

Palliative care at home: Carers and medication management

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ABSTRACT

Objective: The decision to receive palliative care at home brings with it the complexity of managing a medication regime. Effective symptom control is often directly linked to medication management and relies on access to medications at all times. In home-based palliative care practice, polypropylene syringes of medications may be drawn up and left in clients' domestic refrigerators for subcutaneous administration by carers to provide immediate relief for symptoms such as pain and nausea. However, although there has been some discussion in the literature about the need for ready access to medications for symptom control of clients receiving care in the community, the feasibility of this practice has received scant attention. The aim of this article is to present the carers' experiences of administering medications in this manner.

Methods: Semistructured interviews with 14 carers, who were administering medication in a home-based palliative care setting, were analyzed using qualitative methods to develop meaning units and themes.

Results: Interviews revealed that this practice was highly valued. The carers willingly assumed the responsibility of medication administration, as it allowed the clients to remain at home where they desired to be. They could provide immediate symptom relief, which was of utmost importance to both the client and carer. The carers were empowered in their caring role, being able to participate in the care provided, rather than standing on the sidelines as helpless observers. Carers acknowledged the security and ethical issues associated with the presence of certain medications in the home and valued the 24-h telephone support that was available to them. After clients had died, the carers reflected on their involvement in care and felt a sense of pride and achievement from administering medications in this way because they had been able to care for their loved ones at home and fulfill their wish to die there.

Significance of results: These interviews confirm the feasibility of this practice, which is a component of quality end-of-life care.

KEYWORDS: Palliative care, Medication administration, Subcutaneous, Community care

INTRODUCTION

There is an increasing trend in Australia for people at the end of life to choose to stay at home (Hudson, 2003), and even when a person dies in a hospital or hospice, much of the dying phase can occur in the home. The

decision to receive palliative care at home brings with it the complexity of managing a medication regime. Effective symptom control is often directly linked to medication management and relies upon access to readily available medications at all times. Community-based palliative care teams have a pivotal role in medication administration for symptom control and are ethically and legally accountable for their practice in administering, delegating, and monitoring medicine regimens. A team approach requires

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collaboration between clients, medical practitioners, nurses, pharmacists, and families and significant others to minimize negative reactions and optimize therapeutic outcomes for those treated with medicines. A common community palliative care practice has been to leave breakthrough medications in syringes in clients' refrigerators for subcutaneous administration by carers as required to provide immediate symptom relief. This practice raises many questions, such as how carers manage this responsibility and what it means to them to be able to administer medications in this way.

Most people prefer to die at home in familiar surroundings (Thomas, 2001; Watson et al., 2005; Canadian Hospice Palliative Care Association, 2006; National Council for Palliative Care, 2006; Tice, 2006); however, there are many factors that may work against this actually happening. Statistics indicate that despite most people preferring to die at home, approximately one quarter actually do (Costello, 2001; Thomas, 2001; Watson et al., 2005; Canadian Hospice Palliative Care Association, 2006; National Hospice and Palliative Care Organization, 2006). Many people are admitted to a hospital in the weeks preceding their death due to a breakdown in the provision of home care or for financial reasons related to the cost of some medications (Watson et al., 2005). One of the main reasons for admission to a hospital in the last weeks of life is for better pain or symptom management (Watson et al., 2005; Amass, 2006). The principles of good symptom management (Costello, 2001) include anticipation (of medication needs), evaluation and assessment (of the symptom present and where it fits with the person's overall condition), explanation and information (reassurance and involvement), individualized treatment (uniqueness of each person's symptoms), supervision (close monitoring to identify side effects, therapeutic effects, etc.), and attention to detail (nothing is overlooked).

Symptoms that commonly occur at the end of life include pain, nausea, fatigue, anorexia, anxiety, gastrointestinal obstruction, and weakness, the most common being pain, fatigue, and anorexia (Urie et al., 2000; West Midlands Palliative Care Physicians, 2003; Amass & Allen, 2005; Watson et al., 2005). Rarely do people suffer only one symptom. A major challenge in palliative home care is the effective control of symptoms and maintaining the person in a pain-free and comfortable state. Frequently the condition of the dying person changes rapidly, which can cause distress to the person and their carer (who may be a family member), especially when it occurs out of hours when access to health services is limited. Therefore, it can be important that carers have the ability to quickly access and administer medications in the home to provide relief and comfort (Thomas, 2001; National Advisory Committee on Palliative Care, 2001; Ellershaw et al.,

2003; Australian Government Department of Health and Ageing, 2004; National Institute for Clinical Excellence, 2004; Amass & Allen, 2005; Canadian Hospice Palliative Care Association, 2006).

