

# Supporting Family Caregivers With Palliative Symptom Management: A Qualitative Analysis of the Provision of an Emergency Medication Kit in the Home Setting

John P. Rosenberg, PhD<sup>1,2</sup>, Tracey Bullen, DCP/MSc<sup>1,3</sup>, and Kate Maher, MNursing<sup>4</sup>

American Journal of Hospice & Palliative Medicine®  
2015, Vol. 32(5) 484-489  
© The Author(s) 2014  
Reprints and permission:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1049909114531326  
ajhpm.sagepub.com  


## Abstract

**Purpose:** The purpose of this qualitative analysis was to examine the experiences of family caregivers supporting a dying person in the home setting. In particular, it explores caregivers' perceptions of receiving palliative care at home when supplied with an emergency medication kit (EMK). **Results:** Most family caregivers described preexisting medication management strategies that were unable to provide timely intervention in symptoms. The EMK was largely viewed as an effective strategy in providing timely symptom control and preventing readmission to inpatient care. Caregivers reported varying levels of confidence in the administration of medication. **Conclusion:** The provision of an EMK is an effective strategy for improving symptom control and preventing inpatient admissions of home-dwelling palliative care patients.

## Keywords

caregiver, emergency medication, home care, palliative care, qualitative research, personal narratives

## Introduction

Home is the preferred place of death for most palliative care patients<sup>1,2</sup>; however, for many family caregivers, providing care at home is a highly demanding and stressful experience.<sup>3,4</sup> To enable family caregivers to successfully provide palliative care in the home setting, a number of factors must be in place which offer information, support, and effective symptom control.<sup>1,5,6</sup> In their review, Bialon and Coke<sup>7</sup> identified the burden experienced by family caregivers in providing support to dying family members yet also established that good symptom management has a positive influence upon caregiver burden.<sup>8,9</sup> A strong relationship between caregiver burden and symptom distress in some patients has been reported.<sup>10</sup> One intervention that can facilitate symptom control is through the implementation of an emergency medication kit (EMK).<sup>11</sup> An EMK provides parenteral medications in the home setting to enable a timely, appropriate response to exacerbations of symptoms that may lead to otherwise preventable admissions to inpatient care.<sup>12,13</sup> Additionally, there is evidence to suggest that good symptom control may contribute to improving congruence between preferred and actual place of death for home-dwelling patients.<sup>1</sup>

Furthermore, with the limited resources that are available for inpatient hospice care due to costs, there are organizational

incentives to develop interventions that facilitate home deaths.<sup>14-16</sup> In 1 Australian economic evaluation, it was found that the mean direct costs of home care packages for palliative care were largely offset by inpatient cost savings.<sup>17</sup> With a single EMK costing less than Australian \$50, their inclusion into home care has a negligible impact upon home care costs.

Therefore, the provision of an EMK to a family caregiver can present both benefits and challenges. The purpose of an EMK is to enhance symptom control in a timely manner; importantly, its provision is embedded in strategies of education and support to optimize its contribution to home

<sup>1</sup>Formerly Calvary Centre for Palliative Care Research, Australian Catholic University, Watson, Australian Capital Territory, Australia

<sup>2</sup>Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Queensland, Australia

<sup>3</sup>Institute of Child Protection Studies, Australian Catholic University, Watson, Australian Capital Territory, Australia

<sup>4</sup>Palliative Care, Clare Holland House, Canberra, Australian Capital Territory, Australia

## Corresponding Author:

John P. Rosenberg, PhD, Institute of Health and Biomedical Innovation, 60 Musk Avenue, Kelvin Grove, Queensland 4059, Australia.  
Email: jprosenberg@bigpond.com

caregiving. In this trial of the implementation of EMKs in the homes of palliative care patients in Canberra, Australia, we included the collection of qualitative descriptions by caregivers in the trial.

## Methods

### Aim

The aim of this qualitative review is to examine the lived experience of caregivers who have supported a dying person at home. In particular, it explores caregivers' perceptions of receiving this care when supplied with an EMK.

