

PALLIATIVE CARE AT HOME: Nurses, Carers and Medications

INTRODUCTION

Clinicians providing home based palliative care to people at end-of-life may prepare and leave single doses of injectable medications in a client's refrigerator. The syringes are labeled and carers are supported, informed and prepared to administer the medications, subcutaneously, in order to alleviate symptoms. This newsletter reports the findings of research conducted collaboratively by the RDNS Research Unit and Palliative Care team. The aim of the research was to answer questions raised by RDNS nurses about how the storage of these medications may affect the medication, and how carers themselves experienced administering the medications to their family member. The findings have informed RDNS Palliative Care practice.

What was the issue?

Medication administration by carers in the home, although widely adopted and valued by clinicians, clients and carers, was not evidence-based. Nurses were concerned about the sterility of medications drawn up and stored in polypropylene syringes; whether these syringes needed to be stored under refrigeration; and for how long these medications could be stored.

What did we do?

Literature about medication administration in home-based palliative care programs was sourced, we conducted interviews with nurses and carers about their experiences with this practice and conducted sterility and stability testing on syringes of 'test' medications drawn up and stored under refrigeration. Ethical approval to conduct interviews with nurses and carers was obtained from the RDNS SA Inc Ethics Committee. The research outcomes are briefly presented in this newsletter; however the full report will be available shortly at www.rdns.org.au/research_unit/research_projects.shtml

LITERATURE REVIEW

How does storage in a home refrigerator impact on the effectiveness (stability and potency) and sterility of subcutaneous (SC) medications? SC administration involves the injection of medications into the fat or adipose tissue underlying the skin. Medications may be administered SC when the person can no longer swallow tablets due to physical deterioration. This route is considered safe and more comfortable than other alternatives. SC administration of medication is suited to home care {Kennedy, 1999; Hernandez, 2005}.

People may receive medications through pumps or syringe drivers; however this equipment is not always effective at times when a person's symptoms such as pain and nausea are uncontrolled {South Western Staffordshire Primary Care Trust, 2004}. SC medication is prescribed 'as needed', to supplement medications administered via a syringe driver. This type of prescribing equates to good practice {Ellershaw, 2001; National Institute for Clinical Excellence (NICE), 2004; Department of Health, 2004}. The literature review revealed little about the feasibility of storing pre-filled syringes of medications for administration by carers in the home. No protocols or guidelines regarding this practice could be located.

Guidelines and booklets developed by palliative care services provided information about the stability and potency of medications commonly used in palliative care, however these publications related to medications administered by syringe drivers {Capital Health, 2005; Northern Health and Social Services Board (NHSSB), 2003; West Midlands Palliative Care Physicians, 2003; Palliative Medicine Handbook, 2001}. Limited research had been reported to identify the extent of the practice of the drawing up of syringes of medications for SC administration by carers, to provide symptom relief in the community setting.

Some evidence was located on medication stability and potency; however it was important to have relevant information about the medications commonly prescribed, collated and presented in a usable format for RDNS nurses. By so doing, the potential of palliative care to be provided in the community setting would be maximised, the person receiving palliative care would be safeguarded and health professionals and carers would be secure in the knowledge of the appropriateness of their care. The research team decided that testing of the sterility, potency and stability of those SC medications commonly used to alleviate symptoms of RDNS palliative care clients was warranted.

STERILITY, STABILITY AND POTENCY OF MEDICATIONS

The research team assembled the following list of medications widely used in palliative care in the Adelaide metropolitan area and a rural district.

Sterility Testing

a. Aseptic technique

The aseptic technique of a random sample of nurses from one RDNS Division was tested. On analysis, no bacterial contamination was found.

b. Samples of drawn up medications – "test syringes"

"Test syringes" of 8 medications regularly used in palliative

care were drawn up and stored in an opaque container in a domestic refrigerator for 28 days. Scientific analysis did not detect aerobic bacteria, yeast or mould in any of the syringes.

Stability and Potency Data

Evidence was found for stability and potency of most of the identified drugs in polypropylene syringes. The stability of other drugs (eg methadone) is currently being tested by Forensic Science SA. Testing of the following medications revealed no bacterial growth in test syringes after 28 days. Most medications were stable when stored between 4-24°C in polypropylene syringes for up to 7 days, with minimal loss in potency. Light affected the stability of some medications, so an opaque storage container is recommended.