The literature is sparse on the experience of lay carers administering medications. Lee and Headland (2003) found few references that have discussed carers administering as required medication. They suggest that the idea of lay carers administering medication is a new development in the United Kingdom and acknowledge the need for education and support. In Australia, medications for subcutaneous (SC) administration are left drawn up by health professionals for lay carers to administer as required. A butterfly needle or plastic cannula may be left *in situ* and carers can be taught to administer medications (Watson et al., 2005). However there is little discussion of the feasibility of this practice.

This article presents the findings of interviews with carers who had been provided with syringes of medications such as morphine, Maxolon, and Midazolam, to be stored in their domestic refrigerators and administered subcutaneously to provide immediate symptom relief. The interviews were conducted as part of a larger study that investigated the sterility, potency, and stability of medications commonly used in palliative care in South Australia.

METHODS

Aim

Our aim was to understand carers' experiences of administering SC medications to a relative receiving palliative care at home.

Setting

The findings reported in this article are from the interview data collected in 2007 for a mixed methods study that explored the sterility, potency, and stability of SC medications administered by carers at home. The research was conducted in collaboration with multidisciplinary palliative care clinicians and representatives from a community health care organization. The community health organization provides palliative care services to clients of any age within the Adelaide metropolitan region in South Australia. In the period January 1, 2006, until December 31, 2007, 1,819 clients received palliative care services. Three hundred twenty-four of these clients had a subcutaneous care indicator; 264 clients had a syringe driver care indicator. In this period, of the 1,271 clients who died, 854 clients had a goal of care to die at home. Three hundred and sixteen (37%) of these clients achieved their goal and died at home.

Participants

Participants were initially invited to participate in the research by palliative care Clinical Nurse Consultants practicing in the Adelaide metropolitan area and a rural region. When the carer had expressed interest to be involved, the researcher made contact by telephone to arrange a suitable time for consent to be obtained and the interview to be conducted. Fourteen carers were interviewed. Nine women cared for their husbands, 2 men cared for their wives, and 3 mothers (2 of whom were assisted by their husbands) cared for their children (2 teenagers and 1 infant). Two women participants were registered nurses. In one interview, the mother and the father both shared their experiences and insights about caring for their teenage son. Their comments are reported as carer a and b. For the purposes of consistency, in the reporting of these interviews, “client” has been adopted as the name to be used for the person receiving palliative care services and for whom the carer was providing informal care.

Ethical Considerations

Ethical approval to conduct interviews with carers was obtained from the organizational Ethics Committee. All interviewees were provided with an information sheet about the research and a consent form which indicated, *inter alia*, that the interview would be audiotaped and that they were free to withdraw from the study at any time. All interviewees signed a consent form. All interviewees were provided the opportunity to make comment on this article prior to its submission for publication.

Data Collection

Semistructured interviews were conducted with carers. Topics covered in the interviews included why medications were administered in this way, carer experiences with this practice, and what it had meant to them to be able to administer medications in this way. The majority of interviews were conducted in the carers' homes, lasted between 20 and 45 min, and were audiotaped and transcribed verbatim. To protect the carers' identities, when quoted, their names have been replaced with numbers, that is, Carer 1, Carer 2, and so forth. The identities of clients, nurses, and doctors, when their names have been used by carers, have been protected by replacing them with general titles, such as [wife], [husband], [nurse], and [doctor].

Data Analysis

The interview transcripts were analyzed guided by the techniques of Miles and Huberman (1994).

The context of the dialogue was preserved because the authors were involved in the conversations. The transcripts were read carefully, and a number of broad categories were identified. Meaning units were then developed that were comprised of a significant statement supported by verbatim quotes from the participants. The meaning units were developed into themes. Where appropriate, findings have been attributed to the relevant participant. To establish “truth value” (Morse & Field, 1996), participants were presented with the researchers' interpretations and were provided the opportunity to comment on this article. No suggestions for changes were made.

RESULTS

The following themes were identified: desire to be at home, capacity to respond to symptoms, security and ethical concerns, valuing support, empowered in the carer role, and personal fulfillment.