### Participants

Participants were drawn from a sample of 99 patient–caregiver dyads in a specialist community palliative care service in Canberra, Australia, who were provided with an EMK on admission. A subsample of 18 caregivers self-selected to participate in a telephone interview; 12 were female, 6 were male; ages ranged between 29 and 89, with a mean age of 55 years. All identified as either Australian or New Zealander. Fifty-five percent were bereaved spouses of the patients, with most of the others being children or grandchildren of the died patients; 1 caregiver was the parent of the patient. Notably, 22% had been family caregivers previously. Most were caregivers of patients with cancer; all 18 caregivers interviewed accessed the EMK during the caregiving period.

### Interviews

Of the wide range of research study designs available, qualitative methodologies are best suited to explore and understand lived experience.<sup>18</sup> In order to gain a deeper understanding of the caregiver experience of being provided with an EMK at patient admission, 18 semistructured interviews were conducted by telephone. Topics addressed included reasons for introduction of the EMK to the home setting, caregivers' understanding of its purpose, and the perceived positives and negatives of being provided with an EMK.

### Analysis

The telephone interviews were audiorecorded and transcribed verbatim; all identifiers were removed and replaced with general terms such as “husband,” “doctor,” and so on and are reported here coded with the letter P and their participant number (eg, P29). The interview transcripts were read separately by the 2 researchers in the project team. Using an inductive approach, narrative data were subject to open coding and categories were identified; emergent themes were developed from the data. NVivo10 software (QSR International 2012) was utilized to facilitate data management.

## Ethical Considerations

Ethical approval was obtained from the relevant industry and University Human Research Ethics Committees to conduct this study. Particular consideration was given to the risk of distress among participants in recalling aspects of the care they had provided for family members; strategies included the allocation of phone interviews to a clinical psychologist experienced in the conduct of interviews with vulnerable populations and the provision of information for ongoing support if needed.

## Results

### Interview Themes

An overriding concept was that the EMK itself was viewed as being 1 component of the much larger undertaking of providing palliative care to a family member. For this reason, we included descriptions of pre-EMK caregiver experiences. Exemplars noted subsequently should be considered in light of this. This analysis identified 4 key themes—pre-EMK experiences, usage patterns, positive factors/benefits, and negative factors/challenges. Each theme contained a number of subthemes.

### Theme 1: Pre-EMK Experiences

Within this theme, we identified the subthemes of *self-management* and *need for support*. Lay caregivers, and indeed patients themselves, were managing medications prior to their admission to specialist palliative care services and supply of the EMK. This responsibility was viewed as a very important part of caregiving by some:

(Interviewer): It sounds like you were managing the medication and symptoms quite well even before home-base (team) got involved?

(P29): Yeah, it's something obviously I treated very, very seriously.

Respondents identified a number of strategies, including maintaining a written record of all medications and care activities:

We were just recording, writing down. I set up a table, made up a table on the computer so everyone knew where we were at. So we'd all write on it, whoever was there, so we knew what mum was having and we sort of got her to describe her pain so that we'd know if she needed more or less. (P14)

However, in this sample, it was clear that these responsibilities were not without challenges:

It was a bit scary because I didn't know what to do and I didn't know what to expect. (P46)

Nevertheless, for most respondents, the strategies employed were not sufficient to maintain acceptable levels of symptom control, and the need for support was identified. In this

example, the caregiver notes problems with timely administration of medication:

Right at the end we started to realise that . . . the drugs weren't getting taken at the right time. (P21B)

Importantly, caregivers demonstrated some preexisting capacity to cope with specific stressors and, to some extent, master the demands related to their caring. However, the advancing disease of their family member demanded a referral to specialist palliative care services and, for this cohort, the introduction of the EMK.

