

How much information is 'reasonable'? A qualitative interview study of the prescribing practices of palliative care professionals

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Abstract

Background: Prescribing clinicians have to negotiate ambiguities around information provision and consent for medications on a daily basis, despite the availability of professional guidance.

Aim: This study aims to explore some of the many factors prescribing clinicians in the United Kingdom take into account when deciding what information to give to patients about medication choices, and when.

Design: In depth face-to-face interviews, utilising both a hypothetical scenario and semi-structured prompts, were conducted in order to elicit extended reflections on how clinicians individually work through such dilemmas and make decisions.

Setting/participants: 10 prescribing clinicians (doctors and nurses) from a large combined team of National Health Service (NHS) secondary and community palliative care providers in England.

Results: Palliative care staff regularly face choices about information provision in prescribing discussions, in particular when considering whether information might increase distress. Participants presented three overlapping framings that helped them assess the range of factors that could potentially be taken into account; 1) assessing the individual patient, 2) tailoring the provision of information and 3) jointly forming a plan.

Conclusions: Information provision about medication choices and effects is a demanding, ongoing process, requiring nuanced judgements that constitute an unacknowledged yet significant aspect of clinical workload. Although current medical guidelines allow clinical discretion about information provision, this can leave individual clinicians feeling vulnerable. Further evolution of guidelines needs to establish a more sophisticated way to acknowledge professional and legal requirements, whilst also promoting professional autonomy and judgement.

Key Words

Palliative Medicine, Prescribing, Communication, Scope of Practice, Patient Medication Knowledge, Decision Making

Key Statements

What is already known about the topic?

- Professional guidelines regarding what information to give patients about their medications have evolved over time to include a greater degree of clinical autonomy and individual judgement.
- UK law has paralleled these developments, with the expectation that a clinician adopts the criteria of 'reasonableness'.
- Palliative care specialists routinely have to address this concern, as both the need to palliate and the decline in patient health often requires medication that can have known risks.

What this paper adds

- This paper presents interview data of prescribing palliative care clinicians that illustrate the different factors they take into consideration when deciding what information to provide to patients, framing the topic in terms of; 1) assessing the individual patient; 2) tailoring the provision of information; 3) jointly forming a plan.
- Decisions regarding what information to give a patient and when are rarely straightforward; there are multiple and competing factors that often mean a decision cannot be arrived at by one set of criteria alone.
- Findings highlight that although current medical guidelines allow clinical discretion about information provision, in practice this can leave individual clinicians feeling vulnerable and unsupported, particularly those who have less experience and confidence in prescribing within palliative care practice.

Implications for practice, theory or policy

- Decisions regarding how much information to give patients are often complex and ongoing, and should be recognised as a significant and demanding aspect of clinical workload.
- Any requirement to potentially offer a justifiable defence if ever a decision is disputed needs to acknowledge the non-clinical as well as clinical criteria a professional often has to consider.
- Further evolution of guidelines needs to establish a more sophisticated way to acknowledge professional and legal requirements, whilst also promoting professional autonomy and judgement.

Introduction

As the nature and authority of the medical profession has shifted[1], there has been a growing commitment to ensure patients are better informed[2] and have a more active role in decision-making.[3,4] In the context of this, what constitutes appropriate prescribing practice is an international concern.[5,6,7] However, guidance about what information should be provided about a particular drug remains country-specific, often varies depending on the type of medication, and may well depend on the preferences of individual patients.[7,8,9]

In the United Kingdom, largely driven by an initial concern over potential accusations of medical negligence, the General Medical Council (GMC) developed guidance on how information about

medication and associated risks should be given to patients.[10,11] Further parameters were introduced following the landmark legal case Montgomery vs Lanarkshire Health Board in 2015.[12] This judgment underscored the duty of a clinician to ‘take reasonable care’ to ensure a patient is aware of any risks associated with a medication or intervention, and that a ‘reasonable person’ should be able to recognise those risks as significant.[13,14]. The double evocation of the threshold of reasonableness, which underpins much of UK law[15], is telling; by applying it to both clinicians and patients in parallel, the ruling reflected the reality that, whilst an aspect of a clinician’s duty of care should be to provide necessary and sufficient information, this is counterposed by the need not to confuse a patient by conveying information that is irrelevant or might add to their distress. The most recent GMC guidance reflects a further focus on the patient perspective, and what their understanding of risks might be.[16] It acknowledges that clinicians inevitably need to apply their own individual judgment in relation to this, although it nevertheless also outlines their professional, legal and moral imperatives.[17]

Questions of how much detail to provide about possible adverse effects of medications, and when to convey it, impacts clinician-patient partnerships across all areas of healthcare.[18] Indeed, different national healthcare systems invoke the idea of shared-decision-making in different ways[19], and often have to respond to diverse cultural ideas about illness and treatment.[20] But within palliative care it is a particularly pressing issue. Treatment frequently entails prescribing drugs for off-label use or that are unlicensed for the population they are being used for.[21,22] Additionally, with its evolving remit of palliation, weighing up risks versus benefits constantly alters over time.[23] Moreover, clinicians must constantly take into account the fact that patients are confronting emotional, psychological and social impacts of a life-limiting diagnosis and that there may be specific concerns about patient capacity near the end of life.[24]

Little is known about how individual professionals actually navigate such ambiguity, or how they reconcile being independent to make a judgement with the need to follow formal requirements. The aim of this qualitative study is to explore how palliative care clinicians determine the appropriate level of information to provide patients when prescribing new medications or adjusting doses. We provide insight into the ways in which clinicians navigate the gap between professional guidelines and responding to patients in practice, and what they do in situations when they judge telling patients about all possible risks is neither reasonable nor desirable.

