Te Omanga Hospice Foundation
Murray Bond Research Fellowship

Te Omanga Hospice Syringe Driver use in Palliative Care:

Patients' and Family Caregivers' Understandings and Experiences

**Report for the Trustees of the Te Omanga Hospice Foundation
and the Te Omanga Hospice Trust**

Valerie Norton MA RNZRN, 2011 Murray Bond Research Fellow

Te Omanga Hospice Foundation

March 2012

Te Omanga Hospice
Te Whare Manaaki Tangata

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The views expressed in this report are those of the author and are based on the research findings. Te Omanga Hospice is publishing this report to encourage discussion and contribute to the ongoing development of palliative care practice.

To protect participants' identity all names used in this report are fictitious ones provided by each participant.

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Whakarongo Ki Te Iwi
Listen to the People

Foreword

Research primarily increases a body of knowledge in a particular field. *The Te Omanga Hospice Research into syringe Driver use in Palliative Care* achieves significantly more than that.

Valerie Norton's research was made possible by the establishment of the Te Omanga Hospice Foundation Murray Bond Research Fellowship. This Fellowship recognises and honours Murray Bond who gave much of his life, energy and resources as a fundraising leader and a trustee of Te Omanga Hospice.

Another pivotal aspect of this research is the voice it gives to patients and particularly to the unsung providers of devoted care, the family carers.

These interviews have identified the major role that syringe drivers play in providing a better quality of life for patients and therefore peace of mind for carers. The pleasure both carers and patients gain from quality time together in a relatively pain-free situation is a very significant element.

Additional value is provided in the recommendations for clinical and strategic consideration.

Te Omanga's reputation for "Excellence in Palliative Care" is further enriched by this valuable contribution towards the global knowledge of important social aspects of the syringe driver's role in palliative care.

Elaine Moffat QSO

Te Omanga Hospice Trustee

Acknowledgements

In particular I pay respect to the patients and family caregivers for giving their time and part of themselves to the study. It is their words that give power to this report.

I also mark my special respect for Murray Bond in whose name the Fellowship supporting this study was established in March 2011.

Thank you to the Trustees of the Te Omanga Hospice Foundation and the Te Omanga Hospice Trust for awarding me the 2011 Murray Bond Research Fellowship.

I also want to thank Biddy Harford (CEO Te Omanga Hospice) and Bronwyn Lindsay (previous Director of Nursing Te Omanga Hospice), for your initial support in bringing the research concept to the board.

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I am indebted to the people who carried out the critical work of editing and proof-reading: Dr James Conner, Otago University, Mrs Elaine Moffat QSO J.P, Te Omanga Board of Trustees, Rhondda Knox, Te Omanga Director of Nursing and Clinical Support Services and Professor Rod McLeod, Palliative Care, Goodfellow Unit, University of Auckland.

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Beth Johnson Taylor, then Research Director, Mary Potter Hospice, thank you for your wonderful collegial support.

Many colleagues at Te Omanga Hospice have supported me during this period: Tess Sullivan, Raelee Jensen, Kate Gellatly, I value our friendships.

Valerie Norton
March 2012

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Executive Summary

This study provides insights into the use of syringe drivers in palliative care symptom management. The research captures, through conversational interviews, the lived experience of 27 people (12 patient/family caregiver couples and 3 caregivers) experiencing palliative care, as a patient or family caregiver. The use of a syringe driver made a **very positive difference** in the lives of everyone interviewed. Swift symptom relief, following administration of prescribed medications, resulted in a greatly improved quality of life. In the words of Geoff **"It gave me life".**

A key message for palliative care practitioners is the importance of being receptive to patients' and their families' comments about what is most meaningful for them at this precious time. To listen and learn.

Consideration of when to introduce a syringe driver needs to involve informed patient choice. Patients and their family caregivers believe that syringe drivers could be introduced earlier and declared **"Don't wait until we are struggling".** Intermittent use of the syringe driver to provide swift management of pain, from an early stage of palliative care up until time of death, may improve the life of the patient. Such an approach may require a change in clinical directives and current practice.

The recommendations contained in this study reflect the words of those most intimately involved: patients prescribed a syringe driver to administer medications, and their family caregivers. For practitioners to be effective in symptom relief, it is vital to listen to the patients and their families, and let them be the driver of care. The study may lead practitioners to renewed reflection about conversations with people who are dying and how listening can lead to valuable learning.

Te Omanga Hospice

Te Omanga Hospice is a non-government organisation providing free specialist palliative care to people residing in the Hutt Valley who have a life-limiting illness. Palliative care is delivered across the spectrum: community home care, day care, hospice inpatient, aged residential care, Hutt Hospital and in conjunction with GPs. One hundred and eighty patients each day access the hospice services through an interdisciplinary team of specialist doctors, nurses, therapy services, family support staff and volunteers. Consultation and advice is available 24 hours a day.

Referrers are able to select between a comprehensive programme (where Te Omanga takes lead responsibility for palliative care) or a partnership programme where the GP has lead responsibility with Te Omanga staff support.

Te Omanga Hospice Murray Bond Research Fellowship

Since 2011 the Te Omanga Hospice Foundation has sponsored the Murray Bond Research Fellowship, under the auspices of the Te Omanga Hospice Board of Trustees. The Fellowship was established in recognition of Murray's outstanding contribution, over two decades, as a Board member of the Hospice Trust and Foundation.

The goal of the Fellowship is to add to the body of knowledge available within New Zealand and internationally in the field of palliative care.

Valerie Norton, the principal investigator of this research, was the inaugural Murray Bond Research Fellow for 2011.

Syringe Driver Use in Palliative Care

Syringe drivers provide continuous delivery of drugs through a small cannula, easily inserted subcutaneously (just under the skin). It:

- allows several drugs to be given simultaneously.
- usually requires filling only once a day (Mitten 2001).
- uses a portable, battery-operated motor calibrated to deliver small doses at a given rate over a specified period of time (e.g. approximately 0.7ml/hour over a 24-hour period) through an extension line connected to the cannula. The pump actuator drives the syringe plunger at a controlled rate.
- once set, the speed cannot be altered accidentally (Te Omanga Hospice Syringe Driver Protocol 2009).

The introduction of syringe drivers has revolutionised management of symptoms including pain, nausea, vomiting and respiratory distress at the end-of-life phase of palliative care (Costello et al 2008). It has become commonly accepted practice to prescribe the use of a syringe driver when other routes of drug administration are ineffective or inappropriate. (Dickman et al 2005).

Graham and Clark (2005) in reviewing the development of syringe drivers, identified an opportunity for researchers to explore patients' and their family caregivers' experiences, and attitudes. Practitioners had assumed patients would find the syringe driver acceptable because of its compact nature and facilitation of independence. Also reported was anecdotal evidence that patients (and carers) sometimes considered the syringe driver a *"harbinger of death*".

The lack of inquiry was particularly pertinent in a specialty *"that emphasises the importance of patient preferences in care."* (Graham and Clark 2005). A challenge for the sector was that in 2011 there remained a dearth of research including a patient/family caregiver voice about being prescribed a syringe driver. Te Omanga Hospice has responded to this challenge by supporting this study.

Ethical Approval

Ethical approval for the study was received from the Upper South A Regional Ethics Committee, Christchurch, in May 2011.

Participant Profiles

There was an equal gender distribution amongst the study participants. Six of the 12 patients were male and six were female. Their ages ranged from 46 years to 81 years with most being aged between 70 and 79 years. Eleven patients identified as New Zealand/Pakeha/European and one patient identified as Maori.

Of the 15 family caregivers, six were male and nine were female. Thirteen of the family caregivers were husband/wife/partner, one was a daughter and one was the sister of the patient. One family caregiver identified as Maori while the remainder identified as New Zealand/Pakeha/European. Their age profile was similar to that of the patients.

Patients and their family caregivers were part of the Te Omanga Hospice Comprehensive Programme or Mary Potter Hospice Community Care. All patient participants in the study had a primary cancer diagnosis, most having an advanced cancer with widespread metastases.

Awareness of Death

As patients on a hospice progamme, participants had all been involved in very direct conversations about the nature of their progressive illnesses. They were aware and understood that they were dealing with a life-limiting illness. Nearly all patients and their family caregivers expressed their acceptance that the end of life was approaching, and that this time would arrive sooner or later. This understanding was expressed in comments from both patients and their family caregivers:

> *"I won't be here when …"* *"I am probably deteriorating with my condition ..."*
> *"The family are gathering."* *"We are planning a funeral."*

Being aware that death may be pending does not stop people being hopeful of some recovery and planning future events. Simultaneously accepting that death is closer and being hopeful for the future is not contradictory. It reflects a common human experience when anticipating such circumstances: "*Focusing on today, the immediate future."*

Key Findings

This study has looked at outcomes that matter to patients and their primary family caregiver. After using a syringe driver for at least 48 hours their overarching response was that it made a difference for the better. They welcomed the patient being prescribed a syringe driver to provide medications to control symptoms.

The most important impact was the ***relief of distressing symptoms***, frequently referred to in terms of *"nightmares", "horrendous*". Bridgeman (c) declared vehemently "*Use the syringe driver at the earliest possible time!* ***Don't wait until people are struggling.***"

Using a syringe driver removed the need for patients to ***struggle with swallowing pills, pills and more pills***. This also had a big impact for family caregivers who very much appreciated having certainty that their patient was receiving the right amount of medication. It greatly reduced their anxiety about being responsible and providing the best possible care, watching the clock, setting the alarm to ensure drugs were taken, and the uncertainty when the person vomited, about what drugs they retained.

Prompt relief of physical symptoms was very important. Of equal importance were the emotional and social consequences this had on the way people lived their lives on a daily basis. Relief of symptoms brought improved **quality of life** for patients – and so too for their family caregivers. Family caregivers, in particular, gained **peace of mind** when they had certainty that the medications were "right", the symptoms were well-managed and much of the stress removed because they were confident they were providing optimum care for their patient. Quality of life and peace of mind are fundamental to a "***good death".*** A crucial consequence of having both quality of life and peace of mind is ***good memories.*** Good memories allow for grieving, untroubled by doubts and guilt. This is important so that life can continue with few regrets, albeit with sadness, and return to an even keel.

The need for family caregivers to be prepared for their role was also emphasised in the findings. Te Omanga's Family Caregiver Programme: *A Map Through the Forest* is a fundamental part of preparing and supporting families through this special time of laying down good memories. This study endorses participation of family caregivers in such programmes and encourages organisations to invest in such support.

While outside the scope of the study, participants all commented on the significance of a daily home visit by the Home Care Nurse. Patients with a syringe driver are visited every day to assess symptom management and refill the syringe driver. ***Being at home*** was intrinsically related to the ***daily nursing visit.*** There was more talk about this aspect of using the syringe driver and the care provided than any other part of their experience.

The daily Home Nurse visit was integral to patients being cared for at home. Such visits:
- Meant that home circumstances were checked on a daily basis.
- Boost confidence that the family caregiver is managing well and doing everything "right".
- Maintains the family's independence and integrity

This was particularly important for family caregivers. John said:

> *They boost my confidence. I welcome them here. I'm always pleased. I'm looking out the window waiting for them to come. When they've been and gone, I feel so much better.*

It is the role of the specialty palliative care service to impart the skills, knowledge and confidence to the family caregivers, those providing the care directly for patients when they are at home.

This means, as Francis and Hamish's story reveals, identifying and facilitating opportunities for families to enhance their ***independence*** and establish a ***new normality.*** Providing education and skills to carry out the specialist technological aspects of care, in this instance, refilling and reloading the syringe driver, is key to facilitating this.

This study informs professionals that the knowledge and skills in palliative care that a family caregiver has, increases over the period of caring for their patient. The need to ***build more community capacity and self-management capabilities*** is strongly endorsed. As demand for palliative care increases nurses will be, more and more, supporting family caregivers to provide specialist palliative care at home.

The work of specialist palliative care nurses could be one of mentoring, showing family caregivers *how to provide* the care, as opposed to *doing* the care. Direct face-to-face contact will always be of primary importance, and will be further enhanced through palliative care practitioners' input to developing communication technologies, for example, tele–video processes.

To recognise the family caregiver as the primary provider of care may require a change in attitude and perspective of all parties (practitioners and funders, as well as patients and families). A move to such collaboration will require openness, flexibility, management of gate-keeping and willingness to take a lead.

This study reveals that while few people, not surprisingly, had little knowledge about syringe drivers prior to using one, all participants, where relevant, became sufficiently knowledgeable about how they operated and skilled to manage disruptions to their continuous infusion.

Everyone who participated in this study was motivated because they wanted to make a difference for future patients and their caregivers. In response to thinking about these people, without exception, they said that having the syringe driver was a good thing. In every instance it had made a difference for the better. This study provides specific advice to be used in the development of an information manual, or booklet to supplement the technological information currently available.

Recommendations

1 For Strategic Workforce Development

1.1 Acknowledge family caregivers as a central part of the health workforce capacity in providing palliative care.

1.2 Explore identifying family caregivers in New Zealand Health Workforce statistics.

1.3 Stop referring to family caregivers as “informal” caregivers. This downgrades the knowledge they have gained and demeans and undervalues the work they do, thus reducing awareness of the need to adequately support them.

1.4 Explore how to enhance the capability of family caregivers through:

- Structured support and family caregiver courses.
- Encouraging nurses to act as educators/mentors.
- Maximising technology e.g. Skyping and developing “apps” for cell phones.

2 For Palliative Care Practitioners

2.1 Early identification and reporting of symptoms by nurses so they can be alleviated prior to causing distress.

2.2 Medical staff review, in symptom management, the best timing to initiate prescribing a syringe driver with a view to initiating use sooner rather than later.

3 For Te Omanga Hospice and Other Palliative Care Organisations

3.1 Prepare policy and establish a process for training and supporting family caregivers to prepare and administer syringe driver medications.

3.2 Strategic planning through to 2020 and beyond, takes account of the anticipated reduction of resources for palliative care services and changing demographics placing greater demand on services:

3.3 Nurses as mentors with a focus on equipping family caregivers with specialist skills and knowledge (see 1.4).

3.4 Continue to provide Family Caregiver Courses and increase uptake by family caregivers.

4 For Te Omanga Hospice

4.1 Improve continuity of care in the delivery of nursing practice through the allocation of a lead/key nurse for each patient and their family. .The principles of continuity of care would also apply to medical and other patient services provided.

5 Recommendations for Future Research

5.1 Two issues were identified in this report for further inquiry:

- Investigate the health status of family caregivers involved in care of patients with a life-limiting illness.
- Explore the transition from hospital to hospice services which cause unexpected disruption for patients and family caregivers.

1. Introduction

1.1 The Te Omanga Hospice

The Te Omanga Hospice is a Charitable Trust that provides specialist palliative care for more than 600 patients and their families, free of charge, each year.

Te Omanga Hospice opened on the 6th September 1979 in Lower Hutt. Eight years earlier, the first Te Omanga Hospice Director of Nursing, Marion Cooper, sat at the bedside of a close friend dying of cancer distressed with severe and unremitting pain. When Marion asked on behalf of her friend for pain relief she was told "*she is not due for medication yet, I will give it early this time but we can't keep on doing this."*

Marion worked with her local community to foster the establishment of a hospice to provide a better way:

> A way that provides a new dimension to care of the terminally ill. Not a replacement of general practice, hospital practice or nursing practice, but an added facility and an added strength, where there is no dichotomy between science and compassion, one inspires and nourishes the other.

Initially situated at 1 Bloomfield Terrace in 1979 and extended to incorporate 4 Bloomfield Terrace in 1986 to provide day-care services, expanded education activities and administration, Te Omanga Hospice is now located at 136 Woburn Road, Lower Hutt. The services include a 10 bed in-patient unit, the focus of which is symptom control and respite care and a 24-hour home care service. These are supplemented with occupational therapy services, day group, art therapy, touch therapy and counselling as well as family and whanau support and chaplaincy (http://www.teomanga.org.nz/Article.aspx?ID=458).

1.1.1 Te Omanga Hospice Services 2011

Te Omanga Hospice is a non-government organisation providing free specialist palliative care to people residing in the Hutt Valley who have a life-limiting illness. Palliative care is delivered across the spectrum: community home care, day care, hospice inpatient, aged residential care, Hutt Hospital and in conjunction with GPs. One hundred and eighty patients each day access the hospice services through an interdisciplinary team of specialist doctors, nurses, therapy services, family support staff and volunteers. Consultation and advice is available 24 hours a day.

Referrers are able to select between a comprehensive programme (where Te Omanga takes lead responsibility for palliative care) or a partnership programme where the GP has lead responsibility with Te Omanga staff support.

1.1.2 Te Omanga Hospice Programmes of Care

In-Patient Services and Home Care (Community Services) are provided by specialist nursing and medical staff. This is underpinned by a range of services including family support and whanau liaison, bereavement counselling and occupational therapy. Te Omanga Hospice also provides art and music therapy, spiritual care and complementary nurse therapies including touch and massage. Te Omanga Hospice Specialist Palliative Care Service now offers two key programmes: the Comprehensive Programme and the Partnership Programme (Appendix 1: Te Omanga Hospice Comprehensive and Partnership Programmes).

