



**THE UNDERSTANDING, PERCEPTIONS AND EXPECTATIONS OF FAMILIES OF
TERMINALLY ILL PATIENTS ON INTRODUCING THE SYRINGE DRIVER IN A
PALLIATIVE CARE UNIT**

By

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ABSTRACT

The syringe driver is a battery-operated device which accurately delivers a continuous subcutaneous infusion of a combination of medication to alleviate symptoms, such as pain, nausea and vomiting, noisy moist breathing and preterminal restlessness. The researcher who works in a palliative care unit in Cape Town noticed the ambivalence and negative attitudes from family members regarding the use of the syringe driver. This gave rise to distress, conflict and ambivalence in patients and between family members.

This study aimed to gain insight into the understanding, perceptions and expectations of families of terminally ill patients commenced on a syringe driver in a palliative care unit.

A descriptive, qualitative research method was employed using semi-structured interviews, diaries, observation and documentation as the data collection methods. Data was coded and arranged into themes. Thematic analysis and coding were used to analyse the data during this study.

This study found that the lack of education and written information were the two major contributing factors towards negative attitudes causing ambivalence in family members whose relatives were on a syringe driver. This study also highlighted the need for quality improvement control when using the syringe driver in the palliative care unit. The need for continuous education and written information and support for the immediate and extended-family members was evident.

KEY WORDS: Syringe driver, Symptom control, Family members, Terminally ill, Palliative care unit.

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DEDICATION

I dedicate this thesis in memory of my two friends and colleagues:

Sister Pat Lello

Died 2005 in a car accident, returning home from work.

Sister Ester Pepper

Died 2010 from Myeloma.

Thank you for teaching me perseverance when life gets difficult.

ACRONYMS AND ABBREVIATIONS

Hospice Palliative Care Association	HPCA
International Association for the study of pain	IASP
South Africa Medicine Formulary	SAMF
United States Agency International Development	USAID
World Health Organisation	WHO

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CHAPTER 1

CONTEXTUALISATION AND ORIENTATION OF THE STUDY

1.1 INTRODUCTION

This research study describes the use of the syringe driver within the palliative care setting. The global, African and South African contexts of the use of the syringe driver will be discussed. The history of the syringe driver will be described. The research question, research problem and the background to the research will be expanded on. Additionally, the significance and justification for the research, the study aims and the objectives will be explained. The design and delineation of the study, as well as the terms and concepts used in the study, will be described.

The syringe driver is a battery-operated, medical device which accurately delivers a continuous, subcutaneous infusion of one or a combination of medication to alleviate a variety of symptoms. It is commenced as the patient's condition deteriorates, generally towards the end of life when the patient becomes too weak to swallow oral medication (refer 2.7). The syringe driver is frequently used in the in-patient unit where this research study took place. This medical device can also be administered to patients at home. Not all palliative care patients are commenced on a syringe driver. Currently, little is known about the understanding, perceptions and expectations of family members of terminally ill patients when commencing the patient on a syringe driver in a palliative care unit.

1.2 PALLIATIVE CARE

The World Health Organization (WHO) (2002) defines palliative care as an approach that improves the quality of life of terminally ill patients. Support is given by an interdisciplinary team (refer 2.17) to the families and the patients through managing the physical, psychological, emotional, social and spiritual symptoms. The interdisciplinary team consists of doctors, professional nurses, social workers and spiritual counsellors (WHO cited in Simon, 2009:264). All staff are palliative care trained. Palliative care is the active, holistic care of patients with advanced progressive illness in which the management of pain and other symptoms is provided (McQuoid-Mason & Dada, 2011:212).

The Hospice Palliative Care Association (HPCA) affirms life and regards dying as a normal process. Palliative care aims to enhance the quality of life and positively influence the course of the illness, by providing relief from pain and other distressing symptoms. It intends to neither hasten nor postpone death (HPCA, Clinical Guidelines, 2012:10).

The syringe driver has been used in palliative care symptom management for more than thirty (30) years. Depending on the patients' symptoms and as their symptoms change, patients are commenced on a syringe driver (Flowers & Macleod, 2005:54). The stage at which a patient is commenced on the device can vary from several months, to a few days or less than an hour before death. Patients are admitted to an in-patient unit and commenced on a syringe driver and can be discharged home with the syringe driver in situ. A family member needs to accept responsibility for the syringe driver and must be willing to be trained how to reload the device at home.

1.3 THE USE OF SYRINGE DRIVERS AT THE RESEARCH SETTING

The name of the palliative care unit has been withheld to protect the confidentiality and anonymity of the participants and patients. The palliative care unit is situated in a suburb of Cape Town. It was opened in 1980 and has continued to play a leading role in palliative care, both regionally and nationally. This unit serves the greater part of the Cape Town community (Hickman, 2008:30). It has a ten-bed in-patient unit, where the study took place. It also has another twenty-bed, in-patient unit in another suburb situated in Cape Town. The two in-patient units are used to admit patients for symptom control, family respite and terminal care. Each unit has a palliative trained doctor, professional nurses, carers, social workers, spiritual counsellors and volunteers working as part of the interdisciplinary team (refer 2.17).

Community professional nurses from the palliative care unit provide nursing care to the patients in their homes in most of the suburbs of Cape Town. They provide nursing care for approximately seven-hundred and fifty (750) terminally ill patients, who are looked after by their families at home. The syringe driver is frequently used both at home and in the in-patient units for the control of symptoms, such as pain, nausea, vomiting and restlessness. Patients are limited to a two-week stay in the in-patient unit, due to the high demand by other very ill patients to be admitted. The patient may be discharged with the syringe driver in situ. In such cases a family member is trained to administer the prescribed dosage at home. The community professional nurse monitors the use of the syringe driver in the patient's home.

1.4 THE RESEARCH QUESTION

What are the understanding, perceptions and expectations of families of terminally ill patients on the use of a syringe driver and the effect of the medication delivered?

1.5 THE RESEARCH PROBLEM

Family members of terminally ill patients seem to have little understanding of the syringe driver. They are unaware of the implications of the use of the syringe driver and the possible side effects of the medication used. During the many years of the researcher's experience of working in a palliative care unit, the comment that it is "an injection which might hasten death" was heard on numerous occasions. This comment underscores the lack of knowledge of family members with regards to information pertaining to the syringe driver. This perception gave rise to the interest that the researcher developed in this research topic.

1.6 BACKGROUND TO THE RESEARCH PROBLEM

The researcher who works in a palliative care unit at a Cape Town hospice noticed the ambivalence and negative attitudes from family members regarding the use of the syringe driver. This gave rise to distress, conflict and ambivalence in patients and between family members.

The syringe driver is commenced when the patient's condition has deteriorated and the patient is very weak and unable to swallow oral medication, and either has severe pain, nausea and vomiting, or experiences restlessness. Some family members, who were not present when the syringe driver was commenced, assumed that the deteriorating condition of the patient was due to the medication in the syringe driver.

Other family members were concerned about the use of the syringe driver and made comments, such as "It is an injection which might hasten death." Such misconceptions about the syringe driver could engender fear about the service the palliative care unit provides and lead to conflict and ambivalence if all family members do not agree on the use of the syringe driver. This adds to the stress burden of the family during an already stressful time when a family member is terminally ill. A verbal explanation of the syringe driver is given to the family who are present before commencing the device, but this does not seem to inform them enough. The purpose of the syringe driver is to deliver essential medication for symptom control to ensure patient comfort and dignity when the patient is too ill to take medication orally.

The identification of the research problem stems from the fact that some family members, patients and other medical professionals are not educated in the skills of palliative care. Doctors and nurses have been confused, on the one hand, between their duty to care for the patient and, on the other hand, the concern regarding the misconceptions about the legal rights of the patients. The duty of the medical and nursing staff is to relieve agonising pain and other distressing symptoms, for example restlessness. This leads to a reluctance to administer the necessary medication to a terminal patient, who might suffer a "bad death" in severe pain and struggling to breathe or may have terminal restlessness (Browde, 2011:7).

David (2010:259) acknowledges the fact that the lay person may feel that pain medication "hastens death". However, everyone has an ethical right to demand adequate pain control and relief from distressing symptoms.

1.7 SIGNIFICANCE AND JUSTIFICATION OF THE RESEARCH

Family members of terminally ill patients have not been exposed to syringe-driver technology as a method of controlled administration of medication. It is unclear what the family members' experiences of the use of the syringe drivers are. It is also not known how they view this device and what its impact on them is during an already stressful time in their lives. A holistic approach to nursing must include the patient's family, as each family member contributes towards the life experience of each other (Pera & van Tonder, 2011:117).

This study will provide insight into the understanding, perceptions and expectations that family members of terminally ill patients have about the syringe driver. It will also determine the effects of the medication. It will attempt to reduce the ambivalence felt by the families towards the use of a syringe driver. As a result of this study, it is hoped, firstly, that the patient will be commenced on the syringe driver with the full support and confidence of their families; and, secondly, that findings of the study will give the medical staff insight into what is understood and perceived by the family members when the terminally ill patient is commenced on the syringe driver.

1.8 RESEARCH AIM

The aim of this study is to determine the understanding, perceptions and expectations of families of terminally ill patients on commencing a syringe driver in a palliative care unit.

1.8.1 Research Objectives

The objectives of this research are:

- To assess the understanding, thoughts and feelings of families of terminally ill patients' on the use of the syringe driver.
- To assess the perceptions and expectations of families of terminally ill patients of the effect of the medication used in the syringe driver.

1.9 THE THEORETICAL FRAMEWORK

Orem (2001) refers to her conceptual model as the self-care deficit theory of nursing. This can be applied to palliative care. In the case of a life-limiting illness, the individual may no longer be capable of performing self-care actions to maintain life, health and wellness. Nursing is a health-care service provided to patients with self-care deficits. This also assists the families to help patients satisfy their self-care demands (Orem, 2001, cited in Desbiens, Gagnon & Fillion, 2011:2115). These were the reasons why this framework seemed most appropriate for this study.

1.9.1 Major Assumptions

Orem (2001) identified the following factors underlying the general needs of nursing:

- All humans need continuous input towards themselves and the environment to live and function.
- Humans exercise a form of self-care or care of others, according to the identified needs.
- Humans experience limitations in the process of performing self-care.
- Humans discover and develop ways to identify needs and perform self-care towards self and others.
- A group of humans form structured relationships, allocate responsibility and provide care to group members (Orem, 2001, cited in Alligood & Tomey, 2010:272).

1.9.2 Theoretical Assertions

There are three theoretical assertions which are:

- Theory of nursing systems.
- Theory of self-care deficit.
- Theory of self-care.

Nursing is the action of nursing systems, designed and produced by nurses for people with health limitations in self-care (Orem, 2001). Healthy individuals know how to take care of themselves (self-care). If they are dependant in some way, family members take on the responsibility (dependent care). If the individuals need special care, the family member must acquire special skills to provide that care (therapeutic self-care) (Orem 2001, cited in Burns & Grove, 2009:138). This seemed appropriate for this study. Considering when the patient is in the in-patient unit, the nurse commences the syringe driver to administer the medication. If the patient is discharged then a family member must accept the responsibility and acquire the knowledge to operate the syringe driver at home. Self-care deficit is related to the action of health-care limitations that the person presents. It provides a guide for what form of self-care is needed for the patient (Alligood & Tomey, 2010:274).

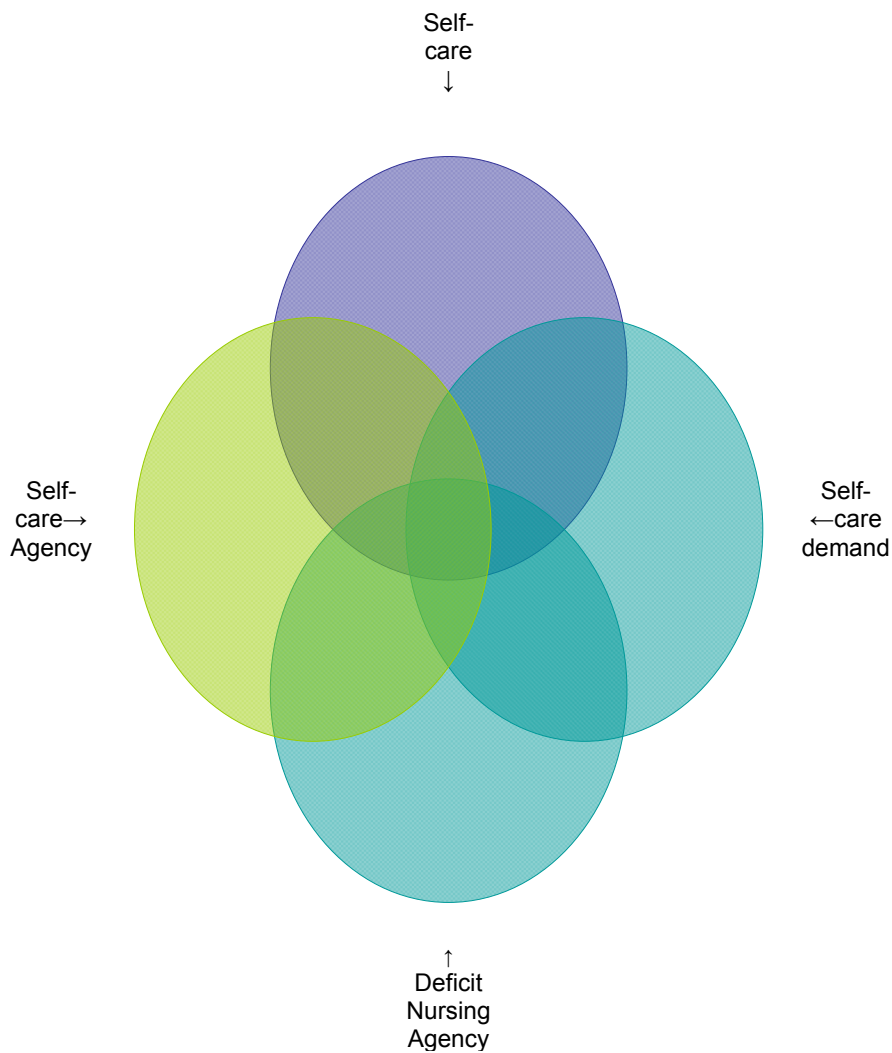


Figure 1.1 A Conceptual framework for self-care deficit (adapted from Alligood & Tomey, 2010:275).

1.9.3 Nursing Systems

This theory proposes that nursing is an action system. The (nursing agency) includes concepts of deliberate action. In this case the action is the commencing of the syringe driver to control distressing symptoms. This nursing system is produced for individuals who need dependent care.

Table 1.1 Basic nursing systems (adapted from Orem, 2001, cited in Alligood & Tomey, 2010:273).

Nurse Action	Reasons	Families
Accomplishes patients' therapeutic self-care	Reasons for commencing the syringe driver	Families understanding, perceptions, expectations of the syringe driver
Compensates for patients inability to engage in self-care	To control pain, nausea and vomiting, restlessness and noisy moist breathing	Assists patient as required to control symptoms
Supports and protects the patient	Contains the distressing symptoms	Accepts the care and assistance from the syringe driver.

1.10 DELINEATION OF THE RESEARCH

Family members of terminally ill patients who are commenced on a syringe driver were included in this study. As participants were adults over the legal age of 18 years old, no proxy consent was needed. Interviews were conducted in English and/or Afrikaans. In a situation where the family speaks Xhosa or any other languages, other than the aforementioned, the help of an interpreter was available. All patients have access to the syringe driver, regardless of the language they speak.

1.11 RESEARCH DESIGN

A descriptive, qualitative approach was used to gather information from participants who are families of terminally ill patients on their understanding, perceptions and expectations of the use of the syringe driver.

1.11.1 Population sample

Purposive sampling was used to select family members of terminally ill patients who were commenced on a syringe driver. Only families, who were in the in-patient unit during the time of the study, were considered for inclusion in this project. Purposive sampling is also known as selective sampling. Only family members who had some knowledge of the syringe driver were selected (Brink, van der Walt & van Rensburg, 2012:141). Family members, who were too distressed, due to the preterminal condition of the patient, were not selected to be interviewed. More than one family member from a patient could partake in the study. The participants included eleven (11) family members from eight families.

1.12 METHODS OF DATA COLLECTION

The following methods were used to collect the data, individual interviews, group interviews, diaries, observation and documentation.

1.12.1 Individual Interviews

- Six individual semi-structured interviews with various family members were conducted. Open-ended questions were asked about their understanding, perceptions and expectations of the syringe driver.

1.12.2 Group Interviews

- Two group semi-structured interviews were conducted. The first group interview consisted of two family members from a family. The second group interview was with three family members from another family.
- One interview was conducted in an office in the in-patient unit. The other interview was conducted in an empty, single ward. Their family members were patients who had been commenced on syringe drivers.
- The order of questions varied between participants, depending on the issues raised during the interviews (refer appendix 7).

1.12.3 Diaries

- Diaries and pens were given to the participants. The same open-ended questions were pasted in each diary and participants were asked to answer these questions. This provided them with the opportunity to write down their thoughts and feelings

about the use of the syringe driver. The researcher asked participants to return the diaries when completed. Keeping a diary was optional and they were not obligated to write any responses. The researcher thought that some participants might find it cathartic, which is a means of purging their emotions by expressing themselves in the written format. This form of data collection has been used in nursing research to elicit important information (Burns & Grove, 2009:416).

1.12.4 Observation

- Notes were taken during the interviews with the participants' permission. This allowed the researcher to observe and record the participants' body language and responses to different cues.

1.12.5 Documentation

- Documentation on the diagnosis, the medication used in the syringe driver, as well as the amount of syringes that were in situ at the time of the research, was reviewed.

1.13 ETHICAL CONSIDERATIONS

The ethical approach of this study was based on the rights of participants to be respected as human beings. The following ethical principles were applied; autonomy, privacy, confidentiality, protection from discomfort and harm. The researcher respected the fact that families preferred to spend as much time as possible with their dying family member. All interviews were handled with sensitivity, discretion and consideration for the limited availability of participants. Whiting and Vickers, (2010:60) stated that family members objected about spending the remaining time away from their dying relative by taking part in a research study. The researcher tried to overcome this problem by asking a nurse to be at the patient's bedside while the interviews were in progress. The nurse could call the family member should the patient's condition deteriorate during the interviews. With possible emergencies in mind, the interviews were not prolonged.

There is a minimal risk of emotional and psychological discomfort during the interviews due to the vulnerability of the participants. All the participants gave their written, informed consent and were able to withdraw from the study at any time (refer appendix 6). Confidentiality and privacy were maintained by interviewing the participants in a quiet office without interruptions. No mention was made of the participants' or the patient's names. The interviews were numbered and the participants had a code number known only to the researcher.

1.14 DATA ANALYSIS

Individual interviews and group interviews were recorded and transcribed by a professional transcriber (refer appendix 10). A thematic content analysis with coding of the data was done.

1.15 RIGOUR IN QUALITATIVE RESEARCH

The reliability and validity of the research refers to the trustworthiness of the research study. Credibility, transferability, dependability are the criteria that researchers should apply to ensure that the qualitative research process is followed and the emerging findings are trustworthy (Streubert & Carpenter, 2011:48).

1.16 TERMS AND CONCEPTS

For the purposes of this study, the following definitions apply:

- **Autonomy:** Respects the ability of mentally competent patients to make decisions for themselves. It can also be interpreted to include the need to protect patients with diminished autonomy (Mcquoid-Mason & Dada, 2011:24). In this study autonomy will refer to conscious patients taking the decision themselves to be put onto the syringe driver.
- **Bad Death:** When “a patient dies in severe physical pain or psychological anxiety. When a person dies suddenly or during a traumatic event. Not dying in a place of choice and dying alone with no farewells done” (Tookman, 2003:1).
- **Beneficence:** Imposes a duty of health care workers to do good for their patients but not against their will (Mcquoid-Mason & Dada, 2011:31).
- **Death Rattle:** Described as “a sound produced in the throat immediately before death, caused by the passage of air through a collection of mucus which the patient is unable to cough up” (Wee, Coleman, Hillier & Holgate, 2006:180).
- **Family:** In this study, family refers to the next of kin, as written on the admission file; relative or significant other as in partner or close friend. This will also include those

“related through committed heterosexual or same sex partnerships, those related by birth or adoption and others who have strong emotional and social bonds with the patient” (Payne, Seymour & Ingleton, 2008:30).

- **Good death:** Defined as “an absence of suffering and pain, with an awareness of dying, all personal preparations having been completed. Daily activities are reduced and farewells have been said. The person dies in the place of his own choice” (Doyle, Hanks, Cherny & Calman, 2005:187).
- **Home Care:** In palliative care, a patient has the right to be cared for at home by a family member, or in the home of a relative or friend (Doyle et al., 2005:1097).
- **Home Care Professional Nurse:** A professional nurse qualified in palliative care who attends to the patient’s who are nursed at home, in the community by a family member or friend (Hickman, 2008:43).
- **In-Patient Unit:** Where the study was done. A ten-bed ward which responds to the physical, emotional, social and spiritual needs of the terminally ill. Patients are admitted for symptom control, family respite or terminal care (Hickman, 2008:41). The admission period is two weeks but patients may be discharge at any time within the two-week period.
- **In situ:** In the natural or original position (OND, 1990:253).
- **Interdisciplinary Team:** A variety of health professionals, such as professional nurses, physicians, social workers, who work together as a team to deliver health care, based on the needs of the patients and families (Burns & Grove, 2009:704).
- **Living will:** An advance directive given by the patient regarding their future treatment should they become incompetent to consent to or refuse such treatment (Mcquoid-Mason & Dada, 2011:171).
- **Non-Maleficence:** The duty of health-care providers not to harm their patients (Mcquoid-Mason & Dada, 2011:195).
- **Palliative Care:** An “approach that improves the quality of life of patients and their family members facing problems associated with a terminal illness. By preventing pain and suffering by means of early identification, a comprehensive assessment and

treatment of pain and other physical symptoms, psychological, social and spiritual problems” (HPCA, 2012:10).

- **Terminal illness:** An illness that will inevitably result in the death of the patient (Mcquoid-Mason & Dada, 2011:279).
- **Terminal Phase:** “An irreversible deterioration in the patient’s condition which may start gradually or suddenly. Death occurs within a few hours” (HPCA, 2012:104).

1.17 CHAPTER DIVISIONS

The chapters are divided, as described below.

1.17.1 Chapter 1 Contextualisation and Orientation of the Study

This chapter describes the introduction to the research project, the background and the history of the syringe driver. The use of the syringe driver at the research setting is discussed. The research question and research problem are provided. The significance, aims and objectives and delineation of the study are discussed. The methodology and design, ethical considerations and data analysis are summarised. Terms and concepts are given, pertaining to the study.

1.17.2 Chapter 2 Literature Review

An extensive literature review will be conducted. Relevant literature from the internet, journals and other resources, such as books and conference reports will be consulted on the extensive use of the syringe driver globally, nationally and provincially.

1.17.3 Chapter 3 Methodology and Design

In this chapter the various methods of data collection will be discussed and an explanation of the design of the study given.

1.17.4 Chapter 4 Implementation Analysis and Interpretations of Data

Semi-structured, group interviews and personal interviews were conducted. Recordings will be transcribed. Qualitative data will be analysed and interpreted, using thematic analysis. Coding will be utilised and themes will be developed.

1.17.5 Chapter 5 Recommendations and Conclusion

Limitations of the study will be highlighted. Finally, recommendations, personal reflections and the conclusions will be discussed.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, the syringe driver will be explained in detail. I will review the reasons for using the syringe driver and the medication used to control a variety of symptoms. The advantages of using the syringe driver and the equipment required for assembling the driver will be discussed. The infusion sites and the cause of infusion site reaction will be explained. An explanation of the combination of medication used in the syringe driver will be given. The uses of this device, successes and the problems encountered will be explored. The global, national and local use will also be discussed.

2.2 HISTORY OF THE SYRINGE DRIVER

Two hundred and fifty years (250) ago, physicians attempted to introduce medication through the skin. Alexander Wood, a physician, thought that a hollow needle would be effective hence the production of a narcotic injection syringe also known as “subcutaneous” in Latin or “hypodermic” in Greek (Graham, 2006:138).

In 1970, there was a renewed interest in using the subcutaneous route, opposed to the intravenous route. Richard Propper and his team at The Boston Children’s Hospital in the United States of America made a significant discovery (Graham, 2006:138). They found that the medication used in the treatment of childhood Thalassaemia was more effective subcutaneously than intravenously. Dr Bernadette Modell, a palliative care practitioner in London, commissioned a device to deliver subcutaneous infusion. This device is now known as the syringe driver. Since then the syringe driver has been used in palliative care globally (Graham, 2006:139).

2.3 THE GLOBAL USE OF THE SYRINGE DRIVER

Research about the use of syringe drivers in palliative care has been documented in countries, such as the United Kingdom, Canada, United States, Australia (Israel, Reymond, Slade, Menadue & Charles, 2008:390). Studies undertaken regarding the syringe driver has been about the medication, the compatibility of the medication used in the syringe driver, as

well as the diluent used. Research on site reactions are also highlighted (Graham, 2006:138).

