Family members' perceptions and expectations of the use of syringe drivers: a South African study

Margaret Wilkinson, Hilda Vember

Abstract

Aim: This study aimed to explore and gain insight into the perceptions and expectations of family members of terminally ill patients pertaining to the use of syringe drivers. ***Background:*** There is a lack of research regarding the use of syringe drivers in Africa and, more specifically, South Africa. However, syringe drivers have been in use for around two decades in some South African settings. Some family members' ambivalence about the use of syringe drivers and the lack of research prompted this study. ***Method:*** A qualitative exploratory research design was used. Data was collected using semi-structured interviews, diaries, observation, and documentation. Thematic analysis and coding were used to analyse the data. ***Results:*** Four main themes were identified: the rationale for the need for the syringe driver, positive perceptions pertaining to the use of the syringe driver, negative perceptions, and concerns/anxieties. The study also highlighted the challenges of drug addiction in some households when caring for terminally ill patients. ***Conclusion:*** The need for more continuous education and written information and support for immediate and extended family members was evident.

Key words: Palliative care ● South Africa ● Syringe driver ● Family perceptions

A syringe driver may be commenced when a patient is experiencing severe pain, nausea and vomiting, or restlessness or has noisy moist breathing (Dickman et al, 2005) and oral administration of medication is no longer effective. For example, a syringe driver may be used when a patient's condition has deteriorated to the point that they are very weak and unable to swallow oral medication. Syringe drivers are a means of delivering medication subcutaneously at a continuous rate, e.g. dexamethasone for the treatment of headaches, nausea and vomiting caused by raised intracranial pressure due to intracranial oedema (Walker et al, 2010).

There is a lack of research regarding the use of the syringe driver in Africa and, more specifically, South Africa. Some research has found reasons why syringe drivers have sometimes not been used, which include the unacceptable use of a 'machine', the cost and limited availability of medication, and the fear that some people feel it will 'shorten the life of the patient' (Merriman, 2006). However, syringe drivers have been in use for around two decades in some South African settings. Owing to the expanding need of palliative care in South Africa (Defilippi and Cameron, 2009), hospices have been providing access to quality palliative care in the local state hospitals. According to a talk by Crede and Krause (2012), the syringe driver has been introduced for symptom control for some palliative care patients in two state hospitals in the Cape Town area.

A holistic approach to nursing must include the patient's family. Family members contribute to each other's life experiences (Pera and van Tonder, 2011). Some people in South Africa have large extended families, and different family members may visit a patient at different times. Caring for a terminally ill family member can cause problems such as tiredness and lack of personal time, loneliness, and anxiety or depression (Henriksson and Andershed, 2007). Family members who administer medical care to terminally ill patients can also suffer from stress and anxiety at having to reload a syringe driver (Israel et al, 2008). Families need to receive clear and relevant information regarding syringe drivers and medications, especially when the patient is being sedated (Brajtman, 2005). Competencies in drawing up the correct medication and in providing information and training for the family on setting up the syringe driver lie with the community or in-patient unit nurse (Cruickshank et al, 2010).

Aim

The aim of this study was to explore the perceptions and expectations of family members pertaining to the use of syringe drivers in a palliative care unit in South Africa.

Methods

A qualitative exploratory research design was used. According to Begley (2008), exploratory

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Box 1. Interview guide

- What did you experience when your family member was commenced on the syringe driver?
- What thoughts do you have regarding the syringe driver?
- What is your understanding regarding the syringe driver?
- What were your expectations of the medication used in the syringe driver?
- What effect did the use of the syringe driver have on other family members?
- What can be done to improve this experience?
- What information were you given when your relative was commenced on the syringe driver?

research is appropriate when researchers are aware of little research having been conducted in a field. The researchers were not aware of any South African studies investigating the use of syringe drivers.