- **Comprehensive Programme**

People who are part of the Comprehensive Programme generally have a quite rapidly progressing disease which usually results in death within a few weeks or months. The needs of these patients may exceed the resources of the generalist providers.

- **Partnership Programme**

The Partnership Programme provides shared care with the patient's general practitioner, offering support to the primary care providers and clinical and ancillary services to the patients. These patients generally have a slowly progressing illness characterised by long periods of stability punctuated by intermittent acute exacerbations. (http://www.teomanga.org.nz/Article.aspx?ID=1362)

1.2 Background to the Study

1.2.1 Research Concept

The Principal Investigator, Valerie Norton, was required to review a policy document as part of her Competency Assessment Programme (CAP) clinical placement at Te Omanga Hospice to regain her Nursing Practicing Certificate.

The introduction of syringe drivers in palliative care for relieving symptoms, in particular of pain and nausea, was, from her perspective, a very significant development since her involvement in oncology/palliative care nursing in the 1970s. She was conscious, given her enthusiasm for this practice, that she needed to be aware of any possible shortcomings. The most effective way to do this was to base her policy project for the CAP Course on syringe drivers. This, initially, involved a review of the literature.

A brief review of the literature revealed a possible shortcoming: patient/family negative experiences and attitudes to using a syringe driver because they *"sometimes consider it a harbinger of death"* (Graham and Clark, 2005; Costello et al 2008).

Te Omanga Hospice's Syringe Driver Policy and Hospice New Zealand's Syringe Driver Competency Programme, Niki T34, focussed specifically on the technical and operational aspects of inserting a subcutaneous line, loading and operating a syringe driver, and education of patient and family about the use of a syringe driver. Neither organisation specifically includes a communication competency in regard to patient experience or associated meanings related to using a syringe driver to administer medications.

Several of the papers reviewed and published in the International Journal of Palliative Nursing and the Journal of Pain and Symptom Management strongly recommended further research of patient experiences.

1.2.2 The Te Omanga Hospice Foundation Murray Bond Research Fellowship

The Te Omanga Hospice Foundation Murray Bond Research Fellowship is sponsored by the Te Omanga Hospice Foundation, under the auspices of the Te Omanga Hospice Board of Trustees, for the benefit of the palliative care community locally, nationally and internationally.

Since 2011 the Te Omanga Hospice Foundation has sponsored the Murray Bond Research Fellowship, under the auspices of the Te Omanga Hospice Board of Trustees. The Fellowship was established in recognition of Murray's outstanding contribution, over two decades, as a Board member of the Hospice Trust and Foundation.

The goal of the Fellowship is to add to the body of knowledge available within New Zealand and internationally in the field of palliative care.

Valerie Norton developed a research concept to explore patients' and family caregivers' understanding and experience of syringe drivers which was presented to the Te Omanga Hospice Chief Executive Officer, the Te Omanga Hospice Board of Trustees and the Te Omanga Hospice Foundation. This led to the establishment of the inaugural Te Omanga Murray Bond Research Fellowship in March 2011 so that the study could be undertaken.

1.2.3 Study Aims

The aims of the study included:

- Identifying current patterns of use and purpose for using syringe drivers in palliative care.
- Ascertaining the experiences, perceptions and assumptions patients and their family caregiver(s) have about a syringe driver being used in their palliative care to identify benefits and shortcomings.
- Preparing a report for publication in response to an international call for such information.
- Preparation of educational resources for patients, their family caregiver(s) and medical/nursing staff to assist clear communication about the use of syringe drivers.

1.3 International Literature

A preliminary literature search revealed that there is very little research dealing with patients' experience of syringe drivers.

Ronnie Parton, Te Omanga Librarian, searched Pub Med with no limit on the time frame with the following key word requests:

Key word request	Results
['Patient Experience' in Title/Abstract + 'end of life' in Title/Abstract]	7,718
[Patient Experience' in Title/Abstract + 'end of life' in Title/Abstract + 'syringe driver' in Title/Abstract]	0
[Patient Experience' in Title/Abstract + 'end of life' in Title/Abstract + 'syringe driver' in Text]	0

1.4 Syringe Driver Use in Palliative Care

Syringe drivers provide continuous delivery of drugs through a small cannula, easily inserted subcutaneously (just under the skin). It:

- allows several drugs to be given simultaneously.
- usually requires filling only once a day (Mitten 2001).
- uses a portable, battery-operated motor calibrated to deliver small doses at a given rate over a specified period of time (e.g. approximately 0.7ml/hour over a 24-hour period) through an extension line connected to the cannula. The pump actuator drives the syringe plunger at a controlled rate.
- once set, the speed cannot be altered accidentally (Te Omanga Hospice Syringe Driver Protocol 2009).

The syringe driver was initially created by Dr Martin Wright in the mid 1970s. It was further developed with palliative care in mind in the late 1970s and first used in this capacity for a *“cachexic, nauseated man with lung cancer”:*

> As his pain resolved, the improvement in his quality of life was dramatic and he remained mobile until the day of his death (Graham and Clark 2005).

It is well-established that the introduction of syringe drivers has revolutionised management of symptoms including pain, nausea, vomiting and respiratory distress at the end-of-life phase of palliative care (Costello et al 2008). When other routes of administration are ineffective or inappropriate it is now common and accepted practice to use a syringe driver to administer medications (Dickman et al 2005).

While Graham and Clark (2005) reported that practitioners assumed patients would find the syringe driver acceptable because of its compact nature and facilitation of independence and domiciliary care, they also reported anecdotal evidence that patients (and carers) sometimes considered it a *“harbinger of death*”. They advised that research, taking account of patients’ and their family caregivers’ experiences and attitudes, was long overdue, *“particularly in a specialty that emphasises the importance of patient preferences in care.”* (Graham and Clark 2005).

Costello et al (2008) endorsed this when they reviewed the benefits and drawbacks of syringe drivers in palliative care. Their study recommended that patients and their family caregivers be provided with sound information so they can actively participate in the decision-making process. Moreover, the study highlighted attention to the involving of patients in the decision-making process that should take place prior to using these devices. Providing information to inform patients and relatives of the benefits and risks of treatment is an important professional principle (Costello et al 2008).

Significantly, the New Zealand guidelines for management of syringe drivers in palliative care, developed in 2009, recognised this and included a specific section “Patient, Family and Whanau Education Needs” and advise that patient and family education include *“reassurance to alleviate misunderstandings or fears about the use of a syringe driver”* (Ministry of Health. 2009).

Cruikshank et al (2010) included four patients, nine family caregivers and twelve community nurses in a study set in a rural community palliative care setting. They too, noted much of the literature focussed on the practical aspects of syringe driver use, medications and compatibility of drugs, and less on the significance for patients and their family caregivers.

2. Implementing the Study

2.1 Study Design

Phase 1: Retrospective review of case files

- Palcare data search programme developed specifically for this study[1]

Phase 2: Gather the evidence and analyse information

- Recruitment
- Informed consent
- Procedure
- Semi-structured interviews with patients and their family caregiver(s)
- Analysis

Phase 3: Prepare report and education resource

2.2 Retrospective Review of Te Omanga Hospice Syringe Driver Use

A review of current practice around prescribing a syringe was completed to provide a context for this study. (Appendix 2: Syringe Driver Use for Te Omanga Patients: 1 January to 30 December 2010).

It provides a ‘snapshot’ of prescribing a syringe driver for patients who receive care from Te Omanga Hospice (excluding patients residing in a rest-home) from 1 January 2012 to 31 December 2010. During this time some data entry processes changed so some extrapolation of data has contributed to this analysis.

One hundred and seventy three patients, cared for by Te Omanga Hospice in the inpatient unit or at their home during this period, had a syringe driver prescribed to administer drugs to relieve symptoms. (Note: patients residing in a rest-home were not included in this study). On 31 December 2010, 166 (96%) of these people had died and seven (4%) were still alive. Te Omanga Hospice provided care for a total of 575 patients referred to its comprehensive and partnership programmes during this year. The extrapolated estimate is that about 30% of all patients used a syringe driver during this year.

Of the total patients (575) who received care during 2010, 361patients (63%) had a cancer-related diagnosis and 214 (37%) had a non-cancer-related diagnosis. Of the 173 people who were prescribed a syringe driver, 131 (76 %) had a cancer-related diagnosis while 42 (24%) had a non-cancer-related diagnosis. This means that the syringe driver use outcome

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[1] Palcare is an electronic patient management programme developed specifically for palliative care services to record patient contact, clinical and family/carer information. The patient data in the programme is hosted in Melbourne. Access to patient and family information is obtained via a secure website enabling multiple users to view the same information at the same time.

difference is that people with a cancer diagnosis almost twice as likely to use a syringe driver (36%) as those people with a non-cancer diagnosis (20%).

All of the 12 patients in this study exploring patients' and caregivers' experience had a cancer-related diagnosis.

2.3 Scientific Review and Ethical Approval

Scientific assessment was provided by Mrs Kate Reid (who teaches 3 post-graduate palliative care courses), and Associate Professor Pauline Barnett and Associate Professor Ray Kirk, Health Sciences Centre, Canterbury University. Professor Victoria Grace, Sociology Department, Canterbury University, and Dr Bruce Curtis, Department of Sociology, University of Auckland, and Dr Suzanne Phibbs, School of Health and Social Services, Massey University, also strongly endorsed the methodology. The scientific review comments also noted the skills and experience required to carry out this study.

The proposal was presented to the Upper South A Regional Ethics Committee, Christchurch, on 16 May 2011. Ethical approval to proceed with the study was received 10 days later (Appendix 3: Upper South Regional Ethics Committee Approval Letter).

This Committee congratulated Te Omanga Hospice on *supporting "a very interesting and timely application. The study promises to provide very worthwhile outcomes in terms of information, interpretation and better preparedness of patients receiving palliative care, and their families."*

2.4 Methodology

The purpose of this study was to explore participants' experience of syringe drivers and the understandings this experience creates for them. A well-documented technique for gaining insight into understandings and experiences is Thematic Analysis. This technique is an inductive approach to dealing with interview data that involves the creation and application of 'codes' to data in order to better reveal shared and unique experiences or meanings. It is a highly effective and appropriate means of giving voice to vulnerable participants and is also well-regarded in the social sciences. Thematic Analysis is a well-documented process in social science research (Boyatzis, 1998).

2.4.1 Recruitment

From 27 June 2011 all patients who were part of Te Omanga's palliative care Comprehensive Programme, who had a syringe driver prescribed to administer continuous subcutaneous medications, were eligible to participate in the study. Their primary family caregiver was also eligible to participate.

The inclusion criteria were that the patient:

- was at least 16 years old,
- was able to speak and understand English,
- had been using a syringe driver for not less than two days
- was viewed by the hospice palliative care nurse/doctor as competent and capable of participating in the study.

Sufficient numbers of participants were recruited so that data saturation was fulfilled. This was evident when the tenth patient/family caregiver interview was completed. The additional interviews were completed because the process for inviting these patients and family caregivers to participate had been completed. These interviews also confirmed that data saturation had been achieved.

Note: Mary Potter Hospice was invited to participate in the study initially as a separate arm of the study. In practice, due to time and resource constraints, only one patient/family caregiver unit was recruited from Mary Potter Hospice. The resulting interview data endorsed the themes arising from the Te Omanga interview data and is included in the analysis.

Recruitment Operational Steps and Rationale

The operating steps for inviting participants into the Te Omanga Hospice Syringe Driver Study and confirming their contribution, involved the seven steps outlined below.

- The day a syringe driver was established, the person was assessed for possible participation by the Te Omanga Home Care Nurse or In-Patient Unit nurse or medical practitioner.
- The next day the person and his or her family caregiver were given the study information sheet by the Te Omanga Home Care Nurse/In-patient Unit Nurse and asked if their name could be given to the Principal Investigator. Note: If the person agreed to be contacted, this does not imply their willingness to participate in the study (Appendix 4: Study Information Sheet).
- The nurse informed the Home Care Co-ordinator or the Clinical Nurse Leaders who advised the Principal Investigator of the names of potential study participants so that consent forms could be prepared.
- The Principal Investigator contacted the patient and his or her family caregiver in the In-patient Unit or made telephone contact with them at home. Their agreement to participate in the study (or not) was confirmed and a convenient time to sign the consent forms and carry out the interviews was arranged (Appendix 5: Study Consent Form; Appendix 6: Study Interview Schedules).
- The Principal Investigator met the patient and his or her family caregiver in the In-patient Unit or at their home. She again advised them of the voluntary nature of the study before confirming their agreement to participate in the study. The information sheet was also revisited. The consent forms were signed and interviews completed.
- The interviews were transcribed.
- The transcribed interview texts were returned to the interviewees for confirmation.

Rationale

The above steps were agreed in discussion with Senior Clinical staff at Te Omanga Hospice: Dr Lindsay Tanne, Te Omanga Medical Director; Dr Ian Gwynne-Robson, Te Omanga Palliative Care Specialist; Denise Walsh, Te Omanga Home Care Co-ordinator; and Anne Wilson and Michelle Gibbs, Clinical Nurse Leaders, Te Omanga In-Patient Unit.

At the initial stages of the research project, when inviting participants into the study, it became clear that the nurses needed to provide the patient and family caregiver with the study information sheet at the time the Syringe Driver Study was initially raised. Thus, the patient and family caregiver could make an informed decision about their participation or not.

This process minimised the number of contacts between the patient, family caregiver and the Principal Investigator/Interviewer to two rather than three contacts. As there can often be different nurses visiting the patient each day, this process also allowed just one nurse to be involved in the research conversation with the patient and family caregiver.

2.4.2 Training for Nurse Interviewers

Four Te Omanga nurses and three nurses from Mary Potter Hospice indicated their interest in participating in the study by assisting with interviewing. The integrity of the study is dependent on the information provided in the patient and family caregiver interviews. These nurses participated in a training workshop including a short experiential coaching exercise to give assurance to the complete interview process (tape recordings, interview schedule and prompting, and closure) (Appendix 7: Nurse Interview Training). They also signed a confidentiality agreement (Appendix 8: Interviewer and Transcriber Confidentiality Agreement).

In fact the constraints of time, (where the window of opportunity to complete the interview was often short and the nurse may not have been available for a couple of days) and conflict of interest, (where providing direct nursing care for a patient meant that it was not appropriate for the nurse to carry out the research interview) resulted in all interviews, with participants who were part of the Te Omanga Hospice programme, being carried out by the Principal Investigator who was able to adjust her time to that of the participants. One patient/caregiver couple interview was completed by a nurse from Mary Potter Hospice.

2.4.3 Interview Process

For this study, a semi-structured interview was used to guide the in-depth interviews with the study participants (Appendix 6: Study Interview Schedule). This was set in a conversation about the person, his or her family, living in Hutt Valley/Wellington. The interview covered relatively neutral and general aspects of the person's life, and moved gently to more specific and intimate questions, ending with a debriefing. Although mostly the same, individual patient and family caregiver interview guides were slightly different so as to accommodate the unique perspective of each group.

All participants provided a pseudonym to use in the report to protect their identity.

2.4.4 Transcribing of Interviews

All the interviews were transcribed verbatim by a medical typist previously employed by Te Omanga Hospice who also signed a confidentiality agreement (Appendix 8: Interviewer and Transcriber Confidentiality Agreement).

2.4.5 Analysis of Interviews

Once the digitally voice recorded interviews were transcribed verbatim, thematic analysis using constant comparison and coding followed. Colaizzi's (1978) six step approach guided this process:

1. Read and re-read the transcript to gain familiarity and a sense of the whole;
2. Extract the significant statements or phrases that refer to participants' experiences;
3. Reflect, re-formulate and code meaning for each significant statement;
4. Organise coded meanings into clustered themes;
5. Write clustered themes into an exhaustive description that integrates all the themes; and
6. Validate theme clusters by reviewing data to see if any data is not represented in the theme clusters and confirm validation for analysis by returning to the informants for feedback and/or clarification.

Reliability and validity in thematic analysis was achieved in a variety of ways, for example:

- Through assessments of intra- and inter-coder reliability (e.g. external validity);
- Measures of internal validity secured via confirmation of coding and themes with interview participants; and
- Peer validity, comparing findings with similar studies and using peer review.

2.4.6 Reporting

This report was prepared for the Trustees of the Te Omanga Hospice Foundation and the Te Omanga Hospice Trust. It includes full details of the complete research process with comprehensive appendices so that, in future, it may be used as a reference and a resource.

In addition, a conference abstract and presentation were prepared as well as a paper submitted for journal publication.

2.4.7 Education Resources

Education resources for both palliative care practitioners and patients and family caregivers resulting from this are to be developed and produced by the Te Omanga Hospice, post-Fellowship.

3. Study population and analytic process

3.1 Data Collection

Interview and data collection took place over 14 weeks from 27 June to 4 October 2011. During this time 30 patients from Te Omanga Hospice were prescribed medications via a syringe driver. Fourteen of these patients were not eligible for the study as they were too fatigued, or were unresponsive, or used the syringe driver for less than 48 hours prior to their death. Another two patients (and therefore their respective family caregivers) declined to participate. This resulted in an 88% participation rate.

