Behaviours of patients who take their strong opioids as unmeasured 'sips'

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ABSTRACT

Context – Some patients take their strong opioid painkillers as unmeasured sips.

Objectives – To investigate how and why patients take their medication in this way.

Methods – Patient receiving specialist palliative care who take their strong opioid painkillers as unmeasured sips were recruited. Measurement was made of the mass of 2 sips per patient and qualitative interviews using a topic guide were conducted. Interview transcripts were thematically analysed using a phenomenological approach.

Results - Only two of 16 patients were taking within 20% of the correct dose of their breakthrough liquid strong analgesia. Many varied the dose depending on the severity of the pain episode. Convenience, confusion about the correct dose, and issues with spoons were the other main reasons for people choosing to sip.

Conclusion – This is the first published study exploring the behaviour of patients who take their strong analgesia as unmeasured sips. Knowing that sippers are likely to be taking an incorrect dose, and the reasons behind sipping may help clinicians to help these patients to manage their pain better.

Key Words: Pain, pharmacology, cancer

Running Title - Strong opioids as unmeasured ‘sips’

Key Message

Some patients receiving specialist palliative care take their strong opioid painkillers as unmeasured sips. Some take much more, others less than prescribed. The main reasons cited are convenience; confusion about the correct dose; altering the dose according to pain severity; and issues with spoons.

Introduction

Hypothesis: Patients taking their strong opioid medication as unmeasured sips would take close to the prescribed dose.

For patients suffering from cancer, pain is a common experience, often requiring the use of strong opioids(1). These opioids should be given regularly, and additional fast acting analgesia available for pain that occurs in between regular doses (often called breakthrough pain)(2).

It is common for the breakthrough dose to be calculated as 1/10th to 1/6th of the 24 hour strong opioid dose(3). However, some patients do not follow the directions for these medicines and take their breakthrough medication without accurately measuring it, taking it as a sip from the bottle. Taking the wrong dose risks adverse effects if too much is taken, and lack of efficacy if too little. There have been no studies investigating volumes of medication taken as unmeasured sips. This study's aim was to investigate how and why patients take their strong opioid painkillers as unmeasured sips.

Material and Methods

The study was undertaken at a specialist palliative care unit in England with support from the local community and hospital specialist palliative care teams. When patients or carers were contacted by a Specialist Palliative Care Team member, they were asked if pain medication was taken as an unmeasured 'sip'. If patients were thought to have capacity and a prognosis of more than two weeks, they were asked if they were happy for their contact details to be passed to a research team member.

An experienced research nurse (AP, RD or RP) then called the patient or carer to discuss the study. If agreeable, participant information leaflet(s) were posted or emailed – one for patient and one for carer (if the carer was helping the patient with the study). After a minimum of one day to consider participation, they were telephoned to agree a time and place to meet, usually at the patient's home.

At this meeting informed consent was obtained and the research nurse showed participants how the weighing scales (Weiheng Digital Electronic Kitchen Scales, accurate to 0.01 gram) worked and how to complete a dosage record form. Patients were asked to weigh their bottle of strong opioid before and immediately after taking their medication (their usual unmeasured sip from the bottle). This data was collected for two separate doses. The research nurse kept in touch by telephone and, once two weighed doses had been taken and recorded, she met with the patient / carer again in a setting most convenient to the participant, either in their home or a quiet room at the specialist palliative care unit. At this meeting the dosage record form and scales were collected. A phenomenological approach was used to examine

the experiences of the patients. After re-confirming consent verbally to proceed, a semi-structured, digitally recorded interview was then conducted with the patient (and carer if they wished to contribute) using a topic guide (Appendix 1). Interviews were conducted between July 2015 to February 2020. Recruitment ceased in March 2020 due to the restrictions imposed by the COVID-19 pandemic.

As reflective researchers the authors have considered their own thoughts and actions in light of the study findings. Of interest, one author assumed that participants may aim to sip the correct dose of the medication, this did not bias how interviews were conducted or interpreted as open-ended questions were used to explore why participants chose to take their medication in this way. Furthermore, researchers used a bracketing approach, which involves the process of setting aside preconceptions about a topic(5). This process of acknowledging what is already known about a subject relies on the researcher being self-aware and able to free oneself of assumptions.