### Theme 2: EMK Usage

When considering EMK usage, we identified subthemes of *use by caregivers*, *use by nurses*, and *the medication diary*. The purpose of the EMK was well articulated in this group, who understood its goal of symptom relief:

It was there for when the pain became too intolerable and that the oral medication wasn't going to be sufficient, and to give her better pain relief and hopefully make her more comfortable. (P41)

However, there were divergent views about who the EMK was to be used by. A number of respondents saw it as a resource for them to access:

(It was) for us to use if he took a sudden turn and sort of suddenly got into difficulty or pain, or sort of extreme agitation and so we would be able to administer something to him so we wouldn't have to wait and try and handle the situation until one of the nurses could come back. (P16)

The issue of timely administration of medication, possible because of its availability to caregivers for use, was noted as a key justification for its presence in the home. Nevertheless, a substantial proportion of the interviewed sample understood it as a resource for use only by the visiting specialist palliative care nurses:

My understanding of what it was for was that it was medication that could alleviate or ease some of her more painful symptoms and it was to be administered by a professional carer, not by myself, but it was available on-site so that if she experienced severe symptoms that I could call a carer [ie: nurse] and say it's after-hours, we've already got the medication here, I just need you to come and administer it. (P43)

For some respondents, this was contextualized by their reluctance to use the EMK to administer medication; the EMK usage by nurses was a default for such caregivers:

I wasn't going to administer anything but . . . the nurses were . . . available to us, that was great. (P20)

Nevertheless, the narrative data reflect opposing understandings of how the EMK was to be used; what is not clear is whether inconsistent instructions were given to caregivers or the instructions were modified by the visiting nurse's judgment about each caregiver's capacity to manage the EMK. These examples suggest the former possibility:

. . . the day I went over there and the nurse from palliative care brought the medications, I was a couple of minutes late and she and [patient] had been talking and she just handed me this package you know and I didn't really know what it was. (P24)

In contrast, this caregiver describes a comprehensive explanation of the EMK:

What was more important was how they showed us what to do, how to keep him comfortable, and what signs to look out for to show that he was uncomfortable or if he was in pain and, you know, it was all new territory for me but they were very patient and able to answer any of our questions and explained everything so thoroughly. (P16)

Significantly, in a related arm of the wider EMK study, specialist palliative care nurses were asked for their views on the usage of the EMK; it includes commentary on the perceived impact of more information given to the caregiver on admission as a result of including the EMK. The level of understanding of the goal of the EMK was observed to be highly variable among caregivers, as reflected in these findings.

The medication diary was utilized by some, but by no means all, of the caregivers interviewed. For those who did, it was considered to be very useful for recording information at a difficult time:

But we weren't left out on a limb at all and it was good to actually write down what we had done because otherwise you'd—with all the stress of it all and everything you could—I suppose you could easily get a bit confused with what you had given him. (P16)

It also acted as a communication tool between the caregivers and the health care professionals involved:

I just wrote it all down, everything that I was giving to her, getting her pain scale and working on it from that and so when the palliative care team came I could say, "This is what I've given her, nothing's helped. Her pain was at this and it's gone down to that but she's still in pain." (P25)

### Theme 3: Positive Factors and Benefits

Overwhelmingly, the introduction of an EMK into home-dwelling patients' homes was viewed positively by caregivers. In this theme, we identified 4 subthemes: accessibility, timeliness, effective symptom control, and caregiver confidence.

Caregivers found it reassuring that the EMK improved accessibility should symptoms become difficult to control; the EMK was viewed as a solution to a problem:

Well, it's good to know that the kit's there. It's always helpful that it's, you know, that you know that if she needed something . . . stronger than an over the counter, there was stuff in the kit that would . . . that's sort of like a peace of mind sort of thing. To have the kit there obviously means that . . . it was easier to solve the problem. (P50)

Perhaps the most significant benefit identified by caregivers was that the EMK enabled a timely response to the exacerbation of symptoms. A number of experiences were recounted demonstrating the difficulties in accessing medication in the community:

. . . in the old scheme, you know, you had to go and get a prescription and you had to find a doctor and then you had to find a chemist and you were away from them for untold hours, you know, and of course it meant that they . . . were still in pain and everything like that before you actually got the medication and then you had to get someone to come and put it in and . . . it was a big performance. (P5)

Caregivers with a regular general practitioner also related experiences of limited options:

. . . cause your GP is only open between certain hours . . . because mum was so ill, you're not going to take her to the hospital every time there as something pretty minor . . . other than that you've got those super clinics that you can wait forever in and I'm not a big fan of them either. (P43)

For some, the option prior to the introduction of the EMK was to attend the accident and emergency department of the local hospital, which was problematic:

. . . just to know that the nurses could come out and administer it to [name] as needed and that we didn't have to go to the hospital and wait like we had done previously for hours and hours to be seen to and be given something. It was reassuring to know that. (P22)

The introduction of the EMK provided a timely response at the home of the person being cared for.