Morphine Sulphate is the drug most commonly used in the syringe driver to control pain. The vast majority of Morphine is consumed in developed countries. This represents a small part of the world's population and consumption varies greatly from country to country (Anon, 2006:2) (refer appendix 1).

2.4 THE AFRICAN USE OF THE SYRINGE DRIVER

Most African countries have no published research papers regarding the use of the syringe driver, as neither the syringe driver nor the medication is available in many African countries. Zambia, a landlocked country in Southern Africa. In a report on palliative care provision in Zambia, Merriman (2006) describes that in 2004 there were six hospices that provided palliative care but most of these hospices do not have syringe drivers. Although some of the appropriate medication is sometimes available, these drugs are expensive. Some hospices do not have Morphine, as they do not have a doctor on site to prescribe it. An American based donor sometimes provides Morphine (Merriman, 2004:7).

In Uganda and other African countries, reasons raised for not using the syringe driver to administer medication include the unacceptable use of a "machine", the cost and the limited availability of medication, as well as the fear that some people feel that it will "shorten the life of the patient". As a result, oral Morphine is used to keep the patient comfortable. When obtainable, they would sometimes attach a syringe to a subcutaneous butterfly needle in situ. At home, relative injects the patient with a measured amount of medication every four hours (Merriman, 2006:258).

2.5 THE SOUTH AFRICAN USE OF THE SYRINGE DRIVER

There is a lack of published research regarding the use of the syringe driver in South Africa. Regardless of this, the syringe driver has been in use over the past twenty (20) years and is available together with the appropriate medication in most of the palliative care units in South Africa. According to Credé and Krause (2012:11), the syringe driver has recently been introduced for symptom control of palliative care patients in a Cape Town government hospital. A pilot project introducing palliative care has been commenced in an emergency department of this hospital. This project is now in the course of being audited. Over four hundred (400) patients were treated and the medical staff felt that the application of the syringe driver on some of the patients has been successful (Krause, 2013).

2.6 THE SYRINGE DRIVER

The syringe driver is a portable battery-operated device, which accurately delivers a continuous subcutaneous infusion of medication. Medication is delivered over a calculated period based upon the speed setting which is adjustable. The syringe driver uses standard disposable syringes, connected to tubing which is attached to a butterfly needle that is inserted subcutaneously, as indicated in the picture below (refer figure 2.1). A safety feature of the syringe driver is that an alarm will go off to alert the staff that the syringe is empty. A flashing light also indicates that the machine is in working order.

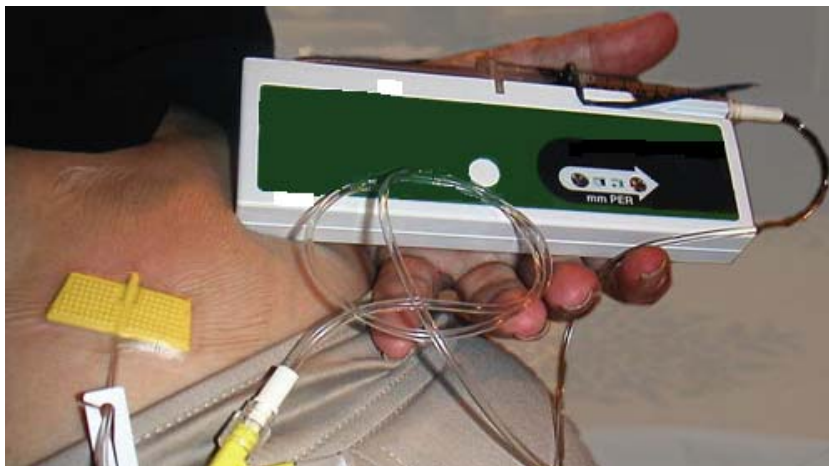


Figure 2.1 A syringe driver in situ (Medipost, 2012)

2.7 REASONS FOR THE USE OF THE SYRINGE DRIVER

A primary reason for the use of a syringe driver is the inability of the patient to swallow and intractable vomiting. Continuous subcutaneous infusion, where the medication infuses slowly under the skin, is a method of symptom control that can provide relief from multiple symptoms through one route by using the syringe driver. This process keeps a flow of medication in the bloodstream, which makes the route suitable for the treatment of symptoms like pain, nausea and vomiting and decreased level of consciousness (Doyle, Hanks, Cherny & Calman, 2005:219). Tookman (2003:102) says that terminal restlessness and a noisy, moist chest can create distress for the patient and their family members. However, in the majority of patients, these symptoms can be controlled with analgesics, sedatives and anti-secretory drugs administered via a syringe driver. The administration of the medication in the

syringe driver is observed and monitored. The medication is adjusted as new symptoms arise (Shaw & Meek, 2007:490).

2.8 ADVANTAGES OF USING THE SYRINGE DRIVER

Continuous subcutaneous infusions have the following benefits over regular intramuscular injections or intravenous injections:

- The variation of the medication in plasma concentration levels between injections is reduced and thus the syringe driver prevents the patient from requiring frequent injections.
- Four-hourly injections are avoided. These are unpleasant and also may be difficult to arrange in the home situation.
- The syringe driver is a small device that is light and portable. The patient's mobility is maintained, as the driver can be placed in a holster and carried around.
- The syringe driver is less invasive but as effective as intravenous injections. Due to the patient's deteriorating condition, intravenous injections become more difficult to give. Generally due to the effects of chemo therapy, venous access becomes challenging.
- Control of the dosages of medication is maintained, especially when the patient becomes weaker, confused or unable to communicate (Smiths, 2006:28).

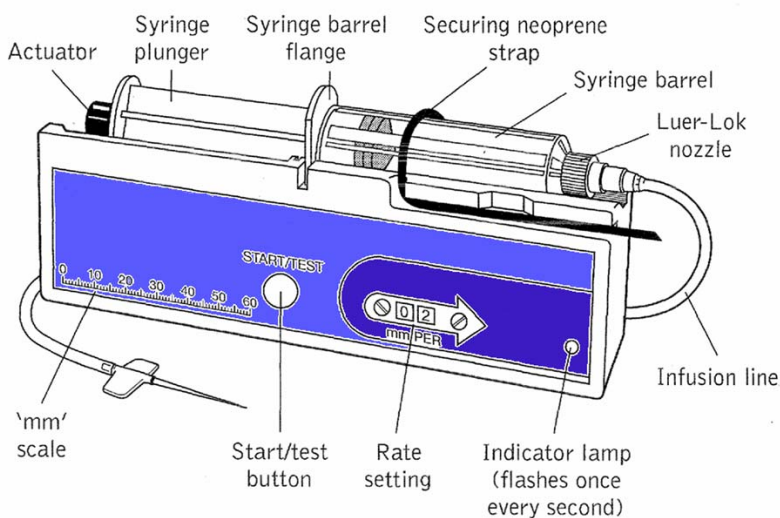


Figure 2.2 A Loaded Syringe Driver (Smiths, 2006:6).

2.8.1 A Loaded Syringe Driver

The loading process of the syringe driver will be described, proceeding in a clockwise sequence, from the upper-left corner, as illustrated in figure 2.2:

- The actuator and the syringe plunger fit into the black groove. The plunger moves forward along the groove and must be moved back when the syringe is empty.
- The syringe is placed in the appropriate groove of the actuator.
- The syringe barrel flange fits into the appropriate groove on the driver.
- A securing neoprene strap is placed over the syringe to secure its position on the driver.
- The syringe barrel contains the prescribed medication.
- The Luer-lok syringe is used. The nozzle is part of the syringe which connects it to the infusion line.
- An infusion line connects the syringe to the butterfly needle. The infusion line must be primed with sterile water for injections before use in order to evacuate the air out of the infusion line (Dickman, Schneider & Varga, 2005:8).
- An indicator lamp indicates the working of the battery. If the lamp does not flash, the start button has not been pressed or the battery is flat or it has been incorrectly placed in its compartment.
- The rate setting should only be changed by a medical professional using the correct tool (a device resembling a screw driver) provided with the syringe driver. No other sharp instrument should be used, as it destroys the screw.
The following settings indicate the time the syringe driver would take to empty:
 - Set at 01 the syringe would take 48 hours to empty.
 - Set at 02 the syringe would take 24 hours to empty.
 - Set at 03 the syringe would take 18 hours to empty.
 - Set at 04 the syringe would take 12 hours to empty (Smiths, 2006:11).
- The start button must be pressed to activate the syringe driver. This button is also a boost button. To administer a small booster dose (bolus) of medication, the button can be pressed and the number of beeps of sound counted. With each beep, the syringe plunger moves forward in a controlled distance. Each beep is equivalent to 0.23 mm of plunger travel. The total time is added up in a period of time and the medication should be increased accordingly (Smiths, 2006:22).

- Syringe drivers are calibrated in millimetres (mm) per unit of time, not millilitres. The “mm” scale therefore is the scale to be used to measure the loaded syringe. This is to allow for different brands and sizes of syringes to be used. Therefore, a 10 ml or 20 ml syringe can be used depending on the amount of medication which needs to be drawn up. It is the length of liquid within the syringe, not the volume, which determines the rate of delivery. The set length is always 48 mm for the MS16A syringe driver (Shaw & Meek, 2007:490).

2.8.2 Required equipment for assembling the syringe driver

When the patient is to be commenced on the syringe driver, the following equipment needs to be assembled:

- The MS16A syringe driver (Smiths, 2006:14) is the only make of syringe driver used at the research setting and is currently in use. This type of device was also used for the research project.
- It has a clear plastic protective cover which prevents the loaded syringe from becoming dislodged and is manufactured with the driver.
- The syringe driver can be placed in a holster to enable the patient to be ambulant.
- A device resembling a screwdriver rate adjuster is used to adjust the rate of this device according to the prescription. Generally it is set on rate 02. Then the adjuster turns the screw up to 02 which then runs over a 24hour period.
- The instruction manual should be consulted if there is any uncertainty about assembling the syringe driver.
- The MS16A syringe driver operates with a 9 volt alkaline battery. The recommended battery is the Duracell MN1604, as other batteries fit poorly and need to be replaced more often. This battery should last for fifty daily infusions. A flashing light indicates when the battery is working and an alarm will sound for 15 seconds when it stops working. Families need to be made aware of this and they need to have spare batteries on standby when the patient is discharged home with a syringe driver in situ.
- A 0.5 mm (25G) “winged” needle known as a butterfly needle is inserted subcutaneously into the patient. This is then attached to the infusion tubing.
- Clear plastic infusion tubing which should be 100 cm long connects the butterfly needle in the site to the syringe which is then placed on the driver.
- The skin should be cleaned with an antiseptic wipe before inserting the needle.
- The correct size syringe with a 21G transfer needle for filling the syringe with drugs from the ampoules should be used. If one or two drugs is used a 10 ml syringe can be used. If three drugs or more are used, then a 20 ml syringe must be used. The

reason is that the concentration of the drugs would irritate the site if three or four drugs were used in a smaller syringe (Dickman, Schneider & Varga, 2005:58).

- Prescribed drugs by the doctor, and rechecked by a second nurse, are drawn up into an appropriately sized new sterile syringe.
- Sterile water is the required diluent, except when using the drug Ketamine when normal saline is used. The diluent is mixed with the drug mixture, so that the solution reaches 48 mm in the syringe, regardless of using a 10 or 20 ml syringe. This is checked against the “mm” scale on the front of the syringe driver.
- A clear surgical dressing should be placed over the needle to secure it. This dressing is transparent and allows the site to be observed (Dickman et al., 2005:58).

2.9 SELECTION OF INFUSION SITES

The anterior upper chest wall is the most convenient area for an infusion site, as it is easily accessible for checking of the site without disturbing the patient. Other sites are the abdominal wall and the anterior aspect of the thighs and the anterior-lateral aspect of the upper arms (Smiths, 2006:30). If the patient is restless and confused, the placement of the site on the scapula area on the back will reduce the likelihood of the patient removing the syringe driver. The nutritional state of the patient should be taken into consideration. If the patient is very thin, then the site should be on the abdominal wall to assist with the absorption of the medication (Graham, 2006:140). Refer to (figure 2.3) below, for the indication of infusion sites.

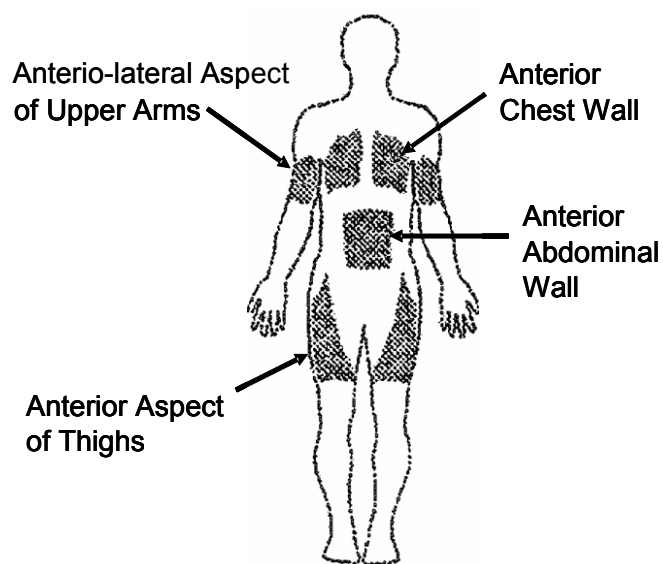


Figure 2.3 Infusion Sites (Smiths, 2006:30).

2.9.1 Areas not Suitable for Infusion Sites

The following areas should not be used as syringe driver sites:

- No areas of oedema are suitable, as drug absorption may not be effective. The needle may cause an ulceration which will lead to infections.
- Avoid the upper arm in bed-bound patients who require turning at regular intervals because movement of the arm or lying on the arm may lead to the development of bruising and ulcers (Dickman, et al., 2005:17).
- Avoid areas near a colostomy, open wound, or any part of the skin which has had radiation. This may pose as increased risk of infection. Irradiated area may cause poor drug absorption.
- Avoid the abdomen if ascites is present due to poor drug absorption as this can lead to ulceration of the skin (Graham, 2006:140).

2.9.2 Infusion Site Reactions

The site should be routinely changed every three to four days in order to minimise site reactions. This is not always possible but health professionals should monitor the infusion site carefully. The butterfly needle should be re-sited when the skin area becomes sore, sensitive to touch, swollen or red. Changing the site more often should be considered if reactions are problematic (Dickman, et al., 2006:17).

2.9.3 Causes of Site Reactions

Site reactions can be caused by an allergic response to nickel needles. Very fine glass particles from the opened glass drug ampoules and an infection or a chemical reaction can decrease the effectiveness of the medication in the syringe driver (Dickman, et al., 2006:16).

Some drugs are not suitable for subcutaneous use. Diazepam, for example, is an irritant drug. Only water soluble drugs that are compatible with each other can be used for subcutaneous use. (Graham, 2006:139). The concentration of the drugs may cause site reaction. As patients with liver cancer bruise easily, the site needs to be changed more often.

2.10 ASSEMBLY OF THE SYRINGE DRIVER

The syringe driver is assembled as follows:

- The prescribed drugs and diluent are drawn up into a sterile syringe and the infusion line and the butterfly needle connected. Air bubbles need to be disposed of.
- The site is cleaned with an antiseptic wipe.
- Avoid touching the needle for sterility purposes. It is held by the wings and inserted into the skin at an angle of 45 degrees.
- Part of the tubing can be looped over the wings of the needle to prevent any tension which could result in the needle pulling out of the site.
- The site is then covered with a clear surgical dressing. This allows for the site to be observed.
- The syringe is placed on the syringe driver, ensuring that the plastic flange of the syringe fits in the actuator groove of the driver.
- Place the securing neoprene strap over the syringe.
- Press the start button. The flashing light will indicate that the syringe driver is working.
- The clear plastic cover is placed over the driver to protect the syringe, should it be dropped. Place the syringe driver into the fabric holster, if the patient is ambulant.
- The syringe driver should not be placed near a mobile phone to avoid levels of electron magnetic interference (Dickman et al., 2005:4).

2.11 SYMPTOM CONTROL

Symptom control is the main function of the syringe driver which can be used to control up to four symptoms simultaneously. The symptom control of pain, nausea and vomiting, terminal restlessness and noisy, moist breathing, will now be discussed.

2.11.1 Pain

In palliative care, the term “total pain” describes pain that is more than just physical pain. It includes emotional, psychological, social and spiritual components. The patient may have more than one pain and each pain can have a different location. Pain control is not solely an analgesic treatment and the syringe driver infusion does not achieve “total pain” control on its own without treating the emotional, psychological and spiritual components (Bass, 2010:486). Due to the complex nature of pain, an interdisciplinary team should manage it.

Pain is described by the International Association for the Study of Pain (IASP) as a sensory and emotional experience, associated with actual or potential tissue damage (Kirkova & Davis, 2006:103). This definition does not differentiate between cancer and non-cancer pain which fits under the same definition since both have similar causes of tissue damage, nerve

compression or damage from tissue invasion, injury, inflammation or pain caused by treatment. According to van den Beuken-van Everdingen (2012:4), chronic pain in cancer survivors is caused by treatments that they have received. Such pain results either from surgery or chemotherapy this can cause peripheral neuropathies which is caused by the neurotoxin agents. Radiotherapy can cause fractures or pelvic pain.

According to the World Health Organization, freedom from pain is seen as a right of every cancer patient. Access to pain therapy is a measure for acknowledging every individual's rights. Not treating a patient in distressing pain is regarded as a serious breach of the patient's fundamental human rights (WHO cited in Gwyther, 2011:9).

Pain is divided into bone pain, visceral or neuropathic pain. Bone pain is usually caused when cancer metastasis into the bone. This can happen in prostate and lung cancer. Bone pain is described as a constant ache resulting from movement and weight bearing activities. An incident pain is often caused by pathological fractures of the bone. Neuropathic pain is caused by damage affecting the central or peripheral nervous system. The damage to the peripheral nervous system may be caused by disease, radiotherapy, chemotherapy, nerve compression, as in spinal cord compression (HPCA, 2012:17).

The most important element is the assessment. Pain varies for each individual and it becomes more difficult to assess a patient when the level of consciousness declines. Facial grimacing, tachypnea and moaning when moved are some of the indicators that the patient is in pain. Pain remains a significant indicator of distress for all patients and family members and is a barrier to comfort (Krause & Stanford, 2011:270).

2.11.2 Nausea and vomiting

Nausea and vomiting are unpleasant symptoms. The symptoms are separate but related. Nausea occurs before vomiting and is an unpleasant sensation associated with the urge to vomit. Experiencing nausea leads to autonomic symptoms like pallor, cold and clammy skin. Vomiting is the reflex action of ejecting the stomach contents through the mouth (HPCA, 2012:44).

These symptoms arise in many conditions, including cancer, hepatic or renal failure. In advanced disease nausea and vomiting may have more than one cause. In order to prescribe the appropriate anti-emetic an impeccable assessment of the patient is required in order to plan an intervention aimed at reducing nausea and vomiting (Mannix, cited in Doyle, et al., 2005:459).

Some of the common causes of nausea and vomiting encountered in palliative care are bowel obstruction, bowel colic, constipation, renal failure, hypocalcaemia and raised intracranial pressure. The choice of anti-emetic will depend on the causes of nausea and vomiting. Most patients have multiple and often irreversible causes (Dickman et al., 2005: 107-109).

2.11.3 Terminal Restlessness

Terminal restlessness is a phenomenon which is seen during the last weeks, days or hours before death. The patient can become restless, agitated and confused. Terminal distress and preterminal agitation are terms that describe terminal restlessness (Brajtman, 2005:176).

Physically, patients are restless, for example getting in and out of bed, and are often unable to settle. Sometimes the patient removes their clothing which may upset visitors or family members. Some patients become agitated and aggressive and can experience hallucinations or nightmares. The cause of terminal restlessness could be multifactorial. Some causes can be caused by a brain tumour or brain metastasis, hypercalcaemia, hypoglycaemia, renal failure or liver failure (Dickman, et al., 2005:112).

The professional nurse or the doctor needs to undertake a comprehensive assessment of the patient to ascertain the causes of restlessness. Health professionals should not assume that it is terminal restlessness (Tookman, 2003:5). Other common causes of restlessness can be urinary retention, pain, hypoxia, rectal compaction and nicotine withdrawal. Most of these symptoms are treatable and need treatment promptly. The following procedures could be done to treat severe restlessness: catheterisation for urinary retention, analgesia for pain, oxygen for hypoxia, suppositories for rectal compaction and a nicotine patch for nicotine withdrawal. Changing the patient's position sometimes helps to reduce restlessness because the patient becomes more comfortable. Additionally, emotional causes, such as spiritual distress, may cause the patient to be restless. Patients may benefit from a visit from their own religious minister or a spiritual counsellor.

2.11.4 Noisy Moist Breathing

As the patient's condition weakens, the patient loses the ability to cough up secretions. This gives rise to noisy, moist breathing known colloquially as the "death rattle" (Tookman, 2003:3). This sound is common in terminal patients and causes distress in family members who are at the bedside.

Family members can interpret the sound of the death rattle in a variety of ways, ranging from the patient being phlegmatic, to choking or drowning which sounds like the fluid collecting in the chest. The interdisciplinary team should explain these symptoms to the family and provide the family with adequate information in order to diminish hidden fears. Particular emphasis should be placed on dealing with the fear of the patient choking (Wee, Coleman, Hiller & Holgate, 2006:180).

2.12 MEDICATIONS USED IN THE SYRINGE DRIVER

Discussed below will be the medications used in the syringe driver to control symptoms associated with pain, nausea and vomiting, restlessness, noisy and moist breathing.

2.12.1 Morphine Sulphate used for Pain Control

Morphine Sulphate has been shown to be chemically and physically compatible with most other drugs is used in the syringe driver (Dickman, et al., 2005:71). The Morphine Sulphate dose should increase as the pain increases. The suitable commencement dose in a Morphine Sulphate naïve patient, (who has not used opioids for pain control) is, 10 - 20 mg delivered by the syringe driver over 24 hours. Morphine Sulphate is well absorbed and is predominantly metabolised in the liver to Morphine-3-glucuronide and Morphine-6-glucuronide. Morphine excreted in the urine. Patients in renal failure are at a greater risk of developing Morphine toxicity. An accumulation of Morphine metabolites can pose a problem as the patient's condition deteriorates. Signs of Morphine toxicity may be confused with general deterioration (Dickman, et al., 2005:72).

The undesirable side effects of Morphine Sulphate can be nausea, vomiting, drowsiness and constipation. Treat each side effect effectively, while continuous observation of the patient should be maintained. A reduction of Morphine Sulphate may provide adequate analgesia without the development of undesirable side effects such as excessive drowsiness in the elderly. Caution is required when administering Morphine Sulphate to patients in renal failure, the elderly and those patients who have hepatic impairment (South African Medicines Formulary, (SAMF) 2012:432).

2.12.2 Metoclopramide used for Nausea and Vomiting

Metoclopramide is an anti-emetic used in palliative care for subcutaneous infusion for the treatment of nausea and vomiting. Do not use Metoclopramide if complete intestinal obstruction is present or suspected (HPCA, 2012:47). The dose of Metoclopramide can

range from 30-100 mg over 24 hours in the syringe driver. It is a D-2-receptor antagonist, with non-sedating anti-emetic properties. It is useful in the treatment of nausea and vomiting caused by other drugs, gastric stasis or partial outflow obstruction. Extra pyramidal reaction can occur, especially if another D-2-receptor antagonist, such as Haloperidol is used. Metoclopramide can cause irritation at the site of the injection due to the presence of chloride ions in the injection formulation. Discard the solution if it is discoloured. Metoclopramide is physically compatible with Morphine Sulphate in the syringe driver (Dickman et al., 2005:66).

Metoclopramide may cause parkinsonian symptoms in older patients. This may include involuntary and repetitive movements of the body. Reduce dosages in renal or hepatic impairment, as well as in the elderly patient (SAMF, 2012:48).

2.12.3 Haloperidol used for Nausea, Vomiting, Agitation

Haloperidol is an anti-psychotic agent chemically related to Chlorpromazine. It has minimal sedative properties. A low dose of Haloperidol ranging from 2.5 mg-10 mg over 24 hours has been shown to have an anti-emetic effect to control nausea and vomiting. At higher doses 10 mg-30 mg Haloperidol is useful to control agitation. Higher doses result in sedation and are used to control agitation and confusion. Extra-pyramidal side effects are sometimes evident, particularly in the elderly. It is useful when nausea and vomiting is due to stimulation of the chemoreceptor trigger zone by drugs, intestinal obstruction or hypocalcaemia. Haloperidol is chemically and physically compatible with Morphine Sulphate in the syringe driver (Dickman et al., 2005: 52).

Haloperidol is metabolised extensively in the liver and excreted in the urine and faeces. Caution has to be taken with patients with impaired liver function and kidney impairment. The elderly commenced on small doses initially, followed by more gradual increments (SAMF, 2012:471).

