

Involvement of the Family Physician in Palliative Care

An Outcome Analysis

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ABSTRACT

Involvement of the Family Physician in Palliative Care: An Outcome Analysis

Objective: An evaluation of the degree of involvement of family physicians in the care of patients with terminal illness was conducted. The outcome of this care was correlated with the degree of involvement.

Background: The background to the clinical situation, ethical issues and the context of the study in South Africa is explored, with special reference to the private practice milieu of medical practice. Particular reasons for the study to be undertaken at all are indicated.

Method: Quantitative research methods were employed in the analysis of both involvement and outcome. Novel questionnaires to obtain information from the surviving care-giver and family physician were designed and used for the first time in this study.

Results: The results of the analysis revealed that there is a high degree of correlation between the involvement of the family physician and the outcome of palliative care in the subjects of the investigation. This was statistically significant. It was noted that the family physicians and care-givers assessed involvement and outcome differently.

Some factors which may have influenced the replies were considered, and the fact that the questionnaires were not yet validated was explored.

Reflection: The conception, process, conduct and conclusion of the research project were subjected to reflection and analysis. This process itself yielded valuable insights. It is suggested that further work be done to validate and improve the questionnaires so that they may be used for other research in palliative care and related disciplines.

KEY WORDS

palliative care, family physician, involvement, outcome, questionnaire

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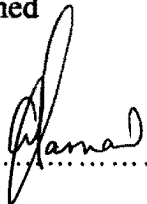
DECLARATION

I, Alan John Barnard, declare that this research project is my own work and that it is submitted to the University of Cape Town to fulfil the requirements of the M Phil (Palliative Medicine) degree.

I declare that this work has not previously been submitted to any other university or similar institution.

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Signed



.....

Date

12 November 2004
.....

DEDICATION

This work is dedicated to the pioneers of palliative care who have started a good work, and entrusted us with the task of continuing it.

My loyal and patient wife, Penny, and daughters, Laura and Charlotte, are my inspiration and a joy forever.

Thank you.

ACKNOWLEDGEMENTS

This has been a challenging and exciting assignment, with many aspects which have surprised me. The difference between having a good idea and the exploration and execution of that idea has been profound. I have learnt much about the field of palliative care, about research and about my dependence on the people around me to support and encourage my work.

My first thanks go to my wife, Penny, who has waited a long time for household chores to be neglected yet again! Her encouragement has sustained the momentum and filled the lamp with midnight oil. Thank you too for honest criticism and reading the text with care and attention to detail.

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To Dr Liz Gwyther who unexpectedly took the role of supervisor late in the process, a huge debt of thanks is due. Her passion for the field of palliative care is infectious and her criticism of work always accurate, sensitive and encouraging.

Other members of the department of Family Medicine at the University of Cape Town who were helpful include Ferdi Franz who supported the project from the start and was the project supervisor until his work took him away from the department. Professor Derek Hellenberg was likewise encouraging and Rauf Sayed was very helpful with the statistical analysis.

The co-operation of the staff at GVI Oncology at Constantiaberg Mediclinic was also much valued. Georgina McAdam allowed the research project to be undertaken in her practice. Clair Manicom helped with confidential correspondence, sending and receiving of questionnaires as well as sorting the responses and ensuring that the ethical duty of absolute confidentiality was respected. She also supported and encouraged me to persist when the workload seemed too great. Adri van der Westhuizen also helped with the sorting of questionnaires.

Many friends have helped along the way. Thanks are due to Albie Jacobs for late night computer tutorials, Mandy Speechly for reading the manuscript for errors of grammar and style, Fiona Rawlinson for her enthusiastic teaching of palliative care and many others for patient advice and encouragement.

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University of Cape Town

CHAPTER 1 – INTRODUCTION

Background

The practice of palliative care and family medicine have much in common. Each discipline considers the patient as the centre of the care offered, and not the illness or diagnosis, as medical students have been taught over the years. The context of the patient in the family and in society is central to the care that is offered. The care offered extends beyond the simple diagnosis and treatment of specific problems and moves into more intimate and undifferentiated areas of need, like spiritual care and psychological support. It is axiomatic that patients need complete care extending from the competent diagnosis and management of physical ailments to the complex integration of psychosocial and spiritual care. The concept of holistic care has been misinterpreted by many to mean complete care, but in palliative medicine the care is always greater than the sum of its parts.

Many of the problems addressed are insoluble in the general understanding of the world and the curative medical disciplines in particular, yet the patients and family members who receive competent care report that their needs are met very well, despite the fact that answers are elusive and cure is impossible. The healing of illness and of the effects that such illness has had on relationships is a different goal, and is often better addressed in a non-curative model of care.

The deep need for people to understand exactly what is going on in their frail bodies may be a reflection of the scientific revolution in medical practice, and the expectation that medical science can and will know everything. Those who have practiced clinical medicine know this to be a vain hope. We do know a lot about some

conditions, but are confounded by the different individual responses of similar patients to the same set of circumstances. Disillusionment with the results of care, given even by competent and caring doctors, has led many to seek answers from other models of health care like complementary therapy. This is, at least in part, a post-modern reaction to the failure of medical science to provide all the answers.

There is a fundamental fear in every person regarding death. This of course is written from the perspective of western society and philosophy. Even the most reverent and observant religious person prays for cure and healing. The Judeo-Christian religious ethic, which underpins western law and ethics, values life very highly. Faith dictates that life continues beyond the grave but faith is often weak, or questioned, especially when facing the reality of the end of life. Palliative care and competently practised family medicine honestly address this fear, admit that the answers are not all clear and continue to care for the patient and the family as best possible.

Palliative care and family medicine are the only medical disciplines which are able, in terms of their core values and approach, to offer complete, contextual and honest care. Truth, tempered by love, is offered to all patients: those with unexplained viral illness, fatigue *or* metastatic malignancy. All of the patients with these conditions will die, and some will suffer. Not all will die of the conditions mentioned, but the care that each needs on a human level is exactly the same. Competent medical management includes therefore, complete care of the person with the condition and the extended circumstances which prevail in that situation. In a patient with cancer, for example, it is important for the tumour to be treated vigorously and aggressively. The first goal of therapy should be cure, if this is possible. During this stage of treatment, the treating

doctors should be sensitive to the emotions and reactions of the patient to the illness beyond the simple reduction of tumour burden. The family support and financial circumstances as well as mental state should be considered and treated as well. It is well established that depressed patients respond less well to medical intervention than patients without depression.

The South African Context

The South African situation in which medical care is offered and received is fraught with many complex societal, political, financial and legislative issues. That most of these issues are outside the control of either the doctors (or other care-givers) delivering the care or the patients receiving that care leaves an untenable situation of anxiety and distress in many people. The dissatisfaction generated manifests in a mood of unhappiness among doctors and other care-givers. This may be one of the factors leading to the loss of medical professionals from the public sector to the private sector and from the country to emigration. Some doctors and paramedical care-givers also leave the profession altogether. The general public is also dissatisfied, and this manifests, in part, in the seeking of care beyond the medical model. This is sometimes helpful, if it relieves symptoms or has other benefits. There are also risks to the patient should delays in treatment be prolonged, or financial resources are consumed by therapies of dubious benefit.

South African society is deeply divided by poverty. The effects of misguided social engineering like apartheid are manifested for generations. The extreme depersonalisation of individual human beings which apartheid perpetrated, by classifying them by race group is particularly offensive to practitioners of family

medicine, which treats each patient as a person, and not as a member of an artificially defined group. We should learn from the past, however, and rather address the issues as they are presented to us every day, taking care not to be politically correct for the sake of image but simply to see each person in context. This research project is based in a privileged sector of the community, but this principle is applicable in every sector of society.

The effects of apartheid have been to concentrate poor, mostly black, people in the rural areas and on the urban fringe. Medical services are available, but the queues are long and many people have to travel a long way to see a busy overworked clinic at great personal cost. If the ill person has employment, then at least one day of wages would be lost in order to consult a doctor. The wealthy live in comfort, as they do all over the world, and have very quick access to medical care. They are particularly demanding of the best available care. This is often confused with the most technological care, and at great expense. This aspect will be addressed further below.

Political action often confuses the electorate, or rather the individual people who stand in queues to elect politicians. In the context of this discussion, the action involves the development of very good legislation for some aspects of medical care delivery, and the ambivalence towards the obvious needs in others – notably HIV infection and AIDS. The interaction of health departments and the politicians affects the really important task of helping the individual patient to know what is wrong and how to feel better. South Africa is not unique in this situation, but there are special aspects which affect us more than others in the world. It seems to those practising in the private sector that the new legislation being developed to govern the delivery of

health care will move some of the patients currently cared for by the state into the private sector, and some of the patients currently cared for by the private sector into the state system. It is to be hoped that the consequences of legislative changes like these have been properly anticipated by the planners.

The development of palliative medicine as a distinct discipline which is understood and respected by members of the public, the medical profession and the health department will contribute to the improvement of patient care and even to the development of better frameworks for the delivery of care like legislation, clinic operations and communication between members of the clinical team.

The delivery of medical care in the private sector in South Africa also has challenges to be addressed by the doctors and consumers of that care. Patients are consumers of health care in a fee for service environment which has had elements of managed care imposed upon it in the past ten years. These changes have not led to cost saving for the consumers, and neither have the providers of the care been remunerated adequately for the service which they provide. The provision of private hospital services and pharmaceutical expenses as well as the high cost of new technology has consumed a disproportionate fraction of the total health care expenditure. The payment for services is undertaken by a third-party funder, with the employed person paying for services in advance by means of a monthly contribution. The principle of cross-subsidisation ensured, for as long as it was able, that the young and healthy met the expenses of the elderly and sick. This in the knowledge that they would be in that position one day, and that there would be a new group of low claimers to meet the financial demands required. The advent of new and expensive technology, as well as

the demand for more information by the well-informed patients is one of the factors that have led to the demise of that system. Suffice it to say here that the system is undergoing fundamental change, which is unsettling to all involved – those who receive care and those who deliver it.

There is also a division among those who deliver care to patients within the private sector. This may broadly be defined as the division between specialists and family physicians. Patients are referred from the family physician to specialists for specific diagnosis or treatment who then hold onto the patient for reasons of fees, professional pride, the real or perceived lack of expertise among family physicians or other reasons. There is not always good communication between the specialists and referring doctors. Cross referrals between specialists often lead to the duplication of investigation and further fragmentation of care. This also increases costs severely. Fragmentation of care occurs in the state system of delivery for reasons other than financial ones, some of which have been mentioned above.

HIV Infection and AIDS

No discussion of the South African medical system and the delivery of care, particularly palliative care would be complete without referring to the situation of HIV infection and AIDS. Despite the fact that this research project is concerned with cancer patients, the report would be diminished if this particular aspect of the South African medical landscape did not receive a mention. HIV medicine is family medicine, as it affects millions of people who receive their care from family physicians every day. The consequence of the prolonged debate and delayed responses, as well as the high cost of treatment and support has been to focus the

attention of the profession and the very valuable and prominent advocacy groups on that small part of the overall picture, that is to say the availability of anti-retroviral drugs. This is but a small part of the proper care of any patient. The benefits of taking anti-retroviral agents are clear, and these drugs are essential for good palliative care as well as good family medicine, but the principles of palliative medicine should be applied to every patient from the time of diagnosis, to the time of the onset of AIDS and into the care of the surviving family members after the patient has died.

In the South African and African context, the delivery of palliative care to patients who do not have HIV related illness runs the risk of being overwhelmed by the huge needs of HIV related illness. The channelling of resources, human and financial, to this worthy and essential cause may take away from the delivery of good palliative care to patients with cancer and other terminal illness.

Ethical considerations

The basic tenets of medical ethics apply to this field as to any other. The delicate and sensitive nature of the care that is required and given confers an even greater responsibility than usual on the doctors, and other team members, to examine their ethical standards and behaviour.

The four principles of ethics enunciated and explained by Gillon in the British Medical Journal in 1994² are never more clearly applied than in the delivery of good palliative care. The apparently obvious notion of *beneficence*, or the need to do good, has an interesting counterpoint in palliative care, in terms of which some suffering has to be borne and moderated rather than averted altogether. This is difficult for medical

professionals trained in curative disciplines. The seeming withdrawal of “care” by the profession once a terminal stage of illness has been reached may actually reflect inadequate skills and training at the undergraduate and post-graduate level. There is an ethical responsibility therefore, on the trainers of medical professionals to ensure that there is balance in the expectation and expertise of new graduates.

Non-malificence, or the avoidance of doing harm, seems equally obvious: the officious extension of life in the intensive care unit or the poor management of pain could both be considered ethically indefensible in terms of this principle. Issues of confidentiality arise under this heading too.

Autonomy is a particularly important ethical principle. Aspects of autonomy are best articulated before the patient is in a position to require us as carers to apply them. Terminal illness often encompasses periods of delirium and confusion, and even coma. Patient autonomy is therefore compromised and the carers have to act with the best interest of the patient at heart. Autonomy may be understood better by considering the notion of *authenticity*, as articulated by Janssens and Ten Have³ in which the tension between the absolute independent needs of the patient and the needs of the family and the care-givers, amongst others, is held, weighed and balanced.