I was particularly grateful that he was able to be kept comfortable ongoing without us having to be waiting for someone to come. (P16)

It was reassuring to know that it was here and that if we did need it, it was all sorted out. We didn't have to wait to see a doctor or anything like that. (P22)

In turn, this timeliness was seen to directly and positively impact upon symptom control.

I just rang up and the lady came round in twenty minutes . . . and they just administered it and it was all under control again like within an hour or two, and it made a huge difference. (P5)

. . . especially as he sort of deteriorated, we were able to just keep him comfortable. (P16)

It was very clear that caregivers gained confidence through the education provided to them by the palliative care specialist nurses when the EMK was introduced. This respondent was fulsome in their feedback and illustrates the overriding context of the EMK being understood as one part of the overall caregiving experience:

They explained it so well and the nurse who came—well everyone who came was excellent but the one who came and gave me the most instruction explained—she spent a long time there and she explained it all so well, and not only how to use that but how to help him, and move him, and all of that sort of thing. No, because of the time they put in they didn't just sort of leave it there and blurt out a few obscure instructions . . . I was able to really have much more of an understanding of what to do. (P15)

#### Theme 4: Negative Factors and Challenges

There were few reports of negative factors or challenges in these data. Nevertheless, narrative analysis identified subthemes of *low caregiver confidence*, *fear of hastening death*, and *storage safety*.

This respondent clearly articulated how overwhelming and intimidating the expectations of being a caregiver can be:

The nurse was saying we would have to administer these intravenous drugs and although they put a catheter in her leg I felt yucky about doing that, and also the nurse was very worried about me being here on my own with her and having to turn her on my own. I kept thinking I'm not trained for any of this, I know nothing about caring for someone else. (P20)

However, this respondent suggested that communicating this low self-confidence to the visiting nurses went some way to addressing this concern:

I suppose the main thing is too, you're letting those people know that it is okay if you're not confident. (P21)

Some caregivers were reluctant to administer medication to the person in their care, reporting concerns that this may in fact hasten death. This caregiver recounted her bereaved mother's concern that the medication administered to her late husband may have hastened his death:

. . . mum has been grieving a great deal but she sort of said "What did they give him or what we gave him there at the end that might have made him . . . (pause)" She is starting to comprehend it was pretty awful but she was not wanting us to hasten his passing. Well that was a concern for her and I have had to try and explain to her and she's sort of getting it now that it was just to help him feel comfortable. (P16)

An important part of having the EMK in the house was the reassurance caregivers received that, used properly, this was not the case:

...having the support to know that you're doing the right thing... because to me deep down you know that's, that's euthanasia, that went through my mind a couple of times. (P24)

Quite a few participants noted the need for safe storage, particularly where small children were regular visitors to the house or where they considered there may be a risk from others:

We kept it up high because a lot of little grandchildren and people came like that, we kept it up high. The only thing I would say is that—I mean you would be very discerning I'm sure of who you left it with. (P16)

This was particularly challenging for 1 caregiver who lived and provided care in a caravan park, going to great lengths to ensure her safety; fortunately, her concerns were not realized:

My only concern was that if anybody found out it was there, I didn't really have a safe secure place to have it and I didn't want to get robbed because we were living in a caravan park and I didn't know what sort of security it was like, I mean as it turned out it was fine and that was my only concern... I tried to wrap up the packet so that they were unidentifiable, so that people didn't see them in the rubbish and I tried not to let on that we had anything like that... (P5)