2.12.4 Midazolam used for Seizures, Anxiety, Terminal Restlessness

Midazolam is a short-acting benzodiazepine, which is suitable for use in the syringe driver. The dose of Midazolam can range from 10 mg-60 mg over 24 hours, depending on the patients condition. Midazolam is administered for seizures, anxiety, terminal restlessness and intractable hiccoughs. It is metabolised in the liver mainly to a less active metabolite, which is excreted in the urine. Reduced dosages may be necessary in liver and renal diseases. Some patients build up a tolerance to Midazolam, requiring increased doses or the introduction of another drug. When treating a major haemorrhage, immediately

administer Midazolam intramuscularly because of its rapid onset of sedation. Midazolam is chemically and physically compatible with Morphine Sulphate in the syringe driver (Dickman et al., 2005:69).

Midazolam controls anxiety and restlessness in the terminal phases of illness. Its onset of action is rapid and the subcutaneous absorption is advantageous, as it seems to be less irritating to subcutaneous tissue when given via the syringe driver. Doses and the effects should be monitored carefully (Breitbart cited in Doyle et al., 2005:748).

2.12.5 Hyoscine Butylbromide used for Noisy Moist Breathing

Hyoscine Butylbromide can range from 40 mg to 180 mg over 24 hours used in the syringe driver. It is generally the treatment of intestinal colic associated with bowel obstruction. The side effect of Hyoscine Butylbromide is a reduction of secretions and it assists in drying a moist chest when the patient does not have the ability to cough up secretions. Hyoscine Butylbromide does not cause central nervous system effects, such as sedation and paradoxical agitation. The adverse reaction for the patient can be a dry mouth and slight urinary retention. Hyoscine Butylbromide is compatible with Morphine Sulphate (Dickman et al., 2005:56). Give Hyoscine Butylbromide 20-40 mg as soon as the onset of noisy breathing starts. If longer time passes, it becomes less effective (HPCA, 2012:104).

2.12.6 Dexamethasone used for Raised Inter-Cranial Pressure

Dexamethasone is formulated as Dexamethasone Sodium Phosphate. Dexamethasone is an alkaline, thus likely to be incompatible with acidic solutions. If Dexamethasone is to be mixed with other drugs, as much diluents as possible should be added before the addition of Dexamethasone. A second syringe driver should rather be used (Dickman et al., 2005:41).

The dose of Dexamethasone can range from 4 mg-16 mg over 24 hours. This drug has a long half-life and therefore should be given once a day, preferably in the morning. If administered late in the day, the patient will have difficulty sleeping. Most patients should tolerate a single dose. If high doses are given, give in divided doses or as a continuous dose via a syringe driver (Dickman et al., 2005:40). Cerebral tumours that cause headaches, blurred vision, nausea and vomiting and confusion cause raised inter-cranial pressure. Dexamethasone helps to reduce the swelling surrounding the tumour and alleviates these distressing symptoms. Side effects of this medication are insomnia, delirium and restlessness and raised blood glucose levels (Dickman et al., 2005:40).

Dexamethasone should be administered via a separate site and used in a separate syringe driver. This medication can also be used in very small doses (0.5-1.0 mg) for site preservation. Evidence suggests it can lengthen the time the syringe driver remains patent (Walker, Lane & McKenzie, 2010:497). All the above discussions provide a broad, but specific use of the syringe driver that is important for the family members to take note of.

2.13 FAMILY MEMBERS' UNDERSTANDING OF THE SYRINGE DRIVER

According to Cruikshank, Adamson, Logan and Brackenridge (2010:128), much of the literature on the syringe driver focuses on the practical aspects of how this device operates. This includes medication and the compatibility of drugs. However, the significance to the patient and family members are seldom the focus of attention. The introduction of the syringe driver simultaneously controls pain, vomiting, noisy moist breathing and restlessness. The successful management of these symptoms enhances the sense of trust and confidence between the patient, their families and the medical professional team (Cruikshank et al., 2010:126).

The syringe driver is not without certain challenges, such as site reactions, which can cause distress to the patient and their family members (Graham, 2006:138). These site reactions can be redness, tenderness, a painful lump or swelling. Use two separate syringe drivers when using large doses of Dexamethasone (Walker, Lane & McKenzie, 2010:496).

In addition to setting up the syringe driver, professional nurses have the responsibility of preparing family members with regards to the understanding of how the device operates and why the syringe driver has been commenced. In addition to this, family members should be prepared to manage the emotional distress that they might experience, especially when the patient is unable to communicate with them. The medication used in the syringe driver could lead to the patient's inability to communicate with family members, as well as staff. This has been acknowledged in the literature (Walker, Lane & McKenzie, 2010:497).

2.13.1 Family Needs

Literature indicated that the information needs of family member were not consistently or automatically met. This lack of information led to incorrect assumptions regarding the use of sedation. The availability, accessibility and approachability of the interdisciplinary team to the family members are all factors that may influence communication between the patient, care team and family members (Brajtman, 2005:178).

Within the family itself, different members may be visiting the patient at varying times and each one may have different information needs at any given time. Information and explanations offered to the various family members must be tailored to meet individual needs. For example, some family members may require additional psychosocial needs to be met or others may need information on the progression of the disease (Panke & Ferrell, cited in Doyle, et al., 2005:988). Understanding the emotional and psychosocial needs of both patient and family members demonstrates the importance of the interdisciplinary, care team approach.

Studies done by Israel, Reymond, Slade, Menadue and Charles (2008:390) recognised that those family members who are involved with the medical care of the patient, suffered distress and anxiety. This is due to the medical role of administering the medication in the syringe driver. Family members willingly undertook the role of administration of medication or, but felt that it was demanding and placed a major responsibility on them. The fears identified were the anxieties associated with their ability to administer the syringes on the device. In addition, they worried about overdosing their family member.

Families play a critical role when taking care of a palliative patient, especially if the patient prefers to die at home. It is very important that they receive the correct amount of education and information regarding the syringe driver, medication and nursing care. Health professionals need to support the family members and to address all concerns (Israel, et al., 2008:395).

Reports by some family members in a study (2011) in Queensland, Australia indicated that the device had a negative impact on the patient and family members' lifestyle. It was noisy and inconvenient and frequently needed a battery change. The family member caring for the patient needed information about daily activities, such as bathing, sleeping positions with regards of the needle in situ. The negative views of the syringe driver were that the syringe driver was an invasion of the body, poor prognosis and fear of the medication and the impending death of the patient (Queensland Government, 2011).

2.14 THE IMPACT OF TERMINAL ILLNESS ON FAMILY MEMBERS

Terminal illness and its management can affect the family members' own quality of life. The health of the patient's partner or spouse may be affected. It is important to achieve the best quality of life for both the patient and the family members during the terminal illness and into the bereavement phase. Family focused interventions should be implemented early and continue during the illness. The family needs support and assistance in identifying their own

strengths and weaknesses. This depends on the coping skills family members have and the number of resources at their disposal to manage an event. Such resources may include finances and time available to assist the patient and having adequate information and focusing on the positive part of caring for the patient (Pearson, Östlund, Werrman-Larsen, Wengström & Gustavsson, 2008:239).

Research carried out on terminal restlessness by Brajtman (2005:174) found that family members were prepared to sit with the patient twenty-four hours a day to try and control disturbing behaviours. The presence of the family appeared to comfort the patient and less sedation was required. However, it was noted that many family members needed to witness the patient suffering from terminal restlessness before they would accept the decision of the medical care team to use sedation (Brajtman, 2005:174).

Cruikshank et al., (2010:130) stated that pain remained a significant indicator of distress. Pain was observed by the family as a barrier to comfort. This resulted in the family readily accepting the introduction of the syringe driver. However, they were disappointed when the patient's pain was not totally resolved. The professional nurse needs to explain to the family that there are limitations to what the syringe driver can achieve. It cannot replace the loving touch and affection of a loved one. This indicates that the syringe driver cannot achieve "total pain" control as discussed in (refer 2.11.1) (Bass, 2010:486).

The WHO highlights the importance of meeting the supportive care needs of family members and the palliative care patient. A family caregiver undertakes a complex role when looking after a patient at home, including hygiene and medication administration. It is important to give families support and acknowledge their complex roles (Hudson, Quinn, Kritjanson, Thomas, Braithwaite, Fisher & Cockayne, 2008:270).

Krause and Stanford (2011:270) stated that when a patient is in pain, the patient exercises a negative effect on the entire family. The interdisciplinary team should explore the pain and the meaning of suffering with the family, as well as the extended family members. The concerns and suggestions of the relatives must receive serious consideration, especially when making treatment decisions. The interdisciplinary team has to acknowledge the family as an integral part of the comprehensive care of the patient. This can have a positive influence of families' perceptions of the terminal care received and the use of the syringe driver. Brajtman (2005:177) reported that caring for the terminally ill could have a significant effect on the family member's health, coping ability and stress levels. Stress affects the ability to cope during the period before the patient's death.

2.15 SEDATION

Despite attempts to develop operational criteria for the use of sedation when used for symptom relief, significant inconsistencies exist in definitions of degree of sedation. These were reflected in the findings of the study by a palliative care team's expressions of ambivalence and conflict surrounding the use of sedation (Brajtman, 2005:177). According to Grogan (2009:569), there is "no substantiated" research evidence to suggest that a patient's life is shortened, either by opioids or sedatives, when used in line with accepted palliative care practice of pain or distress management. If this misconception is not addressed, inappropriate symptom control will result in the patient suffering unnecessarily. In a study undertaken by Claessens, Menten, Schotsmans and Broekaert (2011:5), the researchers concluded that palliative sedation is an intentional medical treatment. Only when refractory suffering occurs then palliative sedation administered in a proportional way. Sedation, however, remains a controversial topic.

Palliative sedation is described clearly when sedatives are used in palliative care in a number of ways, such as, to calm the anxious patient or assist with sleep without depressing the patient's level of consciousness. The aim of the use of sedatives is to control anxiety and agitation and to control distressing symptoms that are exacerbated by anxiety and agitation, for example, pain, nausea and vomiting, dyspnoea by calming the patient and titrating the dose of sedative so that the patient is still alert and able to interact with family members and others. The European Association of Palliative Care defines palliative sedation as the use of sedative medication to relieve intolerable suffering in palliative care. In palliative sedation the intention is to relieve intolerable suffering, the procedure is to use a sedating drug for symptom control and the successful outcome is the alleviation of distress which may require doses that depress the patient's level of consciousness (Materstvedt, Clark, Ellershaw, Forde, Boeck Gravgard, Muller-Bush, Porta, Sales, & Rapin, 2003 97-101). The EAPC explains further in palliative care mild sedation may be used therapeutically but in this situation it does not adversely affect the patient's conscious level or ability to communicate. The use of heavy sedation (which leads to the patient becoming unconscious) may sometimes be necessary to achieve identified therapeutic goals: however, the level of sedation must be reviewed on a regular basis and in general used only temporarily. It is important that the patient is regularly monitored and that artificial hydration and nutrition are initiated when clinically indicated.

Browde (2011:7) states that when pain medication proves inadequate to control pain, then sedation of the patient with conventional dosage of a sedative is added to the pain

medication as a co-analgesic. Such treatment keeps the patient sedated until the patient dies naturally. This is considered good palliative medicine.

David (2010:259) says that if the medical professionals are concerned regarding the use of sedation when the patient is restless and in pain, as the literature acknowledges, it is understandable that the layperson feels that sedation may hasten death. Everyone has an ethical right to demand adequate pain relief available to relieve relentless pain and symptom distress. In a systematic review of literature published from 1980-2010 on palliative sedation in end of life care, it states that when sedation is used correctly and appropriately, it did not have any detrimental effect on the survival of patients with terminal cancer. Sedation may be given superficially or deep, continuously or intermittently, gradual or rapidly (Maltoni, Scarpi, Rosati, Derni, Fabbri, Martini, Amadori & Nanni, 2012:1378).

A survey was done in South Africa in 2004 on the use of sedation for the relief of refractory symptoms. Deep sedation, enough to induce loss of consciousness, is only occasionally used in severe haemorrhage, severe pulmonary embolism and in complete airway obstruction (Cameron, Bridge, & Blitz-Lindeque, 2004:445). The conclusion was similar as reported in the international literature in palliative centres in England, Japan and Australia (Cameron, Bridge, & Blitz-Lindeque, 2004:445). Palliative sedation may be used safely and efficaciously to treat dying cancer patients with refractory symptoms when carefully administered by palliative care specialists (Alonso-Babarro, Varela-Cerdeira, Torres-Vigil, Rodríguez-Barrientos & Bruera, 2010:486).

Cruikshank et al., (2010:126-132) thus perceived that family members suffered from distress which was associated with the rapid alteration in their loved one's ability to communicate once the syringe driver with sedation was commenced. The family members thought that this deterioration was linked to the syringe driver. Sedation is commonly used in a number of circumstances, such as when a patient is agitated or pathologically restless. The purpose of sedation is to bring about a state of relaxation, both physical and mental, to induce sleep and to subdue awareness of unpleasant experiences. In a study done on palliative sedation it was concluded that managing symptoms in younger patients needed more aggressive treatment than older patients (Alonso-Babarro, et al., 2010:490).

2.16 LACK OF PALLIATIVE CARE KNOWLEDGE

Medical professionals not trained in palliative care lack knowledge regarding the syringe driver and the medication used in the syringe driver. More health professionals are gaining this knowledge, as palliative care services expand around the world. Patients with advanced,

progressive and terminal illness need good control of physical symptoms and psychological, social and spiritual distress (Brennan, 2008:119).

The patients and family members need informed discussion regarding the benefits and burdens of all interventions, as well as the process of the illness, deterioration and dying. This can be overwhelming for the family members because death is not often a topic of conversation spoken outside a palliative care setting. According to Bennett, Davies and Higginson (2010:459), there is a need for more research that addresses and understands end-of-life situations. Most doctors acknowledge their role of easing the suffering of patients, but studies have shown that they lack the confidence and competence of palliative care, as they have had little training in it (Doyle et al., 2005:3). For that reason it was benefitting in the context of this study to explore the role of the interdisciplinary team in the care of patients who are receiving palliative care.

2.17 THE INTERDISCIPLINARY TEAM

The interdisciplinary team is the strength of palliative care. The many issues facing a dying patient and a family, who must adapt to the illness and the death of one of their members, exceed the expertise of one medical carer. The identity of the interdisciplinary team supersedes individual personal identities. Members of the team share information and, while working interdependently, they strive towards reaching a common goal. Leadership is shared among team members, depending on the task at hand (Cummings, 2013:95). The interdisciplinary team at the research setting attended daily meetings to discuss their individual care plans, as well as the patients' performance status.

2.17.1 Members of the Interdisciplinary team:

- **The Patient and Family**

The patient and family are central members of the interdisciplinary team. Patients and families must be part of the decision-making process. The patient is best able to report which problem is of primary importance and must feel comfortable to express feelings without fearing any judgement (Cummings, 2013:96).

- **Doctor**

The control of physical symptoms is the foundation of palliative care. Therefore, the doctor plays a central role in the interdisciplinary palliative care team (Cummings, 2013:96).

- **Nurse**

The nurse is the team member who spends the most time with the patient. She has the opportunity to get to know, observe and report on the patient more than the other team members (Cummings, 2013:96). It is the nurse's responsibility to assist the patient to cope with the effects of terminal disease. Attention to detail of all the self-care deficits and helping to assist the patients in the details of physical care is important. This relates to Orem's theoretical framework (refer 1.9, 1.9.1, 1.9.2, 1.9.3).

- **Social Worker**

The main function of social work is to assist patients and families to deal with personal and social problems of illness, disabilities and impending death. The social worker can be helpful to the team when there is dysfunction within the family, financial concerns and problems regarding future care for the patient on discharge planning. Emotional support includes individual counselling with the patient and the families. Bereavement counselling also forms part of the social worker's functions (Cummings, 2013:96). The social worker in the in-patient unit assists with counselling the unit staff when the need arises or refers the staff member for appropriate care.

- **Spiritual Counsellor**

A chaplain who is a skilled listener is a key team member. The presence of a chaplain provides a focus for patients and families to discuss questions of meaning and spirituality (Cummings, 2013:96). The spiritual leader has a team of volunteer spiritual counsellors from a broad spectrum of different religions working at the research setting.

- **Volunteer**

Volunteers assist the interdisciplinary team to provide good quality of life for the patients and families (Cummings, 2013:96). Volunteers come from all social and cultural backgrounds. The research setting has about seven hundred volunteers, With some working as nursing volunteers, spiritual volunteers, fund raisers and flower arrangers, and at the reception desk over holidays and weekends.

In South Africa not all the palliative care settings have access to dieticians, occupational therapists, physiotherapist and pharmacist. Most of these therapists from other organisations come and assist the patients in voluntary capacity. The palliative interdisciplinary team has a significant clinical effect on improving the symptoms of cancer patients. Interventions are

based on the interdisciplinary team having additional knowledge and the skills to treat patients with cancer symptoms (Jack, Hillier, Williams & Oldham, 2003:501).

2.18 ADMISSION TO AN IN-PATIENT UNIT

Admission to an in-patient unit can have a positive effect on a dying person. The patient and the family benefit from pain and symptom management. The imminence of the approaching death becomes clearer to the family member when the patient is admitted to the in-patient unit. Perault, Fothergill-Bourbarrais and Fiset (2004:143) stated that family members described how doctors shared information about the prognosis and available palliative treatments. Additional medication and treatments are generally prescribed for other symptoms during the stay in the in-patient unit. In an in-patient unit, the emphasis is on comfort and care of the patient. The patient often starts to withdraw from daily activities and becomes drowsier (Perault, Fothergill-Bourbarrais and Fiset, 2004:143). Hospice staff can explain why it is that the patient starts to withdraw from daily activities and becomes drowsier. This helps to prepare the family for the patient's death. Family members stress was one of the reasons for admission to the in-patient unit when a patient was on a syringe driver. This would give them some form of family respite. Family members have to extend their role beyond personal care and deal with medical and clinical procedures outside their field of expertise. This administration of the "last injection" provoked anger and guilt in family members who had participated in this action (Israel, Raymond, Slade, Menadue & Charles, 2008:390).

2.19 THE NEED FOR EDUCATION

The interdisciplinary team often need to explain delicate issues surrounding terminal care to patients and their family members. Although educational material cannot substitute for the exchange of information between the interdisciplinary team and patients and their family members, such material can be as an important means to clarify and highlight important issues. Patients and their family members are ultimately responsible for making important decisions (Ache & Wallace, 2009:545).

2.20 DYING WITH DIGNITY

Leung (2007:171) states: "When the patient is dying, the patient depends upon others for immediate bodily care". This is the deficit of care, as described by Orem's theory (1.9, 1.9.1, 1.9.2, 1.9.3). Care can also be expressed in words and gestures towards the dying patient in

ways that serves as a basis for a death with dignity. Human dignity means that all people have a basic right to be relieved from all kinds of pain and suffering (David, 2010:260).

Brajtman (2005:176) states that a “good death” can be viewed from the philosophical perspective of a “good life”. It can be argued that one’s capacity for living a good life depends on the quality of one’s life experiences. Life is not good if every waking moment is enduring intractable pain and suffering. Such a belief regarding the nature of a good life, influences views on the nature of a good death. It follows that a “good death” is one in which unpleasant experiences are eradicated or minimised. Tookman (2003:1) describes a “good death” when distressing symptoms of pain, nausea and vomiting, restlessness and a noisy, moist chest have been well controlled. Such a death is an indication that patients are at peace when they die in a place of their choice, surrounded by family members or loved ones. A “bad death” is when the patient is severely distressed and has incomplete or unfinished business. Patients who die suddenly and in a crisis are considered to have had a “bad death.” Not dying in a place of choice or with no close people around is described as a “bad death” (Tookman, 2003:1).

Understanding what constitutes quality care during the terminal phase is an intricate process. Such a situation can be very emotional. A study undertaken by Cruickshank et al., (2010:131) identified a number of influences that, when taken together, contribute to a “good death” for the patient. This means a good experience for the patient, as well as for the family. This also leads to a feeling of work satisfaction for the medical staff.

During the terminal phase, there is a renewed opportunity to address issues around death. Family members become more aware of changes in the patients condition. This is particularly so as changes in communication and alertness of the patient often occurs, as well as changes in physical symptoms (Cruikshank et al., 2010:131). The nursing staff or the doctor should give a clear explanation to the family members present about these changes and recognising the inevitability of death. Some patients do become drowsier and withdrawn before death. The patient can still hear and therefore family members need to be encouraged to say their farewells even if the patient cannot respond to them. Nursing staff need to explain all physical symptoms as they occur in the patient’s breathing and body temperature. All changes in the patient’s condition should be viewed holistically (Cruikshank, et al., 2010:131).

2.21 SUMMARY

An overview of the literature review has been given in this chapter. The use of the syringe driver was reviewed. The reasons for the commencement of the driver and the advantages of the syringe driver were explained. The required equipment and how to assemble the device, as well as the different rate settings, were explained. The lack of palliative care knowledge by patients and families and other medical professionals was described and the need for education and support emphasised. These aspects also provide a rationale for the importance of investigating the understanding, perceptions and expectations of families on introducing the syringe driver to terminally ill patients in a palliative care unit. A dignified death or “good death” verses a “bad death” was explained.

Chapter 3 describes the research design and methodology.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The aim of this study is to establish the understanding, perceptions and expectations of families of terminally ill patients on the introduction of the syringe driver in a palliative care unit in Cape Town. Details of the design and methodology that was considered most appropriate for the study will be discussed.

3.2 METHOD AND DESIGN

A descriptive qualitative approach was used to gather information for this research. This method was chosen to establish the participants' own understanding, perceptions and expectations of the use of the syringe driver.

3.2.1 Qualitative research

The qualitative, research approach is described as a broad range of research designs and methods used to study certain phenomena. The descriptive designs gather new information and knowledge (Brink, van der Walt, & van Rensburg, 2012:121). Qualitative research is used to understand the lived experience of individuals. Hence the researcher chose a qualitative approach to explore the participants' understanding, perceptions and expectations of the use of the syringe driver in a palliative care unit.

According to Babbie & Mouton (2001:270) and Leedy & Ormrod (2010:135) cited in Brink et al., (2012:121), the key feature of qualitative research is that it is conducted in lived situations. It provides in-depth descriptions and understanding of peoples' culture and perceptions. The researcher is seen as the main tool in qualitative research, while the interpretations of the subjects are of importance. Qualitative research involves interacting with the participants in their own language and in their own environment where they feel most comfortable. In contrast quantitative research which involves statistical processes, qualitative research is concerned with the spoken word or narrative information, analysed in an organised way (Brink et al., 2012:121). The researcher must approach the research with

an open mind and set aside any preconceived thoughts and ideas about the phenomena. This procedure is known as “bracketing” (refer 3.2.2).

3.2.2 Bracketing

Streubert and Carpenter (2011:452) stated that bracketing requires a “deliberate identification and suspension of all judgments or ideas” about the subject being investigated before the start of the study. The researcher must remain neutral regarding any perceptions or ideas and knowledge of the subject. Bracketing must be constant and continued throughout the research process. Haggman-Laitila (1999) pointed out that the researcher cannot detach from his/her own views entirely, but must make a concerted effort to do so (Haggman-Laitila, 1999, cited in Streubert & Carpenter, 2011:77). The researcher attempted to do these at all times during this study. Ahern (1999), (cited in Streubert & Carpenter 2011:27) stated that it is important that the researcher writes down his/her thoughts about the subject. When they are written down, the researcher should reflect on what is written and try to understand why they were written. The researcher must be aware of the impact that personal agendas can have on data collection and analysis (Streubert & Carpenter, 2011:27).

The researcher attempted to lay aside or “bracket” her own preconceived ideas, perceptions, thoughts and understandings of the use of the syringe driver during the research process (Burns & Grove, 2009:690). This was achieved by acknowledging her personal assumptions about the use of the syringe driver. She wrote them down and made a conscious attempt not to think about them during the research process.

3.3 PREPARATION OF THE RESEARCHER

In qualitative research, the researcher is viewed as the research instrument. This implies that the researcher must be prepared before conducting the research. Conducting research interviews requires sensitivity and good interviewing skills. The researcher could improve her interviewing skills by doing a role play of an interview in order to enhance her interviewing skills (Burns & Grove, 2009:404).

The researcher is a trained and qualified palliative care nurse and has worked at the hospice in the in-patient unit for the past nineteen years. Interviewing skills were enhanced by attending meetings with the medical doctor, social worker, patients and their family members. These interviews are conducted with each patient during their stay in the in-patient unit. In these meetings, the patient and their family members present discuss many topics.

3.3.1 The Research Setting

The research was conducted at a palliative care in-patient unit, near Cape Town, South Africa. This 10-bed palliative care, in-patient unit responds to the physical, emotional, social and spiritual needs of terminally ill individuals and their families, by means of an interdisciplinary palliative care team. The team comprised of doctors, social workers, spiritual counsellors and volunteers. All the patients admitted to the in-patient unit are terminally ill and are admitted for family respite, symptom control or terminal care. The majority of patients admitted to this unit have a cancer-related illness. The syringe driver is used frequently to control distressing symptoms of pain, nausea and vomiting, restlessness and noisy, moist breathing.