The principle of *justice*, both distributive and legal, is also central in palliative care. The allocation of scarce resources is not a problem which is unique to the poorly resourced world. There are always more needs than resources. It behoves us all as carers to ensure that we do not exhaust our capacity to care by emotionally draining

ourselves, thereby distributing fairly to ourselves, our patients and our colleagues, the support and psychological care required.

The advocacy role of the family physician

This is, of course, another of the central tenets of good family medicine; that is to say *patient advocacy*, starting with the individual person presenting in the clinic with a medical problem, to the issues of *community advocacy*, like access to care, proper facilities, better drug formularies, poverty alleviation and so on. The paternalistic model of caring for patients has been outdated and in the current South African context of respect for human rights and the autonomy of the individual, patients and communities should be afforded the right to make informed choices about the care that they receive. The spirit of community that is expressed in the African word *ubuntu* is another cornerstone of the reality that we face in the care of our patients. *Ubuntu* may be understood to mean, “I am because we are”. Both individual people and communities as a whole should be encouraged and developed to seek the best care that is available and to exercise autonomy in the making of these choices. The individual autonomy, which is so highly prized in western thought, may sometimes be held in tension by the needs of the community and other individuals.

This research project was conceived as part of the advocacy process, and has been developed by a family physician working in the private sector of health care delivery in South Africa. It was personal experience, anecdotal reports from colleagues and intuition – that valuable tool of family medicine – that led to the development of the hypothesis, and then the research, which followed.

The tendency of the system to move patients away from their primary care doctor towards specialist and super-specialist care for the treatment of all serious illness, including cancer, may deprive the patient and family of the care that their family physician can offer. This is of particular importance when considering palliative care. The family physician is in a unique position to co-ordinate the care of both the patient and family with the well-established principles of continuing contextual care being applied as they are in everyday family medicine.

It is the personal experience of the researcher that active and committed involvement of a family physician in the care of patients with any medical condition requiring specialist input is beneficial to the *patient*, to the *care* itself, and to the *doctors* who deliver the care. This is of particular importance in the field of palliative care, where the family physician is able to co-ordinate the delivery and optimise the common objective of excellence in the outcome of the care.

CHAPTER 2 – AIM AND OBJECTIVES

Aim

To evaluate the outcome of care in patients with terminal cancer and relate these outcomes to the involvement of the family physician in the care

The following hypothesis was formulated to evaluate the intuitive correlation between the involvement of family physicians in the management of patients with terminal cancer and the outcome of care in these patients.

“Outcomes in palliative care are improved if the family physician is involved at all stages of care.”

Definition of terms

The hypothesis as stated above contains terms, which although well established in the literature and in clinical practice, require explanation for the purposes of this study.

Outcome: The perception by the care-givers and family physicians regarding the impact of treatment of the patient with cancer was considered to be the outcome for the purposes of this study. This included communication and support, symptom control and a general assessment of quality of life.

Palliative care: This study was conducted in a group of patients who were treated by a clinical oncology practice, and who had already died. It was assumed that all of these patients received end of life, terminal type care, which for the purpose of this study was called palliative care.

Improvement of care: The quality of outcome was assessed in two groups of patients, and improvement was judged to be the presence of a higher outcome score in one group than the other group. A higher outcome score indicated a more satisfactory outcome. The score was derived from the questionnaire submitted to each subject. This is fully described in the section describing the research method of this project.

Family physician: For the purposes of this study, the family physician was defined as the doctor who was recorded on the oncology file as the family physician of the patient. The terms 'family physician' and 'general practitioner' are used interchangeably in this report.

Involvement: An involvement score was assigned to each patient on the basis of the replies to the questionnaires. This involvement included aspects of communication, clinical care and continuing care.

All stages of care: The involvement of the family physician from the first onset of the illness to the terminal stage of care and beyond that, to subsequent contact after the death of the patient, was assessed within the limitations of the study design.

Objectives

- The promotion of the role of the family physician in palliative care
- Improvement of patient care
- Advocacy for the discipline of Palliative Care
- Research development

The promotion of the role of the family physician in palliative care

The family physician has an important role in determining the outcome of care in these patients with terminal cancer. If outcomes are to be improved, then family

physicians should be engaged in the care *actively*. Family physicians should themselves seek active involvement in the care of their patients right into the palliative stage of illness.

Improvement of patient care

The analysis of the information collected and knowledge gained by this investigation should be applied to improve outcomes in patients in need of palliative care. The engagement of family physicians with the specialists involved in the care of their patients should move the focus of care at all stages of illness back to the model of family medicine. The specialists who take care of patients and who bring valuable technical skills to bear on the exacting process of treating life threatening illness should also be encouraged to engage the family physicians in the care of the patient in the interest of optimal outcomes. In competently practised medical care, teamwork is essential as no single doctor or paramedical specialist has all the skills needed for complete patient care. The development of the team with deliberate collaboration between the referring physician, the technical specialists, the support professionals and the administrators should be encouraged and even managed.

Advocacy for the discipline of Palliative Care

Palliative care is a new, unrecognised and relatively unknown discipline in South Africa at the time of writing. The knowledge that the discipline is practised at all is not widespread in the general public domain, and even among health care professionals. The fact that there is research being conducted in the field of palliative care, and then published in widely read medical journals brings the discipline into the view of more doctors and other professionals caring for patients with end stage

illness. The more that palliative care principles are known and applied by all medical professionals in the care of their patients, the better the outcomes of that care will be, either in terminal or other care.

Community advocacy is another thread of the same process. Increased awareness of optimal care for people who have serious medical illness, and how best to deliver it, is important to foster in the community. This will ensure a well-informed consumer group, who are in a better position to understand the illnesses assailing them, and interact in a broader way with the people offering medical care. The final objective remains therefore, optimal outcomes.

Research development

The learning of research principles and the development of the skills required has been an important objective of this particular research project. The valuable interaction with colleagues in the field and the planning of further research, which has arisen simply as a result of the project having been conceived, is part of that developing process. The exploration of new relationships, new fields of research and co-operation across the disciplines within and outside of traditional medical care must lead in the end to better information and optimal patient care as well. The extension of professional relationships into research relationships as well as the sharing of individual patient care has the greater good of the whole community in mind, as well as the benefit to the particular patients of those clinicians.

CHAPTER 3 - LITERATURE REVIEW

A literature search was conducted using the internet with the assistance of the university librarians of the medical library of the University of Cape Town. Some further articles were found by hand search in the library of St Luke's Hospice, Cape Town, and one article was reviewed before publication with the permission of the authors.

This limited literature review is divided into three parts; firstly, publications reporting patient and carer satisfaction with palliative care were reviewed; secondly, some articles relating the relationship of family physician involvement in care to outcomes of that care were reviewed; and thirdly, some reports regarding research techniques were reviewed.

Satisfaction with Palliative Care

The involvement of primary care physicians in the palliative care of patients with terminal illness of any kind varies from country to country and from east to west with the Atlantic Ocean being the divide we have become accustomed to. There was no developing world, either African, Latin American or Asian content reported.

Wilkinson and others reported in an article entitled "Patient and carer preference for, and satisfaction with, specialist models of palliative care: a systematic review"⁴ that there is no real consensus or reliable trend observable in the North American experience. There seemed to be a sense that the consumers of palliative care were more satisfied in the United Kingdom than in North America, however.

Despite there being a large number of papers found by the search, 83 in total, the comment was made that there is a “dearth of high quality, comprehensive research” into this field. The suggestion is made that knowing consumer views can help to develop future models of care. Many issues of study design were raised with the subjectivity of “satisfaction” being one. The measurement of outcome was also found to be difficult. All responses to the same question do not necessarily carry the same weight, and may be read differently by different observers. The precise wording of the questions affects the responses too. The focus of the researcher also affects the type of information sought as well as the interpretation of that information. The validity of consumer responses was also explored with the suggestion that proxy accounts of satisfaction or otherwise do not necessarily reflect the views and experience of the patient. Retrospective accounts are also modified by the grieving process. Patients and families are also known to be reluctant to criticise the care that they have received, and to want to give the socially acceptable answer to the questions posed. It is noted that Wilkinson has been unable to identify clear trends of consumer satisfaction with palliative care despite the large number of papers reviewed.

Aspinal, Addington-Hall, Hughes and Higginson reported on a literature review regarding the use of satisfaction as a measure of the quality of palliative care⁽¹⁹⁾. They reported that ‘satisfaction’ is problematic as an indicator of quality of palliative care. The use of satisfaction surveys to plan and implement changes to services should be considered in this light.

Hearn and Higginson reported on the development and validation of an outcome measure for palliative care ⁽²⁰⁾. The Palliative Care Outcome Scale (POS) was shown to be acceptable in terms of validity and reliability.

Hughes et al reported that understanding the process of outcome measurement is important for improving their implementation ⁽²¹⁾. Wider social, cultural and structural contexts should be considered, as these may influence the implementation of these measures. Outcome measures should be developed in the light of the needs and experiences of individuals and services.

A research paper by Field and others, published in *Palliative Medicine* in 1992, refers to the Care and information received by lay carers of terminally ill patients. ⁵ The results seem to show that the care in hospice by nurses and hospice medical staff was better than the care in the community. The assessments were based on interviews modelled on the landmark 'Life before death' approach of Cartwright and others, published in 1973. The care in the community was further analysed and nurse-based care seemed to deliver better re-assurance and support than GP-based care (63% *good* vs 42% *good*). The overall evaluation of care rated *good* was 51% for the nurses and 28% for the GPs. These findings lead to several possible conclusions, the most obvious of which is that doctors need to learn from nurses about the delivery of care, and that there is progress to be made in the training of doctors for the delivery of palliative care. The use of the term palliative care rather than palliative medicine should be encouraged and promoted.

Lecouturier and others reported on the results of a postal survey to evaluate the satisfaction of lay carers with community palliative care. ⁶ The main conclusion

drawn was that there is inadequate provision of information to lay carers, who need this information both to provide care and for their own understanding of the process of care and grieving. Many factors affect the perceived quality of care and information, amongst which are: actual quality of care, time available, bereavement, carer depression or other illness and financial constraints.

Another survey of outcomes of palliative care was conducted throughout Italy in 1995 by Peruselli and others.⁷ The trend observed and reported was that there was general satisfaction in the *fair or good* range of assessment in the following list of indices: pain control, patient anxiety, patient insight, predictability, planning, financial, spiritual, communication and inter-professional communication. There was room for improvement in the control of symptoms other than pain, family anxiety, practical assistance and the communication between the patient and the family. Reference was made to the “medicalisation of death”. This was not always viewed as an adverse outcome variable, but the absence of “common criteria and guidelines” for intervention or not was highlighted and suggested as a worthy topic for future discussion and consensus among palliative care teams. The “Quality of death” questionnaire was used in this survey. This is a well-accepted and validated outcome assessment for use in palliative care used by this research group.

Sykes, Pearson and Chell reported on an evaluation of quality of care from the carer’s perspective.⁸ The main symptoms regarded by the carers as being poorly controlled were pain, anorexia, nausea & vomiting, constipation, incontinence and pressure sores. Support was provided to carers by GPs, social workers, nurses and community workers. The general comments regarding technical aspects of care were positive, but

the provision of information was perceived to be very poor. Carers particularly valued the offering of information by the professional team as opposed to having to ask for it. In particular, the expectation of symptoms and possible deterioration was felt to be beneficial to the carers if it was volunteered by the doctor or another team member. Other indices of quality of care were neither positive or negative. These included organisational aspects, relationship aspects and hotel aspects. The concept of 'unit of care' was introduced into the discussion as an important development and extension of the care of persons with and affected by terminal disease. The ethical considerations of privacy and confidentiality need to be explored when caring for family units as opposed to individuals. Consent should be sought for sharing of information when the patient is still able to give that consent. It is noted that this was a prize-winning paper and yet makes the point that there is room for better studies, better reporting and the addressing of issues of quality in the delivery of palliative care.

The concluding paragraph of a paper by Fowlie and others⁹ has some powerful points to make which are best quoted rather than paraphrased: *"In advanced cancer, when the patient's life is limited and he has some awareness of this, his needs and concerns are highly individualistic, not readily amenable to measurement or estimate by observers. His quality of life is not determined so much by the extent of his symptoms, the quality of his support system, or his knowledge of or involvement in his disease or treatment, but rather by the extent to which he has to come to terms with his condition and is at peace with himself."*

The issue of continuity of care was addressed in a paper entitled “Encounters with doctors: quantity and quality” by Smith and others.¹⁰ This evaluated the number of doctors seen by individual patients during the course of contact for an illness. The care was being given in the context of a large and variably efficient government run health service, namely the National Health Service in the United Kingdom. The *average* number of doctors seen by patients with a history of less than one year was twenty-eight! The maximum number of doctors seen in the group studied was 97 and the minimum number was 13. The conclusion reached was that ‘The large number of...doctors...involved in the care...represents a major challenge to seamless and consistent communication between those involved.’