The final study population consisted of 12 patients and 15 caregivers. A total of15 patients and their respective family care givers consented to participate in the study. This included one patient/caregiver couple from Mary Potter Hospice Community Care Service. Three patients died before they were able to participate in an interview. However each of their family caregivers asked to continue their participation in the study.

This means that the final study population comprised 12 patient/and family caregiver couples and 3 caregivers only (that is 12 patients and 15 caregivers).

Nine patients were being cared for at home by the Te Omanga Home Care Team and two patients were in the Te Omanga In-patient Unit. One patient and family caregiver were part of the Mary Potter Hospice Community Programme. (note: patients being cared for in rest-homes were not included in the study).

3.2 Patient/Family Caregiver Profiles

There was an equal gender distribution amongst the study participants. Six of the 12 patients were male and six were female. Their ages ranged from 46 years to 81 years with most being aged between 70 and 79 years. Eleven patients identified as New Zealand/Pakeha/European and one patient identified as Maori.

Of the 15 family caregivers, six were male and nine were female. Thirteen of the family caregivers were husband/wife/partner, one was a daughter and one was the sister of the patient. One family caregiver identified as Maori while the remainder identified as New Zealand/Pakeha/European. Their age profile was similar to that of the patients.

Patients and their family caregivers were part of the Te Omanga Hospice Comprehensive Programme or Mary Potter Hospice Community Care. All patient participants in the study had a primary cancer diagnosis, most having an advanced cancer with widespread metastases. The primary diagnoses included colon, oesophagus, breast, pancreas, prostate and ovarian cancers, multiple myeloma, leiomyosarcoma and chronic myelomonocytic leukaemia.

No patients with a non-cancer diagnosis were part of this study even though 25% of patients who used a syringe driver as part of the Te Omanga Hospice Programme in 2010 had a non-cancer diagnosis (Appendix 2: Syringe Driver Use for Te Omanga Patients: 1 January to 31 December 2010).

3.3 Te Omanga Comprehensive Programme

All patients and their family caregiver who participated in this study were part of the Te Omanga Hospice Comprehensive Programme or Mary Potter Hospice Community Care. This means they had been assessed by a palliative care physician and a specialist nurse which involved a direct conversation with the patient and family caregiver about the nature of the patient's life-limiting illness.

The length of time between patients being admitted to the programme and having a syringe driver prescribed, varied between one day and 20 months. Three patients had been part of the programme for one week or less, with two having the syringe driver established within one day of admission. Another three patients had been admitted to the programme between two and 12 weeks prior to having the syringe driver prescribed, while the other six patients had been part of the programme for between 13 weeks and 11 months. The three people who died before they were able to participate in the study and whose family caregiver participated, had been part of Te Omanga's Comprehensive Programme for five, seven and 20 months respectively (Table 1).

Table 1: Length of Time Between Admission to Hospice Programme and Use of Syringe Driver

Comprehensive Programme prior to using syringe driver	1 week or less	2 – 12 weeks	More than 3 months
	1 day 7 days 3 patients 1 day	5 weeks 8 weeks 3 patients 12 weeks	3.5 months 5 months 6 patients 6 months 7 months 9 months 11 months

3.4 Prescription of Syringe Driver

Four patients had been prescribed a syringe driver at the time of their death. Each of these people used it for one continuous period. One person used the syringe driver for 118 days, another for 25 days, while the other two patients who were prescribed it used it 14 days and six days respectively.

Of the seven patients who continued to receive care from the Te Omanga Hospice, one patient had been prescribed the syringe driver continuously for 76 days (to 4 October 2011) while another six people had their syringe driver discontinued when they were able to take their medications orally again. One patient used the syringe driver for one week; one patient used it for 11 days; another two patients used it for 14 days; and one person used the syringe driver for 19 days. Of these seven people, one person was prescribed a syringe driver for 11 days then again 8 weeks later and continued to use it for another 22 days. The three patients whose family caregiver only was interviewed had also been prescribed medications via a syringe driver for between three and eight days at the time of death. One of these patients had used a syringe driver previously for four days, three weeks earlier.

3.5 Drugs prescribed for Use in the Syringe Driver

Two patients had been prescribed a combination of two drugs, one of which was morphine. Five patients were receiving three drugs in combination via the syringe driver, two of whom were receiving no opioid analgesic medication, two were receiving either morphine or oxycodone via the syringe driver, and one was using a fentanyl patch while receiving two antiemetics and an anxiolytic drug via the syringe driver. Another five people were receiving four drugs in combination, four of whom were receiving an opioid drug (morphine, methadone or oxycodone) via the syringe driver. One was using a fentanyl patch (Table 2).

Table 2: Drugs Prescribed for Used in the Syringe Driver

Primary Diagnosis	Analgesic	Antiemetic	Anxiolytic/ Anti-psychotic	Anti-secretions	Anti-spasm	Steroid
Oesophagus	morphine			hyoscine		
Pancreas	morphine	meto-clopramide				
Colon		meto-clopramide	haloperidol midazolam			
Prostate		cyclizine	haloperidol			dexa-methazone
Leiomyo sarcoma	oxycodone	metho-trimeprazine	midazolam			
Colon	** fentanyl patch*	meto-clopramide cyclizine	haloperidol			
Unknown primary	morphine	meto-clopramide cyclizine				

Breast	oxycodone	metoclopramide cyclizine	methotrimeprazine			
Multiple myeloma	methadone	metoclopramide	midazolam	atropine		
Multiple myeloma	oxycodone	cyclizine methotrimeprazine			buscopan	
Ovary	morphine	metoclopramide	haloperidol		buscopan	
Myelo monocytic leukaemia	** fentanyl patch*	methotrimeprazine	haloperidol		*buscopan*	dexamethazone

Eight patients were receiving an opioid analgesic via the syringe driver, in combination with 1-4 other drugs. Two people were using a fentanyl patch (synthetic opioid durogesic) in addition to antiemetic and anxiolytic drugs subcutaneously through the syringe driver. Two people did not require any opioid analgesia.

3.6 Analysis

Analysis of the interview data identified a number of themes outlined below. Rather than being a *"harbinger of death"* (Graham and Clark, 2005), using a syringe driver to administer drugs to relieve symptoms was a very positive experience for both patients and family caregivers in this study. At the same time, the people who participated in this study were highly aware that death would likely present itself some time soon.

3.7 Themes

The analytical themes have been organised around five key areas in order to address specific issues and separated into individual chapters:

- Awareness of death
- Physiological impacts
- Emotional/social impacts
- Knowledge and advice
- Associated consequences of using a syringe driver

In fact, all are inextricably intertwined in the day-to-day experiences of patients and their family caregivers. The subheadings use words taken directly from the conversations with participants in the study.

In addition to the above themes, two issues have been noted under “Related Experiences” because they are both important and require more detailed focus/further research than this study can allow. They have been included in this report so as to “flag” them for future consideration.

4. Awareness of Death

The review of literature revealed that a possible shortcoming of using a syringe driver to administer medications was that patients and their families had negative experiences and attitudes to using a syringe driver because *they "sometimes consider it a harbinger of death"* (Graham and Clark 2005: Costello et al 2008).

That this is a general public understanding was borne out in many conversations with members of the public during the study. In particular, when a group of about 12 professional people at an education meeting were asked what it would mean to them if they were told a family member was using a syringe driver, they all responded without hesitation that it would mean the person would die soon (Personal Communication, Elaine Moffat, QSO, J.P. then Chairperson Te Omanga Hospice Board of Trustees,19 January 2011).

It should be noted that in this study, patients and their family caregivers were part of the Te Omanga Hospice Comprehensive Programme or the Mary Potter Hospice Community Care and accordingly had been involved in very direct conversations about the nature of their progressive life-limiting illnesses. As part of their ongoing assessment and planning, most patients and family caregivers had previously talked about their wishes and plans relating to the person's death prior to participating in this study. Lokker and colleagues endorse this practice: "*A good death*". This is characterised by an awareness and acceptance of dying. They advise that open communication which fosters an acceptance of dying can contribute to the quality of dying (Lokker et al 2011).

Note: patients are identified by (p). Caregivers are identified by (c).

In this study one family caregiver touched on the notion that people might think using a syringe driver was a last resort, only to discount that with her new knowledge. Sylvia (c) commented:

> *I think that when people think they are getting a syringe driver that they must feel it is the last resort. That they are on their last legs but that is not really true as with Jay it is a temporary thing to help her recover and get back to normality.*

If her sister needed the syringe driver again she wouldn't hesitate:

> *Because the alternative is pain and discomfort and not being empowered with your own life. At least this has given Jay the opportunity to be at home, to fall asleep when she likes, to walk where she likes. If having a syringe driver keeps her like that then go for it*.

Another family caregiver, Linda initially said *"it was a bit of a jolt.*"

When she learned Antony (p) had been prescribed medications via a syringe driver, Linda said:

> *You get a shock and realise that it is worse than you thought. I was going to say another nail in the coffin but this is not the good use of words. It was an indication that things were slipping away and progressing.*

She didn't think it meant that his dying was closer. She was very thankful that his *"horrendous"* vomiting stopped.

All patients had been receiving medications via the syringe driver for no less than 48 hours so they and their family caregiver were able to talk about their ”lived” experience. With this experience no one regarded the syringe driver as having negative connotations, nor that using it was the *“harbinger of death”.*

All patients and family caregivers were aware they were dealing with a life-limiting illness. Nearly all patients and their family caregivers expressed their acceptance that end of life was in the frame and that this time would arrive sooner or later. Glasser and Stauss (1965) categorised this as *“open awareness”* of death where both the dying person and their family caregiver knew the person was dying. This understanding was expressed in comments from both patients and their family caregivers:

> *I won’t be here when …* *I am probably deteriorating with my condition ..*
> *The family are gathering.”* *“We are planning a funeral.*

Being aware that death may be pending does not stop people being hopeful of some recovery and planning future events. Simultaneously accepting that death is closer and being hopeful for the future is not contradictory. It reflects a common human experience when anticipating such circumstances: *“Focusing on today, the immediate future.”*

This awareness was evident for two families when the distinct improvement in the patient’s condition was noticeable.

Charles (c) said in his initial conversation:

> *We all really thought she was passing away on Friday afternoon. ... She was calm but at a low ebb and saying all the time ‘I’m being such a nuisance. I want to go. It is time I went’. She hasn’t said that the last couple of days. In fact she said the reverse. I’m hanging on to see my hydrangeas at Christmas.’*

Then two weeks later, when the interview transcript was returned, their circumstances had changed. Wyn (p) was dressed with her makeup on, sitting on the couch. She had been in to the city the previous day for afternoon tea, and an outing to the local cinema was planned.

At this time Charles noted that *“much has changed.”* As he began reading the interview transcript he started to say *“no that’s not right*”, then with a smile he said *“It’s not right now but it was right on 6^{h} July”.*

Rewi (p) had improved substantially once he received the medications via the syringe driver. He said:

> *I’d just love my disease to go away now but I don’t think it will unless a miracle happens.*

For his partner Ngawai (c) it was somewhat strange:

> *It’s like he is getting better which is quite weird, we have been organising his funeral and he has come right. ....It’s like you are getting ready for something and now it’s put on hold. People have taken time off work and that is strange. .....Having him with us for quite a longer period is great. It’s fantastic.*

Most people in the study talked quite openly about their sense of dying.

Antony (p) said he had had enough. He wanted it *"all to be over"*. He was not afraid. His wife Linda (c) was torn:

> *It's hard. You get that double edge. I don't want him to go but I don't want him to carry on feeling like he is.*

Mary (p) was matter of fact:

> *I just take it as a matter of fact. I don't really think about it. I just take it in a matter of fact way.*

James (p) was sustained by his faith:

> *It's just another stage on my journey. I do have a strong Christian faith and it is very important to me.*

Annette (c) reflected on her husband, Edward's (p) dying:

> *Yes he did know he was dying. Except, I say he knew he was dying, he knew he was getting weak and he wouldn't probably last very long, but he kept talking about going on trips in the future*.

John and Eleanor had been married for 56 years. John said he never talked directly with Eleanor about her dying. At the same time he told of her preparing a list of things that he needed to do *"afterwards".* When I returned the transcript of his interview he had just completed that list of tasks. He talked of love.

Patients and their family caregivers often foster this discussion enabling "a good death" (Lokker et al 2011) as they seek answers. It is often a relief to break through the pretence that *"things are going well"*. Better conversations would result, when physicians equip themselves to talk directly about this fundamental human experience. David Korones (2010) reflected on his own experience as a physician, of coming to understanding and incorporating a palliative care approach to his work; his struggle to find a balance between getting patients through a critical illness and being mindful that there are limits to what can be done. He notes the conflicting feelings and concludes:

> The struggle is a healthy thing. It makes us think harder about the agonizing decisions that we, and our patients, wrestle with, and it enables us to communicate more openly and honestly with our patients and their families.... Ultimately it makes us better for the patients we serve (Korones 2010).

5. Physiological Impacts

5.1 Immediate Relief of Symptoms

Syringe drivers have been used to manage symptoms in palliative care since the 1980's (Graham 2005). Costello and colleagues note that their introduction has "revolutionised pain control" Costello et al 2008). All patients and family caregivers in this study described the very real difference it made, having symptoms relieved by drugs administered through a syringe driver. One family caregiver depicted it as a *"miracle of modern science".*

The Assessment of Palliative Care Needs (2011) identified pain, loss of appetite, vomiting or feeling sick as the most prevalent symptoms/problems for people who died from cancer (along with sleeplessness). Pain and loss of appetite were the most common symptoms, alongside trouble with breathing and mental confusion for those with a non-cancer diagnosis (Palliative Care Council 2011 p 8-9). As such, this combination of symptoms frequently needs a prompt response.

In this study, while pain control was important, it was the added symptoms of nausea and vomiting that were experienced as *"horrific"* and a *"nightmare"* by both patients and family caregivers.

Norah (p) described how awful it had been for her:

> *It was dreadful. It really was. It was like a nightmare. Yes, very sick. Bringing up mainly bile as I wasn't eating. It was very distressing.*

Her daughter, June (c), endorsed this:

> *Mum was in an awful lot of pain and she was having a lot of trouble with nausea and really finding it very hard to swallow heaps of pills and it was really becoming quite a nightmare for both of us. I was getting up at night, going to check on Mum, trying to force feed her liquid as everyone was saying she wasn't taking enough.*

It was a huge relief to start the syringe driver and have it sorted:

> *I have noticed a huge difference as she was in a fairly bad way. The pain has certainly got under control quite quickly with the syringe driver.*

Norah (p) said it worked very well and noted the process of getting it "right" for her:

> *It enabled the vomiting to stop initially. It also just generally seemed to help then with getting me eating a bit more. Because the medication is being absorbed it was stopping the vomiting.*

Ruth (c) was very worried about her husband, James (p). He had been nauseated and was vomiting:

> *He was bringing everything up as well as the medications. Yes it was a worry.*

It was very important for James to stop the nausea and vomiting:

> *I was having difficulty keeping the medication down, and feeling nauseated. Yes, vomiting and bringing up my meals.*

Using the syringe driver made a big difference for them both. Ruth explained:

> *Because you know it is getting into his body. Where before it was all being vomited up and you wouldn't know how much he has kept down.*

Linda (c) and Antony (p) also struggled to manage. Linda described:

> *Violent vomiting, he was feeling sick and vomiting all the time. It was horrendous.*

She repeated this again:

> *He was so ill and it was tiring as you couldn't sleep as he was vomiting or feeling so ill all the time. I would cat nap occasionally. There is nothing worse than seeing someone being so violently ill as he was. It was horrendous.*

For Antony (p) it was a relief to eat and drink again:

> *It has made a huge difference – the nausea and vomiting has stopped and I can eat and drink a bit now.*

Sylvia(c) was caring for her older sister. She described what was happening prior to Jay (p) using the syringe driver:

> *Jay was in extreme pain and when we gave her the morphine pills within ten minutes she just kept vomiting. She vomited for two nights.*

She said that Jay felt her joy had gone, "nothing makes her laugh". She added that the impact of the drugs in the syringe driver provided "instant relief."

> *Yes a huge difference. It was instant. As soon as it was delivered to her body the nausea stopped. Her colour was so pale as well and that within half an hour she improved, she calmed a lot.*

Jay (p) was very relieved about not having to swallow "all those pills anymore" and said:

> *I haven't been vomiting and I have no pain.*

For Anna (c) the most difficult thing to cope with was Geoff's (p) nausea. She said:

> *Coping with nausea. That was really, really the most difficult thing I found in looking after Geoff. It took that away. I wouldn't be without it.*

Snow (p) talked about the difference using the syringe driver made for him:

> *It has relieved the pain.... I just know that the medication is there. It means that I know the medication is doing its job*.