3.3.2 Gaining Access to the Research Setting

The researcher has worked at the above research setting since 1994 as a full time palliative care nurse in the in-patient unit. Permission to do the research in the in-patient unit was obtained from the Chief Executive Officer (refer appendix 4).

3.4 PURPOSIVE SAMPLING

Purposive sampling was used for this research study. Purposive sampling is a type of non-probability sampling, also known as selective sampling. This means that the researcher selected the participants who were knowledgeable of the subject and would provide in depth information (Burns & Grove, 2009:716). According to Streubert and Carpenter (2011:90), the purpose of using this form of sampling is to obtain “information-rich” study participants. This would enhance the information base which is important for doing the research.

Purposive sample is generally used in qualitative research. When using this sampling method, the researcher does not know how many participants are required. When no new information is forthcoming, then the data collection stops. This is called data saturation. The disadvantage of using purposive sampling is the potential for sampling bias. The sample does not represent the entire population (Brink et al., 2012:141). The researcher tried to eliminate bias by covering a broad spectrum of family members with different educational levels, and who fulfil different roles in life within their extended families.

3.4.1 Selection of Participants

Purposive sampling was used to select family members of terminally ill patients who were commenced on a syringe driver. All of these participants were selected because they had the

experience of seeing the syringe driver being commenced and had observed the effect that the medication had on the patient. Families, who were too distressed due to the preterminal condition of the patient, as well as families of patients who were not on a syringe driver, were excluded from the research. Inclusion criteria for the interviews were all families whose relatives were on a syringe driver and who was willing to participate. However, there were some patients who were on the syringe driver, whose families declined to participate,

The participants included eleven (11) family members from eight (8) different families, with more than one family member from a patient taking part in the study. They were all family members of terminally ill patients who were commenced on a syringe driver. Six individual interviews were scheduled. One family member from six different families was selected. Two family group interviews were completed. These family members requested to be interviewed together. The first group interview consisted of two family members. The second group interview comprised of three family members. All the patients were in the in-patient unit at the time of the interviews. Participants were asked to participate while they were visiting their sick relative. As the participants were all older than 18 years, no proxy consent was required. The participants were either English- or Afrikaans- speaking or bi-lingual in both these languages. The researcher is bi-lingual and could therefore conduct the interviews in both languages. One Xhosa speaking family declined and another Xhosa speaking patient on the syringe driver died before the family visited. No participants were excluded on the basis of race or language choice (refer 1.10).

3.5 INFORMED CONSENT

Written informed consent was obtained from all the participants before starting the interviews (refer appendix 6). The consent forms were printed in English (refer appendices 6.1, 6.2) and Afrikaans (refer appendices 6.3, 6.4). The participant information leaflet explained the aim of the research (refer appendix 5). The contents of the information leaflet were orally explained to all the participants before they signed the consent form. The participants were invited to contact the researcher at any time during the study if they had any queries regarding the study. No participants contacted the researcher during the research process. A participant could request a consent form in English or in Afrikaans. The researcher is proficient in English and Afrikaans and the interviews were offered in either of these languages, depending on the choice of the participants.

3.6 RIGOUR IN QUALITATIVE RESEARCH

Rigour in qualitative research depends on the openness, the relevance and the thoroughness of the researcher during the data collection and the data analysis stages (Corbin & Strauss, 2008; Leininger, 1991; Lincoln & Guba, 1985; Miles & Huberman, 1994, cited in Brink, et al., 2012:126). Reliability and validity are important with regards to conducting research and obtaining the research findings. Validity is concerned with the truthfulness and accuracy of the findings of the research. The researcher must let go of any preconceived ideas and judgements of the subject. The research has to be conducted with an open mind (Burns & Grove, 2011, cited in Brink, et al., 2012:127).

Methods for establishing reliability and validity in qualitative research are not the same as for quantitative research. In qualitative research “consistency, dependability, conformability, audit ability, recurrent patterning, creditability and trustworthiness” are used instead (Brink et al., 2012:126).

According to Streubert and Carpenter (2011:48), the reason for rigour in qualitative research is to represent the study experiences. There are other ways of describing the processes. Guba (1981) and Guba & Lincoln (1994, cited in Streubert & Carpenter, 2011:48) identified the four criteria that researchers should apply to ensure that the qualitative research process is followed and that emerging findings are trustworthy. These criteria are “credibility, transferability, dependability; conformability” (Streubert & Carpenter, 2011:48).

3.6.1 Internal Validity

Ways to achieve credibility depends on remaining in the field for a long period of time (Brink, et al., 2012:127). This requires the researcher to spend enough time with the participants in order for them to feel comfortable with the researcher. This will allow them to express themselves in a relaxed way. Credibility is enhanced when the researcher describes and documents the experience as a researcher. This was done by self reflection, and by keeping notes in which the researcher documented her experience as a researcher, as well as her own thoughts about the syringe driver. The fact that the researcher has worked in the field over a long period, contributes to the credibility of the study.

Using a variety of different methods of data collection enhances the credibility of the researcher (Brink, et al., 2012:127). This was achieved by recording both individual and group interviews, as well as making use of observation, documentation and diaries. The focus group recordings were transcribed by an independent professional transcriber.

Peer debriefing is described by Lincoln and Guba (1985) as a process of “exposing oneself to a disinterested peer” for the ability of the peer or the colleague who has not had anything to do with the participants. Peers or colleagues would then probe the biases or explore the interpretations (Lincoln & Guba, 1985, cited in Streubert & Carpenter, 2011:48). This was done after all the interviews were completed. A presentation of the study was given to the interdisciplinary team (refer 2.17) and a discussion was held about the findings. The biases were probed by some of the team members. Some of the findings were the same as those the team members had encountered when dealing with family members’ fears and concerns about the use of the syringe driver. This presentation was held during an interdisciplinary team educational meeting at the hospice.

Creditability is also confirmed when the participants review and validate the findings (Brink, et al., 2012:127). This was done with the participants. They could verify what they said in the interviews by listening to the recorded interviews which were played back to the participants by the researcher. They could also take another look at the written notes in the diaries.

3.6.2 Transferability or External validity

External validity in qualitative research is referred to as “transferability and/or fittingness”. This is when the project findings can fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences. The findings could be transferable to other contexts (Lincoln & Guba, 1985, cited in Brink, et al., 2012:127).

Authenticity can be established by “context- rich” descriptions of what the participants have expressed. These descriptions are meaningful and are also known as “thick descriptions” (Denzin, 1989, cited in Brink, et al., 2012:128). The researcher provides the descriptions as the participants described them in their own words (refer 4.9.1, 4.9.2, 4.9.3, 4.9.4, 4.9.5).

3.6.3 Dependability

Dependability refers to the consistency of the data. It is to establish the trustworthiness of the study. Another researcher could arrive at the same or a comparable conclusion. During this research the interviews were audio taped, observation notes were taken, diaries were given to the participants to keep notes of their experiences and concerns, and all the interviews were transcribed and analysed. Attached is interview six, (refer appendix 10) thus proving that there is an audit trail which is documented in a way that data can be tracked. There can be no dependability without credibility (Lincon & Guba, 1985, cited in Streubert & Carpenter,

2011:49). The question to ask is “how dependable is the study?” Streubert and Carpenter (2011) state that triangulation of different methods can produce dependability of the findings (Streubert & Carpenter, 2011:49). The different methods of triangulation used in this study were provided for in the data collection stage. Data from individual interviews, group interviews, observation, documentation and diaries were all triangulated. The researcher used different family members as participants. Each participant fulfilled a different relationship role from granddaughter to common-law husband.

3.6.4 Conformability

Conformability is referred to “when the research findings, conclusions and the recommendations are all supported by the data collected and that there is an internal agreement between the researcher’s interpretations and the evidence produced” (Brink, et al., 2012:128). Conformability is established when credibility, transferability and dependability are achieved. This was achieved by keeping all the data would be stored for at least five years in a locked safe within the palliative care facility. Thus, all the documentation can be tracked and audited (Streubert & Carpenter, 2011:49). The findings, conclusions and the recommendations were supported by the data presented (Brink et al., 2012:127).

3.7 DATA COLLECTION TECHNIQUES

During this research, different methods of data collection were used. The data was collected through semi-structured individual interviews, as well as two group interviews. All interviews were voice-recorded and observational notes taken by the researcher. Interviews were done in English and/or Afrikaans and transcribed verbatim by an independent professional transcriber. Diaries which were given to the participants were also a means of data collection. Observation and documentation were part of the data collection.

3.7.1 Individual Interviews

Data collection was done by conducting semi-structured interviews with participants whose family members had been commenced on a syringe driver. The semi-structured interview is free-flowing with its structure being limited only by the focus of the research (Brink, van der Walt & van Rensburg, 2012:158). Open-ended questions were used as the qualitative aspect to the understanding of the human experience during a semi-structured interview. The researcher asked a certain number of specific questions with some probes focusing on the topic of the research study (refer appendix 7).

Data were collected by conducting six individual semi-structured interviews. All participants were family members of patients who were terminally ill, on a syringe driver in the in-patient unit of the hospice, and who had given their written permission.

3.7.2 Group Interviews

Interviews can occur between a researcher and an individual or between a researcher and two or more participants simultaneously. The participants can be known to each other (Burns & Grove, 2009:510). Two group interviews were conducted. The first group interview consisted of two family members from one family. They were a daughter and a granddaughter of the patient. The second group interview consisted of three family members from another family. They were a wife, sister and sister-in-law of a patient.

3.7.3 Diaries

Burns and Grove (2009:416) describe a diary as a record of events completed by individuals to document experiences and feelings. This form of data collection has been used in nursing research to elicit information. For the purpose of this study, after the interviews diaries were given to the participants who were comfortable with writing down their thoughts and feelings about the syringe driver or who may have remembered something that they had forgotten to mention during the interviews. The same open-ended questions which were asked in the interviews were typed in English and in Afrikaans and pasted in the diaries. A pen was attached to the diary. The participants were verbally informed that it was their choice to complete these diaries or not. Participants were not pressurised to do so. The diaries were used in addition to the interviews and did not replace the interviews.

3.7.4 Observations

Observations were made during the interviews. This method enabled the researcher to observe cues from the participants' body language, as well as observing the general circumstances and attitudes of participants during the interviews. The verbal and nonverbal cues of the participants were observed and noted. The expression of emotions was observed. Some participants became sad and tearful. Others appeared stressed and tense.

3.7.5 Documentation

Documentation of the age and the diagnosis of the patients were available in their care plans. Such documentation described the variety of symptoms which needed to be controlled by means of the syringe driver. In addition, documentation in the form of the syringe driver medication charts of the patients was available to the researcher. On these charts, the researcher could assess the medication used in the syringe driver, as well as the prescribed rate setting and how many syringe drivers were in situ (refer appendix 11).

3.8 ANALYSIS OF DATA

The analysis was influenced by the phenomenological method which examines the “human experience” described by those who were involved in it (Giorgi, 2011:2). Once the researcher understood the relevance of the participants own words for the phenomenon, it was expressed as directly as possible. This is called the transformation of “the participants lived experience” (Brink, 2006:113). In attempting to describe the lived experience, the researcher focused on what was happening in the life of the individual, what was important about the experience, and what alterations could be made to improve the experience?

In order to remain as open as possible towards the gathered data and to avoid bias during the analysis, the researcher attempted, as stated, to “bracket” (refer 3.2.2) any preconceived beliefs, opinions and ideas of the syringe driver and the medication used in the syringe drivers. A thematic content analysis with coding of the data was done.

3.9 ETHICAL CONSIDERATIONS

The ethical approach of this study was based on the rights of participants to be respected as human beings. The researcher endeavoured at all times to uphold the ethical principles of confidentiality and protection from discomfort and harm. Confidentiality and privacy were maintained by interviewing the participants in a quiet office without interruptions. No mention was made of the participants’ or patients’ names, as the interviews were numbered and the participants had a code number known only to the researcher.

The researcher respected the fact that families prefer to spend as much time as possible with their dying loved one. Thus, all interviews were handled with sensitivity, discretion and consideration for the participants’ limited availability. Whiting and Vickers (2010:60) stated that family members objected about spending the remaining time away from their relative. All

the participants gave their written informed consent and were able to withdraw from the study at any time.

Ethical approval was obtained from the office of the Research Ethics Committee situated in the Faculty of Health and Wellness Science of the Cape Peninsula University of Technology (refer appendix 2). Ethical approval was also obtained from the Hospice Palliative Care Association of South Africa (HPCA) (refer appendix 3). Permission to commence the research study was obtained from the Chief Executive Officer of the palliative care unit (refer appendix 4).

3.9.1 Ethics in palliative care research

The South African Health Professions Council has clear general, ethical guidelines for the health care professions to assist in ethical decisions in palliative care, based on the four bioethical principles of autonomy, beneficence, non-maleficence and justice (Gwyther, 2011:274). The four main principles apply to all health-care professionals in decision making when providing palliative care and effective symptom management (HPCA, guidelines, 2012:9).

These bioethical principles must be taken into consideration especially when commencing a patient on a syringe driver. The type of medication used in the syringe driver should be discussed with the patient and family members beforehand in order to allay their fears and concerns. This is done using the interdisciplinary team approach (refer 2.17).

3.9.2 Autonomy

Autonomy implies that an individual chooses their own course of action. This is the ability to make decisions for oneself, depending on the person's mental competence, and whether the person has received all the correct and relevant information concerning the subject. The rights of the patient are taken into consideration. The patient is, therefore, an active member of the management team (Gwyther, 2006:21). The patient has the right to confidentiality, privacy and the right to the refusal of treatment (HPCA, 2012:9). Hammick (1996) stated that the respect for the individual's autonomy is a fundamental principle of research which is closely linked to the issue of informed consent. Participants should be allowed to take part in research of their own free will. It is important for participants to spend as much time with their sick relative receiving palliative care, particularly if the patient is nearing the dying stage of his/her life. This needs to be taken into account when conducting research on family members of terminally ill patients (Hammick, 1996, cited in Whiting & Vickers, 2010:62). This

need was respected during the study, as the researcher placed a staff member at the bedside of the patient; so that the participant could be called immediately should the patient's condition deteriorate, while the interview was in progress. The interviews started promptly and ended when the participants had no new information to offer or questions to ask.

Autonomy respects the ability for mentally competent persons to make decisions for themselves. There is also a need to respect people with diminished autonomy (Mcquoid-Mason & Dada, 2011:24).

3.9.3 Beneficence

Beneficence, "provides benefit to the patient and balances the benefits against risks and costs" (Gwyther, 2011:274). The practice of to do good should always benefit the patient. Any medical care or treatment should be done with the intention of benefiting the patient and not harming the patient (HPCA, 2012:9). The researcher must balance the benefits and the risks of a research project in order to protect the participants from any harm during the research (Burns, & Grove, 2009:201). The researcher attempted to do this during this project. The researcher stopped the interview when she sensed that the participant was very emotional. Tissues were offered to them and they were allowed time to cry. Support was offered by listening and reaffirming how well they had managed. One of the benefits of the study was that participants had the opportunity to freely express their thoughts and feelings.

In the event that the interview was stopped, owing to any emotional discomfort or possible harm to the participant, the participant could be referred for counselling and followed up by the appropriate member of the team (Streubert & Carpenter, 2011:61). With this in mind, the researcher had the assurance of the medical doctor of the in-patient unit and the social worker that they would assist the participants should the need arise (refer appendices 15 & 16).

Beneficence in research also affects the institution from which the study population is selected. The reputation of the institution can be affected (Bothma, Greeff, Mulaudzi & Wright, 2010 cited in Brink, et al., 2012:36). The researcher omitted the name of the institution and received permission to do the research from the institution to assist with the beneficence of the participants and the institution (refer appendix 4).

3.9.4 Non-maleficence

The ethical principle of non-maleficence is concerned with the concept that “one should not inflict evil or harm towards the patient” (Gwyther, 2011:274). This is related to beneficence and the balancing of risk and benefit towards the patient. Health-care providers should not harm their patients (Mcquoid-Mason & Dada, 2011:195).

3.9.5 Justice

Justice is “fairness, right to fair selection and medical treatment, right to privacy, and confidentiality” (Gwyther, 2011:175). This also applies to the allocation of resources and access to health care. The prevention of pain and suffering should be the focus of care for all patients with advanced disease and a short life expectancy. All these patients should have access to palliative care and pain medication, including Morphine. Patients have a right to be treated by competent, trained medical professionals (Gwyther, 2011:175).

Participants must be selected with fairness. The researcher must respect any agreements made with the participants concerning punctuality, privacy and information collected. If any incentives were offered, these must be given at the start of the research study (Brink, et al., 2012:36). During this study, no benefits or financial incentives were offered or given. Justice in research also means that everyone eligible should have an equal opportunity to participate in the research. This was the case in this study, as all eligible family members had an opportunity to participate.

3.10 ETHICAL CONSIDERATIONS OF PALLIATIVE SEDATION

When a combination of medication for palliative sedation is used in the syringe driver, family members are concerned that the patient is unable to communicate or that the device might hasten death. It is, therefore, important to get a clear understanding of palliative sedation. Registered medical practitioners dealing with palliative sedation should at all times refer to the ethical principles of beneficence (refer 3.9.1.2) and of non-maleficence (refer 3.9.1.3) when considering sedating patients. Considerations must also be given to the possibilities of exposing severely distressed patients to therapies that provide inadequate relief. During this process, patients might sacrifice conscious function when practitioners do not explore other viable alternatives (Fürst, cited in Doyle, Hanks, Cherny & Calman, 2005:1129).

Other viable alternatives may be aromatherapy, relaxing meditation or for a family member to sit with the patient. If some of these alternative therapies are used, then less sedation may

be required. Hence, there is a need for thorough ongoing patient evaluation and daily assessment of the medication used in the syringe driver. It is the intention, rather than the consequence, that is important in judging whether the action is ethically acceptable or not.

Simon (2009:265) stated that palliative sedation like any medical indication requires the patient's consent. In the event that the symptomatic treatment, the mental, social and spiritual care do not result in an ease of symptoms which is satisfactory for the patient, palliative sedation should be offered. Sedation can be justified only in acute emergencies, such as a sudden fear of asphyxiation or haemorrhage. However, sedation without the patient's consent is a breach of the patient's rights. However, sometimes it is required (Simon, 2009:265).

3.11 SUMMARY

The focus of this chapter was on the methodology and design. The qualitative research method and descriptive design were explained. Bracketing was highlighted. The preparation of the researcher to conduct the interviews was expanded on. The research setting and gaining access to the research setting was described. Purposive sampling and how the participants were selected were explained. Rigour in qualitative research and the methods of data collection were described. The data analysis was noted. The ethical considerations were covered and special attention was given to the provision of ethics in palliative care. Palliative sedation was explained.

Chapter 4 presents the implementation analysis and interpretation of the data.

CHAPTER 4

IMPLEMENTATION ANALYSIS AND INTERPRETATION OF DATA

4.1 INTRODUCTION

In this chapter I will discuss the implementation of the study and the analysis of the data collected. I will then discuss the findings of each data-collection section and provide a summary. The aim of the study is to “determine the understanding, perceptions and expectations of families of terminally ill patients on commencing a syringe driver in a palliative care unit”. I have strived to meet the following objectives at all times:

- To assess the understanding, thoughts and feelings of families of terminally ill patients’ on the use of the syringe driver.
- To assess the perceptions and expectations of families of terminally ill patients of the effect of the medication used in the syringe driver.

4.2 DATA COLLECTION

For this study, no moderator was used for the following reasons: The unpredictability of terminal ill patients’ condition makes it very difficult to make appointments in advance with the moderator. Thus, the appointments were made on the same day of the interview when the family member was visiting the patient. This arrangement also assisted in reducing the expense on transport to attend special interview sessions. Many families make use of public transport and additional journeys may be prohibitively expensive. During the time period of doing the interviews, from November 2010 to August 2011, thirty seven (37) patients were commenced on a syringe driver. Some of the patients died with-in hours or soon after the syringe driver was commenced. Many families were too distressed about the poor condition of the patient and declined to take part in the research study.

Different methods of data collection were used. Six semi-structured individual interviews, two semi-structured group interviews, observational notes, documentation and diaries were all means of data collection. All the interviews were voice-recorded and observational notes were taken by the researcher. Interviews were done in English and/or Afrikaans and

transcribed verbatim by an independent professional transcriber. Diaries were also given to the participants to write down their thoughts and feelings.

4.2.1 Interviews

Interviews can explore greater depths of meaning in a qualitative research study. Interpersonal skills are used to elicit information by means of encouraging and acknowledging the participants role. Participants can express themselves, even if they are unable to read or write (Burns & Grove, 2009:404). These were the appropriate reasons to elicit information for this research.

4.2.2 Preparation for the Interviews

Burns and Grove (2009:404) describe how to prepare for the interview by practising and becoming familiar with the content before the interviews take place. The researcher was identifiable to the participants as a palliative care nurse who worked in the in-patient unit; she had a name badge, clearly visible, pinned to her uniform. A private office was secured where the interviews were conducted. Six interviews took place in this room behind a closed door. One group interview took place in an empty single-bedded ward, with the door closed with the participants and the researcher sitting in comfortable chairs. An individual interview took place in “the Quiet Room” situated in the garden of the hospice, when the private office was not available on those two days. The rooms were prepared beforehand with the correct amount of seating. Tissues were kept at hand, in case any of the participants, should become emotional and start to cry. Pens were available should they wish to make any notes in the diaries that were given to them. Extra batteries were kept at hand for the voice recorder and a “Do Not Disturb sign “was placed on the door.

The researcher is a qualified palliative care nurse, a professional nurse was appointed to relieve the researcher from her nursing duties in the in-patient unit. This arrangement enabled the researcher to focus on her project. The researcher had some quiet time for personal reflection before each interview. This period also allowed her to focus on the interview. She read through the instructions for the participants and the open-ended questions before the appointment. As the researcher was aware of the poor condition of the patients, a nurse was allocated to immediately call the family member being interviewed, if the patient’s condition deteriorated. The researcher undertook at all times to make the participants feel comfortable and at ease during the interviews. This was done by asking if they were comfortable and offering them tea, water or coffee during and after the interviews.

4.3 INDIVIDUAL INTERVIEWS

The researcher asked a certain number of specific questions with some probes, focusing on the topic of the research (Brink, van der Walt & van Rensburg, 2012:158). Open-ended questions were asked about the participants' understanding, perceptions and expectations of the syringe driver (refer appendix 7). Probes were used to elicit more information from the participants. The researcher answered any questions posed by them. The researcher was aware of her tone of voice and tried to keep her body language as neutral as possible. She understood that tone and body movement could have a positive or a negative effect on the participants, thus influencing their responses. For example, keeping eye contact, sitting back in the chair, keeping silent at times and not make the participants feel rushed. The researcher always spoke with compassion in a quieter tone of voice.

Table 4.1 Profile of Individual Interview Participants

Gender	Relationship to patient	Number of syringe drivers in situ
Female	Wife of patient	Two syringe drivers in situ
Male	Husband of patient	One syringe driver in situ
Female	Mother of patient	One syringe driver in situ
Female	Ex-wife of patient	One syringe drivers in situ
Female	Wife of patient	One syringe driver in situ
Male	Common-law husband	One syringe driver in situ

4.3.1 Gender Distribution of Individual Interviews

The majority of participants in this study were females. Four were female participants and two were male. The different relationships between patient and family member can be seen above (refer table 4.1).

4.4 GROUP INTERVIEWS

Interviews can occur between a researcher and an individual or between a researcher and two or more participants simultaneously with the participants known to each other (Burns & Grove, 2009:510).

Two group interviews were conducted. The first group interview was conducted in an empty, single ward in the in-patient unit with the door closed, as the office was not available. The following group interview was conducted in an office in the in-patient unit with the door closed.

Table 4.2 Profile of Group Interview Participants

Gender	Relationship to patient	Number of syringe drivers in situ
Female, Female	Daughter and Grand daughter	One
Female, Female, Female	Wife, Sister, Sister-in-law	Two

4.4.1 Gender distribution of group interviews

All the participants in the group interviews were female, with no males present (refer table 4.2).

4.4.2 Interview Schedule

Interviewers normally have a list of trigger or guide questions. There is space for dialogue and for the participant to offer responses that are not predetermined. Open-ended questions were used during the interviews. The order of questions was asked according to the schedule. Open-ended questions that focused on the topic of the study, that is, to produce more in-depth feedback on the participants' understanding, perceptions and expectations of the syringe driver, were used to guide the interview (refer appendix 7). The questions were translated into Afrikaans (refer appendix 7) and the same questions were pasted in the diaries in English and Afrikaans for participants to complete. The translations were approved by a professional translator (refer appendix 8).

It was explained to all the participants that participation was voluntary and they could withdraw from the interview at any stage without suffering any form of victimisation. None of the participants withdrew from the interviews. Interviews were conducted in the language of their choice which was either English or Afrikaans. In some interviews, participants used a mix, of both English and Afrikaans.