An evaluation of general practitioners’ treatment attitudes and practices in the field of palliative care was reported in 1992 by Lang and others.¹¹ It was encouraging to read that most of the GPs surveyed had a satisfactory approach, felt competent and managed the problem alone. The fact that the GPs managed the problem alone may also be a sign of over-independence and isolation. Another learning point for the proponents of excellence in palliative care from this study is the supporting of the carers and the facilitation of teamwork amongst them.

A further issue to be addressed if primary care physicians are to be encouraged to become involved in palliative care is the way that these traditionally independent and individualistic practitioners adjust to the concepts of hospice care. Teamwork, interaction and communication are the pillars upon which such care is based. Fisher reported on just this issue in the journal *Palliative Medicine* in 1996⁽¹²⁾. The

continuous nature of the adjustment was the most important result highlighted by this report. The study was conducted in the UK where teamwork is actively encouraged.

A recent study by Burge and others in Nova Scotia, Canada, investigated the relationship between continuity of care and emergency room use by cancer patients.¹³ The conclusion that better continuity of care was associated with fewer emergency room visits is encouraging. The cancer patients themselves reported that good continuity of care was seen as desirable. Patients remember the doctors or other carers who demonstrate good continuity of care, and appreciate the personal knowledge that those carers have of them.

Correlation of Family Physician involvement with outcomes

The literature search was extended to evaluate the effect of family physician involvement in care on the outcome of that care. A total of eighteen references were reflected in the results of the search, of which only six were useful for the purposes of this project.

A review of the literature regarding family interviewing in primary care was published in the journal *Family Medicine* in May 2002 by Campbell and others¹⁴. The fact that the physicians are interviewing the family rather than only the index patient immediately indicates a certain degree of involvement, and therefore should have a positive effect on the care. Different categories of family involvement were identified, including “physicians’ family orientation and involvement”, “family genograms”, “family members who accompany patients to office visits” and “family conferences”. Involvement was not shown to be a frequent predictor of a “good outcome”. The

authors suggest that more research is needed to examine the process and to evaluate the outcome of the different types of family interviewing.

A further report was found which was even more intimately concerned with the involvement of the family physician in the care of the patient and then relating this to specific outcomes following a consultation. Mead and others published their findings in the journal *Social Sciences and Medicine* in July 2002, and entitled the paper "The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement."¹⁵ This title conveys their hypothesis very well. Intuitively, those practising in the field of family medicine feel that there should be a strong link between patient-centredness and outcome, but the results are not very convincing. Very rigorous study methods were followed and different styles of patient-centredness were compared and patients outcomes analysed. It was demonstrated that the style of patient-centredness of the family physician did not predict either patient satisfaction or enablement. There may have been an element of selection in this investigation too as all the family physicians had agreed to take part and be videotaped for further analysis and research. The interviews were analysed by review of video-tapes, filmed by the researchers and sorted by external research assistants. In spite of the intuitive expectation that patient-centredness should correlate well with outcomes, this was not demonstrated in this study.

A far more concrete example which seems more encouraging of family physician involvement in the care of the patients was published in *The Canadian Family Physician*.¹⁶ The study seemed to show that there is a good correlation between the involvement of the family physician and the slowing of progress of end stage renal

failure. The point was made that nearly all of the interventions required to slow the progress of end stage renal failure were made by the family physician and fall within the scope of family medicine.

An article published in the Canadian Medical Association Journal in 1989 by Krikke and Bell illustrated that the management of low risk patients in labour was different if patients were under the care of family physicians as compared with specialist obstetricians.¹⁷ Family physicians seemed to have a less interventionist style of management than the specialists, but the outcome of care was essentially the same.

Research techniques

Fairfull addressed the issue of patient numbers in research in palliative care.¹⁸ This is a complex and difficult area of expertise and specialised knowledge, and should be addressed in a team, using the resources of expertise available. The correct power for statistical analysis for the precise research project is essential for the use of the data to make meaningful deductions with very modest sample sizes. There is often not a large budget available for research in palliative care; costs, time available, patient factors and other issues may obscure the research goals.

Lecouturier and others reported on the results of a postal survey to evaluate the satisfaction of lay carers with community palliative care.⁶ This study demonstrated that a postal survey could be used in research of this type, and a response rate of 44% was achieved without any reminders. The response rate could be increased by the sending of a reminder mailing, but this has cost implications, and may not take into

account the fact that those people who did not respond may have chosen not to do so rather than having forgotten.

The use of postal questionnaire to assess carer satisfaction was also reported in the journals in 1999.²⁰ It should be noted that the design of the questionnaires, took time and expertise. The final results showed that long complicated questionnaires received a poor response. This paper reports on those 83/250 trials which were considered important. The salient feature emphasised that this is a very technical aspect of investigation and reporting.

University of Cape Town

CHAPTER 4 – RESEARCH METHOD

Description

This is a descriptive study using quantitative research methods to test the study hypothesis.

Data collection

Data collection was achieved by the submission of a postal questionnaire to the surviving care-giver and the family physician of patients who had died while under the care of a private clinical oncology practice. This practice is situated in Cape Town, South Africa.

The postal questionnaire was chosen above other means of obtaining the responses of the care-givers and family physicians because it was perceived to be less costly than structured interviews and could be sent to people who would not otherwise have been able to respond. This method of data collection has been validated in the literature.

Sample selection

The sample group to which the questionnaire was directed, was chosen to be the care-givers and family physicians of the *patients who had died* while under the care of an oncology practice. These people had easily obtained addresses, and were all under the care of the practice counsellor. This particular oncology practice was chosen because the researcher already had a close working relationship with the doctors and staff of the practice.

Sample size

The sample size was determined by estimating the likely response rate and calculating the number of responses required to obtain statistical significance in the analysis of the results. The sample size was chosen based on a 50% anticipated proportion of good family physician involvement, with a 10% margin of error, and allowing for a 95% confidence interval. A sample size of one hundred (100) subjects was the target as the minimum number of questionnaires required. The sending out of these questionnaires overlapped with the routine bereavement letter of the practice, and a further sixty (60) subjects were added to the sample, giving a total sample size of one hundred and sixty (160).

Questionnaire design

The questionnaire was designed by the researcher from first principles based on a twenty-year interest in palliative care, seventeen years of experience in family medicine and primary care with the last fourteen years having been spent in private practice. The principles of family medicine and palliative care overlap to a great extent and the intuitive techniques of diagnosis and management common to both were used in the design of the questionnaire. Communication issues and teamwork were also addressed in the questions.

The fact that no *simple* and *short* research questionnaires could be found for the assessment of outcome in the sample selected, and that no research questionnaires for the assessment of family physician involvement could be found at all, compelled the researcher to design purpose-made research tools for this project. These

questionnaires were submitted as part of the original research proposal and were scrutinised by the research supervisor, departmental research committee and the ethics committee before being submitted to the care-givers and the family physicians.

The outcome questionnaires were designed with simplicity in mind, and to be as unambiguous as possible. *Communication* between the care-giver and the medical professionals involved with the care was seen as an important outcome question. An adequate *response* by the medical professionals as well as information transfer so as to facilitate *understanding* was also regarded as key to an improved outcome. Pain control was chosen as a *symptom* index of outcome. A general and open question regarding *perception of quality* of life was also included.

Further work would be required to review the accuracy of these simple outcome and involvement indices, and to compare them with the established outcome indices in the literature. This process is beyond the scope of this project. Further research is to be encouraged in this field, as the researcher believes that brevity and simplicity are important in research questionnaires of this type.

As mentioned above, the outcome questionnaires available in the research literature were all too long to be used in a research project of this nature and extent, so a simple and clear purpose-designed questionnaire was developed. This questionnaire was deliberately short, including only five questions to be answered by the surviving care-giver and the family physician. It was thought that the brevity of the questionnaire would optimise the response rate by both the care-givers and the family physicians, as it would not take too much time. The effect of the questionnaire on the grieving

process of the surviving care-givers would be limited by the fact that the questionnaire was short and less invasive than a longer questionnaire may have been.

Assessment of the outcome of care

The five questions posed to the care-giver to assess the outcome of care were as follows:

1. *Were you given the opportunity to discuss your needs and problems relating to the cancer?*

This question addresses issues of communication between the care-giver and the medical professionals who were responsible for the patient care. Issues of availability and perception of openness to questions are also touched upon in this question.

2. *Were these adequately addressed?*

This question was designed to bring an understanding of the perceived receipt of information by the care-giver. Communication is the central issue here but a deeper level of interpersonal understanding between care-giver and doctor is required for this question to be answered positively.

3. *Were you given enough information for you to understand the treatment?*

The direct transfer and understanding of information is the key point under interrogation in this question, but a greater degree of understanding is required with foresight being needed to anticipate the future treatment and hindsight for the analysis of the understanding which was conveyed. Continuity of care is being addressed by this question.

4. *Was the pain controlled?*

The perception of the care-giver regarding pain control was deliberately addressed with a broad open-ended question. Pain is always subjective and it is acknowledged that this question relies on the intimate and biased perception of the care-giver. Pain is such a central symptom and fear of patients and care-givers alike that the subjective answer to this question was thought to be valuable in assessing outcome.

5. *Did you feel that the quality of life of the patient was as good as could be expected?*

The outcome questionnaire was broadened by this final question, with an attempt to establish whether the care-giver had perceived that more had been done for the patient than simply controlling the pain. It is acknowledged that whole questionnaires have been designed to answer this question, but simple perception in general terms was sought by this questionnaire.

The questionnaire for the family physician of each patient comprised the same questions as above, but was modified slightly so as to reflect the perception of the family physician as to the outcome of the care. The questions are listed below. The issues encompassed by the questions are communication, availability and sensitivity to patient needs. The development of good communication into continuity of care is reflected in the third question, and the subjective aspects of pain and quality of life are included to make the point that there is often a closer relationship between the family physician and the patient than with the specialists involved with the treatment. The questions are included here for completeness.

1. *Was the patient given the opportunity to discuss his/her needs and problems relating to the cancer?*

2. *Were these adequately addressed?*
 3. *Were you given enough information for you to understand the treatment?*
 4. *Was the pain controlled?*
 5. *Did you feel that the quality of life of the patient was as good as could be expected.*
-

The assessment of involvement in care

The assessment of involvement was also undertaken from first principles as no precedent could be found in the literature. The involvement questionnaires were conceived to reflect the perceived involvement of the family physician in the care of the patient. *Communication* between the family physician and the care-giver, as well as between the family physician and the specialist was seen to be an important indication of family physician involvement. The *therapeutic role* of the family physician in the treatment of both cancer related and other ailments was also seen as an index of family physician involvement. Finally, *continuity* was touched upon in the question relating to further contact with the family physician.

The questions submitted to the care-givers for the assessment of family physician involvement in the care were as follows:

Care-giver questions - Involvement of Family Physician

1. *Did your GP inform you about the cancer?*
2. *Did the GP get information from the specialist about the cancer?*

Communication between the family physician and the unit of care (care-giver and patient) as well as between the specialist and the family physician is the central issue under interrogation in these two questions. It is assumed that if there is good communication between the specialist and the family physician, a team approach is more likely to have been taken. It is acknowledged that these answers reflect only the care-giver's perception of this communication.

3. *Did the GP treat the patient for cancer related ailments during the course of the illness?*
4. *Did the GP treat the patient for non-cancer related ailments during the course of the illness?*

The therapeutic role of the family physician in the care of the patient for either cancer-related or non-cancer-related ailments was thought to be a very clear indication of family physician involvement, demonstrating a level of knowledge and trust by the patient and care-giver as well as by the specialist.

5. *Has there been contact with the GP since?*

Continuity of care is one of the cornerstones of family medicine, and in the context of palliative care, the family physician of the care-giver and of the patient is often the same doctor. Even if the care-giver has a different family physician, bereavement support is part of both palliative care and family medicine.

Family Physician Questions – Involvement of Family Physician

The perceived involvement of the family physician in the care of the patient was assessed with the same questions, modified slightly to address them to the doctor, rather than the care-giver.

1. *Did you inform the patient about the cancer?*
2. *Did you get information from the specialist about the cancer?*
3. *Did you, as the GP, treat the patient for cancer related ailments during the course of the illness?*
4. *Did you, as the GP, treat the patient for non-cancer related ailments during the course of the illness?*
5. *Has there been contact with family since?*

The same issues of communication, therapeutic engagement and continuity of care are addressed in these questions but are seen from the point of view of the doctor.

Collating of responses

The envelopes containing the replies and the consent forms were opened and subjected to an initial sorting process by the counselling social worker who had sent them out. Further sorting into categories and the separation of the completed questionnaires from the accompanying consent forms was conducted by a professional nurse who was also part of the team responsible for the care of the patients before they had died. It was ensured that no questionnaire was included in the analysis if there was not a consent form completed by the care-giver or family physician. The compiling of a computerised list of replies with the record of scores for each questionnaire returned was undertaken by the researcher. All returned questionnaires were now identifiable only by individual unique codes. The newly created computerised list of results was double checked for accuracy.

The questions were designed so as to be able to be answered with a simple yes or no. A numerical score was assigned to each answer, so that a total score could be calculated for each questionnaire returned. The answer “no” scored one, the answer “yes” scored two, and if there was no answer, a zero score was recorded. Returned questionnaires were excluded from the analysis if there were zero scores, that is to say, if any one of the questions was un-answered.