## Discussion

The introduction of various forms of the EMK into the homes of palliative care patients has been discussed as a strategy for improving symptom management,<sup>11,13,19</sup> lowering caregiver burden<sup>7-9</sup> and preventing avoidable readmission to inpatient care.<sup>12,13,20</sup> It has also been reported to increase congruence between desired and actual place of death.<sup>1,2,5</sup> Although the documentation of the use of medication kits has been examined and health professionals' perspectives toward EMKs explored,<sup>21</sup> our analysis of the lived experiences of family caregivers adds to the understanding of strategies for implementation and maintenance of EMKs in the home setting.<sup>22</sup>

The introduction of an EMK into the home rarely represents the beginning of medication management for caregivers or, indeed, even patients. In this study, experiences of caregivers prior to being supplied with an EMK were variable, but most described preexisting medication management strategies that were no longer able to provide timely intervention in symptoms. Increasing levels of distress from symptoms, and the growing complexity of their management, presented difficult circumstances for caregivers wherein the EMK represented a key strategy.

In this and other studies,<sup>22</sup> caregivers reported varying levels of confidence in the administration of medication. It was evident that the capacity of family caregivers varied enormously. Although these participants also experienced some reticence about administering parenteral medication, all overcame this concern or, alternatively, had the medications administered by visiting nursing staff; both options characterized a more timely response than would have otherwise been

available under previous practices. There was a clear divergence in caregivers' perceptions of who was responsible for the administration of parenteral medications from the EMK, perhaps reflecting inconsistent information supplied by visiting nurses or a modification of the explanations provided following an assessment of the caregiver's ability to manage the EMK. However, understanding how the clinical staff provided information and education regarding the EMK was not able to be established within the scope of this study. Nevertheless, caregivers uniformly described decreased burden with these more timely responses to the exacerbation of symptoms, and we observed an increase in the rate of home deaths among home care patients from 21% to 41% in the 12-month period when the EMK was trialed.

Caregiver education has been identified as a key strategy in assisting with home care,<sup>23</sup> and the implementation of an EMK in the home setting clearly required strategies of education and ongoing support.<sup>24</sup> However, we identified divergent perceptions among caregivers about the content and manner of information provision regarding the EMK, and it seems an individualized approach to the provision of information at the time of supply and throughout the period of caregiving is optimal. The ongoing availability of specialist palliative care support, not solely to administer medication, confirmed previous observations of providing reassurance to caregivers.<sup>22</sup>

Concerns about security in possessing narcotics and other medication in the home were observed in this study, as elsewhere.<sup>22</sup> It appears that caregivers identified for themselves strategies that addressed these concerns.

## Conclusion

This qualitative analysis demonstrates that the experiences of family caregivers in having an EMK in the home were largely positive. Individualized information giving and caregiver education seem to be key considerations in gauging the willingness and capacity of each caregiver to administer parenteral medications; even if the caregiver cannot administer the medication, the presence of the EMK in the home setting for use by visiting nurses also reduces the time between the exacerbation of symptoms and their relief. The EMK is perceived by caregivers as an effective strategy for the timely relief of symptoms and a mitigating factor in inpatient readmissions. Further, mixed-method research into the implementation of EMKs for palliative care patients in the home setting, including the experiences of caregivers, would add to the body of knowledge about this important practice.

## Authors' Note

The research team comprised Kate Maher, Bradley Smith, Tracey Bullen, and John Rosenberg.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The trial was funded by a Practice Development Grant awarded to Kate Maher by the Australian National University Research Centre for Nursing and Midwifery Practice, Canberra, Australia.