4.4.3 Role of the moderator

The moderator's role during the interview is to encourage participants to talk about the topic. The participants need to be encouraged to talk amongst themselves during the group interviews. If the topic is sensitive, the moderator needs to be able to put the participants at ease (Burns & Grove, 2009:515). The moderator needs to ensure that the interviewer conducts the interviews in a very professional and ethical manner. No moderator was used in this study due to the reasons previously explained (refer 4.2). Hence, the researcher fulfilled a dual role in this study.

4.4.4 Participants

There was a minimal risk of discomfort during the interviews. Burns and Grove (2009:209) describe minimal risk as "the risk of harm (that) is not greater than normally encountered in daily life". The researcher was aware of the vulnerability of the participants and, therefore interviews were scheduled in the morning when the doctor, social worker and volunteer spiritual counsellors were on site. They work at the in-patient unit and all form part of the interdisciplinary team. Despite the fact that these professionals played no part in the interview, they were available to assist the participants, if they required any in-depth counselling, or medical assistance (refer appendices 15 &16). Due to the vulnerability of the participants, a distress protocol was noted on the information leaflet (refer appendix 5).

According to the distress protocol, any participants who appear to become distressed during the interview should be offered the opportunity to cease the interview. Participants may be allowed to restart when comfortable to proceed with the interview again. This option was offered to all participants, who become tearful and emotional during the interviews. None of the interviewees, however, expressed the need for extra counselling or medical assistance.

The researcher waited until participants had composed themselves, offered tissues and a reassuring touch of the hand, when appropriate. Touch was defined by McCorkle (cited in Seaman, 1991:261) as "gentle physical contact made by the investigator". The interview recommenced when the participant was ready.

4.5 DIARIES

Burns and Grove (2009:416) describe a diary as a record of events completed by an individual to document experiences and feelings. A diary was given to the participants after the interview. Participants could write down their thoughts and feelings about the syringe

driver, what-ever other information they deemed important something that they had forgotten to mention during the interviews. The same open-ended questions which were asked in the interviews were typed in English and in Afrikaans and pasted in the diary. Each diary had a pen attached to it. Participants were verbally informed that it was their choice to complete entries or not. The diaries were additional to the interviews and did not replace them.

Comparisons were made with diaries that were returned. Only three diaries out of the eight were returned (refer appendix 17). One family of three members were rushing to a prayer meeting and declined to accept the diary. Other participants said that they had said everything they wanted to say during the interviews. No reasons were provided for two diaries that were left untouched.

4.6 OBSERVATION

Observation is the ability to see, examine and record information (Seaman, 1991:251). Observations were made to support the researcher regarding the body language of participants and the general demeanour they displayed during the interviews. The verbal and non-verbal cues of the participants were observed. Some participants became sad and tearful. Others were stressed and tense.

4.7 DOCUMENTATION

Documentation in the form of medication charts of the patients was available to the researcher. On these charts, the researcher could assess all the medication used in the syringe driver, as well as how many syringes were in situ (refer appendix 11). Documentation in the patients' care plan described the variety of symptoms which needed to be controlled by means of the syringe driver.

4.8 ANALYSIS OF THE DATA

The analysis was influenced by the phenomenological method which examines "human experience" described by those that were involved in it (Giorgi, 2011:2). Once the researcher understood the relevance of the participants' own words for the phenomenon, it was expressed as directly as possible. This is referred to as "the transformation of the participants' lived experience" (Brink, 2006:113). In attempting to describe the lived experience, the researcher focused on what was happening in the life of the individual, what was important about the experience and what alterations could be made to improve the experience. In order to remain as open as possible towards the gathered data and to avoid

bias during the analysis, the researcher attempted to “bracket” (refer 3.2.2) any preconceived beliefs, opinions and ideas (Brink, 2006:113) of the syringe driver and the medication used in the syringe driver.

During this research process the data collected was in the narrative and written format so the analysis was to distinguish general patterns. This made it possible for the researcher during the analysis phase of the data to combine all the interviews into different themes that met with the objectives of this research. The following stages of analysis were completed in order to arrive at the different themes (Brink, 2006:184).

4.8.1 Stage 1: Listening to the voice recorder

All the interviews were audio-taped. The researcher listened and re-listened to the voice recordings, in order to ensure that the interviews were accurately interpreted during the process of analysis.

4.8.2 Stage 2: Reading the transcripts

The interviews were transcribed verbatim by a professional transcriber. Thereafter, the researcher read through the transcripts to get an idea of the structure of the interviews. The researcher attempted to put herself into the interviewee’s shoes. By bracketing her own opinions, she attempted to live through the experience in order to comprehend the precise meanings the person had expressed (Brink, 2006:113). During the interviews the researcher noted the tone of voice, hesitancy and pauses of emotions by the participants. This she observed and noted. Stage two was completed by re-reading the interview transcripts.

4.8.3 Stage 3: Making notes and comparing the diaries

Comparison was made with diaries that were returned. The following quote is from a diary.

“My personal opinion regarding the syringe driver is that it’s the same as giving a patient an injection every hour only in this case it’s a little machine that does it” (refer appendix 17). The following quote said the same; except that it was said during the interviews:
”So this is basically the same thing. It’s just that you don’t physically put it in-now it is just a tiny little box that they are using” (B01/01)

Some participants said that they had said everything they wanted to say during the interviews. Hence, they did not find it necessary to write in the diaries.

4.8.4 Stage 4: Colour coding

The researcher and supervisor marked those places in the transcription with different colours where there were similar descriptions, important comments and reflections, which were relevant to the overall themes.

4.8.5 Stage 5: Categorizing the codes

After the themes were identified and colour coded, they were categorised into a structure for each interview (Brink, 2006:185). Each transcript was re-read several times and put into relation to the others. The themes were compiled into a final list of all the interviews.

4.8.6 Stage 6: Final Themes

All the relevant extracts from each transcript were placed under the appropriate heading on the list of final themes. The final list of themes, with associated extracts, formed the basis of the results. The themes were described and illustrated with extracts from the participants' accounts. These served as a true reflection of what was said during the interviews. The themes are linked to the literature review (refer 2.12, 2.13, 2.17, 2.18). The themes also align with the theoretical frame-work used for the study (refer 1.9).

4.9 THEMES

The following themes were identified from the data collected during the interviews. These interviews were transcribed.

- Understanding the need for the use of the syringe driver.
- Perceptions and expectations of the syringe driver and the medication used in the syringe driver.
- The experience of the use of the syringe driver as a medical device.
- Extended-family views on the use of the syringe driver.
- Development of Trust.

4.9.1 Understanding the need for the use of the syringe driver

Some of the participants understood the need for the syringe driver by observing the deteriorating condition of the patients. They appreciated that the reasons for commencing the syringe driver were to control some of the symptoms that they had observed. These

observations facilitated their acceptance of the syringe driver. They were confronted with difficulties, such as pain control, and the patients' inability to swallow.

I can see how he deteriorates and it came to a point that he couldn't swallow his medication anymore. Even his tablets, I had to grind it as fine as possible this morning, and try to liquefy it and put it in his mouth with a syringe. So, that is a great help for me. It is a great help. (B01/01)

One of the patients was having continual seizures (Staticus Epilepticus) which justified, the need for the syringe driver.

...Die eerste keer wat ek toe sien, wat hy nou rerig in die fit in gaan. Toe is dit al 16, so ver ek getel het, 16 keer in twee ure tyd wat hy daardie fit gekry het. (A05/05)

(The first time I saw that he had seizures. I counted that he had sixteen seizures in two hours.)

Two other patients had preterminal restlessness, six were in pain, four had difficulty in swallowing, two were vomiting and another had headaches and occasional seizures (refer 2.12). In this study, all patients had a combination of the afore mentioned symptoms.

The following quotes illustrate the participants understanding of the need for the use of the syringe driver.

The pain became intolerable even when we gave the mist morphine every four hours. (A03/03)

Well one wonders if one shouldn't use the syringe driver sooner you know when I think back on the medication I have been giving her and the changes that took place in her so much so that I blamed the medication said it is the side effects of the medication that makes her behave in this way. It has been extremely difficult. (C01/01)

The participants observed the deteriorating condition of the patient and these insights facilitated their acceptance of the present condition. They spoke about how life was when being the closest relative to a terminally ill patient, and the different attitudes the other family members had in accepting the patient's condition.

4.9.2 Perceptions and expectations of the syringe driver and the medication used in the syringe driver

The participants expressed their impressions and the anticipated outcomes when the patient was initially commenced on the syringe driver.

The only thing that went through my mind last night was that both of us have a "living will" So is this thing not bordering on extending life? (C01/01)

A participant was concerned that his wife had a "living will" and did not want her life extended. A copy of a "living will" (refer appendix 9) states that "I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress, even if the moment of death is hastened" (refer appendix 9). The participant was reassured that the main intention was to control the patient's pain and restlessness and not to extend or shorten life.

...It's just a machine, injection that you are getting it every hour. If you lay in hospital, every hour or every two hours you must get your injection, and off you go, here comes the nurse with the injection. It's the same thing. (B01/01)

Ek is baie bly daar oor because kyk dit is goed vir haar vir die pyn en dat sy baie swak gely het nou dat sy beter voel ek is bly daaroor. (A06/06)

(I am very pleased because she was so weak and had so much pain now she is feeling much better.)

Is it the syringe driver that is making her sleep like this? She never used to sleep so long at least now she is getting her medication; we never liked to wake her up to give her morphine.(A03/03)

These comments indicate how each individual had their own thoughts, perceptions and expectations of the syringe driver. One participant thought it might prolong life...*So is this thing not bordering on extending life? (C01/01)*

Another participant thought that the medical staff members were experimenting on the patient.

No, you people just want to experiment like they say being a guinea pig so I thought no I can't let them do that because you hear all kinds of things. I thought O! My goodness is this the last because I have never had anything like that. I thought oh, will this bring her down that she can go, you know, or what, because you hear what the people say. (A03/03)

A participant was under the wrong impression and thought that the syringe driver was going to feed the patient.

I was under the wrong impression I thought it is going to put food into the patients body. (A04/04)

One participant assumed that the patient would need an operation to insert the syringe driver, but was relieved to realise that it was only a small needle that was inserted under the skin.

I thought it was going to be like an operation they would cut the patient and it would hurt, but it is only a tiny needle. (A01/01)

4.9.3 The experience of the use of the syringe driver as a medical device

It was significant that the study revealed that the use of the syringe driver was interpreted in a positive light by the various family members. The immediate family members gained insight into the deterioration of the patient, as they were the ones struggling to give the patient the medication. They felt guilty if they had overslept and the patient did not get the medication on time, particularly when the patient was in pain.

...The Morphine we gave through the mouth was a lot of problems because every four hours you must look. Sometimes you oversleep on a weekend, or sometimes we can't be able to do it that time because I have to go to baby clinic or your family planning. But when it came to the syringe driver, I really appreciate that way. (D01/01)

The participants welcomed the syringe driver when they saw the patient's condition becoming weaker and unable to swallow medication. They preferred the syringe driver, instead of giving the patient repeated intramuscular injections.

...It sounded like a logical way of administering, because I could just imagine if she had two injections during the night, you know, how many injections she would be getting. Now here it would be a once-off injection and then it's just fed through that needle, so it made sense to me. (C01/01)

All the participants were anxious about the syringe driver at first, but saw the necessity for it. Once the patient's symptoms were controlled, they felt more confident about it and felt that it was a convenient way of giving medication. It did not matter if they overslept or not, the patient would still receive the prescribed medication. They did not have to wake the patient up to take medication.

...So that is also 'n voordeel want ouma het geslaap. So, ons hoef nie te worry as sy slaap nie want die syringe gaan dit mos nou doen. (D01/01)

(It is an advantage; we do not have to worry to wake grandmother up for her medication because the syringe will give it.)

No I did not have any fears because the nurse showed it to me and explained what it was about the setting of the time and so on, my only concern was how it was operating on a battery and that the battery might go flat. As far as the medication goes that is in the hands of the nurses in any case so if one trusts them to handle a syringe then why not this gadget. (C01/01)

Ek voel onnoorslik ek roep my dogter om te kom help, en dan hoef ons nie in die dag en die nag te worry nie dit is a groot voordeel. (D01/01)

(I called my daughter to come and help me because I feel stupid, but now the biggest advantage is we don't have to worry about giving medication day and night).

Ons is tevrede ons kan sien daar is 'n verandering, ja en die medikasie help hom baie.
(E01/01)

(We are satisfied, we can see a change and the medication helps him a lot.)

I asked the sister does that really help because it seems as if sometimes she can't see, sometimes she walks and then suddenly stops. At first I thought it was the syringe driver but then I realised she is not in pain so much she did not complain so much when we picked her up. Then I got more confidence with the syringe driver. But I must say, now you can say 50% to 100%, I'm so glad that she's got it on. (A03/03)

Vir my was dit die eerste keer ook 'n bietjie skrikkerig gewees, want ek kon sien dat hy nie lekker kon sluk nie maar nou vloei die medikasie reg deur sy body. (A05/05)

(At first I was anxious about the syringe driver, but I could see that he could not swallow any more, so now he is getting the medication through his body).

The participants, who had been with a patient most during the illness and had observed their loved one struggling with pain control and the inability to swallow, were initially nervous about the syringe driver.

I was very nervous at first but the sister explained to me it is for his pain medication is in there and it will be much easier and it is much easier. When my dad was diagnosed with cancer that was many years ago, they did not have things like that and to watch him being injected to help with the pain to see how he had to be injected in his legs wherever they could, it would break my heart and I feel bringing out the syringe driver it is a comfort for the patient and for the family a new learning experience for us. (A04/04)

Participants, however, gained more confidence in the syringe driver when they realised it could adequately control the patient's symptoms.

4.9.4 Extended-family views of the use of the syringe driver

The opinions of the extended family played an important role with regard to the use of the syringe driver and the care of the patient. The participants were asked what the extended family members said about the syringe driver, as any disagreement about its use of could cause disharmony in a family.

Hulle verstaan wat die dokter vir my verduidelik, dit is nie dat hulle sy dae gaan korter maak nie en ook nie sy lewe verleng nie net omdat hy die aanvalle kry en hy nie kan sluk nie het hy die apparaat nodig. Maar hulle is skrigerig sê hulle gaan nie aan dit vat nie. (A05/05)

(They understand as I explained to them what the doctor said that it won't shorten or lengthen his life, but because of the continuous seizures and the fact that he can't swallow he needs the syringe driver. But they said they won't touch it as they are afraid of it.)

They did ask me what is it called, they asked questions but we all agreed to do what's best for him. (A04/04)

So I thought am I doing the right thing; am I going to be blamed? The children said mummy the nurse explained to you and then my son and daughter went on the internet to find out more about the syringe driver. (A03/03)

This is evident that families should be given written information on the syringe driver, as not all families have access to the internet, as illustrated in the aforementioned quotation.

They should understand it, I mean I am the one who took care of him all the time, I know what's best for him at this stage it's the best way for me also. (B01/01)

I am very pleased with the machine because the oral medication did not do much for him, he was vomiting all the time, now he has stopped vomiting, but he still can't eat. (E01/01)

The researcher found no evidence in the literature to substantiate the claim that Morphine prescribed by a palliative trained doctor would "weaken the heart". This is something that some patients and their family members believed. This may be the reason why some patients were not compliant with their medication and remained in pain and discomfort.

Sy skree nee julle moes nie dit toegelaat nie jou ma gaan ander week dood wees. My broers en suster voel die Morphine maak haar hart swak en die masjien sal haar lewe verkort. (D01/01)

(She screamed that we should not have let them put her on the machine as it will kill her and she will be dead by next week. My brothers and sisters feel that the Morphine will weaken her heart, the machine they feel it will shorten her life.)

The extended family members, who did not see the patient on a regular basis, had their own fears of the syringe driver and the medication used. They relayed their misconceptions to the carer in the family.

... *My brother said he would blame me if anything happened to mummy (D01/01)*. This provides scope for discussing that family members displace their anxiety about the illness onto the device and that there is lack of understanding of how advanced is the patient's illness or denial of death and unrealistic hope of recovery. This could cause ambivalence and distrust, and divide some family members in deciding on the use of the device. This needs to be addressed by calling all the family members to a meeting where the relevant issues can be discussed and written information given and reiterated. It became evident that it was the extended family and not the immediate family members that thought that the syringe driver would harm or shorten the life of the patient. Grogan (2009:569) stated that there is no "substantiated evidence" that the medication given via the syringe driver commenced by a palliative trained professional doctor would shorten life.

There is no evidence reported that the syringe driver or the medication used in the syringe driver would prolong life either. The main intention is to use the syringe driver at the appropriate time to control distressing symptoms and to keep the patient as comfortable as possible. During this study, it became evident that the extended family, had little or no information about the syringe driver, was most concerned.

4.9.5 Development of trust

The participants developed a sense of trust in the use of the syringe driver. Information and transparency lead to trust and confidence also in the hospice staff. Once the variety of symptoms including vomiting, pain and distress were successfully managed, the sense of trust between the family members was enhanced. Trust was enhanced by doing the preparations in front of the relative.

She opened everything in front of me, she put the mixture everything that is going into the syringe driver. It's not like something extra going in there she did all in front of me the preparations done in front of me. If I was not the primary care giver then I might have doubts but you see I saw the need for it at the right time. When he could not handle it any more then that was the last option because every time I gave him water with the syringe then he started coughing you see even the medication with the syringe yesterday he could not even suck a straw cause I use to give his Morphine with a straw. Yesterday he couldn't swallow his medication anymore. So the need for the syringe driver was there. (B01/01)

As far as the medication goes that is in the hands of the nurses in any case so if one trust them to handle a syringe then why not this gadget. I've have never come across any group of people who give the support that has been given here all round to the patient and to the family, which I am very pleased to observe. (C01/01)

Voordat was sy baie onderpyn gewees sy kon nie beweeg van die pyn nou is sy verlig van die pyn en die opgooi. (A06/06)

(Before that she was in a lot of pain and could not move because of the pain now is relieved from the pain and the vomiting.)

A sense of trust was built because the syringe driver was explained to the patient and family before it was commenced.

To me it was wonderful the sister and doctor could tell me it's this medication and that medication it is marvellous what all the medication can go into one syringe. It is just wonderful what is being done here at hospice. He did have two syringe drivers and I never had any doubts about either cause I have faith in the doctors that are here, faith in the sisters that are here, and I know that you people do your best. (A04/04)

If no family member was present when the doctor needed to commence the syringe driver, the family would be contacted telephonically to explain the reasons for commencing the syringe driver, what it entailed and what medication was prescribed. On the arrival of the

family member at the in-patient unit, the nursing sister on duty would demonstrate the syringe driver and explain the reason for each medication prescribed. Trust was gained, as the professional nurse opened the ampoules of medication in front of the family member and explained the reason for each prescribed medication. It was evident that transparency lead to trust in the syringe driver and the medication used.

4.10 SUB THEMES

These sub themes emerged from the interviews with the participants:

- Feelings about the in-patient unit.
- The need for a support group.
- The need for more information.
- The effect of drug abuse in the family.

4.10.1 Feelings about the In-patient unit

It was evident, that family members experienced a sense of relief, once the patient was admitted to the in-patient unit. The responsibility of caring for a terminally ill loved one at home was over-whelming and it was perceived as a huge responsibility. On admission to the in-patient unit, patients had access to doctors, spiritual counsellors and professional nurses for palliative care. The family could relax and revert to the role of the spouse and the visitor. Initially some family members were concerned about sending the patient to the in-patient unit.

I thought no I can't let her go to hospice I never thought it would be like this. So when I came here I realised why I had not decided sooner to bring her to hospice because she has got everything here. The syringe driver has helped her tremendously and it gives her real comfort and you should have seen her how she used to shake when she did not have it so I think this is a marvellous thing. (A03/03)

The participants had pre-conceived ideas of the in-patient unit. However, they were pleasantly surprised by the comfort and support offered and felt relieved of the responsibility of caring for their terminally ill family member.

...Coming to hospice, sitting here the first time, it was like I said to people, it's like being in therapy because there are other women here, and we could talk about our experiences with our families. It helps me; it really helped me a lot... (B01/01)

I was always helped .I was shown, affection, comfort. I recommend Hospice to anyone, and that is the truth from my heart. (A04/04)

They understood the reasons for commencing the syringe driver and could ask questions or voice their concerns.

4.10.2 The need for a support group

The family members, who were the sole care givers, felt they would have benefited from a support group. Participants gained a lot of support by visiting the patient in the in-patient unit where they could chat to the other patient's relatives about the problems they were facing. This made them feel that they were not alone.

It's like being in therapy when I come to hospice, because I could talk to the women here about our experiences and families, it really helped a lot and that is why they should have a support group. Because I look after my husband alone as we have no children. (B01/01)

A study undertaken by Henriksson and Andershed, (2007:176) illustrated that relatives of terminally ill patients benefited from a support group during the terminal phase and that participation provided a relief for them in their day-to-day lives. Attending a support group gave the participants a sense of belonging and of being supported. Through the sharing of common experiences and the exchange of information, relatives could benefit and gain insight into the patient's condition, the reasons for the syringe driver and the medication used.

The participants reported a feeling of being "alone" at home and in need of the support of a group of people experiencing the same feelings as them. The admission of one participant's loved one to the in-patient unit was very meaningful and served as good therapy for her.

4.10.3 The need for more information

Family members who were the patient's caregivers often expressed concern when the doctor had commenced a patient on the syringe driver. Education and support are required to eliminate preconceived ideas that "Morphine makes the heart weak."

My broers en suster voel die Morphine maak haar hart swak en die masjien sal haar lewe verkort. (D01/01)

(My brothers and sisters feel that the Morphine will weaken her heart, the machine they feel it will shorten her life).

Some family members think that the syringe driver will shorten life. One participant felt that it might lengthen life. Another participant thought it was "experimental" and that her daughter was a guinea pig. Such divergent views indicate that there is a need more information, and informative talks about all aspects and concerns could be given at the support group meetings. Introducing the families to the syringe driver, showing them what it is and how it works, would give the families a clearer understanding and allay their fears.

The extended family was not always present when the syringe driver was commenced. This appeared to be a concern for the close family member. Two of the participants felt it would be helpful if the doctor or professional nurse could have a family meeting with the extended family to explain the use of the syringe driver to them. This would assist them to deal with their concerns about the medication used in the device.

So ek dink miskien moet die nurse's ook 'n meeting kom hou miskien vir die naaste familie en vir hulle inlig. My uncles hulle was mos nie by die huis toe die nurse daardie ingesit het nie. So hulle weet nie eintlik nie. (D01/01)

(I think the nurse should have a meeting with the extended family to explain to them. My uncles were not there when the nurse put it up.)

The deterioration in the patient's health is seen by the close family member as a natural progression of the illness, but the extended family assumes that the deterioration of the patient is due to the use of the syringe driver. The close family member who cares for the patient is afraid of being blamed when the patient dies because of the use of the syringe driver.

...but my mommy's stepsister, I phoned her, I said cousin, hulle het vir mammie 'n built-in Morfine ingebou, sê ek vir haar so. Toe skree sy nee, jy moenie daardie allow het nie. Jou ma gaan nou ander week dood wees... (D01/01)

(I phoned my mothers stepsister, I told her that they have commenced her on a Morphine driver. She screamed no and said you should not have allowed that. Your mother will be dead by next week.)

4.10.4 The effect of drug abuse in the family

This study has highlighted the concerning issue of a high prevalence of drug abuse within some communities in the Cape Town area. It was acknowledged by a participant that a son of a patient, who was commenced on a syringe driver, was a known drug addict.

I have one brother at home he is 37 years old and he is a drug addict. The home care sister could not leave the medication in the home, because of his drug addiction; she came daily to draw up the syringe driver. (D01/01)

In this situation, the professional nurse from the hospice could not leave the Morphine ampoules needles and syringes in the home. The professional nurse who attended to the patient at home had to visit daily to reload the syringe driver for a period of nine weeks.

This was not an ideal situation, as it added to the burden of the professional nurse's workload and anxiety levels. Such challenges faced by some families' increased the safety risk

encountered by the patients, families, professional nurses and social workers tending to patients at home.

4.11 ANALYSIS AND INTERPRETATION OF THE DIARIES

The same themes extracted from the interviews were used to analysis the data in the diaries. The following quotes were extracted from the three diaries returned (as discussed in 4.11.1 to 4.11.5).

4.11.1 Understanding the need for the use of the syringe driver

One participant wrote that she was very anxious about the syringe driver. Another wondered what it was about.

Thought it was a painful process, but felt as long as it can help then its something good. (A05/05)

Nadat ek ingelig is oor die apparaat en verstaan toe voel ek beter. (A05/05)

(After the apparatus was explained to me I understood and felt better.)

My personal opinion regarding the syringe driver is that it's the same as giving a patient an injection every hour only in this case it's a little machine that does it. (B01/01)

I think it's brilliant especially if patient finds it difficult to swallow. (A05/05)

I was very anxious but. I have full trust in it now and use it with ease. (A04/04)

My understanding is that it is a way to ensure the patient gets prescribed medication when having difficulty taking medicine orally. (B01/01)

Once the participants experienced the difficulty to administer the medication to the patient, they accepted the need for the syringe driver.

4.11.2 Perceptions and expectations of the syringe driver and the medication

The participants expressed their impressions and the anticipated outcome when the patient was initially commenced on the syringe driver.

