑ |
| 28 | Morphine is often a cause of delirium in terminally ill cancer patients | ❑ | ❑ |
| 29 | At terminal stages of cancer, higher calorie intake is needed compared to early stages | ❑ | ❑ |
| 30 | There is no route except central venous for patients unable to maintain a peripheral intravenous route | ❑ | ❑ |
| 31 | Steroids should improve appetite among patients with advanced cancer | ❑ | ❑ |
| 32 | Intravenous infusion will not be effective for alleviating dry mouth in dying patients | ❑ | ❑ |

**Questionnaire III Confidence with Palliative Care in Practice (2)**

|  |  |
| --- | --- |
| 33 | I can assess a palliative care patient’s pain |

0

Very confident

Reasonably confident

No confidence

10

5

|  |  |
| --- | --- |
| 34  0  Very confident  Reasonably confident  No confidence  10  5 | I understand the WHO three-step analgesic ladder |

|  |  |
| --- | --- |
| 35  0  Very confident  Reasonably confident  No confidence  10  5 | I understand how to prescribe opioids analgesic drugs such as morphine |

|  |  |
| --- | --- |
| 36 | I understand the role of palliative care for patients with cancer and HIV/AIDS |

0

Very confident

Reasonably confident

No confidence

10

5

|  |  |
| --- | --- |
| 37 | I understand what is meant by holistic history taking |

0

Very confident

Reasonably confident

No confidence

10

5

|  |  |
| --- | --- |
| 38 | I can discuss anxiety with a palliative care patient |

0

Very confident

Reasonably confident

No confidence

10

5

|  |  |
| --- | --- |
| 39 | I understand the different models/settings for palliative care |

0

Very confident

Reasonably confident

No confidence

10

5

|  |  |
| --- | --- |
| 40 | I feel equipped to break bad news to patients |

0

Very confident

Reasonably confident

No confidence

10

5

**Thank you for taking the time to answer these questions**.

## Appendix 2.2 –Post-workshop questionnaire

Dr Nghi M. To

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Camau Province

Tel: 0780 3567735

Email: drnghicm@gmail.com

**University of Sheffield**

**Camau Cancer Control Committee**

**Questionnaire I**

Please tick the appropriate box

|  |  |  |  |
| --- | --- | --- | --- |
| 1 | The amount of morphine was used in your workplace in last 3 months | Increase ………………….. | ❑ |
| Unchange …………………. | ❑ |
| Decrease ………………….. | ❑ |

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| 2 | How many ampoule of morphine do you prescribe monthly, on average? | | | ……ampoule(s) per month | | ❑ | |
| Not any………………… | | ❑ | |
|  |  | | |  | |  | |
| 3 | In your opinion, what reason(s) make doctors reluctant in prescribing morphine in their workplace? | | | Oral morphine is not available | | ❑ | |
|  | Patients probably misuse | | ❑ | |
|  | Sophisticated regulations  Other . . . . . . . . . . . . . . . . . . . . | | ❑ | |
| 4 | | Have you got any troubles relating to morphine availability in your workplace?  If yes, please elaborate what trouble(s) | | Yes………………………….. No ………………………….. | | |
|  | | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | |
| 5 | Is there oral morphine or transdermal fentanyl in your workplace? | |  | Yes ……………………….. |
|  | No ………………………… |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 6 | How many people with cancer per month do you currently provide palliative care in the workplace? | | 0 . . . . . . . . . . . . . .patient(s) | |
|  | 1-3 | |
|  | 4-5 | |
|  | 6-10 | |
|  | Reason(s) of not having patients . . . . . . . . . . . | | >10  . . . . . . . . . . . . . . . . . . . . . . . | |
| 7 | The number of palliative patients visitting your office in last 3 month is . . . . . . . . | | Increase ……..…………… | | ❑ |
|  | Unchange…………………. | | ❑ |
|  | Decrease…………………. | | ❑ |
|  | Not sure………………….. | | ❑ |
|  |  |  |  |
| 8 | Have you telephoned to palliative care consulting hotline? | | Yes………………………….. | | ❑ |
| No…………………………… | | ❑ |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | | If yes, please describe the requested content | | \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | | |
| 9 | Do you use the National Guidance for Palliative Care in daily practice? | |  | Yes ………………………… | ❑ | | | |
|  | No …………………………. | ❑ | | | |
|  |  |  | | | |
| 10 | Where do you usually make a referal for a cancer patient who need intensive care? | | | District General Hospital | | ❑ | |  |
| Provincial General Hospital | | ❑ | |  |
|  |  | | | Spescialsed Cancer Hospital | | ❑ | |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 11 | How satisfied are you with the training workshop? | Very satisfied…………… | ❑ |  |
| Satisfied………………… | ❑ |  |
|  |  | Neither …………………. | ❑ |  |
|  |  | Unsatisfied……………… | ❑ |  |
|  |  | Very unsatisfied………… | ❑ |  |
|  | Reason(s) of dissatisfaction | …………………………………………………………………… |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 12 | What topic(s) of the training workshop and activities do you benefit ? (multiple choices) | Pain management …………….. | ❑ |  |
| Palliative care principles……. | ❑ |  |
|  | | Break the bad news ……….. | ❑ |  |
| Cancer-related symptoms. . . . | ❑ |  |
|  | | Patient- held record... . . . | ❑ |  |
|  | | Monthly documents by post. .... | ❑ |  |
|  | | Counselling telephoning ... . . . | ❑ |  |
|  | | Others (please elaborate)... . . . . . . | ❑ |  |