## References

- Bell CL, Somogyi-Zalud E, Masaki KH. Factors associated with congruence between preferred and actual place of death. *J Pain Symptom Manage.* 2010;39(3):591-604.
- Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP. Preference for place of care and place of death in palliative care: are these different questions? *Palliat Med.* 2008;22(7):787-795.
- Palliative Care Australia. *The Hardest Thing We Have Ever Done—The Social Impact of Caring for Terminally Ill People in Australia 2004. Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People.* Canberra, Australia: Palliative Care Australia Incorporated, 2005.
- Brazil K, Bainbridge D, Rodriguez C. The stress process in palliative cancer care: a qualitative study on informal caregiving and its implication for the delivery of care. *Am J Hosp Palliat Med.* 2010;27(2):111-116.
- Fukui S, Fujita J, Tsujimura M, Sumikawa Y, Hayashi Y. Predictors of home death of home palliative cancer care patients: a cross-sectional nationwide survey. *Int J Nurs Stud.* 2011;48(11):1393-1400.
- Stajduhar KI, Funk L, Outcalt L. Family caregiver learning—how family caregivers learn to provide care at the end of life: a qualitative secondary analysis of four datasets. *Palliat Med.* 2013;27(7):657-664.
- Bialon LN, Coke S. A study on caregiver burden: stressors, challenges and possible solutions. *Am J Hosp Palliat Med.* 2012;29(3):210-218.
- Andrews SC. Caregiver burden and symptom distress in people with cancer receiving hospice care. *Onc Nurs Forum.* 2001;28(9):1469-1474.
- Given B, Wyatt G, Given C, et al. Burden and depression among caregivers of patient with cancer at the end of life. *Oncol Nurs Forum.* 2004;31(6):1105-1117.
- Kutner J, Kilbourn KM, Costenaro A, et al. Support needs of informal hospice caregivers: a qualitative study. *J Palliat Med.* 2009;12(12):1101-1104.
- Wowchuk SM, Wilson EA, Embleton L, Garcia M, Harlos M, Chochinov HM. The palliative medication kit: an effective way of extending care in the home for patients nearing death. *J Palliat Med.* 2009;12(9):797-803.
- Bishop MF, Stephens L, Goodrich M, Byock I. Medication kits for managing symptomatic emergencies in the home: a survey of common hospice practice. *J Palliat Med.* 2009;12(1):37-44.
- Schonwetter RS, Clark LD, Leedy SA, Quinn MJ, Azer M, Kim S. Predicting emergency room visits and hospitalizations among hospice patients with cardiac disease. *J Palliat Med.* 2008;11(8):1142-1150.
- McCaffrey N, Agar M, Harlum J, Karnon J, Currow D, Eckermann S. Is home-based palliative care cost-effective? An economic evaluation of the palliative care extended packages at home (PEACH) pilot. *BMJ Support Palliat Care.* 2013;3(4):431-435.
- García-Pérez L, Linertová R, Martín-Olivera R, Serrano-Aguilar P, Benítez-Rosario MA. A systematic review of specialised palliative care for terminal patients: which model is better? *Palliat Med.* 2009;23(1):17-22.
- Walker KA, McPherson ML. Perceived value and cost of providing emergency medication kits to home hospice patients in Maryland. *Am J Hosp Palliat Med.* 2010;27(4):254-260.
- Currow DC, Easterbrook S, Mattes R. Improving choices for community palliative care: a prospective 2-year pilot of a live-in support person. *Prog Palliat Care.* 2005;13(5):257-262.
- Mitchell LA, MacDonald RAR. Qualitative research on pain. *Curr Opin Support Palliat Care.* 2009;3(2):131-135.
- Furst CJ, Lindqvist O, Tishelman C. Towards a basic drug kit for the dying patient. *Curr Opin Support Palliat Care.* 2012;6(3):386-390.
- Evans WG, Cutson TM, Steinhauser KE, Tulsy JA. Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *J Palliat Med.* 2006;9(1):100-110.
- Leigh A, Bailey FA, Burgio K, Williams B. A hospice emergency kit (HEK): evaluation of effectiveness by retrospective chart review and hospice nurse questionnaires. Annual assembly of American academy of hospice and palliative medicine & hospice and palliative nurses association: education schedule with abstracts. *J Pain Symptom Manage.* 2011;41(1):295.
- Anderson BA, Kralik D. Palliative care at home: caregivers and medication management. *Palliat Support Care.* 2008;6(4):349-356.
- Hudson P, Thomas T, Quinn K, Cockayne M, Braithwaite M. Teaching family carers about home-based palliative care: final results from a group education program. *J Pain Symptom Manage.* 2009;38(2):299-408.
- Healy S, Israel F, Charles MA, Reymond L. An educational package that supports lay caregivers to safely manage breakthrough subcutaneous injections for home-based palliative care patients: development and evaluation of a service quality improvement. *Palliat Med.* 2013;27(6):562-570.