The calculated scores for involvement and outcome were categorized, so as to be able to evaluate the relationship between low involvement (score 5-7) and low outcome (score 5-7). The same was done for high involvement (score 8-10) and high outcome (score 8-10).

A statistical analysis of the replies to the questionnaires was undertaken. The “p-value” was calculated for each category of result.

The application of ethical principles in the design of the study

Confidentiality

Confidentiality is an issue which is central to the good outcome of any medical intervention. The patient and care-giver or so-called “unit of care” may sometimes be considered as one, but special care needs to be taken to ensure that there is no breach of implied confidentiality between the patient and the care-giver in the answering of questionnaires after the death of the patient. The ethical obligation to respect confidentiality extends beyond the death of the patient. The matter of doctor-patient confidentiality is self-evident in everyday practice, but the fact there is not a great deal of research being conducted in family medicine, particularly in the target group

of family physicians of this research project, raised some questions amongst the doctors who answered the questionnaire. The cohort of patients who were selected for this study had all been under the care of the oncology practice, and the assistance of the practice counsellor was the key to maintaining the confidentiality of the patients and care-givers. The fact that there was an established clinical and supportive link already established before the death of the patient ensured that the ethical duty not to break confidentiality was not breached. A simple system of alpha-numerical codes provided the confidential information to the researcher in a form that did not breach the confidentiality as mentioned above. This system also ensured that any bias that may have occurred in the researcher resulting from the knowledge of the identity of either patient or that patient's attending family physician was eliminated. The initial sorting of the replies to the questionnaires was undertaken by the oncology counsellor, and subsequent administrative assistance was given by the professional nurse in charge of the ward in which the oncology practice managed its in-patients. Both of these persons understand the ethical obligations of confidentiality from a professional point of view, and these obligations were emphasised before the research project was undertaken.

The care of the bereaved and consent

There is an ethical responsibility of the researcher to ensure that good counselling is available to the surviving care-giver of each deceased patient. These people are by definition bereaved, and are also not accustomed to the process of medical research. Proper informed consent is essential in this case. It may be argued that the simple returning of the questionnaire gives tacit consent to the process and further analysis of the answers. For the purposes of this study, however, special consent forms were

signed by both care-givers and the family physicians who returned questionnaires. The counselling professional was the person who sent out the letters to the surviving care-givers, and it was made clear to the care-givers that there was no obligation to participate in the study. It was also stated that there was counselling available with the same person who had been involved with counselling and support before the patient had died.

Considerations regarding validity and reliability

The validity of any research method determines whether the questions posed serve to test the hypothesis. In other words, a high level of validity implies that the information gathered and analysed does actually reflect reality rather than being affected by other variables. A further extension of the concept of validity, which is crucial for the use of medical research to the improvement of future medical care, is the application of the information obtained from the research sample to other groups, given that research samples are limited by numbers, geographical distribution, socio-economic class and so on. A higher degree of validity could be said to be present if the results are widely applicable.

Reliability is the measure of consistency of the research information and process on repeated testing. Issues of the method of information gathering, recording and analysis are important, as well as repeatability of the process in the same research subject and in different subjects who may be expected to answer in similar ways.

Factors which might influence the validity and reliability of the research tools include: the researcher, in that the observations and interpretations of answers are seen in the

light of his own experience and bias; and the participants, who might wish to please the researcher rather than be candid and the context of the research. The method of data collection may also be a risk to validity and reliability, but if the questionnaires are well designed and tested against other standard methods of data collection, these risks will be minimised.

Data gathering in this research project was undertaken in such a way as to minimise bias in the collection and analysis of the data. The questionnaires for both carers and family physicians were designed by a clinician with years of experience of caring for patients and communicating with them as well as with the specialists involved in their care. The questions were discussed with the research supervisors and more experienced researchers, who advised some changes to the original draft questionnaires which would improve validity and reliability.

There was no formal testing of these novel questionnaires to establish validity or reliability before they were used in this research project. In light of the fact that this is a new area of research, and that these are purpose-designed questionnaires, this process could form the basis of further research. The re-designed and validated questionnaires could be the data gathering tools for further more rigorous research to relate outcome of care to involvement in any patient group in future.

This research project should be considered, at least in part, to be a pilot study for the development of these research tools. One of the stated objectives in the introduction to this report was the development of research in the field of palliative care, and this is an important outcome of the study. Brevity and simplicity in research offer both

advantages and disadvantages. The reduction of the response to a simple yes or no may be difficult and limits the chance for shades of opinion to be expressed or for explanation of responses. There is also a risk that a question may be misunderstood; a yes/no answer does not give any sense of the understanding of the subject. A short questionnaire benefits the researcher because it may be easier to analyse. There are also benefits for the person responding because it may be less disruptive of the grieving process.

CHAPTER 5 – DESCRIPTION OF THE RESULTS

Questionnaires regarding the outcome of care and involvement of the family physician were sent out in respect of 160 patients who had died. A total of 320 questionnaires were sent out, 160 to the surviving care givers of the deceased person, and 160 to the family physician who was recorded in the oncology folder as being the family physician of the index patient.

Response Rates

Response from care givers

Of the 160 questionnaires sent out to the care givers, a total of 44 responses were received. This represents a 27.5% overall response rate.

After closer inspection of the responses, 16 of the 44 received were judged to be unsuitable for inclusion. The responses were judged to be unsuitable if the answers were incomplete, ambiguous or unclear. A total of 28 out of 44 responses were suitable for analysis (64%).

Only 28 out of 160 (17.5%) of the total number of questionnaires sent out yielded responses which were suitable for analysis.

Response from family physicians

Of the 160 questionnaires sent out to the family physicians, a total of 74 responses were received. This represents a 46.3% overall response rate.

After closer inspection of the responses, 19 of the 74 received were judged to be unsuitable for inclusion. The responses were judged to be unsuitable if the answers

were incomplete, ambiguous or unclear. A total of 55 out of 74 responses were suitable for analysis (74%).

In this group of respondents, 55 out of 160 (34.4%) of the total number of questionnaires sent out yielded responses which were suitable for analysis.

Total response rate

Of the 320 questionnaires sent out to the care givers and family physicians, a total of 118 responses were received. This represents a 36.9% overall response rate.

After closer inspection of the responses, 35 of the 118 received were judged to be unsuitable for inclusion. The responses were judged to be unsuitable if the answers were incomplete, ambiguous or unclear. A total of 83 out of 118 responses were suitable for analysis (70.3%).

Only 83 out of 320 (25.9%) of the total number of questionnaires sent out yielded responses which were suitable for analysis.

These results are summarised in the tables below.

Questionnaires	Totals sent	Returned	Rejected	Analysed
Overall	320	118 (36.9%)	35 (10.9%)	83 (25.9%)
Doctors	160	74 (46.3%)	19 (11.9%)	55 (34.4%)
Care givers	160	44 (27.5%)	16 (10%)	28 (17.5%)

Table 1. Response rates and usable questionnaires in absolute numbers and expressed as percentages

Assessed by	Frequency	Percentage
Care givers	28	33.73
Doctors	55	66.27
TOTAL	83	100.00

Table 2. Total number of responses

The correlation between involvement and outcome

The assessment of involvement and outcome was reduced to a score and the scores were categorized, so as to be able to evaluate the relationship between low involvement (score 5-7) and low outcome (score 5-7). The same was done for high involvement (score 8-10) and high outcome (score 8-10).

Among the care givers' assessments, 3/28 (10.7%) showed a correlation between low involvement scores and low outcome scores. There were 21/28 (75%) demonstrating correlation between high involvement scores and high outcome scores. There were 4/28 (14.3%) for which a low involvement score correlated with a high outcome score. There were no carer assessments showing a high involvement score and a low outcome score. Adding the two appropriate figures, it can be seen that 24/28 (85.7%) of the assessments showed a significant relationship between involvement and outcome as reported by the carers. This correlation reached statistical significance despite the small number of questionnaires returned. These results are summarised and illustrated in the table and diagram below.

INVOLVEMENT CATEGORY	OUTCOME CATEGORY		Total
	5-7	8-10	
5-7	3	4	7
8-10	0	21	21
Total	3	25	28

Table 3. Tabular comparison of involvement and outcome categories as assessed by the care givers. These results show significant agreement between the two measures of involvement and outcome categories.

Observed agreement: 0.8576

Kappa: 0.529 (P=0.000749)

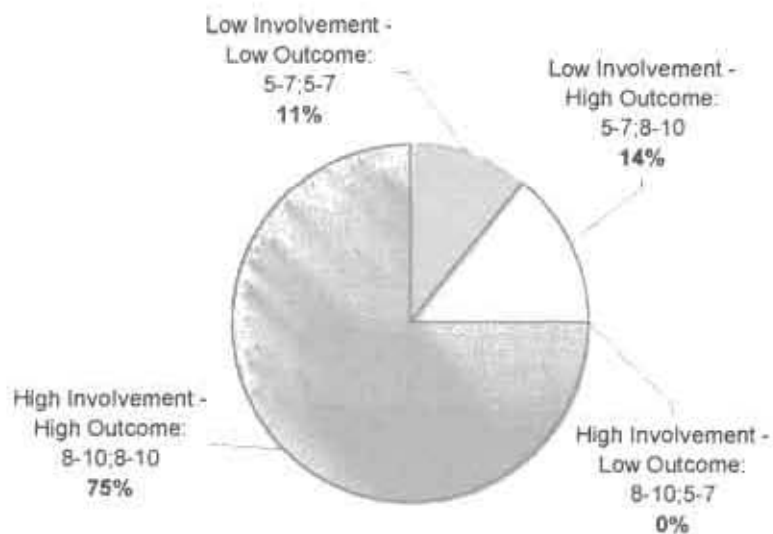


Diagram 1. Care givers' Results by Category as %

Among the doctors' assessments, 1/55 (1.8%) showed a correlation between low involvement scores and low outcome scores. There were 52/55 (94.5%) demonstrating correlation between high involvement scores and high outcome scores. There were 0/55 (0%) for which a low involvement score correlated with a high outcome score. There were 2/55 (3.6%) doctor assessments showing a high involvement score and a low outcome score. Adding the two appropriate figures, it can be seen that 53/55 (96.4%) of the assessments showed a significant relationship between involvement and outcome as reported by the doctors. This correlation also reached statistical significance. These results are summarised and illustrated in the table and diagram below.

INVOLVEMENT CATEGORY	OUTCOME CATEGORY		Total
	5-7	8-10	
5-7	1	0	1
8-10	2	52	54
Total	3	52	55

Table 4. Tabular comparison of involvement and outcome categories as assessed by the family physicians. These results show significant agreement between the two measures of involvement and outcome categories.

Observed agreement: 0.9636

Kappa: 0.4859 (P=0.000013)

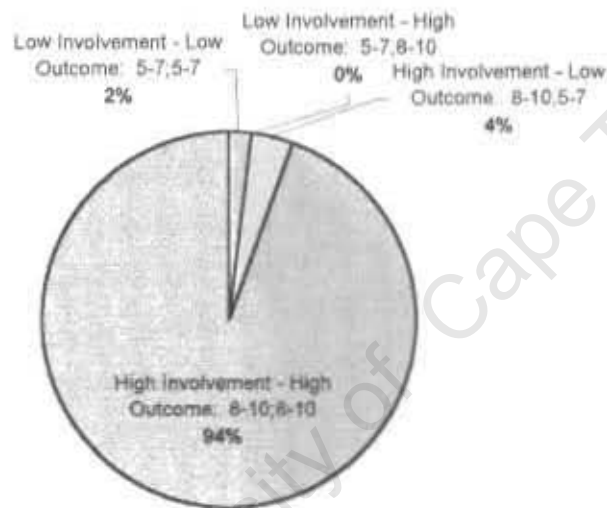


Diagram 2. Family Physicians Results by Category as %

When all the assessments were considered together, the expected correlation between outcome and involvement was confirmed. Among the combined assessments 4/83 (4.8%) showed a correlation between low involvement scores and low outcome scores. There were 73/83 (88%) demonstrating correlation between high involvement scores and high outcome scores. There were 4/83 (4.8%) for which a low involvement score correlated with a high outcome score. There were 2/83 (2.4%) assessments showing a high involvement score and a low outcome score. Adding the two appropriate figures, it can be seen that 77/83 (92.77%) of the assessments showed a

significant relationship between involvement and outcome as reported. This correlation is also statistically significant. These results are summarised and illustrated in the table and diagram below.

INVOLVEMENT CATEGORY	OUTCOME CATEGORY		Total
	5-7	8-10	
5-7	4	4	8
8-10	2	73	75
Total	6	77	83

Table 5. Tabular comparison of involvement and outcome categories as assessed by both care-givers and family physicians. These results show significant agreement between the two measures of involvement and outcome categories.