**Questionnaire II** **Palliative Care Knowledge Test**

**Questionnaire III** **Confidence Rating Scale**

**Thank you for taking the time to answer these questions**

## Appendix 3.1 – Patient Information Sheet

**University of Sheffield**

**Camau Cancer Control Committee**

Dr Nghi M. To

Oncology Ward, Provincial General Hospital

16 Hai Thuong Lan Ong , Camau City

Camau Province

Tel: 0780 3567735

Email: drnghicm@gmail.com

**Evaluation of palliative care training on family doctors in remote areas of Camau Province, Southern Vietnam**

**Invitation to participate in the study**

You are being invited to take part in a research study undertaken by a team of researchers based at the Provincial General Hospital. Before you decide, it is important for you to understand why the research is being done, and what it will involve. Please take the time to read the following information carefully, and discuss it with others, if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

We want to find out whether training on palliative care could lead to positive outcomes on both family doctors and cancer patients.

**Why have you chosen me?**

You have been chosen becauseyouare receiving treatment for cancer at the Oncology Ward or at home by your family doctor. Either the ward staff or the local heath team have identified you as willing to take part in research about your treatment.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to keep this information sheet and will be asked to sign a consent form. You are free to withdraw at anytime without giving a reason. A decision to withdraw at any time, or a decision of not taking part, will not affect your future medical care.

**What does taking part involve?**

Dr Nghi M. To, the principal researcher will interview the patients who agree to participate in our research. It will take 30-45 minutes to complete the interview. Dr Nghi will read and explain the Patient Information Sheet and the Patient Consent Form to you until you understand clearly the purpose of the research and your rights .You have additional 15 minutes to consider or discuss the Consent Form with your family members before signing it. The questions of the interview are about you, your health and your feelings regarding to your choice about the care settings. The content of the interview will be documented and recorded by a tape recorder in order to assist to analyse after that. The recordings together with information identifying patients, whose data are reported in scientific papers, will be destroyed as the research finishes.

Patients will be interviewed at some point of time of the study process. Some patients will be interviewed at the Provincial General Hospital at the beginning of the research; the others will be interviewed at their home when the project will be underway. As part of the study, we would also like to look at information in your clinical records.

We will ask you several short questions regarding to your illness and you decision on place of care.

**What are the possible risks and disadvantages of taking part?**

Answering the questions will take up some of your time. Occasionally, people may feel upset by being reminded of illness or difficulties. Specialist help and support are available in the case you feel any part of the study has upset or affected you in any way.

If you feel tired, the interview would stop immediately until you feel well or could delay to a suitable time. The interviewer always comes to patients’ home with the community nurse who may be consulted in case of distress.

**What are the possible benefits of taking part?**

This study will contribute to identify patients’ perspectives and needs concerning to the choice of place of care, and examine whether the experience is different between groups of patients before and after the interventions.

We hope to learn if conducting our intervention would make a difference in quality of palliative care provision at health stations in remote areas of Camau province. As a result, it would reduce the number of referrals to secondary or tertiary hospitals and patients could receive a good quality care at their home.

**Will my taking part in the study be kept confidential?**

Information from this research will be only given to the doctors and nurses involved in the research team.

Information from the research interviews and your clinical records will be kept strictly confidential and it will be securely stored. All research data about you collected in this study will be treated in accordance with the ethics regulations of Vietnamese Ministry of Health. Information from interviews will be stored separately from identification codes. Data will be anonymised and reported in the form that does not allow identification of the participants.

**What will happen to the results of the research study?**

The research team will use the information you give to help to improve palliative care for patients. The results will be written into a report, along with information from other parts of the study (available to all participants). This report will be presented to the organisation that has funded the research and discussed with the service itself. The results of the study may be published in international medical journals and presented at scientific meetings. The information may be used in the education of other health professionals and contribute to postgraduate studies. You will not be identified in any way.