For Carmen (c) the most important was Snow being free of pain:

> *After it had been going in about six hours was when Snow felt he could have a drink and some jelly. He is much more comfortable and I didn't have to think all the time "should I give him more pain killers?" The most important thing was that he was not in pain because when he was in pain he was very stressed and was anxious*.

Their daughter was pleased too that he was using the syringe driver:

> *Mum that means he is getting continuous pain control dripping into his body all the time.*

Snow's syringe driver had been removed two weeks later when his interview transcript was returned. He made this comment:

> *It had done its job. I know if I need it again sometime it is there. I can ask for it if I need it.*

5.2 The earlier the better – don't wait until people are struggling

The impact on relieving symptoms by providing medications through a syringe driver was so significant that several couples (patients and family caregivers) commented specifically about wishing they could have started using the syringe driver earlier than they had. Others implied this as they talked about the difference it had made.

When the interview transcript was returned to Bridgeman (c) two weeks after Muffin's funeral he wanted to know about the origins of the syringe driver and the technical engineering aspects of it. He was surprised that it was not more widely used and said:

> *Obviously anything that improves the control of pain and nausea in these circumstances is to be lauded. And the earlier that it is possible to offer that to a patient the better. Tablets which have to been downed every few hours even during the night is uncomfortable for the patient sometimes and inconvenient especially if a nurse has to come in and wake a patient to take tablets. But as this operates on a 24-hour basis then that is not necessary. Thinking back, if people are enduring severe pain, use the syringe driver at the earliest possible time. Don't wait until the patient is struggling.*

He wondered if cost was a factor.

Charles (c) too had wondered whether there were a limited number of syringe drivers available:

> *I think it is a great bit of kit and I wondered if these things are in short supply. Is that why they are taking it away? Do they need it more urgently for someone else?*

Jack (c) expressed his frustration for Elizabeth: (p)

> *We should have got onto it earlier. It is not good to see your partner suffer; although she is probably still suffering you don't hear it. Silent suffering.*

He suggested it could have been discussed with them in the Oncology Department:

> *Perhaps they could introduce it a month before as they must see the end of the line is coming. It could have been introduced earlier because Elizabeth was having a certain amount of pain while she was still going to Oncology.*

Francis was emphatic about using the syringe driver earlier:

> *Hamish was throwing up so nothing was working. They were giving him enemas and he didn't need them because that wasn't the problem. The whole two weeks was horrible. They definitely could have offered it earlier.*

John too said "Sooner rather than later". He wondered whether this study might have an impact on this:

> *They might start using syringe drivers sooner.*

5.3 No More Pills or Injections

Taking prescribed medications orally is one of the means of relieving symptoms. Palliative care usually involves taking a range of drugs. Some people have a life-long caution about taking pills. *"It is his psyche that he grew up with. He likes to be independent as well"*. For others they had always found swallowing pills difficult. Sometimes there was a fairly sudden change from just taking *"blood pressure" pills to taking "over 20 a day."*

Both patients and family caregivers talked about the difficulties involved. Swallowing the pills was hard for patients. Receiving the medications via the syringe driver removed this stress.

Rewi (p) said:

> *Even now swallowing pills is really difficult. I find the little weeny ones I put on my tongue and take a swallow and the damn things just sit there. Having the drugs this way [with the syringe driver] it is just beautiful.*

Muffin (p) had never been able to take tablets easily - not only the foul taste she got but the pain she got trying to swallow them:

> *I would have pain around my throat all the time until the capsule finally dissolved and that wasn't pleasant either although once it had gone I was able to get rid of the taste if I had a little bit of jelly or sip of tea.*

Elizabeth (p) said now she didn't have to worry about waking up and having a pill:

> *Was it the right time? This constant administering of the medications. It has made taking the drugs obviously easier. .. It is quite hard to remember, when you spend quite a bit of time sleeping. Wake up, have a pill, go back to sleep, wake up have a pill.*

For Mary (p) it did away with four-hourly injections to reduce her secretions:

> *It is non-invasive which is good.*

Several family caregivers described their struggle to get their patient to take the medications, sometimes to the point of feeling as though they are hassling them. Also in this mix is the responsibility of keeping strict time monitoring to maintain the often complex medication regimes.

6. Emotional/Social Impacts

Prompt relief of physical symptoms were very important. Of equal importance were the emotional and social consequences this had on the way people lived their lives on a daily basis.

6.1 Quality of Life

Geoff (p) said:

> *In the end it just means life to me. It's the freedom. I don't have to worry about anything. It's on and it's there.*

For his wife Anna (c) it seemed like *"a miracle of modern science".* She recalled her experience with her own mother:

> *It's just wonderful to have it and not have that wait that patients used to have. Now my mother was on morphine. She was in the hospital and you know she was waiting for it. So I mean, this is a miracle really, in comparison. Yes.*

When symptoms are well managed, patients and family caregivers were able to get a better rest and sleep. This contributed to a better quality of life for patients. For family caregivers in particular this made a difference to how the next day went. It also meant they could continue providing care for their patient (See also "being at home: daily nurse visit" below).

Using the syringe driver allowed Bruce (c) and Mary (p) to get some sleep:

> *I noticed immediately there were periods through the night where Mary was getting peace and I was getting decent sleep or as well as we can. Before that I was being woken 7-8 times a night.*

Mary endorsed this:

> *It was an immediate positive effect as far as the welfare of the patient and her partner is concerned.*

Carmen (c) also emphasised the importance of sleep:

> *Then he got quite a good night's sleep that night. A really good night. The best night we have had. .... [Having a good sleep] was really good.*

Jack (c) observed that when Elizabeth was free of pain she could sleep:

> *I felt good in that she wasn't in pain and she was comfortable. Well she can have a night's sleep now which she wasn't able to and a bit better quality of life at the end.*

Francis (c) wanted life to be as "normal" as possible for Hamish (p) and their family. She was pleased when he started using the syringe driver:

> *Yes straight away. It was a good thing. He had it put in at lunch time and it was absolutely instant. He is a different person. If he is in bed sleeping all day you don't get boo out of him and it's not the old Hamish. The person lying there incapacitated is not good.*

6.2 Peace of Mind

Peace of mind was a key factor. Family caregivers, previously worried that medicines were not being absorbed, could be confident that right medication has been administered.

Jock (c) remembered caring for his wife Margaret (p):

> *You are looking for anything as you are on edge. [With] the syringe driver there was nothing I had to do and I felt a bit more relaxed about that. .. I think the big thing is that you get peace of mind. The medication is taken out of your hands. The dose is set up so that it runs continuously... Peace of mind is really important.*

Linda (c) wife of Antony (p) said:

> *He hates having drugs unnecessarily and so it takes the stress off me. If it is in the syringe driver he is getting it, he still has to have a couple of pills orally which are actually hard for him to swallow and he struggles. It makes life my life a lot easier and in the end it makes his life a lot easier.*

She added:

> *[It made a difference] physically and mentally I think. It is just something else that you don't have to worry about with medications. Is he going to have trouble taking them? Will it work all right? Is he going to have those ups and downs? A whole lot on that level.*

For Ruth (c) it has made a big, big difference:

> *You know it is getting into his body where before it was all being vomited up and you wouldn't know how much he has kept down. ... I wouldn't have any idea if his body had got any of the medication. It gives you confidence that he is getting what he needs. Yes I can relax a lot more.*

June (c) and Norah (p) had been getting muddled with all the pills. It was becoming a nightmare:

> *[Mum] was having a lot of trouble with nausea and really finding it very hard to swallow heaps of pills. I think that the doctors were a bit concerned because of the nausea and vomiting she wasn't absorbing the medication fully. ....The syringe driver makes it much easier to take the medications. .... She wasn't eating, she wasn't drinking. She was uncomfortable and both she and I were getting muddled with the pills. She was having over 35 a day that she was trying to swallow. And neither of us could cope.*

For Norah the syringe driver changed her life:

> *It alleviated the necessity for all these pills and brought it all together..... You know I got to the stage that if I wanted to go to the loo I would have to set the alarm clock for twenty minutes before and take a pill. And pills and pills.*

6.3 Good Memories

Having peace of mind, as symptoms were controlled and much of the stress removed, gave family caregivers good memories of this end–of–life period. This was very important.

For John (c) not needing to be the task-master getting pills down Eleanor's (p) throat had made such a difference:

> *It was really hard, awful, trying to get pills in - we seemed to be always at her to take the tablets. It seemed to take up a lot of our time.*

With the syringe driver giving Eleanor the medications he didn't have to worry. He could relax. It took the pressure off. He could be doing other things and have good times just being with Eleanor. He talked of love. He has good memories.

Annette's (c) husband, Ed (p), died before he could participate in the study. Good memories were important for her:

> *From that first day he was out of pain. Ed said he could jump over the moon. He had no pain. I thought that was brilliant. Yes it was brilliant. Yes they are nice memories because he wasn't in pain.*

6.4 Independence – The New Normal

One family caregiver discussed being able to manage the syringe driver herself. Again because of the implications for future practice it is discussed as a specific issue in this report.

It is clear that many family caregivers would neither want nor have the capacity to manage the day-to-day responsibilities of the syringe driver. However in the future, the demand for their use is likely to increase through changing practices and the increasing palliative care population. This changing environment is happening in the context of demands for service efficiencies and an emphasis on building community and self-management. So the expectation that family caregivers will step up to take this responsibility (where they are deemed capable), and so the preparation for them to do this should be anticipated and developed now.

Francis and Hamish's story

For Hamish (p) and Francis (c) having the syringe driver prescribed to deliver the medications had been really important to bring Hamish's symptoms under control. At the same time, they were pleased when it was able to be removed. Francis wanted very much to keep their lives on an even keel:

> *Initially when you are diagnosed with cancer it's mind-blowing. Your whole world is turned upside down. And then you go through bits of routine or you get to the stage where you haven't forgotten about it. You are just living with it. And part of that is not having them coming in every day.*

What Francis really wanted was for them to be as independent as possible and for life to be as normal as possible for them and their two young children. At the same time clearly symptoms need to be managed. She felt very capable and confident of managing and operating the syringe driver herself if she was taught how:

> *Yes definitely. I mean there were no needles involved. I think I have actually done a needle under the skin but I wouldn't want to do that bit. But as far as putting the drugs in yeah. I mean we have the morphine here and we had the other drugs here so it's not as though we can't be trusted with them. And they are locked away so the kids can't get near them.*

They had been planning a few days holiday. While Francis appreciated the difference using the syringe driver made to relieving Hamish's symptoms, it also made their lives more complicated.

> *I think it has been great but next week we are going away and we thought that maybe he shouldn't come as the syringe driver was in. Then we thought there must be a hospice in Napier where he could have it done. But it is just organising everything. It is so hard so darn hard. And your life does go on and he needs to get out and do things too so that's where it needs to be looked at.*

Francis was used to being independent and was cautious:

> *Even though we have the phone number of the hospice you don't want to phone them all the time. You want to keep going and try to do things yourself.*

Being able to change the syringe in the driver herself without having to wait for the nurse to call would allow flexibility and greatly enhance her sense of independence and normality.

> *Yes that would have been a better thing if we could have done it ourselves. Maybe they could have come in every couple of days or maybe just a phone call to see if it is all right. Because with cancer it takes over anyway. You've got to live as normally as you can and to have people in your home or having Hamish not being here and having to go a hospice. That's ideally what we try to avoid.*

For Hamish fitting in with different times to have the syringe driver reloaded was a compromise between relieving his symptoms and his independence. He was planning to return to part-time work once the syringe driver had been removed:

> *Well I know that the syringe driver does work and is a solution but it is just a bit more convenient if I can do without it. Next week if I am well enough I can go into work without having to organise to get the syringe driver done at some stage.*

He had contemplated the possibility in the future that he might be able to go to work with his syringe driver:

> *But I would have to be going down to the hospice round about 9.30 – 10 am in the morning to get the syringe driver changed and then go into work.*

Their lives would feel less complex if Frances was able to manage this for them. She was indeed more than ready to do this.

Professor Rod McLeod endorsed the notion of independence and normality as a foundation to palliative care:

> For patients receiving palliative care, maintaining relationships and continuing normal daily activities are just as important, if not more so, than symptom control. This understanding is the cornerstone of successful palliative care (Ross et al 2005 p 2).

7. Knowledge and Advice

Every person who participated in this study did so because they wanted to make a difference for others in similar circumstances to themselves in the future. They talked about how they informed themselves. They provided advice about what they thought people needed to know and they made suggestions for design and technological improvements.

7.1 Past and Current Knowledge

Of the 27 people who participated in this study, 21 had never heard of a syringe driver until it was virtually being set up.

Elizabeth (p) had no knowledge at all:

> *I didn't have a thought about it, didn't have any idea whatsoever. They actually got it out and said it was going to go under my skin. I nearly died I thought they meant to put the box under my skin.*

She was pleasantly surprised when she saw it was just a little cannula under her skin.

Hamish (p) said:

> *No it was a surprise at the time when it was put on me. I wasn't prepared for it or knew what it was but I was having difficulty with nausea and vomiting. The doctor must have made the decision earlier in the day and the nurse came in and said this is what we would like to do.*

His wife Francis wanted better communication with them. She described her experience:

> *We had been telling the hospice how ill he was. He had been vomiting and throwing up and then all of a sudden they arrive with the syringe driver. Instead of talking to us and explaining what they were going to do they just arrived and said here you go.*

Snow (p) didn't want to know:

> *No I don't need to know how it works.*

His wife, Carmen, picked up as much as she needed to know very quickly:

> *No, I didn't know anything and then they explained it to me that it is just like the pain killer going in all the time.*

Wynn (p) had *"No knowledge or expectations*" at the time it was set up. Neither did her husband Charles (c):

> *None at all.... So that was the first time I had heard of a syringe driver. I didn't know what they were talking about. I had* no idea.

When he did inform himself he was impressed with "how clever the little pump was".

> *It was explained that it was going in through the skin and it was going to be there over 24 hours. I thought great. That would be terrific. It would be better than the ups and downs.*

Some people thought it was an intravenous line *"like having chemotherapy*". One person associated the word syringe with a needle and then thought if it needs a driver it must be very big.

The six people who did have knowledge about syringe drivers had some nursing knowledge themselves or a family member who was a nurse or had experienced one being prescribed for a family member/friend previously.

Most patients and family caregivers quickly became acquainted with the technological aspects of how it operated and its purpose as well as the drugs and their expected action. Linda's (c) description shows how she understood the process:

> *The way I understand it, they set the programme up and the drug level goes in at a certain rate so it keeps the medication level rather than if he takes it orally he gets a kick and then it goes down until the next lot is due and it comes in. This way it is constant which is good as he hasn't been up and down.*

7.2 Information for the Future

All participants were asked the question: "Thinking about someone else like you in the future having a syringe driver, is there anything that you think would be important for them to know?"

Without exception, all patients and family caregivers said that having the syringe driver was a good thing. In every instance it had made a difference for the better. The patients said they wanted other patients to know:

- *It is a good thing to have.*
- *It makes quite a difference to how you feel; I would recommend it to others.*
- *The continuous medication has stopped the ups and downs and it can be modified each day if need be. I don't know how I would have managed without it.*
- *Inserting it is not a problem. Having it there is not a problem. It doesn't hurt in any sense. Yes, if it is going to help somebody else go for it.*
- *Let's get the information out there.*

Family caregivers tended to be more pragmatic with their comments emphasising that while care needed to be taken with the syringe driver, it was very robust – not fragile at all.

John wanted people to be reassured:

> *They are easy to work. I found it easy to learn about it. Just make sure you have plenty of batteries about, they chomp through those 9 volt batteries. The nurses are very good at explaining and showing. Every now and again they reconfirm that you still remember how to do what you need to do and that you are still confident. None of the nurses that come here take anything for granted that you remember or not but they don't patronise you, they are very supportive and that is a great plus.*

Carmen said with a smile:

> *Surely there wouldn't be anyone less qualified than me so they should all be able to pick that up and understand that. It was really clear and they showed me how to change the battery and what the different buttons were for and then if I wasn't sure I could phone and they would go through it with me.*

Jack advised:

> *Be patient at the beginning until they get the dosage right and then it's good.*

It took a few days to get the right dosage

> *But then when we see the results now we understand completely. It is a good thing.*

Francis said people certainly need to know about the driver and how much easier it is to medicate a person when they are unable to hold the oral meds down. John reinforced this: It was important people knew about them. It had helped him and stopped him worrying about trying to get Eleanor to swallow the pills.