Medication administered at regular intervals (correct dosages). Patient more comfortable – less stress and less pain. (A04/04)

Ek dink dit is beter aangesien dat hy nie die pille kon sluk nie. (A05/05)

(I think it's better seeing he could not swallow the tablets.)

I expected it should be difficult to administer but it was quite an easy process. (A04/04)

The medication is the same only in liquid form and she prepares and explained step by step in front of me and that made me more comfortable with it. (B01/01)

4.11.3 The experience of the use of the syringe driver as a medical device

The immediate family member gained insight into the deterioration of the patient, as they were the ones struggling to give the patient the medication.

It is something good seeing the comfort it's bringing to the patients state. (A05/05)

To keep him as comfortable as possible and to relieve his pain. (A04/04)

The participants were satisfied when the patient's symptoms were controlled.

4.11.4 The extended- family views of the use of the syringe driver.

The views of extended families play an important role within the family situation, as reported by the participants.

To see my brother pain free and without those dreadful seizures says it all. Medication works well and keeps him comfortable. (A04/04)

Some of the family members weren't sure what it was, but after being explained about it, they were happy that medication should be given with the device. Well I guess we all feel as long as it can help we are happy with it. From the family side they didn't have a problem with the syringe driver and accepted it well. (A05/05)

The quotes from the diaries indicated that the extended family members felt that as long as the patient was comfortable, they were satisfied.

4.11.5 Development of trust

The participants developed a sense of trust in the use of the syringe driver. It was clear to the researcher that the palliative care team played an invaluable role by empowering the family members with information about the syringe driver.

I have full trust in the staff and the medication they prescribed. I am not comfortable setting the driver up. (A04/04)

Yes, I was given all the info possible. Hospice sisters were very thorough in showing me and other family members how to operate the driver. Yes, the information given was accurate and understandable enough given by the sister-in-charge. (A05/05)

Sharing information on why the medication was used and showing family members how to draw up the syringe, helped them to gain trust and confidence in the use of the device.

4.12 ANALYSIS OF THE OBSERVATIONS

Observations were made of the participants' verbal responses and non-verbal body language during the interviews. One participant's body language was calm and she felt comfortable to speak openly. She spoke very lovingly about her husband but felt very lonely although well-supported by her church.

The male participants were confident that the application of the syringe driver was the logical approach. One male participant was sad, as his daughter had already died from cancer, and now his wife was very ill. He was alone with no extended family in South Africa. The other participant was confident about the use of the syringe driver. He had no questions or fears concerning the device.

During the other three individual interviews, the participants were initially nervous. The researcher reassured them and, as the interview progressed, they seemed more relaxed. Their shoulders dropped, and they spoke more openly. One participant drank her coffee, while two participants became tearful during the interviews. They were given tissues and the interview stopped until they were ready to continue. At a certain point during one of the interviews, a participant requested that the voice recorder be switched off. The recorder was switched off immediately.

During the first group interview, the participants were talkative but easily got side-tracked. The researcher had to draw them in with the questions about the study. They were relaxed and seemed to like being interviewed. The one participant's cell phone rang during the interview. The interview was stopped while the participant spoke on the phone and then recommenced when the participant was ready.

During the last group interview, the wife of the patient seemed stressed and upset about the condition of her husband, and she remained a bit agitated throughout the interview. The main concern was the fact that her husband could not eat and she was under the impression that the syringe driver was going to let the patient eat. The researcher explained the reasons why the patient could not eat.

...Toe Suster vir my vertel van die masjientjie was ek onder die verkeerde indruk. Ek het gedink die masjientjie was 'n masjien wat kos na sy liggaam toe gaan lei... (E01/01)

(When sister told me about the machine, I was under the wrong impression. I thought it was a machine that would feed him). This patient also had a subcutaneous infusion of Normal saline insitu.

The other two participants of the group interview were more relaxed and said they were satisfied with the little improvement they had noticed in the patient's condition.

Ons is baie tevrede. Ons kan sien daar is 'n improvement in hom. Die medikasie help baie vir hom...
(E01/01)

(We are satisfied. We can see an improvement in him. The medication is helping him.)

TABLE 4.3 PATIENTS COMMENCED ON SYRINGE DRIVERS

GENDER OF THE PATIENT (Participant)	AGE OF THE PATIENT	DIAGNOSIS OF THE PATIENT	REASON FOR THE SYRINGE DRIVER	SYRINGE DRIVERS MEDICATION
Male (Wife)	51 years	Cancer of the Lung & Brain	Dysphagia, Seizures, Haemoptysis	Morphine Sul 90mg Haloperidol 2,5mg Buscopan 80mg 2 nd SD Midazalam 10mg both on rate 02
Female (Husband)	73 years	Myeloma and Cancer primary site unknown spread to the Liver & Bone	Dysphagia Preterminal Restlessness	Morphine Sul 10mg Haloperidol 2,5mg Buscopan 20mg One SD rate 02
Female (Daughter, Grand-daughter)	65 years	Myeloma	Dysphagia, Pain	Morphine Sul 90mg Haloperidol 2,5mg One SD rate 02
Male (Wife, Sister, Sister in law)	57 years	Cancer of the Stomach	Obstruction, Pain, Vomiting	Morphine Sul 40mg Haloperidol 5mg Buscopan 60mg Midazalam 10mg rate 02 Dexamethsone 8mg 2 nd SD rate 06
Female (Mother)	48 years	Cancer of the Cervix spread to the Brain	Restlessness, Pain, Vomiting	Morphine Sul 15mg Maxalon 20mg One SD rate 02
Male (Ex-Wife)	59 years	Cancer of the Lung spread to the Brain	Pain, Headaches, Restlessness	Morphine 135mg Haloperdol 5mg Midazalam 40mg One SD rate 04
Male (Wife)	61 years	Cancer of the Lung spread to the Brain	Status Epilepticus, Pain	Morphine Sul 10mg Midazalam 15mg Buscopan 40mg One SD rate 02
Female (Common-law Husband)	60 years	Cancer of the Oesophagus	Pain, Dysphagia	Morphine Sul 30mg Haloperidol 2,5mg One SD rate 02

4.13 ANALYSIS OF THE DOCUMENTATION

The table (refer 4.3) above gives the gender of the patients, the age, the diagnosis, the reasons for commencing the syringe driver, the amount of drivers in situ and the medication administered in each syringe driver. Four male patients and four female patients were included in this research project. The oldest patient was 73 and the youngest was 48 years old. Both patients were female. Three patients had the same diagnosis of cancer of the lungs with secondary spread to the brain. Two of the patients had two syringe drivers in situ simultaneously. The other patients had only one syringe driver in situ. This information was obtained from the documentation available. The participants are indicated in brackets. When a patient is on a syringe driver, the doctor writes the prescription on the chart. This includes the name of the patient, the file number, the date and the rate setting of the syringe driver (refer appendix 11). The nurses must sign the chart when the syringe driver is commenced. Daily the patient is seen by the doctor and changes may be made to the medication as any symptom improves or if a new symptom arises. During the period of doing this study the researcher observed that a syringe driver had not moved for twenty four hours. The incident was reported and the researcher redesigned the charts, so that every four hours the nurse must note how much is left in the syringe (refer appendix 12). In another case, the incorrect syringe was put on the incorrect rate setting. The researcher reported this and now when a patient is on two syringe drivers, each chart and syringe must be colour coded. Colour coding is described in the literature (Israel, Reymond, Slade, Menadue & Charles, 2008:394).

4.14 Summary

This chapter presented the implementation of the study and how preparations for the interviews were done. It discussed how data was collected. The gender distributions of the participants were described. Interviews, individual interviews, group interviews and the interview schedule were discussed. The moderator's role and the risk to participants were expanded on. Diaries, observation and documentation formed part of the data collection. The data collected via these methods were analysed. The findings of the study on the understanding, perceptions and expectations of families of terminally ill patients on introducing the syringe driver in a palliative care unit were discussed. Themes and sub themes were presented and discussed.

Chapter five will present the limitations, recommendations and the conclusion of the research.

CHAPTER 5

LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

This study set out to determine the understanding, perceptions and expectations of families of terminally ill patients on commencing a syringe driver in a palliative care unit. The objectives of this research were:

- To assess the understanding, thoughts and feelings of families of terminally ill patients' on the use of the syringe driver.
- To assess the perceptions and expectations of families of terminally ill patients of the effect of the medication used in the syringe driver.

The first chapter described the conception of the research ideas. The second chapter discussed the relevant literature in a comprehensive literature review. The research methodology and design were discussed in the third chapter. Chapter four discussed the presentation of the data and the findings of the investigation. This chapter concludes the study. It highlights the limitations of the study, the recommendations and personal reflections of the researcher.

5.2 LIMITATIONS OF THE RESEARCH

The following limitations of the study were identified:

- The research study was conducted in one palliative care in-patient unit in Cape Town where the researcher works as a professional nurse.
- The study was done in only two of South Africa's 11 official languages, English and Afrikaans.
- No moderator was present during the interviews as explained (refer 4.2). It was difficult to make appointments in advance with a moderator, owing to the unpredictable health condition of the terminally ill patients.
- It was a challenge for the researcher to select the appropriate time to conduct the interviews, owing to the rapidly changing stages of terminal illness patients were subject to and the unpredictability of the dying process.

- The researcher felt it would be an intrusion on the limited time the family had to be with the patient, especially when the patient was close to death and the families were sad and upset about the condition of the patient. These families, therefore, could not be interviewed.

5.3 RECOMMENDATIONS

Based on the findings of the study, the following recommendations are presented for consideration in order to improve the experience of patients and family in the use of the syringe driver in the in-patient unit.

5.3.1 Support for stressed family members

Stress can create problems for the family member who cares for a terminally ill patient. Problems, such as tiredness and depression, lack of personal time, loneliness and anxiety have been reported (Henriksson & Andershed, 2007:176). Loneliness was a problem for two participants. There were no children to support them and one participant had no extended family in South Africa. They alone were caring for their loved one, day and night.

When a husband of a participant was admitted to the in-patient unit, the wife said it felt like “*therapy*” when she could talk to the staff and other patients’ family members. Admitting the patient to the in-patient unit for family respite for at least two weeks would assist in relieving anxiety and stress for the family caring for the patient.

One of the participants was distressed that their loved one could not eat. She was under the incorrect impression about the potential use of the syringe driver and medication. She thought it would assist in the feeding of the patient. The misconception was retained despite the doctor and professional nurse explaining that the medication in the syringe driver was for pain, nausea and vomiting. It is recommended that more supportive, educational pamphlets are provided for participants to take home. Such initiatives would assist the family members in deepening their understanding and clarifying their perceptions of the syringe driver.

One family’s request to take the patient home for the weekend was granted and they were taught how to reload both the syringe drivers which were in situ. They felt confident that they would manage to reload both the syringe drivers at home. On the return of the patient to the in-patient unit, however, it was noted that the syringes were placed in the wrong drivers and that the rate settings were incorrect.

It is evident that some people need to be provided with more education and given more support on how to reload the syringe driver, especially when there are two syringe drivers in situ. Not all family members are competent to reload the syringe driver, owing to the stress that they are under and other problems that are not apparent to the professional staff.

After this incident, the researcher recommended that when two syringe drivers are in progress, each one must be colour-coded (Israel, Raymond, Slade, Menadue & Charles, 2008:394). These colours should correspond to the colour on the prescription chart. The outside of the fabric bag in which the syringe driver is placed also needs to be colour-coded. Such colour-coding would ensure that everyone involved with the patient would clearly be able to see that both drivers would need to be on different rate settings.

The timing of the reloading of the syringe driver needs to be assessed when the patient is discharged. One participant describes setting her alarm clock for the middle of the night to change the syringe driver.

...The times when it was two, three o'clock in the morning or whatever, I set my alarm just in case I've dozed and he's sleeping, that I can wake up, but I wake up before that alarm goes off. Then I know okay, it's almost time, and then I'll change it, and write it down... (A04/04)

This is unnecessary, as the timing can be adjusted to suit the family member whose sleep need not be disrupted.

5.3.2 Assessment of drug abuse

According to Nicholson (2011:6), Cape Town is the drug crime capital of South Africa. One family had a known drug addict as a family member and this had far reaching implications when the patient was commenced on the syringe driver. It was unsafe to leave the ampoules of medication in the household and the home-care professional nurse had to visit the patient daily to draw up the syringe and reload the syringe driver. Drug addiction also affects many of our patients' families and it remains a concern for them. The professional staff must take this into consideration when expecting the family members to take care of the patient at home and be responsible for reloading the syringe driver.

It is recommended that a drug abuse assessment of the patient and family members need to be undertaken and incorporated in the initial medical assessment forms. The staff would be alerted to potential problems with regard to drug abuse that might be prevalent in the home. This can be addressed and the necessary safety measures put in place. An alternative treatment can be commenced, such as using an analgesic patch for pain, instead of using Morphine Sulphate in the syringe driver.

Drug related crimes have trebled in the past five years to over 60, 000 incidents per annum. There is a high prevalence of alcohol and Marijuana (dagga) abuse in the Western Cape where Methamphetamine (tik) abuse is especially widespread (Nicholson, 2011:6). The palliative care team should always be alert and aware of this scourge and the assessment of drug abuse in the homes of patients would assist in protecting the patient and themselves against potential abuse.

5.3.3 Documentation of information

The researcher found, as stated, that some of the participants did not understand the use of the syringe driver. Lack of information can cause the ambivalence families feel about the syringe driver, as expressed in this quote.

...So I thought am I doing the right thing. I'm going to get blamed, and then my son in law and my daughter went on the Internet. (A03/03)

Another participant felt they had *...all the knowledge...* but one night the syringe driver stopped working and the patient was in pain. They were most concerned when they found the patient in pain. On phoning the home-care, professional nurse, it was discovered that the battery was flat. Some written information on the syringe driver needs to be given to the families, preferably in their own language, so that they would have the practical knowledge about exactly what to do should the battery light go out. Such incidents indicate that more education needs to be undertaken. Written information, which can be a reference for family members to read at their leisure, should be provided. A more in-depth, written form of information on the syringe driver needs to be given to the families of patients who have been commenced on the syringe driver, preferably in their own language. English, Afrikaans and Xhosa are the predominant languages in the Cape Town area. This information could be provided in a form of a pamphlet or booklet.

The researcher is drawing up a new booklet in English (refer appendix 13) and Afrikaans (refer appendix 14) which is an improvement on the sparse information which was given to the families prior to this study. The front of this booklet is in English, there are spaces for the name and hospice number, as well as a space for the home-care sister's telephone number. The after-hours telephone number is also included. The information about the syringe driver follows with step-by-step instructions on how to draw up a new syringe and load it on to the driver. The middle page explains the prescription of the dose of the medication to be given (refer appendix 12). There is a space for the family member to record the time it was reloaded. On the next page, the same information is repeated in Afrikaans (refer appendix 14) with space for the telephone numbers. The booklet will include a picture of a loaded

syringe. When completed, the booklet should be translated into Xhosa. The booklet should be completed within the next six months.

5.3.4 Provision of educational material

Education material could provide the appropriate knowledge to assist patients, their families, and medical staff to increase their confidence in handling the syringe driver and their familiarity with the drugs dispensed to patients. Given the complexity surrounding terminal care, it is important that educational material is free of medical jargon and written in a language that can be easily understood by the layperson. In addition, the different South African languages and cultures need to be considered when drawing up educational material.

Educational talks on the use of Morphine and the syringe driver should be given to other medical professionals who do not work in a palliative care setting. The researcher has embarked on doing this by providing talks at other health facilities, (Abundant Life) whose staff members are not familiar with the use of Morphine and the syringe driver. Such talks will assist in reducing the ambivalence that staff members experience about the drug and the device, and enhance their confidence to use Morphine and the syringe driver when appropriate for other patients. It is also recommended that family members are offered a short course on how to reload the syringe driver. Despite the fact that they are shown, they are not all competent in reloading the driver before the patient is discharged. Here the community hospice nurse or the home-based carer visiting the patient can play a big role in providing continuous education to family members.

5.3.5 Creation of support groups

A support group could meet once or twice a month for the family members of patients who are on syringe drivers. Such meetings could be held in the education room in the in-patient unit and the doctor, professional nurse and the social worker could address the group. At these meetings, the family would have the opportunity to ask questions and gain insights and support from the group. Educational talks on self-care and care for the patient could be given. The knowledge of patients and participants would be enhanced, resulting in increased levels of confidence. With the support of the palliative care team, the researcher hopes to start a support group within the next three months.

5.3.6 Arranging family meetings

A family meeting of the extended family should be held when there are fears and concerns expressed regarding the medication and the use of the syringe driver. Meetings would be helpful particularly when there are disagreements among family members. The sharing of information in such a small group would enhance the confidence of extended families in the use of the syringe driver. Questions can be raised about the disease progression and the medication used in the syringe driver. If the patient is in the in-patient unit, then the doctor, professional nurse on duty, and social worker could set up the meeting. If the patient is at home in the community, then the community doctor, community professional nurse, and community social worker would arrange the meeting at the patient's home, at a time convenient for the extended family.

5.3.7 Quality improvement project

Reported problems in the use of the syringe driver in the in-patient unit have highlighted the need to embark on a quality improvement project (refer appendix 18). It had been noted that the medication in a syringe had not moved over a 24-hour period. The researcher, thus, redesigned the syringe driver charts (refer appendix 11). The new charts make provision for the nurse on duty to sign the amount of medication left in the syringe every four hours (refer appendix 12). The problem of the medication in a syringe driver that has not moved for any amount of time, as a result, could be detected much sooner. In addition, the auditing of the syringe driver charts has been included when patients are discharged or when they have died. The reason for the quality improvement project of the overall management and safety of operating the syringe driver is not to compromise the trust of the patient and family. As a participant put it:

... If I trust a nurse, with an injection why not with this gadget. (C01/01)

5.4 PERSONAL REFLECTIONS

The researcher was personally enriched by this research study. My knowledge was enhanced by doing the literature review and conducting the interviews. I appreciated the information participants provided and found the various interactions with the participants rewarding. Participants in this research study were family members of terminally ill patients, who were on the syringe driver. These family members seemed to enjoy being interviewed to determine their understanding and perceptions of the syringe driver. The family members were grateful for the support they received at the institution where their relatives were cared for. They had a deep sense of gratitude towards the staff nursing their loved ones and they

were relieved when their family member was admitted to the in-patient ward for approximately two weeks.

The education of both staff and family members at all palliative care institutions could be increased and more staff and family members become involved in these programmes. Increased education would develop staff, family members, and communities, as well as create advocacy-orientated community members who would eventually become involved in caring for their terminally ill relatives. It is hoped that such a possibility would challenge all staff and care teams at palliative care institutions to take the recommendations to heart.

5.5 CONCLUSION

The study highlighted the problems that the family members endure on a daily basis, while caring for their terminally ill relatives. It gave participants an opportunity to tell their stories and they were able to express their fears and concerns regarding the syringe driver and the medication used in it. They could also express the difficulties they faced as a family. The participants felt valued that somebody was acknowledging them and showing an interest in their opinions.

This research study highlighted the need for quality improvement management when using the syringe driver in the in-patient unit. The need for continuous education and increased written information was evident. The study also revealed that the extended family had more fears and concerns about the use of the syringe driver than the immediate family members. Drug abuse in some patients' homes is a concern that was highlighted during this research study.

Based on the recommendations made, which highlighted those areas needing some attention, the researcher considers the study to have some clinical relevance. The in-patient unit has been using the redesigned charts to good effect. It is hoped that the study would inspire and assist other professional nurses to carry out similar studies on other aspects of the use of the syringe driver and the medication used in the driver. The researcher was personally and professionally enriched by completing this research study, and I hope that my investigation will make a contribution to the care of patients on syringe drivers in all hospices and institutions that make use of this device. I also trust that this research study will help management at all hospices and places of care to realise the importance of educating staff dealing with terminally ill patients, particularly those patients on syringe drivers. Educating immediate and extended family members are equally important. This should form part of the continuous strategic planning processes in all palliative care institutions.

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APPENDIX 1:
MORPHINE CONSUMPTION: AFRICA AND THE WORLD

Table 1

Morphine Consumption: Africa* and the World (mg/capita)

Note: Countries not listed did not report morphine consumption to the INCB for 2004

1	Austria	115.7151	53	Rep. of Korea	2.0304	105	Mexico	0.1957
2	Canada	64.1751	54	Tunisia	1.9579	106	Azerbaijan	0.1810
3	Denmark	63.0390	55	Ukraine	1.8003	107	Turkey	0.1785
4	Australia	55.9482	56	Latvia	1.7505	108	Dominica	0.1714
5	New Zealand	54.8074	57	Bahamas	1.3943	109	Ecuador	0.1615
6	United States of America	48.8145	58	Jamaica	1.3806	110	Grenada	0.1584
7	Iceland	43.9204	59	Malaysia	1.3013	111	Mauritius	0.1521
8	France	41.8355	60	Macao	1.2809	112	Turkmenistan	0.1443
9	Norway	35.4423	61	Singapore	1.2174	113	Swaziland	0.1437
10	Sweden	28.4913	62	Lebanon	1.1213	114	Kenya	0.1400
11	Switzerland	26.5509	63	Argentina	1.0753	115	Wallis & Futuna Islands	0.1333
12	Falkland Islands	22.6667	64	Republic of Moldova	0.8212	116	Syrian Arab Republic	0.1244
13	United Kingdom	19.1548	65	Bahrain	0.7344	117	Vanuatu	0.1238
14	Netherlands	17.8260	66	Oman	0.7175	118	Chad	0.1197
15	Germany	16.0119	67	United Arab Emirates	0.7053	119	Colombia	0.1176
16	Saint Helena	13.2000	68	Panama	0.6261	120	Morocco	0.1153
17	Ireland	12.8478	69	Greece	0.6068	121	Kyrgyzstan	0.1111
18	Gibraltar	12.2069	70	Zimbabwe	0.5718	122	Viet Nam	0.0993
19	Spain	11.8115	71	Belarus	0.5606	123	Anguilla	0.0833
20	Belgium	10.4698	72	Mongolia	0.5511	124	Nauru	0.0833
21	Portugal	7.9790	73	Thailand	0.5421	125	Uzbekistan	0.0713
22	Poland	6.1887	74	Paraguay	0.5353	126	Zambia	0.0704
23	Czech Republic	5.7657	75	Botswana	0.5200	127	Mali	0.0665
24	New Caledonia	5.6591	76	Brunei Darussalam	0.5200	128	Egypt	0.0588
25	Finland	5.4013	77	Jordan	0.4981	129	Algeria	0.0546
26	Italy	5.3206	78	Dominican republic	0.4752	130	Libyan Arab Jamahiriya	0.0527
27	Israel	5.0158	79	Kazakhstan	0.4727	131	Marshall Islands	0.0526
28	Bulgaria	4.9697	80	Micronesia (Fed. States of)	0.4500	132	Bolivia	0.0524
29	French Polynesia	4.9069	81	Saudi Arabia	0.4463	133	Bhutan	0.0461
30	Japan	4.7174	82	Bosnia & Herzegovina	0.4332	134	Guatemala	0.0333
31	South Africa	4.6682	83	Sri Lanka	0.4248	135	Myanmar	0.0327
32	Estonia	4.5458	84	Peru	0.4163	136	Cape Verde	0.0217
33	Form. Yug. Rep. of Macedonia	4.3582	85	Uganda	0.4001	137	Indonesia	0.0180
34	Slovenia	4.3210	86	Cook Islands	0.3889	138	Senegal	0.0157
35	Slovakia	4.3185	87	Tonga	0.3861	139	Rwanda	0.0136
36	Barbados	3.8044	88	Republic of Palau	0.3500	140	Nepal	0.0126
37	Hong Kong SAR	3.4817	89	Qatar	0.3380	141	Benin	0.0112
38	Uruguay	3.3350	90	Kuwait	0.3376	142	Yemen	0.0100
39	Malta	3.2581	91	Montserrat	0.3333	143	Cambodia	0.0098
40	Costa Rica	3.2375	92	Nicaragua	0.3280	144	Burundi	0.0080
41	Brazil	3.0848	93	Iran (Islamic Republic of)	0.3277	145	Cameroon	0.0076
42	Andorra	3.0000	94	United Republic of Tanzania	0.3250	146	Sao Tome & Principe	0.0065
43	Namibia	2.8653	95	China	0.3221	147	Central African Republic	0.0048
44	Georgia	2.7498	96	British Virgin Islands	0.3182	148	Côte d'Ivoire	0.0032
45	Cyprus	2.7115	97	Saint Vincent & the Grenadines	0.2963	149	Dem. Rep. of the Congo	0.0031
46	Seychelles	2.6627	98	Venezuela	0.2961	150	Sierra Leone	0.0028
47	Hungary	2.5857	99	Russian Federation	0.2807	151	Eritrea	0.0021
48	Lithuania	2.4867	100	Guinea-Bissau	0.2368	152	Burkina Faso	0.0016
49	Chile	2.4758	101	El Salvador	0.2303	153	Pakistan	0.0013
50	Romania	2.4616	102	Turks & Caicos Islands	0.2273	154	Guinea	0.0011
51	Serbia & Montenegro	2.0794	103	Suriname	0.2183	155	Mozambique	0.0006
52	Netherlands Antilles	2.0447	104	Philippines	0.2182			



Pain & Policy Studies Group
WHO Collaborating Center for Policy and
Communications in Cancer Care
University of Wisconsin- Comprehensive Cancer Center
UW-School of Medicine and Public Health

APPENDIX 2:
**ETHICAL APPROVAL FROM CAPE PENINSULA UNIVERSITY OF
TECHNOLOGY**

16 October 2010
CPUT/HW-REC 2010/H016

P.O. Box 1906 • Bellville 7535 South Africa • Tel: +27 21 442 6162 • Fax +27 21 447 2963
Symphony Road Bellville 7535

OFFICE OF THE CHAIRPERSON:
HEALTH AND WELLNESS SCIENCES RESEARCH ETHICS COMMITTEE (HW-REC)
Registration Number NHREC: REC- 230408-014

At the meeting of the Health and Wellness Sciences-REC on 4 October 2010 approval was granted to Margaret Mary Wilkinson pending amendments that have now been received and reviewed. This approval is for research activities related to an MTech: Nursing at this institution.

