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"Nasal fentanyl and buccal midazolam carer administration 'as needed' for breakthrough symptom control in a specialist palliative care unit: a nested qualitative study"

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ABSTRACT

Introduction:

When people are dying and unable to take oral medication, injectable medication is commonly used, usually administered by healthcare professionals. There may be delays to symptom relief due to travel to the person's home. In a randomised controlled trial (RCT) previously reported, nasal fentanyl (NF) or buccal midazolam (BM) were administered by lay carers in a hospice.

Objective: (1) To report experiences of lay carers who administered NF and BM for symptom control (2) To use feedback to develop guidance informing a future definitive RCT to determine whether NF and BM administered by lay carers can lead to timely, improved symptom control for people dying at home and fewer 'emergency' community nursing visits than standard breakthrough medication administered by healthcare professionals.

Material and methods:

Semi-structured interviews with lay carers who gave trial medication were conducted. Interview data were analysed using a stage by stage method to code and categorise transcripts.

Findings:

The 6 themes were:

(1) Participation – lay carers welcomed the opportunity to administer medication. (2) Ease of use – lay carers found preparations easy to use. (3) How things could have been done differently – lay carers would have liked access to trial drugs at home. (4) Training – lay carers were happy with the training they received. (5) Timing – lay carers liked the immediacy of trial drugs. (6) Evaluation – assessing symptom intensity and drug efficacy.

Conclusions:

Participation was acceptable to patients and lay carers, and beneficial for symptom relief. The findings will inform planning for a future community-based study.

INTRODUCTION

People with terminal illnesses need access to symptom control and should be able to die in their 'preferred place of care'[1], for most at home[2]. Dying patients are often too weak to take medication orally and the mainstay of treatment in the United Kingdom (UK) is subcutaneous infusions by syringe pump and top-up subcutaneous injections[3].

Family carers can be trained to give injections [4-6] and there has been increasing discussion of this practice to enable more people to remain and die at home during the COVID-19 pandemic[7].

There are preparations that offer an alternative and could be given more rapidly and easily than injections – fast acting fentanyl and BM. In preparation for a community based randomised trial of these modes of administration, it was important to assess feasibility. The findings from the open label feasibility

RCT are reported elsewhere[8]. Here, we report the nested qualitative component focused on the experiences of lay carers.

Purpose of the study

To explore the views and experiences of lay carers who administered NF or BM as breakthrough medication to their dying relative.

Methodology

The study was undertaken at a 16-bedded hospice in England. Lay carers were approached about participation. They were provided training related to medication administration (see Appendix 1) and a participant information leaflet.

Lay carers were supported throughout the study by the research team and, once the patient died, we sought permission to contact them again three to six months later. This timeframe allowed sensitivity around the death while being soon enough for recall.

After this time, the lay carers were contacted and re-issued with a participant information leaflet. Following their consent to participate, arrangements were made to meet at a convenient place, to conduct the interview.

Nine patients received NF or BM. Two had drugs administered only by nursing staff and not lay carers. Of the seven lay carers potentially eligible, the research and multidisciplinary team assessment was that one lay carer's distress meant that they should not be approached.

Six lay carers who administered breakthrough drugs were approached and four agreed; two did not respond.

Written consent was obtained and interviews were semi-structured, digitally recorded and conducted by AP and BD using an interview guide (Appendix 2).

Interviews were digitally recorded and transcribed. The transcripts were checked by AP for accuracy.

Following expert methodological advice from VT, an inductive analysis approach was used enabling patterns, themes and categories to emerge. Interview data were analysed using a stage by stage method[9] comprising a systematic 14-stage approach to code and categorise semi-structured interview transcripts. Two researchers (AP and PP) generated themes independently to ensure accuracy of categorisation and reduce researcher bias. Themes generated were discussed and revised to clarify meanings of categories.

Findings

Table 1 – Participant data

Participant Number	Relationship to patient	Approximate age of participant (years)	Time from patient death to interview (months)
1	Daughter	55	4.5
2	Wife	70	3.5
3	Male partner	60	4
4	Son and daughter	55 – 65	5

Thematic analysis of transcripts identified 6 themes:

(1) Participation (2) Ease of use (3) How things could have been done differently (4) Training (5) Timing (6) Evaluation.