<p>Narcotics</p> <ul style="list-style-type: none"> • Morphine • Hydromorphone • Methadone • Fentanyl 	<p>Other Drugs</p> <ul style="list-style-type: none"> • Ranitidine • Octreotide • Hyoscine • Atropine • Dexamethasone • Ketamine
<p>Anti-emetics</p> <ul style="list-style-type: none"> • Metoclopramide • Haloperidol 	<p>Sedatives</p> <ul style="list-style-type: none"> • Levomepromazine • Conazepam • Midazolam

INTERVIEWS

Palliative Care Nurses

Interviews were conducted with 11 community nurses from two organisations (rural and metropolitan). The interviews lasted approximately 30 minutes and were conducted at the organisation's office. Interviews were audio-taped and transcribed verbatim. The findings of these interviews are summarised as follows.

Community nurses' perceptions of the practice

Nurses considered the ability to draw up medications for SC administration by carers as a positive practice. It empowered clients and carers to have control over a part of their care and enabled clients to have immediate symptomatic relief in their homes, where they wanted to be, and avoid hospitalisation.

...the clients can stay at home. If that wasn't a practice I think a lot of clients couldn't stay at home. You know they would have to be hospitalised. (Nurse 5)

... it's giving pain relief straight away. (Nurse 4)

The practice allowed clients to stay at home, surrounded by family and friends, to enjoy a better quality of life.

..people can now stay at home and have their supply there and their dog can sleep on the bed and their grandchildren can bounce on the floor because no one is telling them to "shhhh, be quiet". So many of our clients are palliative care, we do have quality of life and not quantity usually and the quality is so much better because they are familiar with everything. (Nurse 8)

Identification of suitable carers and clients

Carers were chosen for their suitability to administer the medications and their continuing ability to do so was monitored regularly by the nurses. Criteria to administer SC medications included the client's wish to die at home

and the ability and willingness of carers to administer medication:

...so the carers that have been more involved with the medications, right the way through ...certainly seem to be able to be educated more readily than other carers who maybe haven't been as involved. (Nurse 2)

Other criteria were the client's condition, in terms of phase of illness, symptoms and medications required; client consent, as "*not all clients want their carers to do that sort of thing for them*" (Nurse 7). Home security, with respect to storage of medications, was also assessed to ensure that no one would be put at risk by the presence of certain medications such as morphine.

Education and Training

Nurses provided information about the equipment to be used; nature of medications to be administered, with respect to name, dose, indication; storage requirements and demonstrated techniques to be used. They also observed as the carers administered medications on the first few occasions and left equipment with which the carers could practise their administration techniques.

...usually about the type of medication and what it was for, and the name of it obviously, the dosage, they quite often get written up as a range and the frequency to give it is needed, the possible side effects and how to manage those, the interaction with other medications, and whether they could be used in conjunction with or needed to be given separately,and how to keep the record of what has been given and when and what the effect of it was. (Nurse 6)

we just pretty much go through the whole process and ... they always supply their own medications. We supply them with the syringes, ... alcohol wipes... so it's just a matter of sitting them down and demonstrating it to them first, and then we witness them breaking the ampoule, drawing it and giving it; then even if we do a dummy run with saline, which we quite often do... so they just inject in a little bit of saline just to show that they are capable of doing it...we don't go without watching them actually give it first. (Nurse 10)

Nurses labelled all syringes and the containers in which they were stored. Verbal or written instructions were given to carers. A number of carers wrote their own instructions in ways that were meaningful to them.

It depends on the situation, usually you have something in writing because... when it is a carer doing this sort of thing at home, they are it day and night... They often have a home made chart or something that we use to say what time they have given what and depending on the situation, if they don't remember, you can write Morphine - pain, Maxolon - nausea, and then they would tick them off or write the time and the date that sort of thing. (Nurse 3)

Carers were provided with alcohol swabs for use before injecting the medication and yellow sharps containers for the disposal of needles and waste products.

In the majority of situations, medications drawn up into syringes were stored in the refrigerator and bulk medications were stored safely in cool cupboards.