**Who is organising and funding the research?**

The research is funded by Camau Cancer Prevention Committee, and organised through the subordinates of the Camau Department of Health and Provincial General Hospital.

**What if I am harmed or I am unhappy about any aspect of the study?**

As there are no specific risks associated with this study it is highly unlikely that you will be harmed. However, if you have any concerns or complaints about any aspect of the study please contact, in the first instance, the Principal Investigator on the study

Dr To Minh Nghi – Head of Oncology Ward, Provincial General Hospital.

Telephone: 0780 3567735

**Who can I contact for further information?**

Dr To Minh Nghi. Head of Oncology Ward, Provincial General Hospital.

Telephone: 0780 3567735

## Appendix 3.2 – Patient Consent Form

**University of Sheffield**

**Camau Cancer Control Committee**

Dr Nghi M. To

Oncology Ward, Provincial General Hospital

16 Hai Thuong Lan Ong , Camau City

Camau Province

Tel: 0780 3567735

Email: drnghicm@gmail.com

**Evaluation of palliative care training for family doctors in remote areas of Camau Province, Southern Vietnam.**

**Principal Investigator: Dr Nghi M. To**

**Patient ID Number:** . . . . . . . . . . . . . . . .

|  |  |
| --- | --- |
| 1. I confirm that I have read and understand the patient information sheet for the above named study and have had the opportunity to ask questions. 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. 3. I understand that relevant sections of any of my medical notes and recordings of the interview collected during the study may be looked at by responsible individuals from the research team. I give permission for these individuals to have access to my records. 4. I agree to take part in the above named study.   **Name of Patient:**  **. . . . . . . . . . . . . . . . . . . . . . . . . . . . Date : Signature:** | **Please put a tick** |

**Address: . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . ..**

**Telephone Number: . . . . . . . . . . . . . . . . . .**

**Name of Person receiving Date Signature**

**consent (if different from researcher)**

**. . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .**

**Thank you for participating in this research**

## Appendix 4.1 – Doctor Information Sheet

Dr Nghi M. To

Oncology Ward, Provincial General Hospital

16 Hai Thuong Lan Ong , Camau City

Camau Province

Tel: 0780 3567735

Email: drnghicm@gmail.com

**University of Sheffield**

**Camau Cancer Control Commitee**

**Evaluation of palliative care training on family doctors in remote areas of Camau Province, Southern Vietnam.**

**Invitation to participate in the study**

You are being invited to take part in a research study undertaken by a team of researchers based at the Provincial General Hospital .Before you decide, it is important for you to understand why the research is being done, and what it will involve. Please take the time to read the following information carefully, and discuss it with others, if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

|  |  |  |
| --- | --- | --- |
|  | **What is the purpose of the study?**  We want to find out if training on palliative care could lead to positive outcomes on both family doctors and cancer patients.  The questionnaires are used for assessing the information regarding to doctors. There are 3 sections, each asking about a different aspect of your practice; 40 questions altogether. | |
|  | **Why have you chosen me?**  You have been chosen becauseyouhave been working at the commune health stations, and you are delivering primary health care service in the remote community, and you may be interested in taking part in this research. If you agree to take part the research, we will ask you some matters regarding to your daily practice of palliative care for cancer patients in your area. | |
|  | **What does taking part involve?**  If you do decide to take part, you will be able to keep this information sheet and will be asked to complete the pre-course questionnaire; you will be invited to attend a two-day workshop on supportive and palliative care at Camau city; and, you will be requested to complete the post-course questionnaire after 4 months.  During period of the research you will receive additional documents such as guidelines, specialist papers that will be sent by post to you at your working address. |
|  | If you decide to take part, the only thing you need to do is to complete the questionnaire and sent it back to us (in the stamped addressed return envelopes accompanied). |
|  | **Who can I contact for further information?** |
|  | Dr To Minh Nghi. Head of Oncology Ward, Provincial General Hospital.  Telephone: 0780 3567735 |
|  | **Thank you for taking the time to read the information sheet.** |
|  |  |

## Appendix 4.2 – Doctor Consent Form

**University of Sheffield**

**Camau Cancer Prevention Committee**

Dr Nghi M. To

Oncology Ward, Provincial General Hospital

16 Hai Thuong Lan Ong , Camau City

Camau Province

Tel: 0780 3567735

Email: drnghicm@gmail.com

**Evaluation of palliative care training on family doctors in remote areas of Camau Province, Southern Vietnam.**

**Principal Investigator: Dr Nghi Minh To**

**Please put a tick**

|  |  |
| --- | --- |
| 1. I confirm that I have read and understand the doctor information sheet for the above named study and have the opportunity to ask questions if I want 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. 3. I understand that during the study, the relevant sections of data collected may be looked at by responsible individuals from the research team. I give permission for these individuals to access to my data. 4. I agree to take part in the above named study.   **Name of Doctor:** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .  **Date:** . . . . . . . . . . . . |  |

**Address:** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .. . . . . . . . . . . . . . . . . . . . . . . . . . . .