Observed agreement: 0.9277

Kappa: 0.5328 (P<0.001)

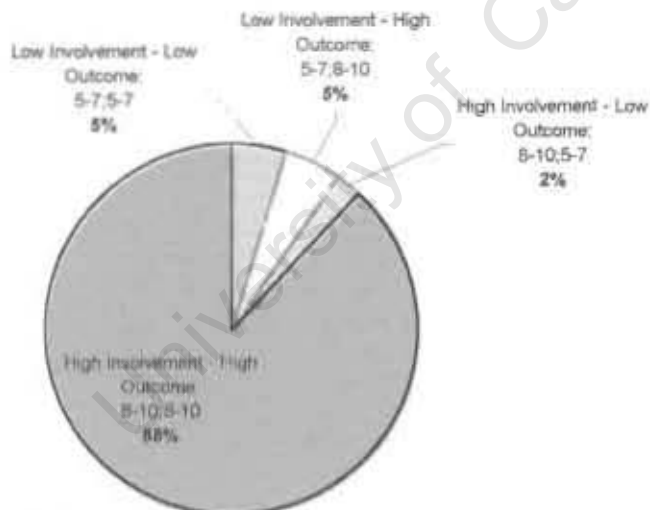


Diagram 3. Family Physicians and Care Givers Results combined by Category %

Comparing the assessment of involvement and outcome by doctors and carers

The scores recorded from the questionnaires have been tabulated below. It can be seen that when doctors assess their own involvement in cases, they give a higher involvement score than care-givers. This difference reached statistical significance, which is demonstrated in the table below.

Group	Number	Median	Mean	SD	Range
Care givers	28	8	8.3	1.2	6-10
Doctors	55	9	9.3	0.7	7-10

Table 6. Comparing assessment scores in involvement between doctors and care-givers. Using the Wilcoxon rank-sum test the analysis shows that the scores are significantly different between the groups ($P=0.0001$).

The results were categorized and analysed by category as well. There was a difference demonstrable by this analysis, which was significant as seen in the table below.

ASSESSMENT MADE BY			
Involvement category	CARE GIVERS	DOCTORS	TOTAL
5 to 7	7	1	8
%	25.00	1.82	9.64
8 to 10	21	54	75
%	75.00	98.18	90.36
Total	28	55	83
%	100.00	100.00	100.00

Table 7. Comparing categories of involvement scores (Low versus High) between the groups. Using the Fisher's exact test the results show a significant difference between the groups ($P=0.002$).

Outcome assessments were also compared and the same trend was observed, that is to say, doctors assessed the outcomes to be better than the carers did. This was not found to be a statistically significant difference, however. The small difference in outcome scores may be seen in the table below.

ASSESSMENT MADE BY

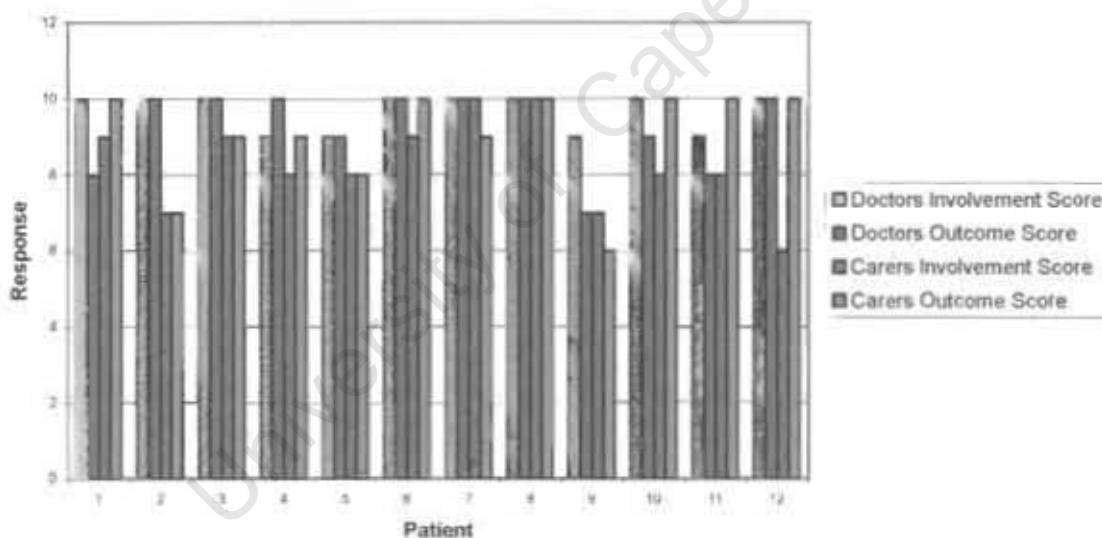
Outcome category	CARE GIVERS	DOCTORS	TOTAL
5 to 7	3	3	6
%	10.71	5.45	7.23
8 to 10	25	52	77
%	89.29	94.55	92.77
Total	28	55	83
%	100.00	100.00	100.00

Table 8. Comparing categories of outcome scores (Low versus High) between the groups. Using the Fisher's exact test the results show no significant difference between the groups (P=0.002).

Sub-analysis of the responses

Of the 160 patients who were included in the survey, a response from both the carer and the family physician was received in only 12 patients. This represents 7.5% of the total number.

The analysis of these scores enabled a direct comparison to be made between the involvement and outcome scores as assessed by the carers and family physicians in this sub-group.



Graph 1. Comparison of responses in the same patient

Involvement of family physician score comparison

Family physician involvement scores in this sub-group were higher when assessed by the family physician than the carer. The average involvement score assessed by the family physician was 9.66 compared with an average involvement score as assessed by the carer of 8.25.

The family physician assessed the involvement score to be higher than the carer's assessment in 10/12 cases (83.3%), and the assessments were the same in 2/12 cases (16.7%). There were no comparisons in which the carer assessed the involvement score to be higher than the family physician.

Outcome score comparison

The patient outcome scores in this sub-group were higher when assessed by the family physician than the carer. The average outcome score assessed by the family physician was 9.25 compared with an average outcome score as assessed by the carer of 9.00.

The family physician assessed the outcome score to be higher than the carer's assessment in 6/12 cases (50%), and the assessments were the same in 3/12 cases (25%). The carer assessed the outcome score to be higher than the family physicians assessment in 3/12 cases (50%).

The assessment of involvement and outcome by the family physician as compared with the carer in this sub-analysis is consistent with the finding of the whole study sample. The family physician assesses involvement and outcome to be higher than does the carer.

CHAPTER 6 – DISCUSSION

Introduction

The concept of this research arose from the perception of the researcher, after many years of experience in family medicine and palliative care, that the care of and outcome in patients with terminal illness was being adversely affected by the fragmentation of that care. The family physician, who usually knows the person presenting with symptoms very well, makes a clinical diagnosis and then refers to specialist doctors for confirmation of the diagnosis and then management of that condition. In some cases, there is a close working relationship between the family physician and the specialists, but this is most often not the case. There is often cross-referral between different specialists without the consideration that there is a competent family physician involved in the care. Many problems that arise in the ordinary course of events are inappropriately managed by other specialists simply because the patient has a terminal illness. An example of this would be the referral by a surgeon to a dermatologist for the diagnosis and management of a straightforward allergic skin rash.

The desired outcome in every person with serious illness is encapsulated in the various well-known definitions of palliative care, once the possibility of cure is no longer available. It is the contention of the researcher that active encouragement of involvement of family physicians in the care of patients with terminal illness will serve to improve that care. That there is no structured relationship between the family physician and the specialist doctors, each of whom has a vital role to play in the outcome of the treatment and palliative care, is to be regretted. Such a structure may

be artificial, but if it is possible to make it work to improve the outcome of care, then it should be considered as part of complete patient management.

Comments on the response rate

The response rate was lower than had been anticipated. This may be accounted for by several factors which relate to the nature of the research, the experience of the researcher and the groups of people who were subjected to the questionnaire. The overall response rate of 37% to this postal questionnaire compares well with the response rate of 44% achieved in a similar study reported in the literature ⁶.

The response rate of 27.5% from the care-givers was lower than anticipated. A higher rate of response was anticipated from this group because it was thought that the care-givers would feel that they could contribute to future improvement in care by returning the questionnaires. The total response rate was increased to 37%, because the family physician response rate was 47%.

The low response rate may have contributed to bias in the results. It is not known whether the results would have been different if the response rate had been higher. The novel design of the questionnaires, as well as doubts cast on the link between patient-centredness and outcome by Mead ⁽¹⁵⁾ and concern about 'satisfaction' as a valid means of assessing outcomes ⁽¹⁹⁾ all contribute to possible bias and uncertainty in the results. Further research would be necessary to reduce this uncertainty.

Possible reasons for the low response rate may include:

1. Failure to return the questionnaires because of bereavement issues

2. Carers not having received the questionnaire because of change of address
3. Unfamiliarity with medical research, especially in palliative care
4. Questionnaire problems
5. Concerns of privacy

Possible reasons for some of the responses being unusable are listed below. The responses were judged to be unusable if they were incomplete, unclear or ambiguous.

The reasons for returned questionnaires being unusable may include:

1. Bereavement issues
2. Unfamiliarity with medical research, especially in palliative care
3. Questionnaire problems
4. The deadline for the return of questionnaires

The correlation between involvement and outcome

This is the central theme of the study hypothesis, and the categorisation and statistical analysis of the data shows a high degree of correlation between the involvement of the family physician and the outcome as perceived by the respondents.

The family physician is more likely to be more intimately involved in the care of their patients than other specialists because of the continuing aspect of care that is inherent in family medicine. There are many more opportunities to become involved in the life of the person in need of care; there is the contact of the presenting complaint, preceded by previous contacts, as well as vicarious contact through and with other family members. It was reasonable to postulate therefore, that a high degree of

involvement of the family physician would lead to a better outcome than would have been the case if there had been less involvement.

The factors which were considered to be important for assessing outcome as assessed in this research project were based on some of the core principles of family medicine and palliative care. The questionnaire was designed with these principles in mind. These principles include communication between the patient and care-giver (the so called 'unit of care') and the doctors concerned with the care, both specialist and family physician. The interaction of the family physician with the specialist in terms of information sharing and joint responsibility for patient care was also considered to be a positive outcome attribute. Symptom control is an obvious outcome variable and perception of pain control was chosen to be representative of this. A broad question regarding perceived quality of life allowed the respondent to consider any other adverse or positive aspects and reflect generally on the holistic outcome of the care.

Despite the low response rate, the results showed statistical significance. The correlation between involvement and outcome was 85.7% when assessed by the carers and 96.4% when assessed by the doctors. The overall figure demonstrating a close relationship between involvement and outcome is 92.8%.

The notion that involvement of the family physician should be an important factor in the determination of outcome seemed at the time that the hypothesis was developed, intuitively to be correct. The results of this survey go some way to supporting this hypothesis, but further study would be helpful.

Most of the questionnaires received from both family physicians and carers indicated a high degree of family physician involvement, and a good outcome. A few results showed a link between low involvement and a relatively poorer outcome. It should be noted that the majority of responses indicated a perception of high levels of involvement and also favourable outcomes. These findings should be considered in the light of the comments on the questionnaire design.

The statistical tests applied to the results were able to demonstrate significance despite the lower than anticipated response rate. It is helpful to restate the hypothesis at this stage: *“Outcomes in palliative care are improved if the family physician is involved at all stages of care.”* These results suggest a likely positive correlation between family physician involvement and a favourable outcome. A more rigorous study in terms of design, sample size and response rate would be required to confirm the correlation.

Comparing the assessment of involvement and outcome by doctors and carers

The assessment of doctors of their own level of involvement in the care of patients with terminal disease was higher than the assessment of doctor involvement by the carers. Although the difference is not great, statistical significance was reached in the analysis of involvement as assessed by this study. It is not certain whether the carers who answered the questionnaire were in the best position to judge the involvement of the doctors, but the observation remains that there is a different perception of involvement by the two groups questioned.

This difference in perception does not imply lack of care by the doctors, but perhaps it may indicate a lack of understanding of the role and function of the different doctors who take part in the care of patients with terminal cancer. The 'team' that is ideally supposed to be responsible for the care of these patients seldom, if ever, involves the family physician of the patient. There are many reasons for this including the fact that there is often more than one specialist treating the patient, and the patient and family do not know who is really involved and who is taking responsibility for patient care on an overall management level. The diagnosing specialist is the first role player, followed by the oncologist who takes the management over when the cancer is confirmed and curative or disease-modifying therapy is undertaken. This doctor often continues treatment into the palliative phase of the illness. It is noted that patients in this research setting are often referred to palliative care service providers once cure is no longer the goal of therapy. These services are, by their nature, better organised in terms of teamwork and communication, but unfortunately do not always include the family physician in the team. The oncology departments of teaching hospitals and private practice, as well as hospice clinical departments do sometimes function as teams, but the majority of patients are not cared for this way. Family physicians are very seldom part of the team, are not included in the discussions regarding management and often feel marginalized when their patients are managed by oncology or palliative care teams.

The one doctor who is well placed to know the particular needs and circumstances of the patient including family background, personal history and financial resources, is the family physician. This doctor is often marginalized and excluded from the care of

the patient and family, to the detriment of the patient and other family members. This study has demonstrated that the outcome for the individual patient may be adversely affected if the family physician is not involved with the care.