Jock emphasised:

> *Don't be scared of them. They are very robust. . The main thing is a cover to go over the syringe and not to be scared of them.*

Choosing the site for the cannula was important for Geoff. He advised:

> *One thing that is important is to look at the person and their situation and their mobility and how they rest in bed and their posture and to find the best place to suit the patient to put the cannula in.*

He noted the need to change the site from time to time and recommended that people trace the exit point of the tubing:

> *How are you going to remove any clothing and how are you going to go to the toilet and the other thing is where do you hang the little bag to put it in?*

Geoff wanted men in particular to know the option of using the abdomen as the site. For him having it sited here gave him much more freedom:

> *I would like them to know about putting it in the stomach because it is so much easier - unless of course it is a woman wearing a dress which wouldn't be simple. Even then maybe it could be done up down the front.*

He also made himself a "butcher's hook" to hang it on when he went to the toilet:

> *I just made mine up using number 8 fencing wire which I used to hold tins of paint. It can be moved around wherever I am getting dried and dressed. Whoever's drying, can do my back more easily. So that is something I'd say could be part of a kit. Not just a bag. It's just an 's' hook. You know what I mean?*

His wife Anna would recommend giving it a name:

> *We kind of have to treat it as a friend. It's actually worked really well because we say "oh don't forget Teddy when you are getting out of bed". He knows exactly what I mean if he's half asleep. And getting up to go to the toilet he could forget Teddy if he is not careful. So calling it Teddy has, I reckon, worked really well as a friend. If you sort of personify it like that it's easier to cope with.*

Anna is very keen that family caregivers are well informed. She learnt a lot over this time.

> *Just a general sort of explanation really I suppose. Just an explanation about why this will fix the problem. You know it is important. There is the 24 hours aspect of it. People can understand that easily I am sure. So whatever is in it is going into the body all of the time and you don't worry about it.*

She too emphasised that it was not fragile:

> *You don't need to be super worried about it from that point of view.*

Anna would also like there to be more general knowledge in the community and suggested *"That guy who writes in the paper Dr Kris something"* *(Chris Kalderimis in the Dominion Post):*

> *If he wrote an article about syringe drivers. It is quite helpful to have heard of them I think. It would be would be quite useful and then it doesn't come as a shock to you. And when we talk about the fentanyl patch you see and we say it's like those patches people get to stop them smoking which I don't really know but I imagine they are similar sort of thing. So just sort of having heard of an idea is useful. It's not such a shock to the system.*

Bleeping is not an emergency!

Two couples particularly wanted people to understand that when the machine bleeped this was a warning that its mechanism had stopped or was near to needing refilling. That nothing was going wrong. That it was not a crisis. The first time it happened it had it sent them into an unnecessary panic. For Anna this was the most important information she wanted to provide:

> *Geoff is now really familiar with the whole system in that it gives a warning beep. The syringe driver gives a warning beep and then a few minutes later it starts beep, beep, beeping so Geoff knows how to turn it off. We know not to be worried about it if nurse is a bit late.*
>
> *You know it's not a matter of life and death that you keep getting that pain killer. If nurse is going to be half an hour late it doesn't matter. This is what you do. You press that button and switch it off so it's not going beep beep beep at you.*

Having this information was very important for Ngawai:

> *We did panic at first when it ran out but we were told it wasn't urgent. It started to beep and I had a look. It said something like it's going to empty and there are so many minutes. So I rang the hospice and told them the syringe driver was beeping. They told me to turn it off because it had run out at that time and that it wouldn't be long before the nurse would be there. And because they weren't worried I wasn't.*

7.3 Syringe Driver Design

Not unsurprisingly, many people made suggestions about design and further development of the technology.

Many comments related to the heaviness around their neck and had adapted the holder themselves:

- *It would be better as a backpack.*
- *A bum bag would help. It would be less conspicuous. It doesn't draw attention to you.*
- *It was heavy around my neck and put a strain on my neck. That is why I have it on as a shoulder bag to take the pressure off otherwise my head is dragged down so much.*
- *We didn't use it around her neck. We safety-pinned it to the side of the bed or we pinned it to the back of the garment she was wearing at the time.*

Several people talked about future technological developments making it smaller. Jock had given this a lot of thought:

> *Well, I think they could design a machine that doesn't have the lever sticking up at the top. You know how you hook it over your two fingers? It doesn't need to stick*

> *out. Putting it in and out of the bag it was always catching. If you just had a tube on top of it. Let's face it, you aren't using the syringe for anything else.*

The look of it was important:

> *Everyone says it is a syringe driver but you can make a syringe that goes in a syringe driver that doesn't have to look like an ordinary old syringe that has great big tags hanging off it*.
>
> *Streamline the top of it. The top is ugly. It is an adaption from a standard syringe. The syringe drivers are used so much these days that it wouldn't be hard to have a special cartridge or cover that goes on top.*
>
> *You could have a cover that goes over the top of it. It would clip over the top and you wouldn't even know. It would hide the syringe. The cover could be clear so you could still view the solution and the position of the disc but that big tag that sticks up is a bit ugly.*

He reflected on the development:

> *Possibly in the early days when it wasn't used as much, everyone was still using these syringes for other applications and then someone said "Let's make a driver to drive it automatically", which is great. But now there are heaps of these syringe drivers out there and I think it would be nice if you had a slim line and it could be loaded and unloaded just as easily with an attachment for drawing it up.*

8. Associated Consequences of Using a Syringe Driver

While not strictly part of using the syringe driver, the fact that when the patient was being cared for at home, the Home Care Nurse needed to visit every day to assess symptom management and refill the syringe driver, was an integral part of the process.

8.1 Being at Home: Daily Nursing Visit

Nearly all patients and family caregivers in this study talked about their wish to die at home. For some this was achieved. Two people did not want to be a burden for their family and expressed a wish to die in the Hospice. One of these people changed her mind when she realised her family's strong wish to care for her and fulfilled all their final wishes that she die at home.

Paddy (2011) argues strongly that patients be given a choice. She agrees that location does contribute to a "good death" but that healthcare providers should not presume to know the patient's preferred location of death.

> There is a significant need for nurses to provide good end of life care in all settings (Paddy 2011 p 36).

As discussed previously, being at home with daily nurse visits contributed to the patient's and family caregiver's overall quality of life and peace of mind and good memories for the family caregivers. This has an influence on whether people would choose to do it again.

Currow et al advise:

> It is a false assumption that family caregivers will simply be there when a patient needs them; systems need to be put in place to support family caregivers because as a community, we are going to rely on them again and again." (Currow et al 2011 p 671)

The Hospice New Zealand 'Hospice Capability Project' endorsed this in the key assumption of their report:

> The majority of New Zealanders want to choose where they die, therefore they will need access to a skilled person/s who takes responsibility for partnering (case managing) them on the journey ahead; skilled symptom management, assistance with practical matters, psychosocial support (or a team who sees them as a whole person - social, spiritual, member of a family and community), carer respite, education of carers, night care, equipment, etc (Hospice New Zealand 2012 p 2).

For most patients in this study, using the syringe driver to receive medications for good symptom control extended their time at home. A consequence of using a syringe driver at home was that the Te Omanga Home Care Nurse or the District Nurse initiated by Mary Potter Community Care called each day to monitor symptom control and refill the syringe with the medications. There was more talk about this aspect of using the syringe driver and the care provided, than any other part of their experience. For family caregivers in particular, this "mentoring" role of the Home Care Nurse gave people confidence.

Currow recognised family and friends as “arguably the largest sector of the health workforce” (Currow et al 2011 p 662). Given the projections of increased demand for palliative care services and that home is identified as the place most people choose when asked (McNamara and Rosenwax 2007), the likelihood of increasing coercion on families to provide even more palliative care/end-of-life care than they currently do, is very real.

Professor Patsy Yates noted, in her presentation to the New Zealand Palliative Care Nurses Conference (Nov 2011), the uncertain world we live in, and stressed that nurses were key players in identifying and implementing reforms in the rapidly-changing context. Like Currow, she emphasised building community and self-management.

As more patients are cared for at home, so will nurses’ work be focused in the community. This means the nurse’s role as a “mentor” could be developed in very substantial ways to provide the support for family caregivers.

This aspect of the service was demonstrated as Charles, caring for his wife Wynn, adjusted to her improvement and so changes were made to the services she needed from Te Omanga Hospice. Charles had no other experience like this to draw on and being a very conscientious man wanted “to do everything right”: For him this was *“a once-in-a-life-time experience”:*

> *Only once in my life will my wife die.*

As Wynn improved and removing the syringe driver was mooted, Charles became very anxious. He also resisted returning the “hospital” bed to Te Omanga Hospice. At the same time Wynn was keen to be back in her own bed. For her, this was an indication of her progressing. Over the next two weeks Charles gained confidence through the gentle encouragement of the nurses:

> *When they first told us that the bed was going we hadn’t reached that level of stability but by the time the bed went no problem.*

Charles reflected on this:

> *We all got an awful fright in those early days. I was very nervous. I felt I needed support. It is good having the discipline of the nurse coming each day which the syringe driver demands. That has been very helpful.*

He explained:

> *It is just the confidence-building. I am not a natural nurse, that’s for sure. I am the complete reverse. I would like them to come every day so I can have a chat about whether we need a bit more of the drug and whether I am doing it right or whatever, you know.*

As his confidence grew he let go of the intensive home care:

> *Well, the services were reduced from every day to three times a week to now two times a week and because we have this stability now I am comfortable with that. In fact we asked her not to come Friday so that will be a week between visits and that’s fine while Wynn is stable.*

He was very aware of being Wynn's primary family caregiver:

> *I mean it is a question of the carer being me. It's a matter of confidence when you are out there in the great unknown. You just want to do the best. So that is really what it is all about.*

The daily Home Nurse visit was integral to patients being cared for at home. Such visits:

- Meant that home circumstances were checked on a daily basis.
- Boost confidence that the family caregiver is managing well and doing everything "right".
- Maintains the family's independence and integrity

This was particularly important for family caregivers who said:

- *They boost my confidence. I welcome them here. I'm always pleased. I'm looking out the window waiting for them to come. When they've been and gone, I feel so much better.*
- *They give you confidence and they reassure you. They spend the time to tell you about this, that and the other thing and show you things. They give you sound advice which makes things easier in the day when I'm on my own – I know exactly what to do and the greatest thing - they are only a call away, you know and I've done that several times - just to check – to make sure I wasn't doing anything wrong. And straight away you feel great.*
- *I've picked up so much information, just little things they tell you each day that takes the pressure off me.*
- *The good thing is that they check with him each day and are able to adjust the doses.*
- *They are marvelous. Yes. The care is just marvelous. Yes now it is once a day and it's amazing because I felt that I needed the support now that he is getting weaker and weaker. The support, well, it means a terrible lot as you don't know from one day to the next how he is going to be and they loan you all the bits and pieces you need and write out prescriptions for us. We are very thankful and grateful to them. She tells me what to do and shows me how to do things like sponging him down or whatever. For a dry mouth she gives me lots of ideas. It is very, very good. They do valuable work don't they?*
- *That was one of my apprehensions. That I would be left with a whole heap of drugs I would have to mix up. But they said "No." They always look after that. So it is all going well.*

Jack (c) spoke of his experience:

> *I thought about it every day for the whole twenty-one months. About what was needed to get through that day and then the next day. Every day was done on a daily basis. You don't look too far ahead because you are not quite sure of what is ahead.*
>
> *I think the hospice waited for some time for us to request assistance but we were managing quite well at home. It was not a matter of not wanting help and not having it offered. Everyone who was there said that any stage to let them know. But we were managing very well at home. We had a good routine going.*

> *Well, the time had come probably for them to start coming in more often as things were getting difficult. It was reassuring to know that they were going to come the next day.*

8.2 A Different Nurse Every Day

Having a different nurse for the daily nursing visit, for some people, counter-balanced the benefit of the daily visit. Two family caregivers specifically mentioned difficulties with having a different nurse each day. Ngawai talked about her experience:

> *It is a bit difficult having different people all the time. I would prefer someone who knows him only because we have to repeat ourselves over again. When they first started coming in from the hospice it was a different person all the time and then when the same person came in a second time she said "I haven't seen him for two weeks and he has just declined so fast." As the others hadn't seen him before they hadn't noticed the rapid decline.*

She said the nurse had discussed the issue with the Home Care Co-ordinator and the problem was solved:

> *So it was really good that we found someone who came back again who knew him. With the same nurse you don't have to explain things. That just means a lot to us.*

This was difficult for Francis too:

> *It is not always the same person. That is a big problem because you don't get the continuity and you are telling them the same thing all the time. You repeat yourself about twenty times.*

These trying circumstances are not conducive to building a trusting relationship and engaging in sensitive end-of-life care conversations which are fundamental to providing a high quality specialist community palliative care service.

Newbury (2009) in her study of family carers suggested that the most valued aspects of home care included having regular and familiar staff coming into the home. Lack of continuity of care e.g. different carers coming each time, were identified in difficulties encountered by the family caregivers. Watson (2011) found that most people would prefer to be cared for and die at home as long as they were provided with high quality care and proper support for their families/carers. She endorsed that continuity of care was considered crucial to delivering a high quality service but acknowledged that this was hard to achieve at times.

This was strongly endorsed by Geoff (p) and Anna (c) in this study. Having the same nurse five days a week was reassuring for both of them. It meant they had *"established quite a relationship with her"*.. Especially reassuring for them was that the nurse kept an eye on everything:

> *Geoff's had every infection going. He has had gout. He's had cold sores in the lips. He's had the infection in the shoulder. He's had thrush in his throat. He's had swollen glands. So then the nurse can say I think the doctor needs to see this or we need a prescription for this. She has done lots of ringing up of pharmacies or the doctor or the surgery and just made sure that things are going smoothly.*

Creating the nursing roster to provide continuity of care is always a challenge. Te Omanga Hospice has organised its allocation of nurses on the rationale that every nurse on the team provides a high standard of care. In addition most nurses are employed on a .6 FTE basis so work three days each week. This employment practice was put in place to reduce the stress of involvement/attachment and emotional burden when providing intensive palliative care and end-of-life care.

It could be argued that an inconsistency in patient allocation contributes to reduced nursing satisfaction and results in increased stress because the nurses have a more superficial therapeutic relationship and so less direct accountability.

Having all nurses informed so as to provide detailed care for all patients raises a number of issues. First, resourcing and time management. Being sufficiently well informed to provide sound palliative care for a number of patients involves a considerable amount of time. Second, the more people involved, the greater the possibility of information being "lost in translation" as people interpret the meaning of the information provided. Third, there are privacy issues when intimate/private personal information is passed between a greater number of people.

The priority must be a service that is patient-and family-focussed. It is essential to achieve this continuity of care. This would be consistent with the concept of comprehensive holistic services based on the development of a therapeutic relationship and the practice of continuity and accountability (Ministry of Health 2008). Nursing employment issues and workplace safety is also very important and must be accounted for through employment legislation, professional competency standards, education, training and supervision.

This study will recommend that Te Omanga Hospice explore, in the first instance, a focus on continuity of care in the delivery of nursing practice, in the short term, through the allocation of a lead/key nurse for each patient and their family. The longer term objective would be to develop a fully integrated primary nurse practice. The principles of continuity of care would also apply to medical and other patient services provided.

8.3 Te Omanga Family Caregiver Programme: *A Map Through the Forest*

Although only one person in this study had participated in the Te Omanga Family Caregiver Programme, the consequences for her were such that it is important to include discussion about it in this report. The programme was developed by Raelee Jensen, Te Omanga Education Co-ordinator, and Kate Gellatly, Palliative Care Nurse Specialist Educator, when they recognised the key group of people providing care were missing out on the support provided through the Te Omanga Education Programme. Raelee noted that family caregivers *"are doing it 24/7. We come and go".*

In response to requests from patients to come with their family caregiver, another programme for patients is on the drawing board.

Te Omanga Family Caregiver Programme (Appendix 9: Te Omanga Family Caregiver Programme: *A Map Through the Forest*) is offered six times a year. An Invitation is sent to the family members on both the Comprehensive and Partnership Programme at Te Omanga Hospice. They participate in discussions facilitated by skilled staff for a two-hour session each week over three consecutive weeks.

The first session looks at support for the family:

- What is palliative care?
- What changes can be expected at the end of life?
- How to manage the changes.
- Self-care/resilience.

The second session gives information and experience about managing the practicalities:

- Moving around safely: ways to avoid a fall.
- What equipment can make moving easier?
- Hygiene and skin cares.
- Medications.
- Massage.

The third explores the challenges and provides opportunities to talk about these sometimes once-in-a-life time experiences:

- Experiencing loss.
- Having a difficult conversation.
- Planning wills and funerals.
- Social issues.

Six to ten family caregivers attend each programme (36-60 per year). This is less than 15% of possible participants. Raelee and Kate understand that while many family caregivers find it hard to make a space for themselves, this is an important part of keeping family caregivers well (see Health of Family Caregiver below).

Carmen's story

Snow had been admitted to Te Omanga's Comprehensive Programme early in 2010. Pain was an ongoing problem over the next 18 months. During this time Snow was admitted to the In-patient Unit five times for a period of about one week each time. He began using a syringe driver at home two days before his final admission, when he died three days later.

Carmen participated in the Family Caregivers Programme six months before. It was a very important experience for her:

> *That was really valuable. I enjoyed coming. They pointed different things out. Just different things they were saying would happen. And I thought to myself "probably that won't happen" but lo and behold a few months down the track "Oh yes!" They were right you know. Like the dry mouth and two or three other things. I thought "Oh yes I know about this". Yes I found that very, very good.*

She talked further about learning how to massage Snow with the oils. She emphasised again that she didn't think some of the things they had talked about would actually happen. When they did she recognised them and was relieved to know these things were not unexpected. At the time it was all new to her, but she was able to absorb all the information because of the way the nurses explained everything.