**Telephone Number:** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .

**Signature:** . . . . . . . . . . . . . . .

**Thank you for** **participating in this research**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Appendix 5 - Key Milestones of the Research Process | | | | | | | | | | | | | |
| Year | 2010 | | 2011 | | | | 2012 | | | | 2013 | | |
| Quarter | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| Developing proposal+Obtaining University Offer |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Ethics research application |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Fundraising and allocation |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Designing questionnaires & forms for collecting data |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Submitting pre-workshop questionnaire & interviewing hospitalised patients |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Organising the Workshop + Additional support |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Submitting post-workshop questionnaire + Interviewing patients at home |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Coding + Inputting Data |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Analysing data |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Writing+Proofread+Submission |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Viva+ Making corrections |  |  |  |  |  |  |  |  |  |  |  |  |  |

Appendix 6 – A Full Transcript of an Interview *(English translation)*

Patient H3.

A male patient with advanced lung cancer who was receiving the care from his local health care team. His KPS is 70

First, I introduced myself to the patient and his family carer. I then presented the purpose of my research, the right of patients, the process of the interviewing session and had the informed consent form signed.

How are you feeling today?

I can walk around my home; just feel a little bit exhausted. I am able to do any daily activities for myself . . . without any help from my wife.

Have you been bothered with troubles recently?

Since the start of 2 weeks ago I have felt some short of breath . . . and got sharp pain in chest . . . right here [pointed at the anterior chest wall] with every cough. The condition has been even worse last week.

How about the pain today?

I’ve still got hurt today . . . right here [directed the pain area again] . . . especially when I was lying . . . However, it seems be better . . .

So, how about your sleep and other activities such as eating or bowel habit?

I couldn’t sleep over night since it [the pain] had got started . . . it usually kept me awake at night to change my position or take medication for soothing the pain.

I really suffer from loss of appetite. However, I don’t vomit up my food as I used to be at the time of chemotherapy.

Can you tell me a little bit about your disease at the beginning?

I didn’t suffer much at the beginning, only a little short of breathe and cough. I persuaded myself that it wasn’t serious and just got on with my life . . . so I ignored it, after a few weeks it was still persistent, then I realised how serious the situation was.

And then . . .

I came to see my family doctor. He said that there would be something wrong with my chest because my symptoms lasted for a long time . . . and I need to take a chest X-ray at first.

When he [family doctor] said to me, after having the result of my chest X-ray, there was possibly a malignancy with my chest, which I needed to be referred to the PGH to get it treated. I was really worried about my situation since that time.

I was then referred the Oncology Ward [PGH] . . . I experienced about one or two weeks with lots of investigations and tests . . . even got my lung viewed under camera [bronchoscopy?] . . . I can’t remember clearly everything now. The doctor [oncologist] informed me that my lung tumour could not be cut out because it had spread out my chest and also close my heart . . . and the best thing for my disease is to start some cycles of chemotherapy. He also informed me that these drugs might only help to shrink the tumour and could not get the tumour rid of.

Did you receive treatments for your illness at that time?

Yes, I did. I had no other options to choice. I even knew some cases people could live longer than they expect . . . than their doctors’ prediction. I travelled to there [oncology ward - PGH] dozens of times for chemotherapy . . .

Who often has gone with you to the hospital?

Usually my wife, sometimes my daughter . . . my wife more often . . . They sometimes had to rent a flat near hospital for staying if the cycle was taken longer [in Camau, chemotherapy is a inpatient service] . . . it was really terrible. I got sickness and vomiting so much after each cycle. I couldn’t eat anything well until the next cycle.

How did you deal with it?

After following several cycles and being in very low spirits for several months, I started to hope that I could survive this terrible disease. Even though I could not eat anything at that time, I was convinced that I still had a good life to look forward to.

When did you get the diagnosis of the terminal stage?