Further discussion regarding questionnaire design

The development of the questionnaires was undertaken by the researcher from first principles. Experience in research methodology was contributed from the departmental research committee and supervisors. The questions posed to the caregivers and to the family physicians were conceived to draw in different aspects of the care which could be offered and received.

The validity and reliability of the questionnaires has not been tested and this could be the aim of a further project. The researcher believes that the development of short and precise outcome questionnaires would have wide application in this field of research as well as in other related clinical disciplines.

The questionnaires used in this study were not piloted formally in a small target group of the eventual study sample. The process of submission of the research proposal and the explanation to the oncology practice, which was necessary for the carrying out of the study, was helpful in refining the questions to be more precise and to interrogate particular aspects of the involvement and outcome as defined for the purpose of the study. This entire research project may be considered to be a pilot study for these questionnaires and to develop these research tools for wider application. Special emphasis should be made that there is a lack of research and research tools developed and validated in the African context. There is much work to be undertaken in

palliative care in South Africa, and even more, further north. There are many trans-cultural aspects, language barriers, religious issues and disease specific aspects which differ from those in the European and North American regions where currently available research tools have been developed.

The information gathered and analysed by these questionnaires should therefore be viewed in the light of the lack of precedent and also from the point of view that the method has not yet been properly validated.

A review paper by Wilkinson⁴ concerning patient and carer satisfaction with palliative care demonstrated that no clear trends have been observed to draw conclusions about consumer satisfaction with specialist models of palliative care. These were discussed in the literature review, but are re-iterated here to illustrate the fact that the research process is always work-in-progress.

Issues of study design were raised by Wilkinson, with the subjectivity of “satisfaction” being one. The measurement of outcome was also found to be difficult. All responses to the same question do not necessarily carry the same weight, and may be read differently by different observers. The precise wording of the questions affects the responses too. The focus of the researcher also affects the type of information sought as well as the interpretation of that information.

The validity of consumer responses was also explored with the suggestion that proxy accounts of satisfaction or otherwise do not necessarily reflect the views and experience of the patient. Retrospective accounts are also modified by the grieving

process. Patients and families are also known to be reluctant to criticise the care that they have received, and to want to give the socially acceptable answer to the questions posed.

This publication is offered as an example of research in palliative care which highlights some of the problems which are encountered when assessing quality of care and outcomes in the delicate stage of life under investigation. Some of these issues were also encountered in the conduct of this research project.

It is desirable that further research be conducted to develop the process and refine the end-points of research begun in this project. Formal pilot studies on the questionnaires to test reliability and validity would be helpful, and a prospective approach with family physician involvement being observed and modified may lead to results which are applicable over a wide range of medical problems.

CHAPTER 7 - CONCLUSION

The results of this study have demonstrated, within the limitations of the study design and application, that there is a direct bearing on the outcome of care by the involvement of the family physician in that care. The fact that, by the criteria of involvement and outcome as defined in this report, there is a large measure of agreement between a high degree of family physician involvement and an improved outcome, is encouraging.

It is perhaps to be expected that family physicians consider their own involvement as well as the outcome achieved as being greater than the carers do, but this finding is rather worrying. The call should be for constructively critical self-review and reflection of our own effect on the process and outcome of palliative care.

The background of separation of patient care into specialist disciplines was the initial impetus to conduct the study. The structural, financial and political background to this situation was related in the introduction. These issues are deep and not amenable to rapid change.

The central role of ethics and the fair and just distribution of resources to deliver optimal patient care, and extending this in the spirit of excellence, to optimal care of all persons who are involved in or touched by the illness was emphasised. This aspect of care extends especially to the team who deliver the care.

The active research community within palliative care demonstrated in the literature review that there are many unanswered questions and therefore excellent opportunities for advancement and a better outcome for the discipline. The improvement of clinical outcome for the patient and the surviving relatives remains the most important goal of all endeavours in this field, however.

The objective of improving the outcome of care in future patients will be achieved in the practice of the researcher immediately, but the publication of these findings and the further conduct of research have the potential to continue this process, and develop it, so that many patients may benefit in future.

A second objective of the project was to be a catalyst for the advocacy of the discipline of palliative care. The fact that this research has been undertaken has already had an effect in that the care givers and doctors who completed the questionnaire have been made aware that the field of study exists and that there is active research being pursued. The findings are to be prepared for publication, and this will add momentum to the advocacy process.

The third objective of developing the research agenda in palliative care has been achieved, at least in the mind of the researcher. The study has raised many questions which need further investigation. In addition, the study has exposed the areas of expertise in the research field which the researcher needs to develop.

This investigation could perhaps even be regarded as a pilot study for a wider and more comprehensive study, relating the involvement of family physicians to the outcome of care.

A list of possible areas of future study and research in this field was compiled. The list is not exhaustive, however.

1. Development and validation of simple outcome questionnaires
2. Development and validation of simple involvement questionnaires
3. Critical examination of the ethics involved
4. Development of recruitment tools (for patients, carers, research staff, doctors)
5. Follow up of the carers and doctors who returned questionnaires

An initial proposal for the further development of this research idea is to be found in the appendix.

It should be clear from the report that palliative care is best offered by a team who contribute technical expertise, cross-pollination of ideas and mutual support. This principle should be applied to research in the field as well.

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POSTSCRIPT

This research project was both exciting and consuming.

If the opportunity arose to do it again, I would grasp it firmly and make a few changes, and hope to emerge with findings that will change the way that I care for my patients, and the way that the profession addresses palliative care.

A quaint, humorous quote from the late Douglas Adams' "The Hitchhiker's Guide to the Galaxy" brought a little perspective to the unending quest for scientific evidence on which to base one's practice of medical care.²²

"...Science has achieved some wonderful things, of course, but I'd far rather be happy than right any day."

"And are you?"

"No. That's where it falls down, of course."

APPENDIX**List of documents in appendix**

1. Letter to oncologist
 2. Letter to research assistant
 3. Instructions for research assistant
 4. Explanatory letter to recipients of consent forms and questionnaires
 5. Consent form for carer
 6. Consent form for carer in Afrikaans
 7. Consent form for doctor
 8. Consent form for doctor in Afrikaans
 9. Questionnaire
 10. Questionnaire in Afrikaans
 11. Research proposal
 12. Further ethical considerations
 13. Personal responses and reflections of the researcher
 14. Personal details of the researcher
-

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12 February 2003

Dr G. McAdam
GVI Oncology
Constantiaberg Mediclinic
Burnham Rd
Plumstead
7800

Dear Dr McAdam

Research Project towards MPhil (Palliative Medicine)

I will be conducting a research project, which will form part of the requirements of study towards a masters degree in palliative medicine. The proposed protocol to be submitted for ethical approval is attached for your consideration, as your agreement to allow me to use the patient list from your practice is essential.

The project will not be undertaken until full ethical approval is obtained from the relevant committee of UCT.

The consent of both the care-giver and the family doctor will be obtained before any questionnaires are administered and confidentiality will be protected in all cases by using unique codes for each patient, caregiver and GP.

If you agree to allow me to use the resource base of your practice for this project, please could you confirm this in writing so that this may be submitted as supporting documentation to the ethics committee.

Thank you,

Yours sincerely

Dr Alan Barnard.

Statement of intent and confidentiality

This document has been prepared to ensure that the research assistants understand the project with which they are helping, and that they are aware of the issues of ethics and confidentiality, which are of prime importance in such work.

A postgraduate student at the University of Cape Town in the Department of Family Medicine is undertaking a research project as part of a masters degree in Palliative Medicine. The title of the project is as follows:

The Family Physician in Palliative Care: An Outcomes Analysis.

Information is being gathered as explained in the enclosed information and consent form and this information will be recorded and analysed to test the hypothesis that:

“Outcomes in palliative care are better if the family physician is involved at all stages of care.”

It is hoped to formulate a strategy to involve the GPs in the care of these patients in the future, and to motivate the specialists and hospice services to involve the GP in the care too.

The method of research is to gather information from the main care-giver by means of a simple questionnaire. This information will include questions about

1. The involvement of the family doctor in the care of the patient.
2. The outcome or satisfaction as judged by the main carer.

A similar questionnaire will be applied to the GP of the patient, and the consent of that doctor will also be obtained.

The information will be gathered, recorded and stored in such a way that the identity and privacy of the patient, the care-giver and the doctor are preserved in accordance with the ethical rules which are applicable to all medical consultations and research. This research project has been submitted for approval to the relevant ethics committee of the University of Cape Town and has been approved.

This consent form is the only document which records the names of the patient and the care-giver. After consent has been obtained, this form will be filed separately from the questionnaires and individual codes will be used to identify the people concerned.

I, _____, declare that I have read the above statement, and that I agree to assist with the gathering of information for further analysis. I undertake to respect the usual rules of medical confidentiality, as required by my professional association, and my own professional ethics.

Signed: _____ (Research assistant)

Print name: _____

Date: _____

Requirements for research assistants

Allocate an individual number to each patient eg P/001, P/002, P/003 etc

Same for each doctor eg D/101, D/102 etc

These codes to be recorded on the list of Family contacts which have been supplied.

Mark both the information and consent forms with name of patient, name of doctor as well as coded ID.

Fill two large envelopes with the supplied letters etc (list below) for each patient. Be sure to do this in such a way that it can be established that both the doctor and the carer receive an envelope. (the contents of the two differs)

The envelopes should be addressed at this stage, using the data-base/ information supplied, or other addresses. eg telephone book

Contents of envelope for carer

1. Letter from Mrs Claire Manicom
2. Information sheet
3. Consent form
4. Return envelope (addressed to Mrs Claire Manicom)

Contents of envelope for doctor

1. Compliment slip and info leaflet (stapled together)
2. Information sheet
3. Consent form
4. Return envelope (addressed to Mrs Claire Manicom)

Thank you.

To whom it may concern

**RESEARCH PROJECT TOWARDS THE FUTURE IMPROVEMENT OF
CARE FOR CANCER PATIENTS**

A postgraduate student at the University of Cape Town in the Department of Family Medicine is undertaking a research project as part of a masters degree in Palliative Medicine. The title of the project is as follows:

The Family Physician in Palliative Care: An Outcomes Analysis.

Information is being gathered as explained in the enclosed information and consent form and this information will be recorded and analysed to test the hypothesis that:

“Outcomes in palliative care are better if the family physician is involved at all stages of care.”

It is hoped to formulate a strategy to involve the GPs in the care of these patients in the future, and to motivate the specialists and hospice services to involve the GP in the care too.

Please complete the enclosed questionnaire and return it with the signed Information and Consent Form, together in the stamped and addressed envelope. There is a very tight deadline for the completion of the project, so a quick response would be appreciated.

Thank you.

Information and Consent form for Carer

This is an information form and consent form for the purpose of conducting medical research.

The purpose of the research is to evaluate the connection between the involvement of the general practitioner (GP) and the outcome of care of people who have cancer.

It is hoped that the results of this research will enable doctors, and the whole team of people caring for people with cancer, to improve this care in the future.

The method of research is to gather information from the main care-giver by means of a simple questionnaire. This information will include questions about

1. The involvement of the family doctor in the care of the patient.
2. The outcome or satisfaction as judged by the main carer.

A similar questionnaire will be applied to the GP of the patient, and the consent of that doctor will also be obtained.

The information will be gathered, recorded and stored in such a way that the identity and privacy of the patient, the care-giver and the doctor are preserved in accordance with the ethical rules which are applicable to all medical consultations and research. This research project has been submitted for approval to the relevant ethics committee of the University of Cape Town and has been approved.

This consent form is the only document which records the names of the patient and the care-giver. After consent has been obtained, this form will be filed separately from the questionnaires and individual codes will be used to identify the people concerned.

CONSENT FORM

I, _____, the main caregiver of _____,

confirm that I have read and understand the information set out above, and agree to take part in this research project. I understand that participation in this research is not compulsory and that I agree to take part willingly. I understand further that my decision to take part, or not to take part, will not affect my own future medical care.

Signed by

Caregiver _____ Date _____

Witness _____ Date _____

Informasie en Toestemmingsvorm vir Versorger.

Die vorm gee inligting en vra toestemming om deelname in mediese navorsing. Die doel van die navorsing is om die verhouding tussen die betrokkenheid van die algemene praktisyn en die finale uitkoms van sorg te bepaal, in pasiente met kanker. Dit word gehoop dat die uitslae van die navorsing, dokters en almal wat tedeoer het met die sorg van kankerpatiente, sal help om *die* sorg in die toekoms te verbeter.

Die metode van navorsing is om informasie in te samel van die persoon wat die meeste verantwoordelik was vir die sorg van die pasient. ('die versorger') Dit word gedoen deur middel van 'n vraelys. Die informasie sal vrae insluit oor:

1. Die betrokkenheid van die algemene praktisyn in die sorg van die pasient
2. Die uitkoms of satisfaksie as beoordeel deur die persoon verantwoordelik vir die sorg van die pasient.

'n Soortgelyke vraelys sal voor die algemene praktisyn voorgele word. Die toestemming van die dokter sal ook gevra word.