This is all part of creating an environment conducive to "a good death" where the patient has the best possible quality of life and the family caregiver has peace of mind and thus good memories as discussed above.

9. Related Experiences

Comment about the two issues below have been included to “flag” them for future consideration. They are both important issues which require more detailed focus than this study can allow.

9.1 Health Status of the Family Caregiver

There is growing recognition that providing care, even for a short period, has consequences for the health of the family caregivers. Cora et al (2012) acknowledged the increased health risk of depression, elevated heart rate and blood pressure of family caregivers of patients with chronic illness or dementia. Their pilot study examined the psychological and cardiovascular responses of family caregivers of people with terminal illness. They found that family caregivers:

> ... reported higher levels of depression, state anxiety, and more sleep dysfunctions than controls. They also revealed heightened systolic and diastolic blood pressure in some measurements. Moreover, elevation of heart rate was associated with caregiving length (Cora et al 2012 p 39).

They concluded that family caregiver stress is associated with considerable psychological vulnerability, sleep disorders, and risk of alterations in the cardiovascular system, which seem to be modulated by family caregiver characteristics. They identify the importance of screening family caregivers for psychological as well as physical symptoms and disorders.

Anna(c) recommended the same such screening:

> *Another thing is probably the state of the health of the caregiver. Actually some assessment of that is probably quite important really.*

She understood this from her own perspective:

> *Well, my physical health is not marvellous but it’s all right. I am strong enough to pull Geoff out of a chair as you saw and I do things like I sit on the end of the bed and he pushes against me with his feet so he can push himself further up the bed.*
>
> *But I mean more the mental health. If you had elderly people - I imagine a lot of the syringe driver wearers and carers would be quite elderly and if you had someone who was quite confused themselves there is a lot to be confused about in terms of all the drugs and taking care of the patient and things like that.*

Anna was aware socio-economic circumstances were important here.

> *I know we are fortunate. We are an organised household basically. We have enough money for instance to have cleaners in. We can afford to buy Complan. We can afford to buy anything extra that we need. There would be households that would find those sorts of extra things quite tricky - if you were living on the benefit or the old age pension. Also, as I say the mental health of the carer is actually quite important, I would say. Their physical health too. That must make a terrific difference to whether people go into the hospice or not.*

9.2 Transition Between Hospital and Hospice Services: Accessing the Hospice

Several people talked about the gaps between the services, particularly between oncology services and the hospice, but also between hospitals and the hospice. This often occurred at a time of critical change when families were dealing with the realisation that an illness was now terminal. The consequences were considerable.

Dose et al (2011) initiated a study because little was known about “the transition between hospital dismissal and onset of hospice services from the patient/family perspective” (p 394). From their study with 19 patient and family units Dose et al (2011) reported:

> There were unexpected disruptions in their lives and the transition experience extended beyond the first home hospice visit.

They recommended “deliberate anticipatory guidance by hospital and hospice staff prior to hospital discharge, support during the time of immediate transition, and ongoing interventions to establish stability as soon as possible for those returning home with hospice care and their family caregivers” (Dose et al 2011 p 401).

10. Discussion

It is well-recognised that syringe drivers provide an excellent safe and effective method of delivering a variety of medications and that their use has revolutionised management of symptoms including pain, nausea, vomiting and respiratory distress at the end-of-life phase of palliative care (Costello et al 2008). When other routes of administration are ineffective or inappropriate, it is now commonly accepted practice to use a syringe driver to administer medications (Dickman et al 2005).

However, sitting alongside this practice, another set of understandings has developed from anecdotal evidence that patients and family caregivers sometimes considered being prescribed a syringe driver to administer medications, as a “harbinger of death” (Graham and Clark (2005).

Dickman (2006) identifies a disadvantage of using a syringe driver in that it is “associated with dying, or as the last resort” in conjunction with the list of advantages:

- Smooth medication delivery, increasing the patient’s comfort by avoiding high and low blood levels.
- No need for repeated injections.
- Once-daily set-up generally required.
- Many symptoms can be managed by the use of a combination of medications.
- Patients’ independence is maintained because the devices are small, light and easily portable (Dickman 2006 p 81).

Less than optimal care can result through seeing the syringe driver’s association with death as a disadvantage and so delaying its use to “the last resort”. Rather, we can use the fact that its use in an end-of–life situation as an advantage, in conjunction with the others listed, to facilitate better communication and preparedness for a “good death”. Where it is prescribed for of end-of-life care, discussion about using a syringe driver is part of the clear conversation about the person’s approaching death. The focus of care is comfort and dignity which allows a sound opportunity and motivation to have this very important conversation.

Where the syringe driver’s prescribed use is not associated with end-of-life care, the perception that its use is associated with dying can be corrected through direct discussion with the patient and his or her family members.

This study has looked at outcomes that matter to patients and their primary family caregiver. After using a syringe driver for at least 48 hours their overarching response was that it had made a difference for the better. They welcomed the patient being prescribed a syringe driver to provide medications to control symptoms.

The most important impact was the ***relief of distressing symptoms***, frequently referred to in terms of *“nightmares”, “horrendous*”. Bridgeman (c) declared vehemently “*Use the syringe driver at the earliest possible time!* ***Don’t wait until people are struggling.***”

Using a syringe driver removed the need for patients to ***struggle with swallowing pills, pills and more pills***. This also had a big impact for family caregivers who very much appreciated having certainty that their patient was receiving the right amount of medication. It greatly reduced their anxiety about being responsible and providing the best possible care, watching the clock, setting the alarm to ensure drugs were taken, and the uncertainty when the person vomited, about what drugs they retained.

The need for family caregivers to be prepared for their role is also emphasised in the findings. Te Omanga's Family Caregiver Programme: *A Map Through the Forest* is a fundamental part of preparing and supporting families through this special time of laying down good memories. This study provides evidence that the beneficial repercussions of participating in this process are very substantial for family caregivers. This study endorses participation of family caregivers in such programmes, currently taken by less than 15% of possible participants, and encourages organisations to invest in such support.

While outside the scope of the study, participants all commented on the significance of a daily home visit by the Home Care Nurse. Patients with a syringe driver are visited every day to assess symptom management and refill the syringe driver. ***Being at home*** was intrinsically related to the ***daily nursing visit.*** There was more talk about this aspect of using the syringe driver and the care provided than any other part of their experience.

The daily Home Nurse visit was integral to patients being cared for at home. Such visits:

- Meant that home circumstances were checked on a daily basis.
- Boost confidence that the family caregiver is managing well and doing everything "right."
- Maintain the families' independence and integrity.

This was particularly important for family caregivers. John said:

- *They boost my confidence. I welcome them here. I'm always pleased. I'm looking out the window waiting for them to come. When they've been and gone, I feel so much better.*

As the demands for more palliative care grow, this study provides some direction for future developments. Palliative care services have been given clear direction that in the rapidly changing environment described in the report on New Zealand Palliative Care Workforce (MoH 2011) and the report on Assessment of Palliative Care Need (Palliative Care Council 2011), we need to be thinking in a radically different way about what palliative care is required and how to provide it.

It is the role of the specialty palliative care service to impart the skills, knowledge and confidence to the family caregivers, those providing the care directly for patients when they are at home.

This means, as Francis and Hamish's story reveals, identifying and facilitating opportunities for families to enhance their ***independence*** and establish a ***new normality.*** Providing education and skills to carry out the specialist technological aspects of care, in this instance, refilling and reloading the syringe driver, is key to facilitating this.

This study informs professionals that the knowledge and skills in palliative care that a family caregiver has, increases over the period of caring for their patient. The need to ***build more community capacity and self-management capabilities*** is strongly endorsed. As demand for palliative care increases nurses will be, more and more, supporting family caregivers to provide specialist palliative care at home.

The work of specialist palliative care nurses could be one of mentoring, showing family caregivers *how to provide* the care, as opposed to *doing* the care. Direct face-to-face contact will always be of primary importance, and will be further enhanced through palliative care practitioners' input to developing communication technologies, for example, tele–video processes.

To recognise the family caregiver as the primary provider of care may require a change in attitude and perspective of all parties (practitioners and funders, as well as patients and families). A move to such collaboration will require openness, flexibility, management of gate-keeping and willingness to take a lead.

This study reveals that while few people, not surprisingly, had little knowledge about syringe drivers prior to using one, all participants, where relevant, became sufficiently knowledgeable about how they operated and skilled to manage disruptions to their continuous infusion.

Everyone who participated in this study was motivated because they wanted to make a difference for future patients and their caregivers. In response to thinking about these people, without exception, they said that having the syringe driver was a good thing. In every instance it had made a difference for the better. This study provides specific advice to be used in the development of an information manual, or booklet to supplement the technological information currently available.

Two issues have been identified for future consideration. They are both important issues which require more detailed focus than this study can allow.

- **Health Status of the Family Caregiver**

There is growing recognition that providing care, even for a short period, has consequences for the health of the family caregivers.

- **Transition Between Hospital and Hospice Services: Accessing the Hospice**

Several people talked about the gaps between the services, particularly between oncology services and the hospice, but also between hospitals and the Hospice. This often occurred at a time of critical change when families were dealing with the realisation that an illness was now terminal and caused unexpected disruption for patients and family caregivers. The consequences were considerable.

11. Conclusion

This study provides insights into the use of syringe drivers in palliative care symptom management. The research captures, through conversational interviews, the lived experience of 27 people (12 patient/family caregiver couples and 3 caregivers) experiencing palliative care, as a patient or family caregiver. The use of a syringe driver made a **very positive difference** in the lives of everyone interviewed. Swift symptom relief, following administration of prescribed medications, resulted in a greatly improved quality of life. In the words of Geoff **"It gave me life".**

This study highlights the need for all palliative care practitioners to listen to and learn from patients and their families about what is most meaningful for them at this time.

Patients and their family caregivers declared ***"Don't wait until we are struggling***".

This study demonstrates the need to consider using a syringe driver when swift control of distressing symptoms is required. This may be a temporary measure that can be repeated if needed. This may be a final intervention as life passes and families grieve, knowing their patient made the transition from life to death with all the care and consideration possible.

This could involve reviewing long-held practices based on clinical directives.

The recommendations contained in this study reflect the words of those most intimately involved: patients prescribed a syringe driver to administer medications, and their family caregivers. For practitioners to be effective in symptom relief, it is vital to listen to the patients and their families, and let them be the driver of care. The study may lead practitioners to renewed reflection about conversations with people who are dying and how listening can lead to valuable learning.

Whakarongo Ki Te Iwi

Listen to the People

12. Recommendations

12.1 For Strategic Workforce Development

12.1.1 Acknowledge family caregivers as a central part of the health workforce capacity in providing palliative care.

12.1.2 Explore identifying family caregivers in New Zealand Health Workforce statistics.

12.1.3 Stop referring to family caregivers as “informal” caregivers. This downgrades the knowledge they have gained and demeans and undervalues the work they do, thus reducing awareness of the need to adequately support them.

12.1.4 Explore how to enhance the capability of family caregivers through:

- Structured support and family caregiver courses.
- Encouraging nurses to act as educators/mentors.
- Maximising technology e.g. Skyping and developing “apps” for cell phones.

12.2 For Palliative Care Practitioners

12.2.1 Early identification and reporting of symptoms by nurses so they can be alleviated prior to causing distress.

12.2.2 Medical staff review, in symptom management, the best timing to initiate prescribing a syringe driver with a view to initiating use sooner rather than later.

12.3 For Te Omanga Hospice and Other Palliative Care Organisations

12.3.1 Prepare policy and establish a process for training and supporting family caregivers to prepare and administer syringe driver medications.

12.3.2 Strategic planning through to 2020 and beyond, takes account of the anticipated reduction of resources for palliative care services and changing demographics placing greater demand on services:

12.3.3 Nurses as mentors with a focus on equipping family caregivers with specialist skills and knowledge (see 1.4).

12.3.4 Continue to provide Family Caregiver Courses and increase uptake by family caregivers.

12.4 For Te Omanga Hospice

12.4.1 Improve continuity of care in the delivery of nursing practice through the allocation of a lead/key nurse for each patient and their family. .The principles of continuity of care would also apply to medical and other patient services provided.

12.5 Recommendations for Future Research

12.5.1 Two issues were identified in this report for further inquiry:

- Investigate the health status of family caregivers involved in care of patients with a life-limiting illness.
- Explore the transition from hospital to hospice services which cause unexpected disruption for patients and family caregivers.

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Appendices

1. Te Omanga Hospice Comprehensive and Partnership Programmes
2. Syringe Driver Use for Te Omanga Patients: 1 January to 30 December 2010
3. Upper South Regional Ethics Committee Approval Letter
4. Study Information Sheet
5. Study Consent Form
6. Study Interview Schedules
7. Nurse Interview Training
8. Interviewer and Transcriber Confidentiality Agreement
9. Te Omanga Family Caregiver Programme: *A Map through the Forest*

The National Application for ethical approval for this research project is available as a separate document.

Appendix 1: Te Omanga Hospice Comprehensive and Partnership Programmes

Programme I - The Comprehensive Programme

Patient Profile
These patients usually have a Trajectory I disease pathway i.e., rapidly progressive and usually results in death within a few weeks or months. The needs of these patients may exceed the resources of the generalist providers.

The programme offers all patients:

1. An initial assessment by a doctor and a nurse.
2. At least weekly home visits by one of the nurses on our homecare programme.
3. Twenty-four (24) hour nursing and medical cover.
4. Monthly outpatient appointments at the Hospice or home visits for medical review.
5. Additional services if indicated:
    a) Inpatient admissions for respite and/or symptom control.
    b) Occupational therapy assessments at home with the loan of appropriate equipment.
    c) Day centre once a week following occupational therapy assessment.
    d) Additional medical home visits if required (as assessed by the homecare nurses)
    e) Counselling.
    f) Art Therapy – especially for children.

Criteria for Admission to the Comprehensive Programme

1. Uncontrolled symptoms beyond the resources of the generalist primary care provider.
2. Patient is imminently dying and has requested to die in the Hospice.
3. Early deterioration is anticipated and the patient does not want general hospital admission.

Programme II – The Partnership Programme

A shared care programme offering support to the primary care providers and clinical and ancillary services to the patients.

Patient Profile
These patients have a Trajectory II disease pathway i.e., slowly progressive and is characterised by long periods of stability punctuated by intermittent acute exacerbations. The Partnership Programme may also include trajectory I patients that are stable and asymptomatic.

The programme offers:
1. An initial assessment by a doctor and a nurse.
2. Regular assessments by the Partnership Nurse who will liaise with the primary care provider.
3. Attendance at day centre after occupational therapy assessment.
4. Counselling.
5. Art Therapy.
6. Twenty-four (24) hour telephone availability (a kind of helpline supplied by doctors or nurses to doctors or nurses).

NB

This programme does NOT offer:

1. Twenty-four hour (24) nursing and medical cover to patients.
2. Occupational assessment for equipment.
3. Regular medical review of the patients either at home or at the Hospice.

Criteria for Admission to the Partnership Programme

1. The patient may wish to return to hospital for management of the life-limiting disease.
2. The patient's symptom control is optimal.
3. The patient is not imminently dying and is stable.

NB

1. Patients may move from one programme to the other on medical review by the Hospice doctors.
2. Patients may have interim periods on the Comprehensive Programme for intensive symptom control and once stable may return to the Partnership Programme.(ie., they may alternate between programmes).

NNB

At the initial visit, the patient, family, whanau and carers are informed of both programmes and the process for moving from one to the other.

Appendix 2: Syringe Driver Use for Te Omanga Patients - 1 January to 31 December 2010

2.1 Te Omanga Hospice Services 2010

Te Omanga Hospice continued to provide a wide scope of services during 2010 for the Hutt Valley. In 2010 Te Omanga Hospice received 413 new referrals to the service. There were approximately 160 patients on the programme at any one time. Care and support was provided to over 575 patients and their families in the year. Three hundred and fifty seven patients died on the hospice programme during that year. (Te Omanga 2010 Fact sheet). (Note these figures include people residing in rest homes).

2.2 Te Omanga syringe driver use 1 January 2010 to 31 December 2010

Prescription of a syringe driver for Te Omanga Hospice patients during this time period was reviewed to provide the context for Te Omanga's study exploring patients' and caregivers' understandings and experiences of using a syringe driver. The methodology and results are discussed below.

2.3 Methodology

PalCare Australia provided detailed information on all patients who were part of Te Omanga Comprehensive programme from 1 January to 31 December 2010 whose PalCare records included a reference to them using a syringe driver. This data request included all variations of documentation referring to syringe drivers e.g. Syringe Driver; s.d.; S.D. ;S/D or s/d. The database included name, date of birth, gender and ethnicity.

Te Omanga PalCare records for each person were then searched to determine: diagnosis, specific details of syringe driver prescription, including number of episodes of use, length of each episode, whether the person had died by 31 December 2010, and whether the syringe driver was in situ at time of death. Details of medication used were also recorded.