TITLE:

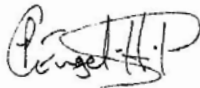
An analysis of the experience of families of terminally ill patients regarding the effects of the syringe driver in a palliative care unit

SUPERVISOR: **Dr P Basson**

Comment:

Research activities are restricted to those detailed in the revised proposal and application submitted in September 2010.

Approval will not extend beyond 16 October 2011. An extension must be applied for should data collection for this study continue beyond this date.



Prof PENELOPE ENGEL-HILLS
CHAIR: HEALTH AND WELLNESS SCIENCES RESEARCH ETHICS COMMITTEE

e-mail: engelhillsp@cput.ac.za

APPENDIX 3:

**ETHICAL APPROVAL FROM THE HOSPICE PALLIATIVE CARE
ASSOCIATION**

Suite 11a, Lonsdale Bldg, Lonsdale Way, Pinelands 7405
P O Box 38785, Pinelands, 7430, South Africa
Tel: 021 531 0277 Fax: 021 531 1704
Email: hpca@afrika.com
www.hospicepalliativecare.co.za



12 April 2011

Sr M Wilkinson
St Luke's Hospital
Private Bag X 4
KENILWORTH
7745
missmeg2468@gmail.com

Dear Sr Wilkinson

Protocol 05/10 : The understanding, perceptions and expectations of families of terminally ill patients on introducing the syringe driver in a palliative care unit. M Wilkinson, St Luke's Hospital

(was) An analysis of the experience of families of terminally ill patients regarding the effects of the syringe driver in a palliative care unit. M Wilkinson, St Luke's Hospital.

The above protocol was reviewed by the Hospice Palliative Care Association Research Ethics Committee (REC) at its meeting held on 24 August 2010. Queries raised have been addressed and approved at the REC meeting held on 11 April 2011. The amended protocol signed on 24 March 2011 is given full ethics approval. The Committee also agreed that data collected for the pilot study prior to ethics approval being given may be used in your analysis.

Please note the following :

- Copies of translated information to participants and informed consent documents, together with an undertaking from a person competent in both Afrikaans and English that the translations are accurate needs to be submitted;
- Ethics approval is valid for one year only. Application for recertification of the protocol should be submitted a couple of months prior to the 11 April 2012 to ensure continuous approval;
- ANY changes to an approved protocol must be reviewed by the Research Ethics Committee.

It would also be appreciated if, once the study has been completed, a summary of the results could be submitted to the REC.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

DR N MALAN
Deputy Chair : Hospice Palliative Care Research Ethics Committee
Reg. No. : REC-250408-005

no end to caring

Palliative Care is an approach that improves the quality of life of patients and their families facing life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Association incorporated under sec. 21 Reg no. 9601887/08. NPO no.003-462.
Patron: Archbishop Emeritus Desmond M. Tutu
Board: B Campbell-Ker (Chairperson), S Blakeman, S Fakroodeen (vice-chair), B Kuwane, S Mogottane, E Scrimgeour, T Thompson, R Wienskus, E Willie, M Wollheim
E Gwyther (CEO), K Henning (COO), C Hodgskiss (CFO) J. Lazarus (Company Secretary)

APPENDIX 4:
PERMISSION TO DO RESEARCH AT THE PALLIATIVE CARE UNIT

St Luke's Hospice



30 years of caring
1980-2010

7th July 2010

Ms Meg Wilkinson
In Patient Unit
St Luke's Hospice
KENILWORTH
7745

Dear Meg

RESEARCH CONSENT

Your letter about the above-mentioned dated 5 July 2010, refers.

I've enjoyed reading your research proposal and have no qualms about giving you the necessary permission to proceed with

- Undertaking a three month pilot study and
- Thereafter undertaking the research interviewing the relevant family members in the in-patient unit and recording their responses.

I agree with you that this study will result in a clearer understanding of the families' experience, what their expectations are and on how St Luke's Hospice can best assist them. It will also be good for the whole palliative care community of South Africa and for that matter that of the world as well.

Just as a matter of courtesy, I will also mention it to our Board Members at their meeting tomorrow night. I am sure they will also be in agreement with you proceeding with the research.

Thank you for embarking on this "adventure", that is how I view research anyway, I am very proud of you undertaking this research because it is something that I've always missed at St Luke's Hospice and I knew we had the necessary expertise to do it.

The only prerequisite that I do have, is that the research should not have a detrimental impact on the functioning of the ward at the time of you undertaking it.

With kind regards and all my blessings

A handwritten signature in cursive script, appearing to read "Priscilla Nelson".

Priscilla Nelson
CEO

APPENDIX 5:
PARTICIPANT INFORMATION LEAFLET
(In English and Afrikaans)

Information Leaflet:

Researcher:

Sister Meg Wilkinson,
St Luke's Hospice, Kenilworth

Would you please be so kind as to spend a moment or two of your precious time during this stressful period for you and your family to take a look at this information leaflet? I would like to invite you to take part in a research study which I am conducting for my M Tech Nursing degree at CPUT. It will be in the form of an interview which will be audio recorded.

Title of Research Study

The understanding, perceptions and expectations of families of terminally ill patients' on introducing the syringe driver in a palliative care unit.

The Aim of the Research Study

To gain a meaningful insight into the experience family members / significant other have of terminally ill patients commenced on a syringe driver.

Privacy and Confidentiality

As a participant in this research, your privacy will be protected at all times.

- The interviews will be conducted in a separate room.
- Everything we talk about in the interview will be kept confidential and should take about 30 minutes.
- Any personal details will be kept strictly confidential.
- You are free to stop taking part in the interview at any time and you may also choose not to answer specific questions if you would prefer not to share this information.
- We need to audio record this interview to assist the researcher to remember everything you say as your opinions are very important.
- The researcher and her supervisor will be the only people who will have access to this information.
- Your participation is entirely voluntary and you are free to decline to participate, without any victimisation whatsoever.
- You are also free to withdraw from the study at any point without any victimisation whatsoever.
- Personal dairies will be made available should you prefer to express yourself in the written format.

Safe-keeping

Data will be stored for at least five years in a locked safe with in the palliative care facility.

Ethical approval

This study has been approved by the Committee for Ethical Research at CPUT and will be conducted according to the ethical guidelines and principles of the South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research, Hospice Palliative Care Association (HPCA) and St. Luke's Hospice.

Benefits and Risks

There is no physical risk, but participants may feel quite emotional. Should the need arise, the interview will be stopped and an offer of emotional counselling from the trained counsellors will be made available.

There will be no financial benefit for participants of this study.

The researcher is self-funding this study.

Distress Protocol

Any respondent who appears to become distressed will be offered the opportunity to cease the interview and either abandon or restart when they are comfortable. The interviewer will pass on any information or request to their nurse at the patient's family's request. All information will be treated as confidential except in the situation of the patient's family's safety being at risk, in which case the information may be acted upon.

Dissemination of Results

It is envisaged that the data collected at the conclusion of this study, will provide insight and guidelines for staff at St. Luke's Hospice on how best to help and support patient's family members when patients commence on the syringe driver. These results may be published in a Medical Journal or at a Medical Conference.

Thank you for giving your time so generously.

Any questions can be forwarded for the attention of the researcher:-

St Luke's Hospice - Sister Meg Wilkinson (021) 7975335

If you have any questions about your human rights or any ethical issues about the study, contact:

CPUT University - Dr P Basson (Supervisor) (021) 959 6274

HPCA-REC - Cheryl Borresen (031) 261 7868

Title of the Research Study: The understanding, perceptions and expectations of families of terminally ill patients on introducing the syringe driver in a palliative care unit.

Deelnemerinligtingspamflet

Navorsers:

Suster Meg Wilkinson

St Lukes Hospice Kenilworth

Sal u asseblief so vriendelik wees om 'n paar oomblikke van u kosbare tyd in hierdie die spanningsvolle tyd vir u en u gesin af te staan om hierdie inligtingspamflet te lees?

Ek nooi u uit om deel te neem aan 'n navorsingstudie wat ek onderneem vir my MTech-graad in Verpleeging deur CPUT. Die onderhoud sal deur 'n opneemtoestel opgeneem word.

Titel van Navorsingstudie

Die begrip, persepsie en verwagtinge van gesinne van terminaal siek pasiënte wanneer met die inspuitapparaat in 'n palliatiewe sorg-eenheid begin word.

Die doel van die navorsingstudie

Om 'n betekenisvolle insig te kry van wat die gesinne en geliefdes ervaar wanneer 'n terminaal siek pasiënt op die inspuitapparaat begin word.

Privaatheid en vertroulik

- As 'n deelnemer aan hierdie studie, sal u privaatheid ter alle tye beskerm word.
- Die onderhoud sal in 'n afsonderlike kamer gehou word.
- Alles waaroor ons in die onderhoud praat, is vertroulik en sal ongeveer 30 minute duur.
- Alle persoonlike besonderhede word as streng vertroulik hanteer.
- U mag enige tyd onttrek wanneer u wil en u hoef nie te antwoord as u nie die inligting wil deel nie.
- Ons moet die onderhoud opneem sodat die navorsers alles kan onthou, want u opinie is baie belangrik.
- Die navorsers en haar toesighouers sal die enigste persone wees wat toegang tot hierdie inligting het.

- U deelname is heeltemal vrywillig en u mag weier om deel te neem sonder enige vrees vir viktimisering.
- U mag enige tyd van die studie onttrek sonder enige vrees vir viktimisering
- Persoonlike dagboeke sal vir u beskikbaar wees indien u sou verkies om uself skriftelik uit te druk.

Veilige Bewaring

Alle skyfies, dagboeke en transkripsies word gebere vir vyf jaar in die brandkluis van St Luke's Hospice..

Etiese Goedkeuring

Hierdie studie is goedgekeur deur die Komitee vir Etiese Navorsing by CPUT en sal aangebied word volgens die etiese riglyne en beginsels van die Suid-Afrikaans Riglyne vir Goeie Kliniese Praktyk, en die Mediese Navorsingsraad (MNR) se Etiese Riglyne vir Navorsing, Hospice Palliative Care Association (HPCA) en St Luke's Hospice.

Voordele en risikos.

Daar is geen fisiese risiko nie, maar 'n emosionele risiko om ongemak te ervaar. Indien die behoefte ontstaan, sal die onderhoud gestaak word en 'n emosionele berading deur opgeleide beraders sal beskikbaar gestel word. Daar is geen finansiële voordeel vir deelnemers aan hierdie studie nie. Die navorser befonds self hierdie studie.

Noodprotokol

Enige respondent wat blyk ongesteld te raak, kan die om die onderhoud staak en of dit heeltemal te los of om oor begin wanneer hulle gemaklik is. Die onderhoudvoerder sal enige inligting op versoek van die pasiënt se familie aan die verpleegster oordra. Alle inligting sal vertroulik hanteer word, behalwe as die pasiënt se gesin se veiligheid op die spel is, in welke geval daar opgetree sal word.

Verspreiding van Resultate

Dit word beoog dat die data wat versamel is aan die einde van hierdie studie, insig en riglyne sal verskaf vir die personeel by St Luke's Hospice oor die beste manier om ondersteuning aan gesinslede van pasiënte te bid, wanneer die pasiënt op die inspuitapparaat begin. Hierdie resultate kan gepubliseer word in 'n mediese joernaal of by 'n mediese konferensie.

Baie dankie dat u u tyd so mildelik afgestaan het.

As u enige vrae oor u menseregte of enige etiese kwessies oor die studie het, kontak:

St Luke's Hospice - Suster Meg Wilkinson (021) 797 5335
CPUT Universiteit – Dr. P Basson (Toesighouer) (021) 959 6274
HPCA-REC – Cheryl Borresen (031) 261 7868

APPENDICES 6: CONSENT FORMS

6.1) CONSENT FORM: IN ENGLISH

6.2) CONSENT FORM: FOR AUDIO TAPING IN ENGLISH

6.3) CONSENT FORM: IN AFRIKAANS

6.4) CONSENT FORM: FOR AUDIO TAPING IN AFRIKAANS

6.1: Consent Form for Pilot / Research Study

I, hereby confirm that I have been informed about
the nature of the research study by Sister Meg Wilkinson.

I have also received, read and understood the study participant information leaflet.

I understand that my personal details will not appear on the transcribed notes or the
personal diaries.

I may at any stage, without prejudice, withdraw my consent and participation in the
study without any form of victimisation.

I have had sufficient opportunity to ask questions /and of my own free will declare
myself prepared to participate.

Signature of participant

(Relationship to patient)

I have explained the research protocol to:

Signature of Researcher

Witness

Date

Title of the Research Study: The understanding, perceptions and expectations of families of terminally ill patients' on introducing the syringe driver in a palliative care unit.

6.2: Consent Form for Pilot / Research Study – Audio taping

I, hereby confirm that I have been informed about the nature of the research study by Sister Meg Wilkinson.

I have also received, read and understood the study participant information leaflet and that the interview will be audio taped.

I understand that my personal details will not appear on the transcribed notes from the audio tapes.

I may at any stage, without prejudice, withdraw my consent and participation in the study without any form of victimisation.

I have had sufficient opportunity to ask questions /and of my own free will declare myself prepared to participate.

Signature of participant

(Relationship to patient)

I have explained the research protocol to:

Signature of Researcher

Witness

Date

6.3: Toestemmingsvorm

Titel van die navorsingstudie: Die begrip, persepsies en verwagtinge van gesinne van terminaal siek pasiënte wanneer met die inspuitapparaat in 'n palliatiewe sorgeenheid begin word.

Toestemmingsvorm vir proef- / navorsingstudie.

Ek bevestig hiermee dat ek deur Suster Meg Wilkinson oor die aard van die navorsingstudie ingelig is.....

Ek het ook die studie deelnemerinligtingspamflet ontvang, gelees en verstaan.

Ek verstaan dat my persoonlike besonderhede nie op die getranskribeerde notas of die persoonlike dagboeke sal verskyn nie.

Ek kan te enige tyd, sonder vooroordeel my toestemming en deelname aan die studie onttrek sonder enige vrees vir viktimisering.

Ek het voldoende geleentheid gehad om vrae te vra, en verklaar my vrywillig bereid om deel te neem.

Handtekening van deelnemer.....

Verwantskap aan pasient.....

Ek het die navorsingsprotokol verduidelik aan.....

Handtekening van Navorser.....

Getuie.....

Datum.....

6.4: Toestemmingsvorm vir opneemtoestel

Titel van die navorsingstudie: Die begrip, persepsies en verwagtinge van gesinne van terminaal siek pasiënte wanneer met die inspuitapparaat in 'n palliatiewe sorgeenheid begin word.

Toestemmingsvorm vir proef- / navorsingstudie vir gebruik van opneemtoestel.

Ek bevestig hiermee dat ek deur Suster Meg Wilkinson oor die aard van die navorsingstudie ingelig is.....

Ek het ook die studie deelnemerinligtingspamflet ontvang, gelees en verstaan.

Ek verstaan dat my persoonlike besonderhede nie op die getranskribeerde notas of die persoonlike dagboeke sal verskyn nie.

Ek kan te enige tyd, sonder vooroordeel my toestemming en deelname aan die studie onttrek sonder enige vrees vir viktimisering.

Ek het voldoende geleentheid gehad om vrae te vra, en verklaar my vrywillig bereid om deel te neem.

Handtekening van deelnemer.....

Verwantskap aan pasient.....

Ek het die navorsingsprotokol verduidelik aan.....

Handtekening van Navorser.....

Getuie.....

Datum.....

APPENDIX 7:
THE OPEN-ENDED QUESTIONS IN ENGLISH AND AFRIKAANS

Research Questions:

Navorsingsvrae:

- **What did you experience when your relative was commenced on the syringe driver?**

Hoe het u gevoel toe u gesinslid op die inspuitapparaat begin het?

- **What thoughts do you have about the syringe driver?**

Hoe voel u oor die inspuitapparaat?

- **What is your understanding about the syringe driver?**

Wat is u begrip oor die inspuitapparaat?

- **What were your expectations of the medication used?**

Wat was u verwagtinge oor die medikasie wat gebruik is?

- **What effect did it have on other family members?**

Watter uitwerking het dit op die ander gesinslede gehad?

- **What can be done to improve this experience?**

Wat kan gedoen word om die ondervinding te verbeter?

- *What information*
• **Were you given enough information when your relative was commenced on the syringe driver?**

Het u genoeg inligting ontvang toe daar met die inspuitapparaat op u gesinslid begin is ?

APPENDIX 8:

PROOF OF TRANSLATION FROM ENGLISH TO AFRIKAANS

26 April 2011

Hiermee verklaar ek, Susanna Elizabeth de Bruin, in my hoedanigheid as Taaladviseur dat die vertaling oor die Navorsingstudie korrek deur Meg Wilkinson gedoen is.

Die uwe,

S.E. de Bruin

076 303 9797

APPENDIX 9:
THE LIVING WILL

THE LIVING WILL

TO MY FAMILY, MY PHYSICIAN AND ANY HEALTH AUTHORITY:

This **advance directive** is made by me

Full Name:.....

Address:.....
.....
.....

at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress, or to render me incapable of rational existence, I do not give my consent to having my dying process prolonged by artificial means, including any pacemaker, nor do I give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.

DO NOT RESUSCITATE: I do not give my consent to any person's attempt at resuscitation, should my heart and breathing stop and my prognosis is hopeless.

This declaration is signed and dated by me in the presence of the two undermentioned witnesses present at the same time who at my request in my presence and in the presence of each other have hereunto subscribed their names as witnesses.

Signature: Date:

N B: Witnesses should NOT be family members or your personal medical practitioner/s, nor should they be beneficiaries in your Last Will and Testament.

WITNESSES:

Signature:	Signature:
Name:	Name:
Address:	Address:
.....

NOTE: Should they wish, any person has my concurrence to apply for a court order to ensure compliance with this directive should any medical practitioner or health authority refuse to give effect to it.

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SAVES – The Living Will Society

PO Box 1460 Wandsbeck 3631

Tel: 031 266 8511 Fax: 031 267 2218

e-mail: livingwill@3i.co.za Web: www.livingwill.co.za

One transcript attached. The researcher is in possession of all the transcripts, should you require them.

APPENDIX 10:

INTERVIEW 6: A 04/04

Interview 6 A04/04

Speaker Key

MW Meg Wilkinson
FI Female Interviewee

MW Thank you very much for taking part in the interview. What did you experience when your relative was commenced on the syringe driver? What went through your mind at the time?

FI Well, I was a bit nervous because when I had to do it, can I say that?

Intimidating

MW Yes, just talk normally.

FI And then Sister – can I mention her name?

MW Yes.

FI Sister Marilyn explained to me, she showed me what to do, she showed me how to break the ampules. I admit I was very nervous about that, to draw up into the syringe. She showed me how to administer, how to put it in. Then I didn't have to do that afterwards, it was just to put the syringe into the driver. I learnt a lot, I did. I've learnt a lot, how it works.

*informer
↓
trust
↓
confidence*

MW But what thoughts did you think, why are they putting him on the driver?

FI I was explained, they explained it to me, that it's for his pain, and it's for his medications in there, and it will be much easier, and it is much easier, because when my dad was diagnosed with cancer, that was years, many years ago, and he died in December 1966, they never had things like that, and to watch him being injected to help with the pain, to see how they used to have to inject him in his legs, wherever they could. It broke my heart.

informer

I feel that bringing out the syringe driver, it's a comfort for the patient and for the family. It's a new learning experience for us, and I will recommend it to anybody if they've got a family or friend that's got cancer and they were told that they have to

understanding

5

39 FI No, not at all.

40 MW And your understanding of the syringe driver, what it actually does?

41 FI To me, if it wasn't in the syringe, it's all that to be administered, and it's all in
 42 there. It was wonderful, because Sister could tell me and the doctor could tell me,
 43 it's that medication, and it's the morphine in there, there's that in there. It's
 44 marvellous what all medication can go into one syringe. It's just wonderful what is
 45 being done here at Hospice.

*Confidence
in
using the
SID*

46 MW And the medication, has he been on it a long time now?

47 FI Yes.

48 MW How long has he been on it?

49 FI On the syringe driver? I can't remember.

50 MW About two months by now.

51 FI A little bit longer, I think from February, March, April, it's four months.

52 MW So he's been on it for four months. What did you think when they first
 53 started it?

54 FI I never had any doubts.

Confidence / Understanding

55 MW You had no doubts?

56 FI No doubts whatsoever. No doubts, and that's the truth, really.

57 MW No, that's good, that's very good, and your expectations of the medication
 58 that they're using, because at one stage he had two drivers, didn't he?

59 FI Yes, he had two drivers, because the one I think is, and I never had any
 60 doubts about that either, because I've got faith in the doctors that are here, I've got
 61 faith in the Sisters that are here, and I know that you do your best.

*Trust in
staff*

62 MW So you know that there's a combination of medications?

63 FI Yes, in that syringe driver.

64 MW So you know exactly that some are for pain and some are for nausea and
 65 some for the restlessness?

66 FI Yes, I was told what all goes in, so I know exactly.

67 MW Okay, and he's had it now for like four months.

68 FI Four months.

69 MW I mean, you didn't think it would hasten anything, those sort of thoughts?

70 FI No, I didn't have that. Not at all. Not at all. I never had that type of thought in
71 my mind, at all. I've also learnt, because now I know how to fit the syringe into the
72 driver. I've learnt a lot.

*Confidence
thought*

73 MW Okay, you can have your coffee in between. Do you think it had any effect
74 on the rest of the family? As we were saying, you're actually the ex wife, so did
75 anyone object in the extended family about the driver?

76 FI No, not at all.

77 MW Did any of them come and help you to look after him?

78 FI Well, my daughter, she was there with me. I said well, you've got to learn. I
79 said to her you've also got to learn how to do this. So I showed her, but I did it
80 most of the time. She did it once. She was nervous. I was also nervous at first, but
81 I'm used to it. Now I'm used to it.

*extended
family*

82 MW So nobody objected?

83 FI No.

84 MW The extended family?

85 FI No, not at all. Not at all. They found it very fascinating. They didn't know
86 that there were things like that, and I showed my daughters, his family, this is it,
87 this is what I do, and they couldn't believe it.

*Attitude to
extended
family*

88 MW So they feel that it's beneficial?

89 FI Yes, they do, they do.

*attitude to other
family members*

90 MW Okay, that's good.

91 FI He's comfortable with it, very comfortable with it. I call it the handbag
92 [laughs].

93 MW Yes, everyone has got different names for them.

94 FI I say to him don't forget your handbag now, and I strap it around his neck.

95 MW And it's not a cause of concern for you, you know, what times you needed
96 to change it or anything?

97 FI No. Well, I'll check to see that I've done it that time, I'll write it down,
98 because I write all, what time I give his medication, I write everything down. Then
99 okay, it's 24, but sometimes it finishes before the 24th hour. No, I don't worry. If it's
100 got to get changed in the middle of the night, that's fine.

*in sight who
medication*

101 MW Is it?

102 FI Yes, and I'll do it.

103 MW Yes, you're very good.

104 FI If it's got to get done two o'clock in the morning, three o'clock, I'll do it.

105 Really.

106 MW That's amazing.

107 FI And that's the truth, because you can ask them and they'll say. The times
108 when it was two, three o'clock or whatever, I set my alarm just in case I've dozed
109 and he's sleeping, that I can wake up, but I wake up before that alarm goes off.
110 Then I know okay, it's almost time, then I'll change it, and write it down, the time
111 again.

112 MW Right, that is good. What do you think we can... so the extended family in
113 that you have to now think in the early days, did nobody object? Did they just feel
114 because you were happy with it, they were all happy? Did nobody say what's this
115 or why is this?

116 FI They did like ask me what is it called, you know, they asked questions, and
117 I said this is it, it's the medication, it's all in here, and they all agree what's best for
118 him.

informed

119 MW What's best for him.

120 FI We all say the same, what is best for him.

121 MW Right, okay.

122 FI Nobody has like gone against it and said no. I've spoken to them about it, I
 123 said this is it, and I showed them. Everybody's answer was what is best for him.