Quantitative data analysis

The mass of 10mls of Oral morphine (10mg/5ml) and Oxycodone (5mg/5ml) liquid was measured so that the masses measured by participants could be converted into doses. Morphine equivalent doses were calculated using the Palliative Care Formulary(4). With regard to the oral morphine to oral oxycodone dose ratio, there is variation in the United Kingdom (UK) with some areas using a ratio of 1.5:1, and others using 2:1. For this study, a 2:1 ratio was used as this is used in the area of the country where the study was conducted. Breakthrough doses of immediate release opioid were calculated

as 1/6th of the 24 hour strong opioid dose. For patients who were not taking a regular strong opioid, a starting as needed dose of 5mg of oral morphine was chosen as appropriate (the usual starting dose for frail, elderly or opioid naïve (4)).

The primary results were reported in terms of frequencies with percentages for categorical variables and as medians with interquartile range for continuous variables.

Qualitative data analysis

Interviews were transcribed, AP checked the transcriptions against the audio recordings for accuracy. Participants' thick descriptions of their experiences of taking their medication as a sip from the bottle rather than a measured dose were captured. An iterative approach was used by the authors (AP, PP) to narrow the categories, until saturation of themes was achieved allowing themes to emerge. The transcripts were reviewed independently to validate the themes, and following this process, discussed together, and revised to clarify meanings of the categories, creating credibility.

Patient and public involvement:

We are grateful to a bereaved carer for her comments on the protocol. She told us that this was an interesting study and thought that patients and carers would be happy to participate, and would not find the study procedures burdensome. She was particularly helpful with the wording of the semi-structured interview Topic Guide.

Results

16 patients participated in the study but only 13 were able to complete interviews (1 was admitted to hospital, 1 was too confused at the time of interview, and 1 was too unwell). Of the 16 participants, 11 were men and the men were older than the women (median age of 69 vs 41 years, respectively). All patients were White British. Table 1 presents further baseline characteristics of the study participants. Three patients had a carer who consented to participate in data collection and/or the qualitative interview. Table 2 presents data on breakthrough doses taken as unmeasured sips. Overall, 11 patients (8 men, 3 women) took a higher dose as an unmeasured sip compared to that which was prescribed, 5 patients took less – Figure 1. Only 2 out of the 16 patients took an oral morphine equivalent within 20% of the prescribed dose for their breakthrough medication.

Qualitative Findings

Following the analysis of the transcripts, four main themes emerged:
(1) Convenience, (2) Confusion about dosage, (3) ‘Spoons’, (4) Gauging the dose.

Convenience

Most participants mentioned convenience as a key reason for taking their medication as an unmeasured sip from the bottle.

> It’s just I find it quite easy to open the top, take a swig and put it back. (S5)

Some participants linked convenience with laziness:

> Like I said, I'm lazy and it's on the table by me so I just pick the bottle up and swig. (S2)
>
> So, for me it was just a practical thing that I would just, and laziness, just swig it out of the bottle. (S3)

Confusion about dosage

Some participants reported being confused by the information given to them around dosage. When asked what information had been provided and by whom, one participant stated:

> This was done by the um, the pharmacy when they gave me all my tablets with a discharge summary in a carrier bag and I couldn't understand head nor heels of it. (S1)

The same participant went on to say:

> I got my helper and his wife, and they sat down with me and these are people that are not affected by the after-effects of chemotherapy and they couldn't understand it either. It was a mystery trip. (S1)

Confusion associated with the units of measurement for the medication was frequently discussed:

> It's not something I am familiar with, I don't know if it's milligrams, grams, micrograms, millilitres. (S3)
>
> It sort of tells you to take a spoonful as you need it really, or you take a sip of it, whatever, whatever suits you really. (S7)

> I think it was millilitres, 15 mls, should be 10mg, I mean I forgot because I would look at it and think yeah. (S4)
>
> Nowhere along the line is it one teaspoon, one tablespoon, one soup spoon – it was no, nothing like that, yeah. (S1)

Spoons

Frequently participants talked about issues associated with ‘spoons’ as being an influencing factor as to how they would take their medication, including:

The location of spoons:

> You can’t find a spoon, as you know our bedrooms are upstairs and our spoons are downstairs, so I used to just get it from the bottle. (S4)

The shortage of spoons:

> So, since August of last year, we are now in April, I have only been given one spoon. (S3)

Using a spoon to measure:

> It’s measuring it out on a spoon and trying not to spill it, because it’s quite sticky stuff and all that. (S5)
>
> If I do put it on a spoon, because I get the shaking business, by the time I actually get it to my lips there’s none left, so easier to do that. (S6)

Gauging the dose

Participants regularly talked about the correlation between the size of the sip and their level of pain:

> Measuring it in my mouth, erm...but I was taking it to sort of react with the pain, the more pain I had the more I take. (S12)
>
> Depending on how I feel I take a bigger, well, sip of it but it doesn't seem to make much, an awful lot of difference. (S7)

One participant stated that taking the medication in this way allowed for a 'decent dose':

> The 5ml, I soon discovered wasn't man enough to do the job, so I started taking a bit more and in fact started swigging it because that's how I thought I could get a decent amount inside me. (S6)

Discussion

While some patients attempted to take the correct dose, many did not. Only two out of 16 took doses that were within 20% of that recommended for them. Participants talked about several reasons for taking their medication as an unmeasured sip. It was more convenient to do it this way and there was confusion about the correct dosage. For some there were issues around access to spoons. It was interesting that many participants varied the dose according to how severe their pain was.

Limitations

This is the first published study investigating how patients take their medication as unmeasured sips. It took four and a half years to recruit 16 participants which was short of our target of 20. It is unknown how frequent 'sipping' is amongst a specialist palliative care patient population. It may be that many patients are not sippers, or if they were, they did not want to admit

to it. All participants were White British, and we, therefore, have no idea whether ethnicity has any impact on sipping behaviour. The setting of the study is not ethnically diverse so this is, to some extent, unavoidable (6). There were more male than female participants. With there being no previous literature in this area, it is unknown whether men are more likely to sip than women. It is possible that involving carers might have led to some inconsistency in data collection. This was a pragmatic decision to allow frail patients to participate. Also, recruitment was reliant on local specialist palliative care teams. As with other studies we have conducted, they have been incredibly supportive colleagues, happy to help us recruit. However, this study may not have been seen as so mission critical. Without any published literature about the frequency of sipping this was always going to be an exploratory study and 20 was very much a speculative target. The study closed prematurely because of the COVID-19 pandemic. The interview guide was not pilot tested, however it was reviewed by a bereaved carer and minor adjustments were made to the wording adding rigour to the findings.

There has been research showing that there is a difference in sip size between natural drinking conditions compared with an instructed experimental situation(7).

In a study where participants were given soup to drink using small sips, large sips or sips of their own choice, people who took larger sips were more likely to consume more; and larger sips led to underestimations of consumption(8).

Studies with children show that there can be errors made by parents when measuring out the correct doses of medication(9,10) and syringes are more likely to be used accurately than dosage cups(11,12).

In the UK, the drug tariff obliges a dispensing pharmacist to supply an appropriate consumable (e.g. spoon, syringe, dropper) with every oral liquid medicine. Payment for consumables is at an average rate of 1.24p per prescription item whether that item needs a consumable or not(13).

According to one of the larger pharmacy wholesalers a 5ml syringe with bung costs 11.2 pence excluding value-added tax (VAT) while a 5ml plastic spoon costs 2.1 pence excluding VAT(14).

Clinical Implications

When prescribing strong analgesia for patients with cancer, an important consideration is whether a pain is opioid responsive or not – a concept which has been advocated for many years(15). Opioid sensitivity can be identified from whether there is relief when a patient takes a dose of breakthrough painkiller. If the patient is taking the wrong dose (particularly if it is too little) then it will not be possible to ascertain opioid sensitivity by this method. When faced with patients who are taking their strong painkillers as unmeasured sips clinicians should take into account that it is likely that the patient is not taking a dose which is close to that prescribed. It may be helpful to get some idea of what dose the patient is taking. One way of doing that would be to replicate our method here – weighing the bottle of strong opioid before and after doses. Other options would be to check that the patient has access to a spoon to measure the medication appropriately, knows exactly how much they should be taking, and the possible consequences of taking the wrong dose; or ask the

dispensing pharmacy to supply a syringe with the medication if the patient is willing to try that.