PalCare is a web-based patient management system developed in Australia in 2003. Te Omanga Hospice began using PalCare in February 2009. One of its functions is that it can be searched for a wide range of information to assist management with operational issues and for the purpose of research whether it be a medical or an operational topic of study.

Caveat on Te Omanga's PalCare data

The completeness of data entry on PalCare of Te Omanga Comprehensive Programme patients from 1 January to 31 December 2010 was variable as staff became familiar with the PalCare Programme resulting in a change to the way syringe driver use was recorded in PalCare. Te Omanga Hospice also changed its process of recording patients' participation in its services from comprehensive to include the partnership category. As a result PalCare data programmers experienced some difficulty in locating the relevant data regarding syringe driver use. This meant that it was not possible to make direct comparisons between the patients who used a syringe driver (where detailed information was obtained) to the total population of Te Omanga patients. As such, indicative comparisons only have been extrapolated.

2.4 Results

2.4.1 Syringe driver use

One hundred and seventy three patients cared for by Te Omanga Hospice in the Inpatient Unit or at their home between 1 January 2010 and 31 December 2011 had a syringe driver prescribed to administer drugs to relieve symptoms (note: patients residing in a rest-home were not included in this study). On 31 December 2010, 166 (96%) of these people had died and seven (4%) were still alive. Te Omanga Hospice provided care for a total of 575 patients referred to its comprehensive and partnership programmes during this year. The extrapolated estimate is that about 30% of all patients used a syringe driver during this year.

2.4.2 Age

Most people using a syringe driver were aged over 60 years (140:81%). One child aged 2 years used a syringe driver. There were no participants in the 5-29 years age group (Table1).

Table1: Age breakdown of people using a syringe driver

Age	0-4	30-39	40-49	50-59	60-69	70-79	80-89	90-99	total
No	1	3	8	21	50	34	43	13	**173**
%	0.6	1.7	4.6	12.1	29.0	19.6	24.9	7.5	**100.00**

2.4.3 Gender

Ninety-six (55%) were women and seventy-seven 45% were men (Table 2).

Table 2: Gender breakdown of people using a syringe driver

Gender	No	%
Female	96	55
Male	77	45
Total	**173**	**100**

2.4.4 Ethnicity

Of the 173 people who used a syringe driver most identified as European (144: 83.2%), followed by Maori (17: 9.8%), Pacific (7: 4.1%), African (2: 1.2%), Chinese (2: 1.2%), and Indian (1: 0.6%) (Table 3).

Table 3: Ethnicity of people using a syringe driver

Ethnicity	No	%		Ethnicity	No	%
European	144	83.2		Maori	17	9.8
Pacific	7	4.1		Chinese	2	1.2
African	2	1.2		Indian	1	0.6
Other	0	0				
Total	**173**	**100.1**				

Note ethnicity categories have been collapsed:

- European includes all people who identified as NZ European/Pakeha (73); European (60) and European Other (11).
- Pacific includes all people who identified as Samoan (5), Cook Island (1), and Tokelau (1).

2.4.5 Diagnosis

Of the 173 people who used a syringe driver, 131 (76%) had a cancer-related diagnosis while 42 (24%) had a non-cancer diagnosis. The indicative estimate of Te Omanga's total patients (N= 575) is that approximately 60% had a primary diagnosis of cancer and 40% had a non-cancer diagnosis. The syringe driver prescription outcome difference reveals that people with a cancer diagnosis were just under twice as likely to use a syringe driver (36%) as those people with a non-cancer diagnosis (20%) (Table 4).

Table 4: Cancer and Non cancer diagnosis use of a syringe driver

	Cancer diagnosis N=361		**Non cancer diagnosis N= 214**		**Total N= 575**	
	No	**%**	**No**	**%**	**No**	**%**
Using SD	131	36%	42	20%	173	30%
Not using SD	230	64%	172	80%	402	70%

Cancer-related diagnosis

Nearly all patients with a cancer-related diagnosis (131) had metastatic and/or invasive spread of the disease. The most common diagnosis for people using a syringe driver were bowel/rectum (27:20.6%), lung (22: 16.8%), followed by a diagnosis of breast cancer or pancreatic cancer with 10 (7.6%) cases of each (Table 5).

Table 5: Cancer-related diagnosis of people using a syringe driver

Diagnosis	No	Diagnosis	No	Diagnosis	No
Bowel/Rectum	27 : 20.6%	Lung	22: 16.8%	Breast	10 : 7.6%
Pancreas	10 :7.6%	Prostate	8 : 6.1%	Oesophagus	7 : 5.3%
Renal	7 : 5.3%	Neurological	7 : 5.3%	Ovary	5 : 3.8%
Stomach	4:3.1%	Liver	4: 3.1%	Nasopharynx	3:2.3%
Bone	3:2.3%	Lymphoma	2:1.5%	Melanaoma	2:1.5%
Adrenal	1:0.8%	Bladder	1:0.8%	Primary Unknown	8:6.1%

Non cancer diagnosis

The main non-cancer diagnosis (42) was related to heart disease (11) followed by neurological/CVA (8) and Alzheimer/dementia (7). Other diagnoses included respiratory/COPD (6), liver disease/cirrhosis of liver (4) and renal failure (2). One person had had chronic pancreatitis and one person had multiple sclerosis. Two people had multiple medical problems (Table 6).

Table 6: Non-cancer related diagnosis of people using a syringe driver

Diagnosis	Heart CHF	Neuro CVA	Alzheimer Dementia	Resp COPD	Liver Disease	Renal Failure	Pancreas	Multiple Sclerosis	Multiple Medical
Number	11	8	7	6	4	2	1	1	2
%	26.2	19.0	16.6	14.3	9.5	4.8	2.4	2.4	4.8

Cancer vs Non-Cancer Diagnosis

All analysis from this point on is based on the cancer- related/non-cancer related diagnosis categories. The rationale for this is two-fold:

1. Hospice services were initially established to provide palliative care, in the main, for people with a diagnosis of terminal cancer. Since 2001 when the New Zealand Palliative Care Strategy directed hospices to increase services for patients with non-cancer terminal diagnoses, the rate of referral has increased substantially. As reported above, in 2010, 76% of Te Omanga's new referrals had a primary diagnosis of cancer and 24% had a non-cancer diagnosis.

    > Note: The New Zealand Palliative Care strategy reported that in 2001 only 10% of people accessing hospice services had non-malignant diseases. (The New Zealand Palliative Care Strategy 2001 p 4).

2. Projections for the future anticipate that by 2026 the number of people requiring palliative care will increase by nearly 25% and just over double that in 2061 (p3). This projection was based on the assumption that 90% of patients with a cancer diagnosis will require palliative care and 40% of patients with a non-cancer diagnosis (p9). (http://www.healthworkforce.govt.nz/our-work/workforce-service-reviews/palliative-care).

    The Palliative Care Council projections, using a different methodology, estimate a growth of 23.5% by 2026 and suggest that 56.7% of adults (19,076) and 5% of children and young people (284) will require palliative care by 2026 (Palliative Care Council 2011 p 8).

2.4.6 Syringe driver use

Cancer-related diagnosis

Of the 131 people with a cancer-related diagnosis, 121 (92%) were using a syringe driver at the time of death. Ten (7.6%) people had used a syringe driver in the period prior to death but were not using a syringe driver at the time of death (Table 7).

Of the 131 people, 107 (81.7%) used a syringe driver for one episode only; 20 (15.3 %) people used a syringe driver on two separate occasions; while 4 (3%) people used a syringe driver on three separate occasions.

The length of time using a syringe driver ranged from 45 minutes (single episode of use until death) to 11 weeks (two episodes of use: 1st episode for 6 weeks followed by the 2nd episode 3 weeks later for a period of 5 weeks until death) (Table 8).

One person who used a syringe driver for 33 days until time of death was using 2 syringe drivers for the last 10 days of life, receiving 6 drugs including oxynorm, atropine, midazolam, dexamethasone, methotrimeprazine and ketamine via one line and a combination of dexamethasone and lignocaine through the second line.

Table 7: Syringe driver use at death: cancer and non-cancer diagnosis

	At death	Not at death	Total
Cancer diagnosis	**121:** **92%**	**10:** **8%**	**131:** **76%**
Non-cancer diagnosis	**35:** **83%**	**7:** **17%**	**42:** **24%**
Total	**156:** **90%**	**17:** **10%**	**173:** **100%**

A syringe driver was being used at the time of death most frequently for all patients (90%) who used a syringe driver (Table 7).

Table 8: Length of time using syringe driver - cancer and non-cancer diagnosis

	Less than 24 hrs	24-48 hrs	3- 7 days	8-16 days	17- 28 days	More than 28 days	Total
Cancer diagnosis	19: 14.5%	18: 14.0%	37: 28%	25: 19%	16: 12.25%	16: 12.25%	**131:** **100%**
Non-cancer diagnosis	12: 34%	7: 20%	11: 31.5%	5: 14.5%	0	0	**35:** **100%**

Non-cancer diagnosis

All the people with a non-cancer diagnosis used a syringe driver for only one episode. Thirty five (83%) of these people were using a syringe driver at the time of death (see Table 7). The length of time they were using the syringe driver prior to death ranged from 1.5 hours to 16 days (Table 8).

Syringe driver use: Cancer vs non-cancer diagnosis.

People with a non-cancer diagnosis used a syringe driver for shorter periods of time than those with a cancer diagnosis. Twelve patients (34%) with a non-cancer diagnosis used a syringe driver for less than 24 hours compared to 19 (14.5%) of patients with a cancer diagnosis. No-one with a non cancer diagnosis used a syringe driver for more than 16 days compared to 32 people with a cancer diagnosis (Table 8).

2.4.7 Medications

Drug combinations used in syringe driver: cancer diagnosis

Pain relief in the form of morphine or another opioid (methadone, fentanyl, or oxycodone) were part of the drug combination for 114 (87%) people. On three occasions morphine and another opioid were part of a three-drug combination with haloperidol or metoclopamide (antiemetics).

Eight people received one drug only via the syringe driver. Morphine was the drug administered in four instances while metoclopramide was used in two instances. The other single drugs used were midazolam and buscopan (Table 9).

Table 9: Drugs and drug combinations: cancer diagnosis

	1 drug	**2 drugs**	**3 drugs**	**4 drugs**	**5 drugs**	**6 drugs**	**7 drugs**	**8 drugs 2 lines**	**Total doses**
Morphine **(analgesic)**	4	15	42	17	11		1		90
Other opioid **(analgesic**		4	17	3	5		1	1	31
Metoclopramide **(antiemetic)**	2	10	33	15	11		1		72
Midazolam **(anxiolytic)**	1	11	27	15	6			1	61
Haloperidol **(antipsychotic)**		2	20	12	11		1		46
Methotrimeprazine **(antiemetic)**		2	14	8	10		1	1	36
Cyclizine **(antiemetic)**		3	12	4	7		1		27
Clonazepam **(anticonvulsant)**			8	6	4		1		19
Atropine **(antisecretory)**			7	6	2			1	16
Dexamethazone		1	2	2	2			+1	8
Buscopan **(abdominal colic)**	1				1				2
Phenergan **(antipruritic)**			1						1
Ketamine **(analgesic)**								1	1
Lignocaine **(analgesic)**								+1	1
No. of Patients	**8**	**24**	**61**	**22**	**14**	**0**	**1**	**1**	**131**
%	**6**	**18**	**47**	**17**	**11**	**0**	**0.5**	**0.5**	**100**

Drug combinations used in syringe driver: non-cancer diagnosis

Only one person received a single medication via the syringe driver. Most people (17:42) received a combination of three drugs in the syringe driver. Twelve people (28.6%) were given a combination of two drugs while another eleven (26%) people received a combination of four drugs. One person was given a combination of six drugs.

Pain relief in the form of morphine or other opioid: fentanyl or oxycodone - were part of the drug combination for 35 (83%) people. Midazolam (anxiolytic) was used for 35 people and in 29 instances this was in combination with morphine or another opioid. The most common three-drug combination included morphine or other opiod + midazolam + haloperidol (6:17) followed by morphine + midazolam + atropine (4:17) (Table 10).

Table 10: Drugs and drug combinations: non_cancer diagnosis

	1 drug	2 drugs	3 drugs	4 drugs	5 drugs	6 drugs	Total doses
Morphine **(analgesic)**		7	13	6		1	**27**
Other opioid **(analgesic)**		4	2	2			**8**
Midazolam **(anxiolytic)**		7	16	11		1	**35**
Haloperidol **(antipsychotic)**		1	6	5			**12**
Metoclopramide **(antiemetic)**	1	2	3	4		1	**11**
Methotrimeprazine **(antiemetic)**		1	3	6		1	**11**
Atropine **(antisecretory)**			7	4			**11**
Clonazepam **(anticonvulsant)**		2	1	2			**5**
Cyclizine **(antiemetic)**				2		1	**3**
Dexamethazone				2		1	**3**
No. of Patients	**1**	**12**	**17**	**11**	**0**	**1**	**42**
%	**2**	**29**	**41**	**26**	**0**	**2**	**100**

2.5 Discussion

A review of current practice about prescribing a syringe was completed to provide a context for this study. It provides a 'snapshot' of medications prescribed via a syringe driver for patients who receive care from Te Omanga Hospice (excluding patients residing in a rest-home) from 1 January 2012 to 31 December 2010. During this time some data entry processes changed so some extrapolation of data has contributed to this analysis.

One hundred and seventy three patients, cared for by Te Omanga Hospice in the Inpatient Unit or at their home during this period, had a syringe driver prescribed to administer drugs to relieve symptoms (note: patients residing in a rest-home were not included in this study). On 31 December 2010, 166 (96%) of these people had died and seven (4%) were still alive. Te Omanga Hospice provided care for a total of 575 patients referred to its comprehensive and partnership programmes during this year. The extrapolated estimate is that about 30% of all patients used a syringe driver during this year.

Of the total patients (575) who received care during 2010, 361 patients (63%) had a cancer-related diagnosis and 214 (37%) had a non-cancer-related diagnosis. Of the 173 people who were prescribed a syringe driver 131 (76 %) had a cancer-related diagnosis while 42 (24%) had a non-cancer diagnosis. This means that the syringe driver use outcome difference is that people with a cancer diagnosis were just under twice as likely to use a syringe driver (36%) as those people with a non cancer diagnosis (20%).

All of the 12 patients in this study exploring patients' and caregivers' experience had a cancer-related diagnosis.

Appendix 3: Upper South A Regional Ethics Committee Approval Letter

Health and Disability Ethics Committees

Upper South A Regional Ethics Committee

c/- Ministry of Health

Montgomery Watson Building

6 Hazeldean Road

Christchurch

Phone: (03) 974 2304

Email: uppersoutha_ethicscommittee@moh.govt.nz

25 May 2011

Ms Val Norton
Te Omanga Hospice
PO Box 30814
Lower Hutt 5040

Dear Ms Norton

Ethics ref: **URA/11/05/014** **(please quote in all correspondence)**
Study title: **Syringe Drivers use in Palliative Care**
Investigators: **Ms V Norton, Ms E Taylor**

This study was given ethical approval by the Upper South A Regional Ethics Committee. A list of members of the Committee is attached.

Approved Documents

- Semi-structured interview schedule version 2 dated May 2011
- Information sheet and consent form version 2 dated May 2011

This approval is valid until 30 June 2012.

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Final Report

A Final Report is required at the conclusion of the study. The Final Report Form is available at www.ethicscommittees.health.govt.nz .

We wish you all the best with your study.

Yours sincerely

Alieke Dierckx

Administrator

Upper South A Regional Ethics Committee

Uppersoutha_ethicscommittee@moh.govt.nz

List of members of the Upper Region A Ethics Committee, May 2011

Liz Richards (Chair)	Consumer Representative Lay member	Female
Murray Cameron	Health Researcher Health Professional Member	Male
Angelika Frank-Alexander	Community Representative Lay member	Female
Allison Franklin	Consumer representative Lay member	Female
John Horwood	Biostatistician Lay member	Male
Ellen McCrae	Pharmacist Health Professional member	Female
Edie Moke	Maori representative Lay member	Female
Barbara Nicholas	Ethicist Lay member	Female
Christine Robertson	Health Practitioner Health Professional member	Female
Russell Scott	Health Practitioner Health Professional member	Male
Jane Ward	Researcher Health Professional Member	Female

Angelika Frank-Alexander and Russell Scott were not present at the meeting of 16 May 2011.

16 May 2011

Alieke Dierckx (Administrator)

Date

Appendix 4: Study Information Sheet

Te Omanga Hospice letter head. Research Fellow business card attached.

Information Sheet: Te Omanga Patient and Caregiver Syringe Driver Study: Introduction

Te Omanga Hospice created the Murray Bond Research Fellowship in March this year to continue its strong research foundation. Valerie Norton holds the inaugural Fellowship to carry out a study exploring patients' and caregivers' experiences of using a syringe driver. Four nurses, Kathy Gill, Shelley Bignell, Bronwyn Lindsay and Raelee Jensen are helping with the interviews.