I got couples of months feeling better after finishing chemotherapy regimes. Although the tumour didn’t disappeared, it seemed to be stable in several months. Three months ago, when I felt a severe pain in my chest, I came back the oncology ward for a routine investigation. After taking the CT-scanner result, the oncologist said to me that there is some fluid in my lung and the tumor possibly develops again. He spoke to me that there's no need for any more treatment for me. They had done all necessary treatments for me . . . It's now better as it is ... and I would not have to visit there [the oncology ward] for any additional treatment . . . I could try traditional treatments if I like.

What was your feelings at that time?

I understood my situation right away. It may be better as you know that it is no longer curable [incurable stage] . . . No need to travel a lot . . . No need to waste lots of money . . . and time. Sometimes, I’ve thought that I’m still lucky because, I’m also aware of how much time I have been given to live . . . at least. When you get to accept its existence, it’s easier than for you to think about some things to fight it. I suppose, things that should come, will come . . . Although like it [his terminal cancer] or not . . . it’s happened to you and the good things you should do is . . . to get on with it.

Can you tell me a little bit about the time when you was in hospital recently?

It was really terrible on my recent hospitalisation, you know . . . eight patients had to share an inpatients room coupled with carers, visitors . . . particularly in the evening, the room was overwhelmed by people and people . . . it was really exhausting. However, to be honest, my trouble seemed to be managed more quicky than at home [with local service]

I see. . .have you been worried with your disease? Are you scared something?

I do understand that my disease [end-stage of lung cancer] cannot be cured . . . I have been prepared for it [death] . . . I am not worried about it [death] much. It could happen to anyone . . . even though without this cancer . . . at anytime . . .

When did you receive the current care with your local family doctor?

Five or six months ago . . . I suppose. When I discharged from the oncology ward in PGH, the oncologist said to me that my problem in future could be treated at the village health stations. If the local team were not able to deal with my trouble, they would refer me to a general hospital.

How do you rate the care you have been receiving with you family doctor now?

Now they [healthcare professionals at the CHS] seem to have enough medication in comparison with a couple of years ago. Besides, I was very impressed when having acupuncture done at the health station. I usually feel more comfortable with it [back pain] for a couple of days until the next session. Besides, he [acupuncture therapist] was always listening to me and giving me lots of useful information.

What do you think about your current care? Why did you choose to be cared for at your local CHS?

They [local HCPs] are very kind to me. They helped with daily practical care every time I came to see them. They seem to be there to help patients. Generally speaking, the care I had was great.

Any else . . .?

Besides, it just takes a couple of minutes to get there [CHS]. I even could get medication injected and infused at home, because there is a nurse who is working near my home. She could help me with this stuff.

Have you made the decision for yourself on choosing place of care or someone else? How were decisions made?

I made the decision by myself. I decided to stay at home and get cared for by them [local healthcare team].

Although my son liked to take me to the hospital [PGH], I didn’t think it would be better for me. I have to admit that . . . hospital doctors could treated my pain better . . . hospitalisation is sometime really annoying . . .especially with the paperwork of the referral procedure.

Besides, at home, you know . . . my offspring are just living around and ready to help me. Their support and empathy for me have been extremely great … I need someone to talk about my illness . . . it makes me have a feeling of my troubles being shared so much . . . and also so and helped me to lift up my spirit.

Have you attended any social activities in the community?

Yes I have . . . but not many. Partly, because I often don’t feel comfortable since the last discharge . . .and I am afraid of answering the questions from my friends concerning my illness too.

Have you got the information card [the patient-held record] as you discharged from the hospital? Does it help?

Yes. I got one . . . I was aware of something related to my disease . . . doctors [clinician] seems to be so busy to make it clear to patients in hospital . . . I’ve been also told about presenting it to my family doctor when I would get trouble . . . however, they [local healthcare professionals] don’t seem to be interested in it so much . . .

In your opinion, is there anything the healthcare system needs to do in order to improve the quality of local health service to fulfill your expectation?

For me so far so good with my current care . . . I think it would be better if the local services [CHS] had enough medication and modern equipment for treating people with cancer.

Thank you very much for your time.

## Appendix 7 – Letter of Ethics Approval from the University Research Ethics Committee (UREC).

**

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1. APM: The Association for Palliative Medicine of Great Britain and Ireland. [↑](#footnote-ref-1)
2. ESMO: The European Society of Medical Oncology. [↑](#footnote-ref-2)
3. Vietnamese currency unit [↑](#footnote-ref-3)
4. Expenses that are charged directly on people using health services (the user fees policy). [↑](#footnote-ref-4)
5. COPD: Chronic Obstructive Pulmonary Disease [↑](#footnote-ref-5)
6. PEPFAR: President’s Emergency Plan for AIDS Relief from the USA [↑](#footnote-ref-6)
7. KPS: Karnofsky Performance Status Score [↑](#footnote-ref-7)