It would be useful to know how commonly patients take their medication as unmeasured sips, and whether sipping is less likely if syringes are given rather than spoons. If this is the case it might be worth the additional cost of syringes to ensure patients are receiving the correct dosage.

Conclusion

When faced with a patient who is taking their strong liquid painkiller as an unmeasured sip it is quite likely that they are not taking a dose close to that prescribed. Knowing the reasons behind sipping may help clinicians to help these patients to manage their pain better.

Contributors: PP conceived the study. AP,BD and RP collected the data. RKA analysed quantitative date; AP and PP analysed the qualitative data. RH gave expert medicines advice. All authors critically revised drafts of the paper. They also read and approved the final version of the manuscript. PP is the guarantor.

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Appendix 1

When patients take their painkillers straight from the bottle, how much do they take?

Topic Guide

1. What were you told about taking painkillers when you have extra pain between doses of your regular strong painkiller (sometimes called breakthrough pain)? Were you told how often you could have it? Who told you this etc?

2. Do you know what dose you should take – do you know how much it should be in mg or ml?

3. Is there a reason why you take your medicine as a ‘sip’ straight from the bottle? How many doses of breakthrough painkiller do you take a day? How many of these are measured and how many are ‘sips’?

4. Do you take these sips at any particular time of the day?

5. Do you think it’s likely you are taking more, less or the same amount compared to what you were prescribed?

6. Does your breakthrough painkiller work? (Perhaps use numerical rating scale 0-10 to ask about pain before and after dose) How long does it take to work?

7. Does it worry you that you might be taking too much or too little?

8. Is there any information that might alter how you take your painkillers, in particular so that you are more likely to take them in a measured way?

9. Is there anything else you want to tell us about your painkillers or your participation in this study?

10. Would you like to see the results of the study when it is completed?

Thank you very much for your participation.

Table 1. Baseline characteristics

	Total n=16 (100%)	**Men** n=11 (68.8%)	**Women** n=5 (31.3%)
Age (years); median (IQR)	64.5 (50.0-71.0)	69.0 (64.0-78.0)	41.0 (40.0-54.0)

Diagnosis, n (%)			
Lung cancer	4 (25.0)	4 (36.4)	0
Breast cancer	3 (18.8)	0	3 (60.0)
Prostate cancer	3 (18.8)	3 (27.3)	0
Colon cancer	2 (12.5)	2 (18.2)	0
Pancreatic cancer	2 (12.5)	2 (18.2)	0
Peritoneal cancer	1 (6.3)	0	1 (20.0)
Renal cancer	1 (6.3)	0	1 (20.0)
Performance status, n (%)			
1	5 (31.3)	2 (18.2)	3 (60.0)
2	6 (37.5)	5 (45.5)	1 (20.0)
3	4 (25.0)	3 (27.3)	1 (20.0)
Unknown	1 (6.3)	1 (9.1)	0
Background opioid medication			
None	1 (6.3)	1 (9.1)	0
Diamorphine via syringe pump	1 (6.3)	0	1 (20.0)
Fentanyl patch	3 (18.8)	2 (18.2)	1 (20.0)
Morphine sulphate MR	7 (43.8)	5 (45.5)	2 (40.0)
Oxycodone MR	3 (18.8)	2 (18.2)	1 (20.0)
Oxycodone via syringe pump	1 (6.3)	1 (9.1)	0

Table 2. Breakthrough medications taken as a sip

	Total n=16 (100%)	**Men** n=11 (68.8%)	**Women** n=5 (31.3%)
Breakthrough medication, n (%)			

Morphine oral solution	12 (75.0)	9 (81.8)	3 (60.0)
Oxycodone	4 (25.0)	2 (18.2)	2 (40.0)
Recommended Morphine dose equivalent for breakthrough dose (mg), median (IQR)	12.5 (8.3 – 23.3)	10.0 (5.0 – 26.7)	20 (11.7 – 20.0)
Oral morphine dose equivalent for the 2 sips (average) (mg), median (IQR)	28.1 (15.4 – 32.9)	28.1 (15.7 – 35.0)	28.2 (15.2 – 28.4)
Difference between recommended oral morphine equivalent dose and actual dose taken as sip (mg), median (IQR)	9.5 (-6.3 – 22.9)	10.7 (-0.8 – 25.0)	8.4 (-11.7 – 16.5)