*although to
 frequently*

124 MW For the patient.

125 FI Yes. His daughters, the same.

126 MW What can we do to improve the whole experience? As you said, Sister did
 127 explain to you. Does the Sister at home also help with it?

128 FI Yes, the Sister at home, she comes and she fills the syringe driver for me.

Attitude

129 MW Okay, so you don't actually fill it yourself?

130 FI No, I don't fill it. I just put it in.

131 MW Change the syringe.

132 FI Yes, that's what I do.

133 MW Okay, but did she offer to teach you how to fill it up?

Just

134 FI Yes, and Sister Marilyn here at Hospice, but I just found I'm very nervous
 135 with that, when I've got to draw it up.

136 MW Nervous to?

137 FI I know how to break the ampules open, but it's just to fill that.

138 MW Nervous that you might draw too much or too little, or it won't go in?

139 FI Might take too long, yes, yes.

140 MW No, that's fine, that's sort of what we need to know and to understand,
 141 because we're so used to doing things, we don't know how families feel about
 142 drawing up and things like that. So basically Sister Yvonne at home draws it up
 143 and gives it to you ready to just change?

144 FI Yes.

145 MW And that you feel comfortable with?

146 FI I feel very comfortable with that. She'll explain to me, it's so many morphine
 147 ampules, it's so much of this and it's so much of that.

*although
 +
 confidence*

148 MW So you know exactly what's going in.

149 FI Yes, and she'll put it there.

150 MW Were you given enough information in the beginning now, when you think
151 back when he first went on it? Do you think we could have given you more
152 information about it, more stuff so that the family could read about it?

153 FI I feel I was explained the right way how to, and I just passed the info onto
154 the family.

Information

155 MW So you feel you had enough?

156 FI Yes, definitely. It wasn't just you must do that, and left me alone, now I must
157 figure it out for myself. No, I was called into the office and Sister Marilyn explained
158 to me, she showed me what must get done, how I've got to put the syringe in,
159 everything, how to move the needle and put it onto the other, the new one,
160 everything.

*Information
Given*

161 MW Oh, okay, so you had enough.

162 FI Yes, and then she called me in again when the next one was due, she said
163 okay, now you try, and the first time I said to her Sister, and what do I get out of
164 ten? She said eight out of ten, and the next time I got nine out of ten.

*Confidence
Trust*

165 MW Oh, there you go.

166 FI It was a learning experience for me, and let's put it this way, if I can say it
167 that way, it was actually a feather in my cap when she said oh, you got eight out of
168 ten, and nine out of ten, and then I thought you know, I am taking this all in,
169 because I'm so interested in this.

*Support
Confidence
Interest*

170 MW And you're willing to help him, and be able to assist him.

171 FI Yes, and I've learnt a lot in that Hospice.

172 MW So you don't have any qualms about it?

173 FI No, not at all.

174 MW And neither any of the extended family?

175 FI No.

176 MW Has he got a large family?

177 FI Yes, he has.

178 MW So you won't get any comebacks from them?

179 FI No, not at all.

180 MW Is there anything else that you want to talk about, about the driver or
181 anything else?

182 FI Sister, could I say this? I would just like to say that Hospice has taught me a
183 lot, the staff, the Sisters. If I needed to ask something, or go into the office and say
184 if he needs this or that. I was never turned away. I was always helped, I was
185 shown affection, comfort. I recommend Hospice to anybody, and that is the truth,
186 from my heart.

Support

187 MW That's good. Okay, that's all I've got to ask you. It sounds like, generally
188 how would you describe that it was a good experience?

189 FI I feel it's a very good experience. It was a very, very good experience.

Trust & Confidence

190 MW And also the fact that doctor changes the medicine, like today she will
191 increase some of the medicines.

192 FI I feel she is doing it to help the patient, and I have got no argument about
193 that.

194 MW All right. Okay, super, okay well we'll stop there then.

195

196 [End of Interview 00:17:26]

Interview 6 A04/04

This table below indicates how each interview was analyzed by grouping the themes together and then forming the recommendations.

	Questions and Answers	Summary	Recommendations
R	Thank you for taking part in the interview.		
R	What did you experience when your relative was commenced on the syringe driver? What went through your mind?		
1.	Well I was a bit nervous. Because then I had to do it.	Nervous, anxious About reloading the syringe driver	Need for support and information on the syringe driver.
2.	Sister explained to me, showed me how to break the ampoules, I was very nervous about that and to draw up the syringe.	Nervous, anxious about breaking the ampoules and drawing up the syringe.	Some families are too anxious to draw up the syringe.
3.	She showed me how to administer to put in, and then I did not have to do it after that just put the syringe into the driver.	The homecare sister recognized that she was too nervous to draw up the syringes.	Daily the homecare sister had to draw up the syringe as the family member was too nervous to do it.
4.	I learned a lot. I did I have learnt a lot. How it works.	Was a learning experience.	Needs recognition and support and information.
R	But what thoughts did you think of why they are putting him on the syringe driver?		
5.	I was explained Sister explained it to me.	Information was given verbally.	Need for written information.

6.	It is for his pain, medication is in there.	Understands to control his pain.	Understands the reason for the syringe driver.
7.	And it will be much easier and it is much easier.	Acknowledges that the syringe driver is helping to control the pain.	Improves the perception of the syringe driver.
8.	When my dad was diagnosed with cancer that was many years ago he died in December 1966.	Reminiscing about her father.	
9.	They did not have things like that and to watch him being injected to help with the pain to see how he had to be injected in his legs where ever they could it would break my heart.		Understanding the need for the syringe driver.
10.	I feel bringing out the syringe driver it is a comfort for the patient and family.	Comfort for patient and family.	Best way to control symptoms.
11.	A new learning experience for us.	Understanding the syringe driver.	Information gained.
12.	I would recommend it for anybody family or friend who has cancer and they were told they have to have a syringe driver. I feel they should say yes.	Positive about the syringe driver.	Could explain to others in a support group.
13.	They should agree to have a syringe driver to me it was a learning experience and I have learnt a lot sister it's wonderful.	It has been a learning experience	
R.	Ok so you weren't hesitant when they wanted to start the syringe driver?		
14.	No not at all.	No doubts at all.	
R.	What is your understanding of the syringe driver what it does?		

15.	To me if it was not in the syringe it's all in there has to be administered and it was wonderful the sister and doctor could tell me it's this medication and that medication.	Her understanding of the syringe driver.	
16.	It is marvelous what all the medication can go into one syringe.	Combination of drugs, for a combination of symptoms.	Combination of medication through one route.
17.	It is just wonderful what is being done here at hospice.	Feels comfortable in the in-patient unit.	
R	The medication as he has been on it a long time now. How long has he been on it?		
18.	Sister I can't remember about two months now from February, March, April, May about four months.	How long patients can be on syringe drivers four months.	
R	What did you think when they first commenced the syringe driver?		
19.	No I did not have any doubts no doubts so ever and that's the truth.	No doubts.	
R	No that's good and your expectations of the of the medication they are using cause at one stage he had two drivers?		
20.	Yes he did have two drivers.	Extra stress for the family member on discharge.	Need support and information.
21.	I never had any doubts that either cause I have faith in the doctors that are here, faith in the sisters that are here. I know that you people do your best.	Building of trust.	Trust in the doctors and sisters.

R	So you know that there is a combination of medication in the syringe driver.		
22	Yes		
R	You know some is for pain and some for nausea.		
23.	Yes, yes.		
24.	Yes I was told so I know exactly.	Understands what medication is in the syringe driver and what it is for.	Has a good understanding of the medication in the syringe driver.
R	Do you think it had any effect on the rest of the family? You know as we were saying you are actually the ex-wife. Did anyone object in the extended family about the syringe driver?		
25.	No not at all.		
R	Did any of them help you to look after it?		
26.	Well my daughter..... he said you also got to learn how to do it so I showed her how she did it once she was nervous. I was also nervous but now I am use to it.	Extended families are nervous about reloading the syringe driver.	Extended families need more information and education about the syringe driver.
R	So nobody objected?		
27.	No the extended family no not at all they were fascinated they did not know that there were things like that. I showed my daughters, his family this is this. This is what I do.	Syringe driver is unknown to the extended family.	Written information to give to extended family.
R	They feel it is beneficial.		
28.	Yes they do they do. He is comfortable with it very comfortable I call it his hand bag. I say now don't forget your hand bag when he gets	No objections to the syringe driver. Patient is comfortable.	Good symptom control.

	up.		
R	It's not a cause of concern the times you need to change it or anything?		
29.	No I change it at that time I write it down whenever I give his medication I write it down.		
30.	I say okay its twenty four sometimes it finishes before the twenty four hours and no I don't worry if it has to be changed in the middle of the night its fine I will do it.	Willing to change the driver in the middle of the night.	
R	Is it you are very good.		
31.	If it must be done 2 or 3 o'clock I will do it really sister and that's the truth you can ask anyone the times when it was 2 or 3 o'clock I set my alarm in case I am sleeping I can wake up before that alarm goes off then I wake and change it and write it down.	Sets alarm clock to reload the syringe driver.	The professional staff should be aware of this, so it can be reloaded at a more convenient time for the family member.
R	What do you think the extended family did nobody object you must think back to the early days?		
32.	They did like ask me what is it called they asked questions I said this is its medication it's all in here they all agreed what's best for him.	All agreed what's best for him.	Family all in agreement about the syringe driver.
R	Nobody had gone against it?		
33.	No I showed them I said this is it everybody's answer was what is best for him even his daughters.	All agreed what's best for him.	Extended family all in agreement about the syringe driver.
R	What can we do to improve the whole experience? Sister did explain to you does the home care sister also help?		
34.	Yes, the sister at home comes and she fills the syringes for me.	Does not fill the syringes.	

R	So you don't actually fill it?		
35.	No I don't actually fill it I just change the syringe yes that's all I do.	Changes the syringe.	
R	Okay but did she offer to teach you how to fill it up.		
36.	Yes sister..... Here at hospice did but I am very nervous of that.	Nervous to draw up the syringe.	
R	Nervous too...		
37.	I know how to break the ampoules but it's just to draw it up.		Professional staff must be aware that some family members are nervous about drawing up the syringes.
R	Nervous to draw too much or too little?		
38.	Yes.		
R	No that is fine that's sort of what we need to know and understand. Because we are so use to doing things we don't know how families feel about drawing it up and things like that.		
R	So basically sister Draws it up and gives it to you ready to change and that you feel comfortable with?		
39.	I feel very comfortable with that, she will explain to me so many morphine ampoules so many of this so you know exactly what is going in.	Done in front of her she knows what is going in.	Helps to build trust with the home care sister.
R	Were you given enough information? When you think back when he first went on the syringe driver?		

40.	I feel I was explained the right way I do and I just passed the information on to the family.	Was explained and passed the information on to family.	Written information could have been more beneficial.
41.	It was not you must do that and left me on my own and I must figure it out myself. No I was called in the office sister.... explained to me she showed me what must be done how I must put it on the new one everything yes, she called me in again and said okay.... Now you try.	Was explained and shown more than once.	
42.	The first time I said sister what do I get out of ten, eight out of ten.(Laugh together) and the next I got nine out of ten.		
43.	It was a learning experience for me and if I can say it was actually for me a feather in my cap when she said eight and nine out of ten.	It was a learning experience.	Made her feel good about herself.
44.	I thought you know I am taking this all in because I am so interested in this.	Interested in it.	
R	Um and you are willing to help him.		
45.	Yes and I have learnt a lot at hospice.	Learning experience	
R	So do you have any qualms about the syringe driver?		
46.	Not at all.	No qualms about the syringe driver.	
R	Neither any of the extended family.		
47.	Yes a large family.	Large extended family	
R	So you won't get any come backs from them?		
48.	No not at all.	All are in agreement with	Extended family in agreement with

		the use of the syringe driver.	the use of the syringe driver.
R	Well done is there anything you want to talk about the syringe driver or anything else?		
49.	Sister could I just like to say this that hospice has taught me a lot. The staff the sisters everyone if I needed to ask something or go into the office for this or that I was never turned away.	Was a learning experience.	Hospice has taught her a lot.
50.	I was shown affection comfort and I recommend hospice to anybody and that is the truth from my heart.	Felt supported.	
R	Okay that is all I have got to ask you generally how would you describe it as a experience?		
51.	I feel it was a very good experience, very good experience.		Good experience.
R	Even the fact that the doctor is changing the medicine.		
52.	I feel she is doing it to help the patient and um I have no argument about that.	What is best for the patient?	Trust in the doctor.
R	Okay then we will stop there then. Thank you.		

**APPENDIX 11:
ORIGINAL SYRINGE DRIVER CHARTS**



St Luke's Hospice
Hospice of the Sacred Heart of Jesus

Please use LUER LOCK syringe for epidurals

SYRINGE DRIVER CHART

SUB CUT

EPIDURAL

NAME & SURNAME: FOLDER NO.:

SYRINGE DRIVERS NO.
NO. OF SYRINGE DRIVERS
IN SITU:

NO. OF SYRINGE DRIVERS		NO. OF SYRINGE DRIVERS							
IN SITU		1	2	3	4	5	6	7	8
1.								
2.								
3.								
4.								
5.								

START DATE:

RATE:

ROUTE:

SIGNATURE:

RATE : HOURS / 10ml

1 = 48

2 = 24

3 = 18

4 = 12

**APPENDIX 12:
NEW SYRINGE DRIVER CHARTS**

APPENDIX 13:
SYRINGE DRIVERS: ENGLISH INFORMATION

The Syringe Driver Information for patients and carers

Introduction

This leaflet has been written to add to what you have been told by your nurse or doctor about the use of your syringe driver. We hope it answers some of your questions.

If you want more information, please ask your nurse or doctor.

What is a syringe driver?

A syringe driver is a small, lightweight, battery operated, portable pump that gives your medication slowly and steadily over a period of time - usually 24 hours. The syringe that is connected to the syringe driver is filled with medication depending on your symptoms.

Your medication will be reviewed on a regular basis and may be changed, if necessary.

How will the syringe driver be connected to me?

Liquid medication is put into a syringe and a long thin tube, with a tiny needle or plastic tube at the other end, is connected to it.

Your nurse or doctor will insert the needle just under the skin. They will put a clear dressing over the needle to keep it clean, dry and in place. Once the needle is in place, you shouldn't feel it and it can stay there for several days.

The needle is usually inserted into your chest or upper arm, although other parts of the body may be chosen for comfort or convenience.

Why do I need a syringe driver?

- Syringe drivers are used for several reasons. It is a simpler and more comfortable way to receive medication for people who would otherwise need repeated injections
- Some people find it difficult to swallow their medication in tablet or syrup form
- Some people may feel sick or vomit frequently which means they can't keep their tablets in their stomach long enough for them to work
- Some people's symptoms are difficult to control by tablets alone and a syringe driver may be used as well.

What do I need to watch out for?

Your skin: Sometimes the medication in the syringe can cause a skin reaction. Your nurse will check the needle site regularly. If the area becomes sore, the needle may be moved to another part of your body.

If you notice any redness or swelling yourself, report it to your nurse.

Check that it is on rate.....
Make sure there is no air in syringe carefully squirt out any air.

The syringe driver: A syringe driver is quite strong but can be damaged by dropping it or standing on it accidentally. Handle the driver with care.

A syringe driver must not get wet. Ask your nurse for advice about washing and showering.

There is an alarm in the syringe driver that will beep if there is a problem. The alarm usually sounds for one of two reasons:

- 1) There is a blockage to the flow of medication caused by a kink in the long tubing.
- 2) The syringe is empty

You may be shown how to manage these problems. If you can't, please contact your nurse straight away. If you don't, you may start to become uncomfortable.

A small light on the front of the syringe driver flashes regularly and shows that the battery and syringe driver are working. If it stops flashing, a new battery may be needed.

There is a 'boost' button on some types of syringe driver. Don't use it - it should only be used by the nurse when the syringe driver is set up.

Keep the syringe contents out of direct sunlight. They must not become too warm. Please ask your nurse for advice on the best place to keep your driver.

Please note: A syringe driver is a very expensive piece of equipment. Please keep it safely when you have finished with it so that it can be returned and used by other patients.

The nurse will complete several forms to make sure that the syringe driver is used safely.

If you have questions or want more information, please ask your doctor or nurse. You may like to use the space below for contact numbers or notes.....

APPENDIX 14:
SYRINGE DRIVER: AFRIKAANS INFORMATION

Die inspuitapparaat

Inligting vir pasiënte en versorgers

Inleiding:

Die blaasjie is geskryf vir bykomende inligting by wat u verpleegster of die dokter u reeds van die inspuitapparaatvertel het. Ons hoop dat dit van u vrae sal beantwoord.

As u verdere inligting benodig, **Wat is 'n inspuitapparaat?** vra u verpleegster of dokter.

Dit is 'n klein, liggewig, kasteryaangedrewe, draagbaar, pomp wat die medisyne stadig en egalig oor 'n 24-uur-tydperk aan die pasiënt lewer. Die inspuiting wat aan die apparaat verbind is, is gewal met versterkte medikasie afhangeende van die pasiënt se simptome. Indien nodig, sal die medikasie sal gereeld dopgehou word en verander word indien nodig.

Hoe word die apparaat aan die pasiënt gekoppelt?

Die medikasie word in die inspuiting gesit en met 'n lang buis met 'n dun maald wat aan die apparaat verbind is.

Die verpleegster of dokter sal die maald onder die vel haarsk en dit dan vasplak met 'n deursynende pleister om die maald op sy plek te hou. Nadat die maald ingestek is, behoort die pasiënt dit glad nie te voel nie en dit kan 'n paar dae op die een plek bly.

Waar word die maald ingestek?

Die maald word gewoonlik op die buik, bo arms of enige plek van vir die pasiënt geneklik en geneklik is ingestek.

Hoekom is die spuitapparaat nodig?

- Dit word om verskillende redes gebruik.
- Dit is meer geneklik vir pasiënte wat dikwels inspuitings benodig.
- Wanneer pasiënte nie meer hulle medikasie kan slik nie.
- Wanneer pasiënte herhaaldelik oopgooi en die medikasie word nie lank genoeg in die maag genehou word sodat dit kan werk nie.
- Painy geson se simptome is moeilik om net met pille alleen te behandel.

Waarom moet ek oplet?

Die vel: Sommige word die vel om die maald rooi of seer. Laat weet die verpleegster sodat sy dit na 'n ander plek op die lyf skuif.

Maak seker dat it op die regte druppel is

Maak seker alle lug uit die spuit is wanneer medikasie oorgetrek word.

Die spuitapparaat is sterk, maar kan beskadig word as dit val of as daar per ongeluk op dit getrip word.

Die spuitapparaat moet net word nie. Vra die verpleegster se advies oor hoe om te was en te stort.

'n Alarma sal afgaan as daar enige probleme is, soos:

-As daar 'n blokkasie in die buis is of

-As die spul leeg is.

U sal getel word wat om te doen wanneer hierdie probleme voorkom. As u onseker is, skakel dadelik die verpleegster. As u dit nie doen nie, kan u ongemak begin ervaar.

As die klein ligte vooraan die inspuiting gereeld flitker, beteken dit dat die batterij en inspuitapparaat werk. As die ligte ophou flitker, beteken dit dat die batterij vervang moet word.

Daar is 'n "toets"-knoppie op sommige inspuitapparate. Moenie dit gebruik nie. Dit mag net deur die verpleegster gebruik word wanneer die apparaat opgestel word.

Hou die inspuiting se inhoud uit drokke sonlig. Dit mag nie te warm word nie. Vra assistent u verpleegster waar die beste plek is om u apparaat te hou.

Onthou die apparaat is baie duur. Hou dit op 'n veilige plek en as u dit klaar gebruik het, gee dit terug vir die verpleegster.

Die verpleegster sal vernu invul om seker te maak dat dit veilig gebruik word.

Indien u enige vrae het of verdere inligting nodig het, vra die dokter of die verpleegster.

U kan die ruimte hieronder vir kontaknummers of aanbevelinge gebruik.

APPENDIX 15:
DOCTOR'S ASSISTANCE



St Luke's Hospice* (NPC)
Accredited to the Hospice Palliative Care Association of SA

Making a difference,

providing quality Palliative Care

01st February 2013

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

I hereby declare that I was on the ward while Sr Meg Wilkinson was interviewing family members in her study.
I could therefore assist if the family required further assistance.

Yours Sincerely,


DR RENE KRAUSE

92 Harfield Road, Private Bag X 4, Kenilworth, 7745, South Africa Tel: (021) 797 5335 Fax: (021) 761 0130 Website: www.stlukes.co.za

*St Luke's Combined Hospices, Reg No. 1998/008839/08 NPO No. 007-350/9399 PBO No. 130004500

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R Ulster, Z Kapile, A Scott, ID Werner, MB Mtwisha, P Simkins

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APPENDIX 16:
SOCIAL WORKER'S ASSISTANCE

**APPENDIX 17:
NOTES FROM DIARIES**

Notes from the Diaries

Diary A05/05

What did you experience when your relative was commenced on the syringe driver?

Ek het net gewonder waste apparaat is dit? (Wife)

I wondered what it was about. Thought is was a painful process. (1st Daughter)

I feel as long as it can help then it's something good. (2nd Daughter)

What thoughts do you have about the syringe driver?

Nadat ek ingelig is oor die apparaat en verstaan toe voel ek beter. (Wife)

I think it's brilliant especially if patient finds it difficult to swallow medication. (1st Daughter)

It is something good seeing the comfort it's bringing too the patients state. (2nd Daughter)

What is your understanding about the syringe driver?

Niks medikasie wat aanbeveel word sal as 'n nadeel op 'n pasient gebruik word nie dit is net 'n voordeel. (Wife)

My understanding is that it is a way to ensure the patient gets prescribed medication when having difficulty taking medicine orally. (1st Daughter)

I think it's a better way feeding them the needed medications seeing that's it is difficult too swallow. (2nd Daughter)

What were your expectations of the medication used?

Ek dink dit is beter aangesien dat hy nie die pille kon af sluk nie. (Wife)

I expected it should be difficult to administer but it was quite an easy process. (1st Daughter)

What effect did it have on other family members?

Som van die gesinslede voel die selfde soos ek voel oor die apparaat tevrede. (Wife)

Some of the family members weren't sure what it was, but after being explained about it, they were happy that medication should be given with the device. (1st Daughter)

Well, I guess we all feel as long as it can help we are happy with it. (2nd Daughter)

What can be done to improve this experience?

Ek dink dit is goed genoeg. (Wife)

As long as the patient doesn't show any discomfort I personally think it is good as it is. It clearly put my dad into a more calm state, seeing that he didn't like the idea of taking so much medication orally daily. (1st Daughter)

I think it is perfect the way it is. (2nd Daughter)

Were you given enough information when your relative was commenced on the syringe driver?

Ja ek het genoeg inligting ontvang. Nadat die suster my verduidelik het, oor die apparaat. (Wife)

Yes, the information given was accurate and understandable enough given by the sister in charge. (1st Daughter)

It was explained perfectly. (2nd Daughter)

Diary A04/04

What did you experience when your relative was commenced on the syringe driver?

I was very anxious at first but comfortable now.

What thoughts do you have about the syringe driver?

Positive thoughts. I have full trust in it now and use it with ease.

What is your understanding about the syringe driver?

Medication admin at regular intervals, correct dosages. Patient more comfortable less stress and less pain.

What were your expectations of the medication used?

I felt comfortable and at ease. I have full trust in the medical staff at hospice and especially sister.....she has been a pillar of strength to us all. To keep him as comfortable as possible and to relieve his pain.

What effect did it have on other family members?

I have full trust in the staff and the medication they prescribed. I am not comfortable setting the driver up. (1st Sister)

To see my brother pain free and without those dreadful seizures says it all. Medication works well and keeps him comfortable. (2nd Sister)

What can be done to improve this experience?

I feel that it is perfect as it is –highly recommend it.

Were you given enough information when your relative was commenced on the syringe driver?

Yes, was given all the info possible. Hospice sisters were very thorough in showing me and other family members how to operate driver.

Diary B01/01

My personal opinion regarding the syringe driver is that it's the same as giving a patient an injection every hour only in this case it's a little machine that does it.

As the primary caregiver it got to the point where I could not administer the medication orally because the patient became too weak to swallow anything.

My thoughts on the syringe driver are that it's the last resort in helping you as the caregiver. The sister explained to me what it was all about.

The medication is the same only in liquid form and she prepared and explained step by step in front of me and that made me more comfortable with it.

From the family side they didn't have a problem with the syringe driver and accepted it well.

I got a lot of support from the staff offrom the doctor to the cook had a word of encouragement to me and that helps a lot, because I came to the conclusion that all of them are not only here to do a job and earn a living they are with a lot of love and care in their hearts. This is what makes.....special. I came here the first time and was so nervous because I didn't expect but soon my fears were gone, you can sense the love they have. I feel blessed to be in this environment that is so surrounded by love and caring

APPENDIX 18:
QUALITY IMPROVEMENT PROJECT