Ongoing monitoring of carers

Nurses monitored the capacity of carers to administer SC medications by reviewing medication records, establishing a relationship with the carer and routine

assessment at each visit.

...we get the carers to record what they're doing and when they're doing it, and how effective it is. So, "Is the pain gone or not... at a certain time?" and then "Did you have to give another dose?" And... we know they're efficient in the first place, because we wouldn't actually leave them to it without being efficient. So I don't think we've ever come across anybody who's started, who found it too much, or who didn't want to do it any more....As a matter of fact, sometimes they feel, you know, once the night nurse comes in... "Oh, I've lost my job!" It makes them feel useful that they're doing something instead of helplessly sitting and watching somebody. (Nurse 1)

Impact on nurses' professional practice

Leaving medications in clients' homes for administration by carers provided nurses with a sense of satisfaction and peace of mind that clients' symptoms could be managed 24 hours a day and meant that additional visits may not need to be scheduled.

... but I think in the end it makes it a lot easier because we know that people are safe at home... they're not going to be all of a sudden in pain or whatever can happen, because there's a back-up... (Nurse 1)

you might not need to increase their visits to evenings or nights, you might be able to get them through with just a daily visit given that they can be educated to give them medication. (Nurse 2)

I think what it does, in some ways, it gives you a sense of relief that the client's going to be okay, they have their 24 hours worth of pain relief on tap. (Nurse 4)

Carers knew that they could immediately provide the relief that was needed and did not have to stand by and watch the person suffer as they waited for nurses or doctors to arrive to administer appropriate medication.

... they still would have to wait an hour maybe, or an hour and a half...before somebody could actually alleviate the pain or discomfort. Family can do it immediately. (Nurse 1)

After clients had died, nurses felt that carers had derived a sense of satisfaction and comfort from the care that they had been able to provide.

Carers, while it is stressful for them, often find they realized what they are doing is helping their loved ones stay at home and that is helpful that they are doing a positive thing and in their grief they feel 'I have done what he wanted or what she wanted. They wanted to stay at home and I have facilitated that'. So they are left feeling positive in the grief process that they have been able to achieve that for their loved ones and that helps them feel resolved through their grief in a more positive manner. (Nurse 5)

Carers

Semi-structured interviews were conducted with 14 carers. Interviews, generally conducted in the carer's home, lasted between 20 and 45 minutes, were audio-taped and transcribed verbatim.

Why medications were administered in this way

Carers were prepared to administer SC medications because it enabled their family member to stay at home, to achieve optimal symptom control, avoid unpleasant or restrictive experiences in hospital, and meet the desire to die at home.

...she wanted to die in her own house, and she wanted her

family to be there... which all worked out fine...my wife had the most beautiful look on her face when she died. (Carer 10)

Familiarity with medications and learning about medication administration

A number of carers had been unfamiliar with medications and medication administration practices before taking up the caring role. However, several carers had been or were still working as a Registered Nurse.

It was a giant learning curve for us both, because neither of us had ever been in a situation like this before and you've got very high stress levels. (Carer 5)

Well, they didn't give me a lot of instructions, really, because I'm a Registered Nurse. (Carer 11)

Learning about the administration of medications often commenced before the client had been discharged from hospital.

...previously I'd been giving him his Sandostatin because at one stage he was having that daily, oh twice a day maybe, ... so I learned that down at the [hospital]. I felt quite comfortable. (Carer 4)

Training received from nurses

The training received by carers from nurses included showing all the equipment to be used, demonstrations of injecting the medications and education about the medications to be used.

[The nurse] came out and she showed me everything and spent time with me ... so I could understand what was happening and what I had to do, how I had to do it, and she was fabulous and without [her], I wouldn't have been able to do it.... RDNS are actually the ones that helped me the whole way through it... like giving the medications and the courage, but also the courage to [my daughter] to allow [her] to know that it was all right for me to do it, as well. (Carer 6)

Carer support

Carers were supported by access to 24 hour telephone advice from the various services. They regarded this service as being invaluable, providing them with timely advice and encouragement, when needed.