Die inligting sal ingesamel, afgeskryf en behou word op 'n manier om die identiteit en privaatheid van die pasient, versorger en die dokter te preserveer in ineenstemming met die etiese reëls van toepassing op enige mediese konsultasie of navorsing. Die navorsingsprojek is vir goedkeuring ingedien tot die relevante komitee van die Universiteit Kaapstad, en is goedgekeur.

Die toestemmingsvorm is die enigste dokument waarin die name van die pasient en versorger afgeskryf word. Die toestemmingsvorm sal apart gebere word van die vraelyste wat verder toegepas gaan word. Individuele nommers sal gebruik word om die mense korrek te identifiseer.

TOESTEMMINGS VORM

Ek, _____, (naam van die persoon wat toestemming gee)

die hoof-versorger van _____, (naam van die pasient)

bevestig dat ek die informasie wat bo vooruitgele is gelees en verstaan het, en dat ek toestem om in die navorsingsprojek deel te neem. Ek bevestig dat ek al die implikasies van die navorsing verstaan.

Ek verstaan dat deelname in die navorsing nie verpligtelik is nie en dat ek vrywillig besluit het om deel te neem. Ek verstaan dat my besluit om deel te neem of nie, my eie verdere mediese sorg nie sal benadeel nie.

Geteken deur

Versorger _____ Datum _____

Getuie _____ Datum _____

Consent form for doctor

This is an information form and consent form for the purpose of conducting medical research.

The purpose of the research is to evaluate the correlation between the involvement of the general practitioner (GP) and the outcome of care of people who have cancer.

It is hoped that the results of this research will enable doctors, and the whole team of people caring for people with cancer, to improve this care in the future.

The method of research is to gather information from the family doctor (GP) of the patient with cancer, by means of a simple questionnaire. This information will include questions about

1. The involvement of the family doctor in the care of the patient.
2. The outcome or satisfaction as judged by the GP.

A similar questionnaire will be applied to the main caregiver of the patient, and the consent of that person will also be obtained.

The information will be gathered, recorded and stored in such a way that the identity and privacy of the patient, the caregiver and the doctor are preserved in accordance with the ethical rules which are applicable to all medical consultations and research. This research project has been submitted to the relevant ethics committee of the University of Cape Town and has been approved.

This consent form is the only document which records the names of the patient and the caregiver or doctor. After consent has been obtained, this form will be filed separately from the questionnaires and individual codes will be used to identify the people concerned.

CONSENT FORM

I, _____, the family doctor of _____,

confirm that I have read and understand the information set out above, and agree to take part in this research project. I understand that participation in this research is not compulsory and that I agree to take part willingly. I further understand that my decision to take part, or not to take part, will not compromise my professional relationships.

Signed by

Doctor sign _____ print _____ Date _____

Witness sign _____ print _____ Date _____

Informasie en Toestemmingsvorm vir Dokter.

Die vorm gee inligting en vra toestemming om deelname in mediese navorsing. Die doel van die navorsing is om die verhouding tussen die betrokkenheid van die algemene praktisyn en die finale uitkoms van sorg te bepaal in pasiente met kanker. Dit word gehoop dat die uitslae van die navorsing, dokters en almal wat tedeo het met die sorg van kankerpatiente, sal help om *die* sorg in die toekoms te verbeter.

Die metode van navorsing is om informasie in te samel van die algemene praktisyn van die pasient. Dit word gedoen deur middle van 'n vraelys. Die informasie sal vrae insluit oor:

1. Die betrokkenheid van die algemene praktisyn in die sorg van die pasient
2. Die uitkoms of satisfaksie as beoordeel deur die algemene praktisyn.

'n Soortgelyke vraelys sal voor die hoof-versorger voorgele word. Die toestemming van die versorger sal ook gevra word.

Die inligting sal ingesamel, afgeskryf en behou word op 'n manier om die identiteit en privaatheid van die pasient, versorger en die dokter te preserveer in ineenstemming met die etiese reëls van toepassing op enige mediese konsultasie of navorsing. Die navorsingsprojek is vir goedkeuring ingedien tot die relevante kommittee van die Universiteit Kaapstad, en is goedgekeur.

Die toestemmings vorm is die enigste document waarin die name van die pasiente, dokters en versorgers afgeskryf word. Nadat toestemming gegee is, sal die vorm apart gehou word van die vraelyste wat verder toegepas gaan word. Individuele nommers sal gebruik word om die pasiente en algemene praktisyns korrek te identifiseer.

TOESTEMMINGS VORM

Ek, _____, (naam van die persoon wat toestemming gee)

die algemene praktisyn van _____, (naam van die pasient)

bevestig dat ek die informasie wat bo vooruitgele is, gelees en verstaan het, en dat ek toestem om in die navorsingsprojek deel te neem. Ek bevestig dat ek al die implikasies van die navorsing verstaan.

Ek aanvaar dat deelname in die navorsing nie verpligtelik is nie, en dat ek vrywillig besluit om deel te neem.

Geteken deur

Algemene praktisyn _____ Datum _____

Getuie _____ Datum _____

INVOLVEMENT AND OUTCOMES QUESTIONNAIRES

Identification of patient by unique number _____

Identification of family physician by unique number _____

Questionnaire applied by _____ Date _____ Sign _____

Questionnaire for Carer

These questions are to be answered by the carer and should reflect the carer's perception of the involvement and outcome. Answers should be unprompted.

Section 1 – Involvement of Family Physician

1. Did your GP inform you about the cancer? Yes / No
2. Did the GP get information from the specialist about the cancer? Yes / No
3. Did the GP treat the patient for *cancer related ailments* during the course of the illness? Yes / No
4. Did the GP treat the patient for *non-cancer related ailments* during the course of the illness? Yes / No
5. Has there been contact with the GP since? Yes / No

Section 2 – Outcome

1. Were you given the opportunity to discuss your needs and problems relating to the cancer? Yes / No
2. Were these adequately addressed? Yes / No
3. Were you given enough information for you to understand the treatment? Yes / No
4. Was the pain controlled? Yes / No
5. Did you feel that the quality of life of the patient was as good as could be expected. Yes / No

Questionnaire for Family Physician

These questions are to be answered by the family physician and should reflect the family physician's perception of the involvement and outcome. Answers should be unprompted.

Section 1 – Involvement of Family Physician

1. Did you inform the patient about the cancer? Yes / No
2. Did you get information from the specialist about the cancer? Yes / No
3. Did you, as the GP, treat the patient for *cancer related ailments* during the course of the illness? Yes / No
4. Did you, as the GP, treat the patient for *non-cancer related ailments* during the course of the illness? Yes / No
5. Has there been contact with family since? Yes / No

Section 2 – Outcome

1. Was the patient given the opportunity to discuss his/her needs and problems relating to the cancer? Yes / No
2. Were these adequately addressed? Yes / No
3. Were you given enough information for you to understand the treatment? Yes / No
4. Was the pain controlled? Yes / No

5. Did you feel that the quality of life of the patient was as good as could be expected. Yes / No

UITKOMS EN BETROKKENHEID VRAELYSTE

Pasient nommer _____ Dokter nommer _____
 Vraestel aangepas deur _____ Teken _____ Datum _____

Vraelys vir Versorger

Die vrae moet deur die versorger beantwoord word en moet die persepsie van die versorger toon.

Deel 1 – Betrokkenheid van die Algemene Praktisyn (AP)

1. Het die dokter (AP) vir jou informasie oor die kanker gegee? Ja / Nee
2. Het jou dokter informasie van die spesialis oor die kanker gekry? Ja / Nee
3. Het jou dokter die pasient behandel vir *kanker simptome* gedurende die siekte? Ja / Nee
4. Het jou dokter die pasient behandel vir *nie-kanker simptome* gedurende die siekte? Ja / Nee
5. Was daar kontak met die dokter sedertdien? Ja / Nee

Deel 2 – Uitkoms

1. Was jy die geleentheid gebied om jou benodighede en probleme met die kanker te bespreek? Ja / Nee
2. Was die bogename vrae beantwoord? Ja / Nee
3. Was genoeg inligting gegee om die behandeling te verstaan? Ja / Nee
4. Was die pyn onder beheer? Ja / Nee
5. Was die lewenskwaliteit so goed was as wat verwag kon word? Ja / Nee

Vraelys vir die Algemene Praktisyn

Die vrae moet deur die algemene praktisyn beantwoord word en moet die persepsie van die algemene praktisyn toon.

Deel 1 – Betrokkenheid van die Algemene Praktisyn (AP)

1. Het jy die pasient inligting verskaf met betrekking tot die kanker? Ja / Nee
2. Het jy informasie van die spesialis oor die kanker gekry? Ja / Nee
3. Het jy die pasient behandel vir *kanker simptome* gedurende die siekte? Ja / Nee
4. Het jy die pasient behandel vir *nie-kanker simptome* gedurende die siekte? Ja / Nee
5. Was daar kontak met die famielie sedertdien? Ja / Nee

Deel 2 – Uitkoms

1. Was die pasient die geleentheid gebied om vrae te vra oor die kanker? Ja / Nee
2. Was die vrae beantwoord? Ja / Nee
3. Is jy met genoeg inligting verskaf om die behandeling te verstaan? Ja / Nee
4. Was die pyn onder beheer? Ja / Nee
5. Was die lewenskwaliteit so goed was as wat verwag kon word? Ja / Nee

A proposed research project for the prospective study of the effect of family physician Involvement on the Outcome of care.

A large, well-designed and adequately supported team research project to examine the application of palliative care principles across the whole spectrum of medical care is proposed. The aims of developing the research agenda and empowering the family physicians and other primary carers to improve patient outcomes would be central to the project. The disparate nature of health services in South Africa would be considered a strength for this study, as the knowledge gained would have wide application in the world, in academic and private medical practice, in many economic circumstances and across the spectrum of medical and social illness. Some areas of enquiry to be considered in a project of this nature are listed below.

1. Cancer
2. Non-cancer terminal illness
3. Chronic illness
4. HIV
5. Childhood illness
6. Surgical operations

This project is at the concept stage of development. The research conducted for the completion of this report may be considered to be a pilot study for this larger and more important work.

The application of ethical principles

Confidentiality

Confidentiality is an issue which is central to the good outcome of any medical intervention. The patient and care-giver or so-called “unit of care” may sometimes be considered as one, but special care needs to be taken to ensure that there is no breach of implied confidentiality between the patient and the care-giver in the answering of questionnaires after the death of the patient. The ethical obligation to respect confidentiality extends beyond the death of the patient. The matter of doctor-patient confidentiality is self-evident in everyday practice, but the fact there is not a great deal of research being conducted in family medicine, particularly in the target group of family physicians of this research project, raised some questions amongst the doctors who answered the questionnaire. The cohort of patients who were selected for this study had all been under the care of the oncology practice, and the assistance of the practice counsellor was the key to maintaining the confidentiality of the patients and care-givers. The fact that there was an established clinical and supportive link already established before the death of the patient ensured that the ethical duty not to break confidentiality was not breached. A simple system of alpha-numerical codes provided the confidential information to the researcher in a form that did not breach the confidentiality as mentioned above. This system also ensured that any bias that may have occurred in the researcher resulting from the knowledge of the identity of either patient or that patient’s attending family physician was eliminated. The initial sorting of the replies to the questionnaires was undertaken by the oncology counsellor, and subsequent administrative assistance was given by the professional nurse in charge of the ward in which the oncology practice managed its in-patients.

Both of these persons understand the ethical obligations of confidentiality from a professional point of view, and these obligations were emphasised before the research project was undertaken.

The care of the bereaved and consent

There is an ethical responsibility of the researcher to ensure that good counselling is available to the surviving care-giver of each deceased patient. These people are by definition bereaved, and are also not accustomed to the process of medical research. Proper informed consent is essential in this case. It may be argued that the simple returning of the questionnaire gives tacit consent to the process and further analysis of the answers. For the purposes of this study, however, special consent forms were signed by both care-givers and the family physicians who returned questionnaires. The counselling professional was the person who sent out the letters to the surviving care-givers, and it was made clear to the care-givers that there was no obligation to participate in the study. It was also stated that there was counselling available with the same person who had been involved with counselling and support before the patient had died.

The ethical duty to improve patient care

The complete care of any individual patient or all patients under the care of a doctor, a specialist multi-disciplinary practice or an organisation like a hospice, implies that the best practice standards are applied to the care of that patient. This extends in the context of palliative care to the care of the bereaved as well. The fact that there is a relative "dearth of high quality comprehensive research" ⁴ in this field places an ethical obligation on those involved in the field to conduct this research in a

competent and rigorous way and for it to be published and publicised widely. This fulfils part of the ethical obligation to improve patient care with best practice standards being able to be measured and tested.

The ethical duty of advocacy

The advocacy role of the doctor, often undertaken on an individual patient basis by the family physician, extends to the wider role of advocacy for the discipline of palliative medicine in the medical community, thereby educating and drawing the full spectrum of medical professionals, both physicians and non-physicians, into the mode of thinking central to palliative care. Advocacy extends to the community at large, and those at the forefront of palliative care provision have an obligation to educate and inform all sectors of the community about the discipline, thereby empowering these people, some of whom will be patients one day, and some of whom will be caregivers, to demand the best possible care available. The importance of advocacy at university and teaching hospital level deserves special mention because the attitude and practice of the next generation of medical professionals is nurtured here. The development of policy and the setting of standards require a high level of understanding and commitment from politicians, bureaucrats and professional bodies like the Medical Association and Health Professions Council. An ethical responsibility rests on them to be informed about palliative care, but it rests equally on those involved in the field to communicate the results of research and develop relationships that will ensure the development of the discipline and thereby, improve patient care on a large scale.