Desire to Be at Home

Carers administered medications for a number of reasons, which included as a means of enabling the client to stay at home to be cared for by his or her family:

Well, primarily for the reason that [husband] wanted to stay at home and be looked after at home by his family. (Carer 1)

My husband had a Level 4 brain tumor. . . and we wanted him to be able to remain in his own home setting rather than go to hospital. (Carer 2)

We could keep him home, and 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. And 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 client 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. (Carer 5)

Dying at home offers opportunity for intimacy with loved ones, a sense of being surrounded by the familiar, and a degree of autonomy and control for both the client and the family that cannot be reproduced in other care environments, such as a hospital. Indeed, a number of clients had strongly indicated that they did not wish to die in hospital.

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. (Carer 4)

The desire to die at home was sometimes a response to unpleasant experiences of clients and carers in hospitals, for example:

I think in a way she was a little bit terrified really, . . . particularly spending her first night in Palliative Care, when a lady kept her up all night. . . . She couldn't sleep. . . . And this lady was. . . dying. . . . And she was crying out all night, . . . "help me, help me," and then she defecated all over the place and then they had to have nurses come in a clean her up and help her out and everything, and. . . she [wife] was in such an agitated state when I got down there that day that she was sitting on the bed rocking backwards and forwards and said, "I can't stay in here any more; I want to come home." So I basically told them, "Look, she's coming home with me," and she told the doctor that she's not staying there. (Carer 10)

For some clients, it was profoundly important to stay at home:

I didn't want her in hospital; I wanted her home; she wanted to be home. That was one thing she actually asked me. . . . She never wanted to go to the hospital. (Carer 6)

Capacity to Respond to Symptoms

Having the capacity to respond to symptoms such as pain in a timely way was important to carers, "My goal all along was to make him as comfortable and as pain free as possible" (Carer 2). Subcutaneous medication administration provided optimum symptom control and was instituted when oral medications could no longer be swallowed: "He got to the stage where he couldn't swallow, so it was too difficult for him to get the tablets down" (Carer 11).

Responding to symptoms enabled a sense of control: "We always felt we had the pain issue under control. . . [a]nd that was very reassuring" (Carer 5). Pain was a symptom that was often feared, so providing the carer with the capacity to administer breakthrough medication at home enabled promises to be kept:

[I] promised him that [I] will do everything in [my] power to make him pain free, because he did make me say that. . . . He was so fearful of hospital, and going to hospital, and wanting to be home and "Please don't let me be in pain." And I made lots of promises to him that way. (Carer 7)

Even though the subcutaneous administration of medication was generally carried out for a short time at the end stage of life, it quickly became a routine part of everyday life.

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 they experienced some initial anxiety about administering medications in this manner, as the carers' confidence grew, this anxiety reduced. A number struggled with the acceptance of the need to administer medications, rather than the practice per se, but the value of the practice in providing quick pain relief was widely acknowledged:

Didn't worry me. . . . The Palliative Care team came in, . . . and they said, "Now, you're going to have to do this; how do you feel about it?" And I said, "That's fine; just tell me what I have to do." . . . I was pleased to [give injectables at home] because to me, it meant that I was helping him quickly. . . . The least that he had to suffer was the best. . . . The injectable medications were far quicker and he responded better to them than the tablet form. (Carer 1)

Carers commented on the difficulties experienced with accessing the sometimes large quantities of medications required and their doctors' willingness to write out authority prescriptions to obtain larger, more appropriate quantities of medications:

In the very beginning we were just getting one little box of morphine at a time and that was obviously not going to last once we got into higher doses. . . . Well, the doctor put through an authority prescription and I got such an incredible amount that when the pharmacist handed it to me, I said [name], "I don't know whether to laugh or cry." I thought, we're never going to get through it. But it's surprising how quickly it goes. (Carer 5)

Some carers initially experienced difficulties in obtaining Schedule 8 (Dangerous Drug) medications.

However, when community pharmacists were alerted to the clients' needs for specific medications, they agreed to keep adequate stocks on hand:

My brother was the one that used to get everything, so... the first couple of times he went [to pharmacy] and got it for me, it was a bit of a problem until they realized that it was okay with him, and then [daughter's] palliative care doctor also advised them that he would be coming to get it, so that I didn't have to leave [daughter]... Otherwise, no, it wasn't too bad... They got the medications that we needed in. (Carer 6)

Security and Ethical Concerns

The storage of morphine created anxiety for some carers, due to potential security issues associated with its presence in the home:

Having all that Morphia sitting in the cupboard was a bit of a worry. I was glad to get rid of it. I thought, "Oh, people get bumped on the head for this."... Well a girlfriend said it wasn't such a silly question for my goddaughter to be asking because another friend of mine said she looked after her husband at home until the last few days, but he had bottles of Morphia in the cupboard and she had a niece came to visit who did have a drug problem, and she was very concerned. (Carer 11—RN)