...[t]he palliative care – they're available 24 hours and I'd be on the phone to them if and they'd be there to help you[so] I think you never felt like you're on your own.... you knew they were there to help you 24 hours a day if needed. So I think that that helped you be able to do things confidently... (Carer 3)

Carers' experiences of administering medications

Carers were generally positive about their experiences of administering medications. Most reported that they had not experienced any difficulties.

It just really became part of the routine. I remember one day, here I am drawing up Morphine syringes and cooking dinner and watching the peas boil over at the same time and thought 'this is bizarre'. But it was just a very accepted part of our routine, what we were doing. (Carer 5)

Although initially anxious about the practice, as the carers grew in confidence, their anxiety disappeared.

Terrified [at the beginning]... [but] then it became a non-event. (Carer 5)

Medication recording

Carers were encouraged to record the details of all the

medications administered. The majority of carers developed their own ways of doing this, ranging from setting up spreadsheets on computers to hand-written records of medications administered; *'I kept a little spreadsheet for myself...'* (Carer 1)

Storage of syringes

Syringes were generally stored in the clients' refrigerators. Bulk supplies of medications were stored in cool cupboards, out of sight. No issues or concerns associated with storage of syringes or medications were mentioned. In the main, medication drawn up into syringes was stored for up to 24 hours.

[I] stored them [syringes] in the fridge and as we got going, they would generally only store for about 24 hours. ...no issues [about storing in the fridge], (Carer 5)

Disposal of syringes

Carers were provided with yellow sharps containers, which, when full, would be taken away replaced with new containers.

I had those yellow... sharps... containers, and they used to take them away about once a week I think... or once a fortnight... something like that. No [issues with disposal]... not at all. (Carer 10)

Support received from palliative care services in the storage and administration of medications

Palliative care services provided excellent support and advice about the storage and administration of medications, when required. They also arranged other services and resources when needed.

... she had one of those beds that you could sit up and...oh, it was a brilliant bed... it had a pump on it with a mattress, that used to... would change her... the pressure positions.... It was brilliant. I don't know what we would have done without it. (Carer 10)

What it meant to carers to administer the medications

Carers mentioned that being able to administer medications meant that the clients could be at home in their familiar surroundings, with other family members. A number of clients had strongly expressed that they did not want to be hospitalised. Carers were empowered by the practice. It gave them the ability to participate in the care of the clients, rather than standing on the sidelines as observers. They could provide immediate relief for symptoms such as pain and nausea, which was important for the clients well-being and also the carers themselves. It was important for carers that their family member did not suffer. Being at home, clients enjoyed a better quality of life, which carers considered had contributed to increased longevity. Without the ability to administer SC medications, clients would either experience symptoms such as pain or nausea for longer periods of time, with associated increases in distress for both clients and carers. The alternative was to be

hospitalised, which was considered a last resort for many clients and carers.

There was nothing, nothing that either of us dreaded more was than him dying in hospital. I know that hospitals have their place, and yes, they were really good to him, but at the end, just knowing that he was in his own surroundings, with the people that cared about him. Because at the last day, everyone was here...it meant he didn't have to die in those horrible grey walls.so I guess that was the big thing. And, that we had ... a little bit of control over ...some choice.So that was probably the two advantages. (Carer 4)

Everything! That we could keep him home. We felt confident that we were in control...and just the fact that he died at home ...he looked beautiful, and it was just a very serene, peaceful moment. I'm sure it would not have been as so called 'easy' as that ...if he'd been in hospital where you go in visiting and he was a patient with a visitor – and it's not quite the same but [husband] was here, he was still part of the family. Everything happened in the bedroom: we ate, we entertained in the bedroom and we could manage all that, mainly because I could give him medication. It was everything. (Carer 5)

CONCLUSION

The practice of drawing up and leaving medications in syringes for SC administration by carers to provide symptomatic relief to those at the end of life has been shown to be feasible on a number of levels:

- Sterility, stability and potency of medications has been demonstrated;
- Enables a timely response to symptom management;
- Carers are able to be educated about relevant aspects of medication management and involved in the care of their family member;
- The practice allows clients to be cared for at home, avoiding the need for hospitalisation;
- The practice is highly valued by both nurses and carers.

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References: Available in the final report found at www.rdns.org.au/research_unit/research_projects.shtml