The ethical duty to conduct good research

It seems self evident, but it should nevertheless be stated that there is an ethical responsibility to ensure that research is conducted well, and is subjected to rigorous interrogation at every stage. The role of the researcher is central in this, and it is noted that much research is carried out by students and part-time practitioners, who are relatively inexperienced in the field as well as in the technicalities of conducting research. It behoves all researchers to educate themselves and to ensure that they are properly supported or mentored in the process. The role of the research supervisor is very important too and often provides the link between the formal research structures of the university and the researcher. The structures of departmental research committees, ethics committees and similar bodies are an essential part of the ethical conduct of any medical research project.

The ethical duty to publish results

There is some overlap in this area with the advocacy role mentioned above, but it should be ensured that the results of all research whether positive or negative, and whether the study hypothesis has been shown to be correct or flawed, should be published. In the quest for advocacy of the discipline, it would be more helpful for a study to be published in widely read and reputable peer-reviewed journals. Once the results of the research are in the public domain, then palliative care physicians, all medical professionals and the general public can use these results to improve patient care and outcomes.

Some responses and reflections

This study has been undertaken primarily to investigate the effect of the involvement of the family physician on the care of patients with terminal illness and then to inform the medical community of the value and contribution of the family physician. The response of all possible involved parties is to be considered.

The response of the researcher

The researcher has the responsibility of conducting the research competently and thoroughly so as to compile reliable information for dissemination. Certain opportunities for the improvement of the research methods and the development of further research in this field have become apparent during the conduct of this research. It is the responsibility of the researcher to continue this process to improve patient care in future. The development of a research group is one possible method of ensuring that this vital discipline develops and that the patients ultimately receive better care in future.

The response of the reader

The response of the reader of these research findings is likely to be informed by his or her current position in the clinical or research team (in broad terms). The ultimate goal of all carers should be the improvement of outcomes and the central person in that outcome is the patient. The response therefore should be to consider the findings of this study in the light of the clinical, research and medical education responsibilities which are at the core of the practice of family medicine, palliative care or other specialist medical care. The literature review showed that there is variable satisfaction with palliative care whether provided in the community or by specialist

palliative care services. The specific studies regarding outcomes of care where family physicians are involved demonstrated that in highly technical areas of care like obstetrics and renal medicine, family physician involvement is beneficial.^{16, 17}

The response of the family physician

The active maintenance of continuity of care is the obvious response which should follow the understanding of the important role of the family physician in the outcome of care. Most family physicians know this intuitively, but this study serves to validate this knowledge and to encourage them to pursue an active role in the patients who are referred to specialist care for the diagnosis and management of potentially terminal illness. The family physician should try to maintain contact with both the patient and the specialist. More family physicians should be encouraged to engage in the process of clinical research in this field in the future. The fragmentation of care in both the private and state sector has been discussed in the introduction, and the proper application of the principles of family medicine and palliative care could go some way to resolving this problem. The managers of the family medicine and primary care services provided by the state should consider the findings of this study, despite the fact that it was conducted in the private sector. The primary carers, who are often family physicians, often feel the blame for poor care, poor outcomes and inefficiency, when in fact deep structural faults are present. In South Africa the majority of patients are treated in state facilities where continuity of care is under severe pressure. The engagement of the family physician in the care of patients with terminal illness has the potential to improve outcomes and continuity of care.

The response of the medical specialists

The importance of the patient-centred approach, and not the disease-centred approach, is demonstrated by this study. It is acknowledged that the specialist knowledge and expertise of the surgeons, specialist physicians and oncologists is indispensable in the complete and competent care of the patient. It has been demonstrated in this study, however, that the outcome of care is adversely affected if the family physician is excluded from the care. It is the ethical responsibility of all medical specialists to engage and involve the family physicians in the care of their patients. The reasons for the fragmentation of the care are complex and were explained in the introduction. Factors include professional boundaries, pride, fees as well as structural and educational and communication barriers. Improvement of outcome should be the goal of all doctors involved in the care of patients: this goal may be achieved if the care is delivered by a clinical team.

The response of the palliative care specialists

A special responsibility rests on those who specialise in the delivery of palliative care to ensure optimal outcomes as the opportunity for correcting adverse outcomes is, by definition, limited. The physicians and other carers who deliver palliative care encompass oncology specialists, hospice services, HIV practitioners and a few family physicians with a special interest. These carers have a special role to play in the delivery of excellent palliative care to the patient and to the community. This community includes the medical community and the dissemination of the results of this research and other information like it is vital to the improvement of the discipline and finally to the betterment of patient outcomes. The palliative care team, which is responsible for the care of every patient, should ideally include the family physician

of the patient. If there is no family physician involved then an effort should be made to find a doctor who could fulfil that role in the team. The palliative care specialists have a responsibility to develop the discipline by educating the medical community about the subject as well as advocacy for the discipline at community, professional and governmental levels.

The response of the medical education specialists

Every patient who consults a doctor will die: the principles of palliative care apply to every patient, therefore. Undergraduate medical training should include the principles of palliative care in every discipline. The important role of the family physician should be emphasised to all trainees. This is equally important in post-graduate medical training where trainee specialists should have the importance of good communication with the primary care doctor of every patient emphasised and inculcated into their practice of medicine.

The responsibility of the individual family physician to maintain and develop clinical skills is also at issue, particularly in light of the fact that there are special skills to be learnt for the practise of competent palliative care. The competence of these family physicians to take the role of palliative carer is very important if there is to be encouragement of this group of physicians to become involved. There will always be learning to be done and education and training is a vital task to be undertaken by the academic proponents of the discipline.

Reflections

General issues pertaining to clinical research

Personal

The researcher has found that this project has extended the boundaries of research work into every aspect of life. Solo research easily becomes solitary, and it has been in the writing stage only that a good working relationship has been achieved with the supervisor. It should be noted that the supervisor of the project changed for reasons beyond the control of any of the parties. The concept of this research project as articulated by the study hypothesis seemed to be straightforward and simple to execute. There have been some unexpected challenges, but, from the single-handed drafting of the original protocol to the preparation of the report, this has been a time consuming and exhausting task.

The motivation of the researcher has been called into question at many different stages during this research project, and this is an important aspect to be considered by any researcher in this field. The subjective nature of the responses served to reinforce the notion that outcome in palliative care needs to be improved. This exposes a degree of prejudice in the researcher, which has to be acknowledged and balanced by critical analysis of every stage of the research: from concept to publication.

The financial cost of doing a research project of this nature is not inconsiderable and, in this case, was borne by the researcher, without recourse to a study grant. A further cost which is more indirect is the loss of productivity in practice. There were direct losses of income as well as reduction in productivity from time to time.

The loss of time to participate in personal, family and leisure activities also had a significant impact on the researcher and perhaps on the research as well. The fact that few people are involved with the discipline also imposes a degree of loneliness on those who carry the role of developing the discipline of palliative care and especially research in their field.

The model of shared care and teamwork with well structured support, as practiced in competent family medicine and even more so in competent palliative care, should be developed to include those who are involved in research. The traditional model of the doctor led team, which paid scant attention to the role of the other members, should be challenged where it is still found. The vital role of professional nurses, social workers, counsellors, chaplains and others should be affirmed and encouraged. The leadership of these professionals in palliative care is acknowledged and acclaimed.

Support

The discipline of palliative care is not yet well developed and widely accepted by the profession, the patients and the public at large. In fact there is a large measure of misunderstanding and ignorance both of the fact that it is a particular discipline, and that it is such a central part of what every doctor does in practice. The “major” medical specialities consumed a disproportionate segment of undergraduate teaching in years past, leading to the concentration of focus on these specialities. The true generalists, comprising family physicians, geriatricians and general internists among few others, have been joined by the palliative care physicians in considering the patient first, the context next and the disease or diseases last. This has been fuelled by

the move of the patients to a consumer model of consulting. The patients are better informed and more able to make autonomous choices.

This background has ensured that the discipline of palliative care has had to develop in a model of curative scientific medical practice. The patients have been critical and demanding, with very good reason, and this has led to the development of a strong culture of communication within palliative care.

The fact that there are relatively few doctors involved exclusively in palliative care has meant that those who are involved have been overworked and over-committed. This has the potential to lead to burnout and disillusionment. The team approach, which is core to the practice of palliative care, should be widely applied in all branches of medicine, and even more so to palliative care.

The lack of formal and structured support for the process of research may be an impediment to the progress of the research agenda. This research is essential for the nurturing and growing of a new discipline in the medical field. The process of research in palliative care should be supported and encouraged from the highest level in the faculty, to departmental heads and then by the supervisors of the researchers. The relationship between the researcher and the supervisor is especially important. The process should be formalised and accountability ensured. Team development has been mentioned above, but is particularly pertinent when considering the nurturing of research and the research team.

Funding is also a vexed question, with the faculty and sponsors demonstrating true commitment by underwriting the research process. The support, or lack of it, has been felt acutely by every researcher who worked hard to have a proposal turned down, or has abandoned good research because of a lack of funding. It is a moot point to consider what may have been achieved if the research agenda had been supported with full commitment before.

Academic

The goal of study should be kept in mind at all times. The aims and objectives of the research project and process should be properly understood by the researcher. The value of a constructively critical support team, including supervisors, peer researchers and research assistants who are in a learning role. Mentoring relationships should be nurtured at all levels, and more so to interrogate motivation carefully at all stages of the process, from concept to publication.

Research skills can be learnt from textbooks, courses, colleagues and supervisors. There is, however, no substitute for personal experience. It is very important to improve basic science skills for competent research to be conducted. Statistics, computer skills, writing and editing are all vital to the completed work which may be well conceptualised, but poorly executed and reported. A particular skill in ethics and the application of the basic principles to the wide canvass of palliative care is vital if the findings of the research are to be published and applied for the betterment of patient care.

The development of the palliative care team should be extended towards finding the role of each team member in the research process. Every person should be valued and extended to the limit of their capacity to contribute; and then be supported to develop further.

Special mention of the encouragement of concept thinking should be made. The opportunity for original thought and the ability to make a real difference to the way that patients may be treated is both realistic and dramatic. Strategic planning is an idea of business management, but should be applied to the process of palliative care in general and, in the context of this report, to the research agenda in the field.

The further use of research tools, which are well established in medical and social science research, may require special adaptation and validation. The development of new techniques and novel sources of information may be required to grow the knowledge base of palliative care, but these techniques would have to be meticulously validated in order to carry weight in the literature. The development of simple and widely applicable short questionnaires is an important step towards the conduct of outcome centred research in palliative care.

The optimal use of the current knowledge base in palliative care is also a very important matter. The completion of the literature review for this research project was a valuable exercise in scanning the large body of work which was turned up by the search. The information was not all directly relevant to the topic under investigation, but subconscious benefit was often recognized later in the research process. The relatively simple editing task of arranging a contents page was inspired by a very

good table in an unrelated paper, for example. Literature review skills are therefore an important academic attribute which need to be developed for research quality to be improved. It is important to be able to analyse academic publications critically and to be able to weigh the research methods, techniques of analysis and presentation so as to ascribe proper value to the results of any research. Library resources are not always available to every practitioner, but the responsibility of the stewardship of knowledge lies evenly with the custodians of that knowledge, with those who use it and with those who strive to develop and improve it.

Study specific issues

The general themes explored above are summarised here to illustrate that the issues are very real and still resolving after the completion of this report. The isolation of a single researcher was felt acutely in this project, and only in the writing phase did the regular contact with the supervisor counter these feelings. The perseverance needed was inspired by passion for the field of research and for the outcome in the actual patients who are the subject of the whole exercise. A sincere determination to see the task done in the end, for the completion of the degree requirement also helped! Without the support and encouragement of my supervisor, family and friends, the task would have been even more mountainous! The value of well-intentioned encouragement and even discipline cannot be over-estimated.

The combination of academic endeavour with the full-time private practice of family medicine is extremely difficult. The conceptualisation is easy, but the execution is often hindered by the need to see patients. Research is possible in private practice, but it is difficult to compare this practice situation to others where the job description

entails research as part of the whole. The importance of team development is emphasised again, but requires special attention in a private practice setting. The role of the supervisor in initiating contact, and in the direction toward goal setting and accountability, is vital.

Quantitative research methods require a measure of statistical expertise. This is not everybody's skill, so the assistance of departmental staff and informal tutorials from experts and peers was essential in this project. The treatment of computer skills was handled in a similar way. Ethics required special attention from concept to design and from execution to reporting. The actual publication of research findings is an ethical responsibility which continues beyond the acceptance of this document for the requirements of the university degree. The additional ethical responsibility to continue the process of research and to develop it further is also felt to be important.

RESEARCHER DETAILS

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