Setting

St Luke's Hospice is situated in a suburb of Cape Town. It opened in 1980 and has continued to have a leading role in palliative care, both regionally and nationally. This hospice serves the greater part of the Cape Town community (Hickman, 2008). It has a 10-bed in-patient unit, which was where the study took place. Patients are limited to a 2-week stay in the in-patient unit, and may be discharged with a syringe driver *in situ*. The hospice has been using the Graseby MS16A for the past 20 years. On discharge from the in-patient unit a family member is shown how to draw up the medication and when to reload the syringe. The palliative community sister then visits the patient at home.

Ethics

Ethical approval was obtained from the Research Ethics Committee of the Cape Peninsula University of Technology (REC: 07/062010). Permission to conduct the study was also obtained from the Hospice Palliative Care Association of South Africa and from St Luke's Hospice.

Written and verbal information was provided to potential participants in English and Afrikaans. The participants were assured that they had the right to withdraw from the study at any time and were invited to contact the researcher during the study. There was minimal risk of emotional discomfort during the interviews (Burns and Grove, 2009). Nevertheless, a distress protocol was in place to assist the participants with support and counselling should it be required at any stage during the study.

Participants

Potential participants were family members of terminally ill patients who were commenced on a syringe driver. Purposive sampling was used. This method involves the conscious selection of participants (Burns and Grove, 2009). Only family members who were not too distressed owing to the pre-terminal condition of the patient, able to converse in either Afrikaans or English, and willing to participate in the study were purposively selected. Eleven people from eight families participated. All were adult family members of patients admitted to the in-patient unit at the time of the interviews.

Data collection

The data collection combined six individual semi-structured interviews and two group interviews. The group interviews took place at the participants' request to be interviewed together. According to Burns and Grove (2009) an interview can take place between the researcher and two or more participants, with the participants known to one another. The researcher is bi-lingual and could therefore conduct the interviews in both English and Afrikaans. The researcher was identifiable to the participants at all times as a palliative care nurse who worked in the in-patient unit as she had a name badge clearly visible. The interviews were audio-recorded and then transcribed verbatim by a professional transcriber. An interview guide was used for both individual and group interviews (*Box 1*). Following the interviews, diaries were given to the participants to provide them with the opportunity to write down their thoughts and feelings and any information they deemed important but had forgotten to mention during the interview. Field notes were made and the documentation was reviewed. Data saturation was reached after 11 participants were interviewed. Descriptions of the patients and the participants are provided in *Table 1*.

Data analysis

Thematic analysis and coding were used to analyse the data. According to Brink et al (2012), thematic analysis refers to the integration and synthesis of narrative non-numeric data that is reduced to themes and categories with the aid of a coding procedure. The interview transcripts were checked for accuracy by both authors, who read them while listening to the audio recordings. Thereafter the authors used colour-coding and marked those places in the transcripts where there were similar descriptions, important comments, and reflections. All

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Table 1. Patient and participant details

Patient	Reason for SD	SD duration	SD medication	Interview type	Participants' relationship to patient	Participants' culture and background
51-year-old male with lung and brain cancer	Dysphagia, seizures, haemoptysis	Two in place, for 11 days and 6 days	First: morphine sulphate 90 mg, haloperidol 2.5 mg, Buscopan 80 mg. Second: midazolam 10 mg. Both at rate 2 mm/hr	Individual	Wife	Non-white, caring for patient alone, no children
73-year-old female with myeloma and other cancer, primary site unknown, liver and bone metastasis	Dysphagia, preterminal restlessness	3 days	Morphine sulphate 10 mg, haloperidol 2.5 mg, Buscopan 20 mg. Rate 2 mm/hr	Individual	Husband	White, retired engineer, only daughter died of breast cancer in 2006, no other family in country
48-year-old female with cervical cancer with brain metastasis	Restlessness, pain, vomiting	14 days	Morphine sulphate 15 mg, Maxolon 20 mg. Rate 2 mm/hr	Individual	Mother	Non-white, widow, supportive Muslim family
59-year-old male with lung cancer with brain metastasis	Pain, headaches, restlessness	98 days	Morphine sulphate 67.5 mg, haloperidol 2.5 mg, midazolam 20 mg. Rate 4 mm/hr	Individual	Ex-wife	White, caring for ex-husband. Large extended family
61-year-old male with lung cancer with brain metastasis	Status epilepticus, pain	28 days	Morphine sulphate 10 mg, midazolam 15 mg, Buscopan 40 mg. Rate 2 mm/hr	Individual	Wife	Non-white, two grownup daughters
60-year-old female with oesophageal cancer	Pain, dysphagia	21 days	Morphine sulphate 30 mg, haloperidol 2.5 mg. Rate 2 mm/hr	Individual	Common-law husband	Non-white, casual house painter
65-year-old female with myeloma	Dysphagia, pain	68 days	Morphine sulphate 90 mg, haloperidol 2.5 mg. Rate 2 mm/hr	Group interview 1	Daughter and granddaughter	Non-white, daughter main care giver. Granddaughter is mother of a 5-year-old daughter. Large unemployed extended family
57-year-old male with stomach cancer	Obstruction, pain, vomiting	Two in place, both for 26 days	First: morphine sulphate 40 mg, haloperidol 5 mg, Buscopan 60 mg, midazolam 10 mg, rate 2 mm/hr. Second dexamethasone 8 mg, rate 6 mm/hr	Group interview 2	Wife, sister, sister-in-law	Non-white, sister-in-law lives in Durban, large extended Muslim family