If you/your caregiver advise the hospice staff that you wish to participate, the Principal Investigator or a research nurse will contact you to seek your formal consent and arrange times for interviews.

Participation in this study is voluntary (your choice). If you decide not to take part, this will have no effect on your ongoing healthcare.

Background information about the study

Syringe drivers are regularly used in palliative care to administer drugs to manage symptoms such as pain, nausea and vomiting when a person is unable to swallow. There has been a lot of research telling us about the technical aspects of syringe drivers and the changes that resulted. There have been no specific studies asking patients and their caregivers what they think about this – both the benefits and the shortcomings - despite a call for this information over the last few years.

Te Omanga is responding to this call. We want to know what you understand and what using a syringe driver means for you. Over the next six months we will be talking to about 15 patients and their main caregiver. The study received ethical approval from the Upper South A Regional Ethics Committee in May 2011.

Your participation in this study is confidential and no material that could identify you will be used in any reports on this study. You can choose a name to be used in the study so that the report reads easily rather than using a numerical identifier. All written notes and voice recordings will be held in a locked filing cabinet when not being used for transcribing. All electronic data will be stored in password-protected computers. When we meet we will talk about what's involved and sign the consent agreement then we will do the interview.

The interview process: We have a short interview guide to keep us focussed on the subject. We can take as much or as little time as you want – probably about 20-30 minutes. Soon after - about a week - our conversation will be transcribed. I will send you a copy of that so you can check that I have got it right.

Then alongside all the other interviews, I will look at what the common factor are that people talk about.

Outcomes of the study: Early next year Te Omanga Hospice will develop an information pamphlet for patients and care givers and we will talk to staff so that they know what you all want done about this. We will also send a report for publishing in palliative care journals and present our study at palliative care conferences.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
Telephone: (NZ wide) 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

You can contact me any time if there is anything more you want to know:
04 566 45 35 or mobile 027 2867 014

Appendix 5: Study Consent Form

Te Omanga Letterhead

Patient Consent Form Te Omanga Syringe Driver Study:

Syringe Driver use in Palliative Care: Patients and Caregivers understandings and experiences

I have had this project explained to me by Valerie Norton principal researcher. I have read and I understand the information sheet for volunteers taking part in the study designed to provide information about patients' and caregivers' experiences and understandings about using a syringe driver to administer palliative medications. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I have had time to consider whether to take part in the study.

I understand that:

- Taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my continuing health care.
- My participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- You are also interviewing my family to talk about my using a syringe driver.
- Information collected during the research will be held in a secure place
- The interview will be recorded.
- I will receive a transcript of the interview.
- This signed agreement will be held securely on file by Valerie Norton.
- I will receive a copy of the study findings.

I hereby consent to participating in this study..

Name...................................... **Signed**: .... **Date**…………….

Statement of confidentiality: Principal Investigator

I, Valerie Norton, Principal Investigator, undertake to ensure that any research notes or reports resulting from this study will not identify you as the source of that information and that all information collected for this research will be held securely.

Signed: Date …………….

Te Omanga Letterhead

Caregiver Consent Form Te Omanga Syringe Driver Study:
Syringe Driver use in Palliative Care: Patients' and Caregivers' understandings and experiences

I have had this project explained to me by Valerie Norton, Principal Researcher. I have read and I understand the information sheet for volunteers taking part in the study designed to provide information about patients' and caregivers' experiences and understandings about using a syringe driver to administer palliative medications. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I have had time to consider whether to take part in the study.

I understand that:

- Taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my continuing health care.
- My participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- Information collected during the research will be held in a secure place
- The interview will be recorded.
- I will receive a transcript of the interview.
- This signed agreement will be held securely on file by Valerie Norton.
- I will receive a copy of the study findings.

I hereby consent to participating in this study.

Name....................................... **Signed**: ....**Date**……………

Statement of confidentiality: Principal Investigator

I, Valerie Norton, Principal Investigator, undertake to ensure that any research notes or reports resulting from this study will not identify you as the source of that information and that all information collected for this research will be held securely.

Signed: **Date …………….**

Appendix 6: Study Interview Schedules

Patient interview schedule Te Omanga Hospice Letterhead

Pseudonym chosen is xxxx
Personal details (from care plan)
Name
Age diagnosis
Length of time with Te Omanga Comprehensive programme.

Introduction

- Confirm that now is a good time to talk.
- Provide brief information about self .
- Recap informed consent and use tape recorder.
- General conversation about patient, family, living in Hutt Valley/Wellington.

Syringe Driver conversation

- So now tell me how you come to have a syringe driver now. How long have you had it?
- What do you know about your syringe driver? .What does it do? .How does it work?
- How did you get to know this? Was that enough information?
- Do you know what drugs are being used? .And what do they do?
- What difference has it made?
- Now I want to understand what it means for you that you have a syringe driver to deliver the drugs you need?
- How does having a syringe driver make you feel?
- Now I want to know what you think other people need to know. Thinking about another person starting out with the Hospice, what would you like them to know about syringe drivers and their use? What do you think they need to know?
- Now that's about all for me. Is there anything else you would like to say? Anything you want to ask?

Debrief and Conclusion

Thank you. I appreciate very much having this opportunity to talk to you. If you want to talk some more about this you can ask any of the nurses to get hold of me.

Note: the interview will use prompts such as "Can you tell me more about that." "What does that mean for you? "

Caregiver Interview schedule Te Omanga Hospice Letterhead

Pseudonym chosen is xxxx

Personal details from care plan
Name
Caregiver to patient

Introduction

- Confirm now is a good time.
- Provide information about self.
- Recap informed consent and tape recorder.
- General conversation about patient, family, living in Hutt Valley.

Syringe Driver conversation

- Xxx has had the syringe for a couple of days now. Tell me when you first heard about it – did you know what they were talking about? .Is it what you expected? Thinking about then and now – do you see it the same or is there anything different?
- How did (patient's name) come to have a syringe driver now?.
- What do you know about syringe drivers? What does it do? How does it work?
- How did you get to know this? Is that enough information?
- Do you know what drugs are being used? And what do they do?
- What difference has it made?
- Now I want to understand what it means for you that (patient's name) needs a syringe driver to deliver the drugs she/he needs.
- What do you think it means for (patient's name)?
- What do you think it means for your family?
- How does (patient's name) having a syringe driver make you feel?
- Now I want to know what you think other people need to know. So thinking about another family starting out with the Hospice, what would you like them to know about syringe drivers and their use? What do you think they need to know?

Let a bit of time pass to consider then prompt: Looking back, has it been helpful?

- Now that's about all for me. Is there anything else you would like to say? Anything you want to ask?

Debrief and Conclusion

Thank you. I appreciate very much having this opportunity to talk to you. If you want to talk some more about this you can ask any of the nurses to get hold of me.

Appendix 7: Nurse Interview Training

Notes on interviewing **Valerie Norton**

The integrity of the study is dependent on the information provided in the patient and caregiver interviews. The research interview is quite similar to a nursing interview with the purpose to elicit information without asking too many direct questions and without asking leading questions suggesting ways of responding.

To many casual observers, research interviewing does not seem to require a great deal of skill: *"It's so easy. Just having a chat to a few people for an hour or so."*

The skill of the interviewer is demonstrated when they make it look easy. The substantial work is invisible in the moment and is a consequence of sound planning and preparation underpinned by respect for, and sensitivity to, the person's dignity and humanity.

- Being familiar and confident with the technology:
  How the tape/voice recorder works.
  The tape is prepared and set to go.

- Being familiar with the interview schedule and confident to be flexible if the interviewee speaks about an item earlier than it is in the interview schedule.

- Being prepared to respond for comments and experiences of the interviewee eg "I'm feeling really frightened"; "I'm really scared"; "I feel really sad ".

This is where the interviewer is the fundamental research tool, working simultaneously with both the content and the process of the interview. .Starting with the process, actively building the interview relationship, then initiating the interview questions. The interviewer's sensitivity to the person's responses, both verbal and non-verbal, involves a deep level of concentration and presence. Being sensitive to energy levels, listening deeply to what is being said (and what is not being said), and developing new lines of the interview "talk" developed from the information just obtained.

Significantly what is not being said may be expressed in a non verbal way. This may be released by a gentle touch, eye connection, soft words providing quiet recognition that this is a vulnerable time.

I describe this as being present, listening with my whole body, noticing the person's whole body. Sometimes I talk about this as seeing with my ears (what does this sound like) and hearing with my eyes (what does this look like) and keeping with the specific topic until I am sure I am not making any assumptions about the meaning of what is being said. In other words, I am confident I have captured the person's experience and their intention. Some people say that it can take probing with a why/how/tell me more type question 5 times.

A semi-structured interview uses an interview guide outlining the set of issues to be explored and serves as a check list during the interview to ensure all the topics are covered. This process keeps the interaction focussed, at the same time allowing individual perspectives and experiences to emerge.

Syringe driver Interview Schedule

Each of you will have your own words. I have put some of my words as an example.

Introduction

- Confirm that now is a good time to talk.

Hello James. I'm xxx - is now ok to come and talk?

- Provide brief information about self.

OK , Let me tell you a wee bit about me. As I said my name is xxxx, I'm a nurse here at Te Omanga and I'm helping with the research study. I've worked here for about 3 years and I live about 3 ks away in Petone.

- Recap informed consent and use tape recorder.

Now you signed the consent form yesterday – I have that here – still happy to go ahead? And OK about the tape recorder – that means you have my undivided attention and I don't have to make notes.

- Establish pseudonym

We also talked about what name you would like to use when this study is written up. You gave me xxxx as the name to be used for you. Is that still OK?

Syringe driver conversation

Start with a general broad comment based on information you know about the person:

"How long have you lived in Lower Hutt." <u>Perhaps make a personal connection:</u> *"I used to come to Lower Hutt to play hockey when I was at school in Masterton – that's a long time ago now!"*

As I said I am doing this study about syringe drivers. Shall we get started? First, can you tell me how you came to have a syringe driver?

<u>Prompts here might be:</u>

When did you first hear about it? Did you know what they were talking about? What did you think about that?

What does t feel like? Are you aware of it?

<u>Respond to any non-verbal cues.</u> "You look a bit worried....

What do you know about syringe drivers? What does it do? How does it work?

How did you get to know this? Did someone explain all this to you?

Prompt: Was that enough information? Respond to any comment or questions eg Would you like to know more about it ?

Do you know what drugs are being used and what they do?

What difference has this made?

Now I want to understand what this all means for you?

What does it mean for you that you have a syringe driver to get the drugs you need?

It is important here to go slowly here, noticing what is happening and responding. Eg. You look a bit worried. Does that worry you?

That seems a bit hard to talk about – we can leave it there for now if you like.

It may be that you shift focus for a short time eg Is this your grand daughter? (looking at a photograph) or comment on something in the garden or birds.

Then refocus: Can we come back to syringe drivers again?

How does having a syringe driver make you feel?

Is that a good feeling? Is that OK?

Now we are shifting to think about other people. Is that OK?

Thinking about another person starting out with the Hospice, what would you like them to know about syringe drivers and their use? What do you think they need to know?

Prompt: Like: has it been helpful to have a syringe driver?

Return to the “hard” topic above :

Now just before we finish can we go back and re-touch on what it all means for you? Can we talk some more about that now?

What does it mean for you that you have a syringe driver to get the drugs you need?

There might be quite a long silence – again noticing what else is happening- be careful not to fill the silence too soon. Sometimes a person might be on the edge of speaking. You will see by the expression on their face. An encouraging smile – or a touch to their hand or gentle squeeze of their hand, a murmur of support, might help..

At the same time respect the boundary of their experience.

Now that’s about all for me.

Is there anything else you would like to say? Anything you want to ask?

Debrief and Conclusion

Thank you xxxx. I appreciate very much having this opportunity to talk to you. If you want to talk some more about this you can ask any of the nurses to get hold of me.

Sometimes as soon as the tape recorder stops the person starts talking again. If it is important research information, I would ask if I can turn the tape recorder on again. I would then recap for them what they have said and say this is important. Can you tell me more about that?

If something has been talked about in the interview that you think needs dealing with in terms of their care, I would say “You said in the interview that you wanted …. “ Or “were worried about ……” I would ask “Would you like me to talk to the Dr/ Nurse about that.” Or I might give them the words how to deal with it for themselves eg “You could ask Dr …. about that.” “Would you like me to alert her/him that you want to talk about this?”

Remember all information provided in the research interview is confidential. Even if you think it is very important, unless the person says so, you can not reveal the information.

It is very important to “be with” the person, to not make judgments and to not make assumptions about their experience, to keep gathering information until you have enough understanding not to make assumptions. At the same time be respectful of their boundaries. Acknowledge if it is difficult to talk about the topic e.g. ask “Is that hard to talk about? Do you want to leave that for now? “

All the time noticing non verbal cues – these are often more revealing about the experience than the verbal conversation and indicate that the person might want some help with this. Be careful not to make a comment too soon. Be comfortable with their silence – the silence might be filled with thoughts about how to speak and what to speak about. You will likely see this happening on their face.

Some interviewing skills snippets

- Eliciting information without asking too many direct questions, without leading or suggesting ideas to the respondent.
- Honed listening skills to unlock the insights.
- Being alert enough to hear mundane or everyday speech in new ways, to question and go beyond the obvious.
- Sensitivity to notice non-verbal indicators of emotional states, and probe appropriately.
- Creating enough trust and empathy for respondents to feel safe in expressing their private thoughts and feelings.
- Using non-verbal techniques such as music, images and actions to access the ‘knowledge’ people have stored as a series of impressions or feelings, to avoid premature rationalisation.
- Keeping people focussed on narrowly-defined objectives, maintaining interest and energy and exploring topics in different ways, and
- Managing projects that have extensive social, environmental, or economic consequences – transport issues for example, maintaining the breadth of vision, while still providing the insights clients need.

All this requires versatility, an ability to be non-judgemental, and enough self-awareness to be able to temporarily set aside your own preconceptions. Being able to think on your feet is also essential.

The researcher has to be keenly aware of the importance of emotion as an essential component of motivation and decision-making, and has to be willing to work with emotional issues.

The qualitative way of thinking must be fluid and the interviewer prepared to change the nature of the questions that need to be asked. Interviewing provides the basic materials for analysis. It follows that the richer and more creative the interview, the more potential there is for making meaning in the analytical process.

The quality of a research interview is affected by the quality of the interviewer's presence – the extent to which they can give their attention fully to somebody else. This ability is perhaps best described as a qualitative way of being. It is possible to know all the theory of qualitative research and not be able to do it at all. It is also possible to do qualitative research by following the practices and guidelines and to do it well, but the most challenging projects require an engagement in the process at every level.

Some things to think about:

What will I say/do if someone says: Does this mean I'm going to die? Or some such variation.

Appendix 8: Interviewer and Transcriber confidentiality Agreement

Te Omanga Hospice Letterhead

Te Omanga Hospice Research Study: Syringe Drivers use in Palliative Care: Patients' and Caregivers' understandings and experiences

Confidentiality Agreement

Statement of confidentiality: Name

I, xxxxx xxxx , Nurse Interviewer, will keep confidential all information recorded on audio tapes and research notes I take, gathered for Te Omanga Hospice Research Study: Syringe Drivers use in Palliative Care: Patients' and Caregivers' understandings and experiences.

Signed: Date …………….

Xxxx xxxxx

Name

Te Omanga Hospice Letterhead

Te Omanga Hospice Research Study: Syringe Drivers use in Palliative Care: Patients' and Caregivers' understandings and experiences

Transcribing Confidentiality Agreement

Statement of confidentiality: Name

I, xxxx xxxxx , Research Transcriber, undertake to ensure that any information contained in the audio tapes I am transcribing will be kept confidential and that all information collected for this research will be held securely.

Signed: Date …………….

Appendix 9: Te Omanga Family Caregiver Programme: A Map through the Forest

Te Omanga Hospice
Te Whare Manaaki Tangata

Support for Family/Friends as Carers

'A Map through the Forest'

Two hour sessions over three weeks

1.30 to 3.30 pm OR 5.00 to 6.30 pm

Wednesday 8 February
15 February
22 February

Wednesday 8 February 2012
1.30 to 3.30 pm OR 5.00 to 6.30 pm

SUPPORT FOR THE FAMILY

- What is palliative care?
- What changes can be expected at the end of life?
- How to manage the changes.
- Self-care/resilience.

Wednesday 15 February 2012
1.30 to 3.30 pm OR 5.00 to 6.30 pm

PRACTICALITIES

- Moving around safely. Ways to avoid a fall.
- Equipment to make moving easier.
- Hygiene and skin cares.
- Medications.
- Massage.

Wednesday 22 February 2012
1.30 to 3.30 pm OR 5.00 to 6.30 pm

CHALLENGES

- Experiencing loss.
- Having a difficult conversation.
- Planning wills and funerals.
- Social issues.

To enroll please contact
the Education Secretary on 566 6158
or secretary@teomanga.org.nz

Title: Te Omanga Hospice syringe driver use in palliative care:
patients' and family caregivers' experiences
and understandings
Author: Valerie Norton
Publisher: Te Omanga Hospice Trust
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