For other carers, the significance of the presence of such medications diminished over time:

We used to think... "Oh, morphine... oh, dear!" But now it's just routine. (Carers 8a and 8b)

Ethical issues also arose for some carers about the possible implications of administering medications on an "as required" basis, and the perception of its use to hasten death:

My goddaughter asked the question: "How do you know... or how does anyone know how much you've given him?" And "You could give him too much," or you know, "If he died and they had an inquest," that was [what] she was thinking, that I could have popped all this into him and helped him along the way. She was quite worried about that. I had to assure her I wouldn't. (Carer 11—RN)

The likelihood of such a scenario happening was extremely low as carers were highly committed to accurate and timely medication administration. Also, they were encouraged to record the details of all the medications administered, which they did in

ways ranging from setting up spreadsheets on computers to hand-written records:

I had to write everything down because like now, my memory isn't all there, so you wanted to make sure that she wasn't getting any more than she needed, ... and with the two of us, we would always check, make sure that, ... giving her the correct medicine or whatever, ... because you are a bit scatterbrained through the whole thing... You don't want to give her a double dose or anything. (Carer 3)

These medication records were often reviewed by the palliative care nurses during each home visit:

[Wife] progressed pretty rapidly and I found it was a bit of a whirlwind, so I found it necessary to do a spreadsheet for myself, to be able to tick off what I'd given because I was not only using those breakthrough, I was doing the regular, ... some twice a day, some three times a day, some four times a day, so towards the end, reached 16–18 injections a day. I developed a spreadsheet myself... I couldn't survive without [it]... It's a shame that wasn't [provided]... I could basically slip back to my computer and change the spreadsheet for the next day, print that off, have it day by day, and when a nurse came in, I could say, this is what I gave, this is what time I gave it, this is the reason I gave it... The nurses found it a help too. (Carer 13)

Valuing Support

Access to support was important to carers. The carers in this study were supported by access to 24-h telephone advice from the various palliative care services. They regarded this service as being invaluable, providing them with timely advice and encouragement, when needed. Carers utilized support services at times when they wanted confirmation and affirmation of their decisions:

And late in the evening when I couldn't settle him, I wasn't sure whether I should give him more Clonazepam or not, and when I rang the after-hour number the [person] there... said, "Just give it to him... If you've given it to him within at least an hour, give him... some more." If I hadn't have had that support, ... I'd be tearing my hair out... [I] wouldn't have known what to do. (Carer 1)

The availability of support was reassuring for carers and meant that they could quickly respond to changes in the clients' condition:

And there were a couple of times that... [husband's] medication wasn't being effective, that I rang Palliative Care and they put me through straight through to the on-call doctor who was fantastic, ... [s]o, that kind of support helped take away those worries... I had great support through the after-hours numbers that you can ring. (Carer 2)

It was important to carers that they felt supported by the health care team to undertake the caring role:

The nurses are fantastic; ... it really is a godsend. ... [Nurse is] wonderful, and she's such a caring person. ... and she'll ring. ... [o]r she'll say, "I'm sending one of the girls around if they've got time at 10 o'clock tonight, just to doubly check on you," ... [w]hich to me is really fantastic. (Carer 14)

Empowered in the Carer Role

Administration of medications was a large part of the caring role, and the carers were generally positive about their experiences of administering medications:

No difficulty at all. ... I knew that I had to do it, and I knew that I had to be as gentle as possible, and so I just did it. ... I loved my wife so much in my life. ... That was the most, probably, the precious time of my life, really, to be able to look after her. But, I mean, because she'd looked after me for 27 years, and it was my duty to do it, and a privilege. (Carer 10)

Carers were empowered by the practice of medication administration, which gave them the ability to participate in the care of the clients, rather than standing on the sidelines as helpless observers. They could provide immediate relief for symptoms such as pain and nausea, which was extremely important for the clients and also the carers themselves, as none of them wanted to see the clients suffering needlessly:

There's a couple of things. The first one is that it, ... being able to take that pain away quickly, makes you feel not out of control, which the whole circumstance you're out of control, ... [s]o it helps to give you a feeling of some form of power over what's going on, both for the person who's administering and for him because he could ask. So it gave more that sense of power. (Carer 2)

It meant that I could do something. (Carer 13)

Personal Fulfillment

After the clients had died, the carers reflected on their experiences and felt a sense of pride and

achievement that they had been able to administer medications in that way and they had been able to look after the clients at home and fulfill their wishes to die at home:

It is definitely something that I never thought I would ever be able to do, but [palliative care services] allowed us to be at home. I still look back and I can't believe that I actually did it. I looked after her at home, here. I am so glad that I was able to do it for her because that gives me a sense of helping her through everything, as a mum. When I look back now—it matters. (Carer 6)

Carers were satisfied that they had been able to attend to the different aspects of care that their family member required:

I felt really good myself about being able to do it, because I knew that he got it when he needed it—not in 5 minutes or 10 minutes, or... I knew what his needs were every minute, and I've still people say to me that they can't believe all the things that I was doing, and I was so tired. (Carer 7)

DISCUSSION

Although it is inevitable that each person will die, the experience of a pain-free, comfortable death is not. Many people suffer in physical, emotional, and spiritual ways as they approach the end of life (West Midlands Palliative Care Physicians, 2003; Jablonski & Wyatt, 2005; Watson et al., 2005). This suffering occurs despite widespread efforts to improve end-of-life care and to develop effective strategies for relieving symptoms (Miettinen et al., 1998). Symptom control is a major part of the physical care component of palliative care. Every symptom must be assessed and alleviated, drawing on knowledge about drugs, products, and resources (Austwick & Goodyear, 2002). Furthermore, the condition of the dying person can change rapidly, often during the night or at the weekends, when there is limited access to health services. Therefore, it can be important that carers have the ability to quickly access and administer medications in the home to provide relief and comfort (National Advisory Committee on Palliative Care, 2001; Thomas, 2001; Ellershaw et al., 2003; Lee & Headland, 2003; Department of Health, 2004; National Institute for Clinical Excellence, 2004; Amass & Allen, 2005; Canadian Hospice Palliative Care Association, 2006).

The practice of leaving SC medications drawn up and stored in clients' refrigerators for administration by carers to provide symptomatic relief is an

important means whereby carers can quickly provide relief and comfort to clients. Furthermore, quality end-of-life care has been identified as consisting of the following aspects: (1) providing dying persons with desired physical comfort, (2) helping the dying person take control of decisions about medical treatment and daily routines, (3) relieving family members of the burden of feeling that they must be present at all times to advocate for the best care of their loved ones, (4) educating the family members so they feel confident in caring for their loved ones at home, and (5) providing family members with emotional support both prior to and after the client's death (Teno et al., 2001).

This practice is an integral part of quality end-of-life care. It provides clients with physical comfort, helps clients and carers take control of decisions about medical treatment and daily routines, and educates family members to care confidently for their loved ones at home, where they have chosen to be. The often daily visits of palliative care team members such as community nurses also provide emotional support for carers as they strive to fulfill the clients' wishes to die at home. Furthermore, death at home has been associated with better early bereavement response and better physical health of carers 6 months after bereavement (Grande et al., 2004).

Limitations

There are a number of limitations associated with this research. First, the interviews conducted with nurses and carers were in one geographical location of Australia and findings may not be replicated in other Australian states or countries. Second, trustworthiness of carer interview findings may be limited by the "gratitude barrier," such that carers were so grateful for the services and care provided that they tended to forget or overlook their less pleasant experiences (Grady & Travers, 2003). Third, this research had a small participant number. Fourth, none of the participants were from culturally and linguistically diverse (CALD) backgrounds.

Further Research

Further research could be carried out to confirm or refute the findings of this study. In any future study, it is recommended that a larger numbers of carers be recruited to participate, in particular, those from CALD backgrounds, so as to explore the impact of culture on health beliefs and medication administration practices.

CONCLUSION

Although the practice of drawing up and leaving syringes of medications in clients' refrigerators for administration by carers has received little attention in the international literature, it is a vital component of quality end-of-life care. It enables carers to provide timely symptomatic relief, enabling clients to be cared for at home, rather than in the hospital setting. As clients' symptoms may change rapidly at any time of the day or night, the ready availability of such medications reduces client and carer anxiety, because they do not have to wait for medical personnel to arrive and administer the appropriate medications.

Although there were some security and ethical concerns about the presence of certain medications in the home, this responsibility was willingly assumed by carers and readily became part of their daily caring routine. Carers highly valued the ability to administer medications in this way, as it empowered them in their caring role. It allowed clients to stay at home in a familiar environment, surrounded by family and friends, with appropriate symptom control and experiencing an enhanced quality of life. Access to 24-h telephone support was greatly appreciated. After the clients had passed away, the carers were able to derive a genuine sense of pride and achievement. Administering medications in this way enabled carers to look after the clients at home and fulfill their wish to die there.

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