SD, syringe driver

the relevant extracts from each transcript were placed under the appropriate heading on the list of final themes.

Rigour

The reason for rigour in qualitative research is to accurately represent the experiences of participants. Guba and Lincoln (1994), as discussed in Streubert and Carpenter (2011), identified four criteria—credibility, transferability, dependability, and conformability—that researchers should apply to ensure the qualitative research process is followed and emerging findings are trustworthy. This was achieved by a peer-review process, which is when peers or colleagues probe biases or explore interpretations (Lincoln and Guba, 1985; Streubert and Carpenter, 2011). A discussion was held with the interdisciplinary team to discuss the biases and comment on the findings. An audit trail was maintained, which included field notes, diaries, and documentation.

Findings

Four themes emerged from the data and are discussed below.

The rationale for needing a syringe driver

The participants 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 patient's inability to swallow.

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'Family members who administer medical care to terminally ill patients can also suffer from stress and anxiety at having to reload a syringe driver ...'

'The pain became intolerable even when we gave the mist morphine every 4 hours.' (Participant (P) 8)

'My husband he couldn't swallow the morphine on his own or the other medication. I mean, even his tablets, I had to grind it as fine as possible and put it in his mouth with a syringe. So the syringe driver is a great help for me. It is a great help.' (P1)

One patient was having continual seizures:

'The first time I saw that he had seizures. I counted that he had 16 seizures in 2 hours. That's when he was admitted to the state hospital and they attached a machine on him. It was the first time that I have seen it. Then I asked the sister and she explained that it is a syringe driver which will give him the medication to prevent the seizures.' (P10)

Positive perceptions

The use of the syringe drivers was mostly interpreted in a positive light by the immediate family members. They had gained insight into the deterioration of the patient, as they were the ones struggling to give the patient the medication. For example, 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 gave us a lot of problems because every 4 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. But when it came to the syringe driver, I really appreciate that way.' (P3)

Another participant perceived the syringe driver as just a machine that gives injections.

'It's just a machine, injection that you are getting it every hour. If you lay in hospital, every hour or every 2 hours you must get your injection, and off you go. Here comes the nurse with the injection. It's the same thing.' (P1)

The participants welcomed the syringe driver when they saw the patient's condition weakening and the patient being unable to swallow medication. They preferred the syringe driver, instead of the patient having to have frequent intramuscular injections given by the nursing staff.

'It sounded like a logical way of administering because I could just imagine if she had two injections during the night, 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.' (P2)

Negative perceptions

One participant was not sure whether the syringe driver was a life-extending intervention or whether its use would honour a living will.

'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?' (P2)

One participant was concerned that the medication in the syringe driver was making the patient drowsy.

'Is it the syringe driver that is making her sleep like this? She never used to sleep so long ...' (P5)

Another thought that the medical staff was experimenting on the patient, as she had never heard of a syringe driver.