Each theme is discussed below, illustrated with quotes.

1. **Participation**

The main reason for participation was altruism.

I think both of us felt that we could be of some use. You know give some help with research…it felt good, it felt like you were making – giving something back – sort of helping in research. It was great. You know yeah we were wearing our white coats. (P3)

Lay carers also expressed the desire to help their loved one:

It was a case of really trying to help Mum with the pain so we would have been willing to try anything. (P4)

2. **Ease of use**

Lay carers talked about preparations being easy to use and preferable to injections. However, most would have given injections if needed:

Yeah I found it ok…She was happy with it and much preferred it over an injection…

Interviewer: *If you had been asked to participate in your Mum's pain management by giving injections?*

I would not have been so keen…Only because I knew she hated needles… But if I had had to do it – if it meant her in pain or not – I would of done it. No question but the very fact that it wasn't an injection was the appeal really. (P1)

3. How things could have been done differently

All stated they wished that these drugs had been available at home for patients, earlier in illnesses.

If they could have it earlier in the home…I think it would have been because I was at breaking point because of problems caused by the pain a lot of it. The fact that he was crying, I couldn't stop it. (P2)

There were concerns about administering preparations at home:

I think it would feel different … I think it felt reassuring to be – to have the staff around – you could always check you had done it right or get some help or whatever so I suppose it would feel different if you were literally left on your own to do it at home (P4)

4. Training

Participants were all happy with training they received and felt prepared.

Because it was so easy to use. Very straightforward. No worries about that at all. (P2)

Participants appreciated nurses being available to support them with drug administration.

I had no problem when given very clear instructions, a couple of times run through it and then we were watched… the nurses would always be there…It was very straightforward.(P3)

5. Timing

Lay carers appreciated perceived immediacy of trial drugs and talked about having to wait for nurses' visits when patients were at home. One respondent stated that they felt it could be a 'stop-gap' while waiting.

My concern when she was at home was always [cries] – can I get hold of the district nurse to give her an injection or how long are they going to be? 'cause I appreciate how busy they are. You know you may not coincide with a nurse's visit so – I was a bit like my mum I didn't want to bother people. You know – would I have gone out and given her an injection myself if it was that bad. I don't know probably not. To have that ability to be able to give something without having to wait for a nurse to come – you know was priceless really (P1)

6. Evaluation

Lay carers talked about how assessing symptoms:

*I could tell from her expression on her face. (*P1)

They also reported evaluating how well medication had worked:

Well through the whole time she was ill I think they gave us some indications, you know movement and stuff like that. I can't quite remember what they were now. You kind of got used to picking up on that and I think I was quite happy about that because I know her so well. I just knew. P3

Discussion

Lay carers found buccal and nasal preparations easy to use, training and documentation to be adequate and had no recommendations about how these could be improved. They said that they would have used injections at home if needed.

Our study is unique as it was conducted with lay carers giving medication while their relative was on an in-patient unit, meaning there was less emphasis on some issues from previous community studies. Participants mentioned that if they had been at home it would have felt like they had more responsibility; but did not raise concerns about needing particular organisational skills; or having 24/7 advice. It is likely this is because they had the constant support of the specialist palliative care unit's staff to rely on. All talked about how they would have liked the opportunity to give trial medication at home sooner, and wondered whether this would have meant less need for hospice admission.

Data from this research suggests that trial materials would be adequate for a future community study. Lay carers felt well supported by the hospice nursing team and were pleased to have nursing oversight when administering NF or BM for the first time. Well planned support for lay carers at home will need to be part of any future study including administration of first doses and 24/7 access to advice.

Limitations:

We planned to recruit all lay carers who had given breakthrough medication in the experimental arms of the trial. We recruited a very ill, imminently dying population for the linked study, and not every patient received a dose of the trial medication administered by their lay carer before death; and not every lay carer who had given medication participated. Some were difficult to contact and it was inappropriate to make more than two attempts to contact them.

Conclusions

This embedded qualitative interview data yields helpful information for understanding the views and experiences of lay carers who administered buccal and nasal medication for breakthrough symptoms, previously unreported in the literature.

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