'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, "Oh! 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.' (P8)

One participant mistakenly thought that the syringe driver was going to feed the patient.

'I was under the wrong impression I thought the little machine is going to put food into the patient's body. Now I see it is only for the medication.' (P3)

One participant assumed that the patient would need an operation to insert the syringe driver.

'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.' (P4)

Concerns and anxiety pertaining to the use of the syringe driver

Participants reported that their extended families, who did not see the patient on a regular basis, had different views on the use of the syringe driver.

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Participants were scared of being blamed for doing and allowing the wrong thing.

> **'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.' (P8)**

> **'My brother said he would blame me if anything happened to mummy.' (P4)**

One participant said that her cousin shouted at her when she told her that the patient had been commenced on the syringe driver.

> **'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.' (P3)**

Some of the participants were anxious about the syringe driver at first but saw the need for it.

> **'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.' (P9)**

One participant said that the patient who they were caring for had a son at home who was addicted to drugs.

> **'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 or the syringes and needles in the home, because of his drug addiction; she had to come daily to draw up the syringe driver.' (P3)**

Discussion

The findings of this study indicated that families who had experienced the difficulty of giving the patient oral medication and controlling distressing symptoms welcomed the introduction of the syringe driver. Much the same was identified by Cruickshank et al (2010) in a UK study: when symptoms including pain, vomiting, and distress were successfully managed, this enhanced a sense of trust, confidence, and support between the families and health professionals.

Negative views of syringe driver use have been reported in Australia (Queensland Government, 2011) and included that drivers were an invasion of the body, noisy, and inconvenient and frequently needed a battery change. Family or carers perceived this as a negative impact on their lifestyle (Queensland Government, 2011).

In another study in Australia, Israel et al (2008) indicated that the family member reloading the syringe driver at home felt empowered by the experience and felt that they had contributed to the value of care. However, health professionals presumed that they gave sufficient information and practical education pertaining to the syringe driver, whereas some caregivers felt the information was inadequate. A fear of the possibility of causing an overdose was also an issue in this study.

More written information and education on the patient's condition, the syringe driver, and medications administered are needed to enhance family members' confidence about the use of the syringe driver. Not everyone residing in South Africa has access to the internet. Developing resource material for patients and family members should form part of the continuous strategic planning processes in all palliative care institutions. This would explain why and how the syringe driver operates and the reasons for the medication used. Lack of education seemed to be the reason why participants thought the syringe driver was going to feed the patient and that an operation was needed to insert the needle.

Some of the participants' concerns were unfounded. For example, there is no evidence in the literature that morphine prescribed for palliative care would weaken the heart. There is also no evidence that a patient's life is shortened either by opioids or sedatives when used to manage pain or distress within accepted palliative care practice (Grogan, 2009). Finally, regarding the implications for a living will, there is no evidence that use of syringe drivers prolongs life.

This study highlighted the concerning issue of drug abuse in a family's home and community. Nicholson (2011) stated that Cape Town is South Africa's drug crime capital, as drug-related crimes have trebled in 5 years. This situation needs to be considered when discharging a patient from the in-patient unit with a syringe driver.

Limitations

The study was conducted in one palliative care in-patient unit in Cape Town, and the interviews were conducted in only two of South Africa's eleven official languages—English and Afrikaans. Therefore, caution should be adopted in generalising the findings. Owing to the rapidly deteriorating condition of the patients and the availability of the family members, scheduling the interviews was a challenge.

'The participants welcomed the syringe driver when they saw the patient's condition weakening and the patient being unable to swallow medication.'

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'The findings have been put to use in forming a support group for family members whose relative is on a syringe driver.'

Conclusion

The need for more continuous education and written information and support for the immediate and extended family members was evident. The findings have been put to use in forming a support group for family members whose relative is on a syringe driver. In the support group educational talks are given and family members can share their experiences and anxieties in caring for their loved ones. Information booklets have been developed and are being distributed in three languages to family members. The researcher has also presented the findings at a palliative care conference in Cape Town. IJPN

Declaration of interests
This study had no external sources of funding. The authors have no conflicts of interest to declare.

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