Methods

Study design

Medical literature often represents decision-making as the logical assessment of different elements, such that they can be compared and weighed against each other.[25] In contrast, social science literature emphasises that frequently it is impossible to establish common criteria between diverse factors; often there are many external, contextual elements that shape a specific assessment, while core values underlying an assessment regularly compete or even contradict each other.[26,27] As a result, real-life decisions about how much information to convey to a patient cannot simply follow

evidence-based directions about prescribing, and will rarely result from a simple balancing of one set of things against another.[28,29] Our theoretical framing was consequently that decisions are not the result of simple calculation of competing factors, but rather emerge from a range of diverse and sometimes incommensurate considerations.[30] Decisions may appear rational and logical in retrospect, but this fails to acknowledge the many diverse factors that are often drawn upon. Consequently, the study consisted of interviews that included a hypothetical scenario (Table 1) to encourage participants to respond to common prompts in an open and reflective way and explore the tensions and dilemmas they foresaw.

Study information and setting

The study took place in a UK specialist palliative care service comprising a large London inner-city community team and an acute secondary, tertiary and quaternary hospital. This location was selected as the study was part of the wider research project being undertaken by the team (Forms of Care; project reference ES/P002781/1).

Recruitment

An email was sent to all staff who were able to prescribe medications within the palliative care service (n=17) inviting them to participate. Since nurses in the UK can become registered as Independent Prescribers of medications, including unlicensed and controlled drugs[31,32], those who were qualified were included. Both doctors or nurses are referred to as clinicians in the following sections as comparison between professions was not a study aim. Ten clinicians expressed interest, gave written consent and were interviewed in their workplace setting.

Data-collection

Interviews were conducted between July and October 2019 by KD, a female palliative medicine doctor who had a prior professional relationship with the participants. No other individuals were present during the interviews. To develop her research skills, KD was supported by the other authors in how to prepare and undertake the interviews.

Participants were asked to consider a case vignette describing a hypothetical scenario (Table 1), which had been refined after pilot testing. They were asked how they would manage the situation, including what information they would provide. This was followed by a series of general prompts to promote an open-ended conversation about their experiences and what approaches they had personally developed to assess what information might be appropriate to impart to a patient, and how best to communicate it. Rather than consider the case vignette and interview as two distinct methods producing discrete datasets, they were treated as facets of the same interview encounter; the former providing a way to introduce the topic and set participants at ease, after which they were all much more able to articulate their personal concerns and experiences.

All interviews were audio-recorded and transcribed verbatim by an NHS approved agency and then anonymised. The average duration was 35 minutes (range 22-49 minutes). Field notes were made during the interviews. No repeat interviews were carried out and the transcripts were not reviewed by participants. Data was stored and managed according to institutional policies on data security.

Table 1. Case Vignette

67yr Female

New referral to Community Palliative Care team for symptom control from Oncology team

Background:

Metastatic ovarian cancer with liver and peritoneal metastases.
Recent disease progression despite chemotherapy, and chemotherapy has now been stopped.

Past medical history:

Nil

Social history:

Lives with husband in own home.
Independently mobile
Husband does all shopping/cleaning

Drug History:

Morphine modified release 30mg BD PO
Immediate release morphine 10mg PO PRN.
Patient has needed 1 x PRN dose /24hrs on average.
Metoclopramide 10mg TDS PO
Lansoprazole 30mg BD PO
Docusate 200mg BD PO

Assessment:

On symptom review main symptom and concern is nausea.
She has had this for a few weeks and it is getting worse.
Bowels are open regularly.
Metoclopramide was started 3 weeks ago and has helped a bit.
The patient has had a recent trial of steroids - this did not help nausea.
The patient has pain in their abdomen right upper quadrant which is well controlled on current analgesia.
The morphine was titrated up by GP and Oncology team over the last 4 weeks.
The patient also complains of fatigue.
There is no confusion.

Examination:

Abdomen is soft & non tender, bowel sounds present, liver edge non tender and palpable 3 cm. Chest clear.
No signs of opiate toxicity.

Investigations:

The GP did some blood tests this week and renal function, full blood count and calcium all normal. Liver function tests are mildly deranged.

Starter Questions

1. How would you approach addressing the nausea in this case?
2. WHAT would you discuss with patient with regards to management of nausea?
 - a. WHY would you discuss this?
3. What would you choose NOT to discuss with patient in this case?
 - a. WHY would you NOT discuss this?
4. What factors might modify your decision/change your decision?
5. If this patient lived alone would it change how you would discuss?
6. Would prognosis change how you would discuss?
7. If this patient's or carer's expectations were for very 'active intervention' would it change how you would discuss?

8. If you saw this patient in hospital would it change how you would discuss?
9. If time was limited would it change how you would discuss? (Time could be patient fatigue/ability to concentrate/service constraints/prognosis)
10. Do you have any similar cases/stories?
 - a. What was your rationale for how you discussed with the patient in these cases?
11. WHEN do you feel it is reasonable to NOT give some information about potential side effects/risks
 - a. WHY is this?

Data analysis

Analysis of the transcripts was initially driven by the structure of the interviews. It was further coded inductively, adding new themes to the existing set. To establish coding reliability, KD and AD separately read three transcripts, discussed existing and emergent themes and adapted the codes where appropriate. They then coded a further five interviews, discussed additional refinements, and had these reviewed and corroborated by EB, SC, SY and JM [Insert Figure 1]. No further themes were identified in the final interviews suggesting data saturation. All authors contributed to drafting or critically revising the article.

Ethics

The study was part of the larger research project Forms of Care (project reference ES/P002781/1), which received formal research and ethics approvals (IRAS 239197 and Camden & Kings Cross Research Ethics Committee review), and had been granted permission by the R&D service of the hospital.

Results

Ten interviews were conducted in total; participant characteristics are described in Table 2.

Table 2. Characteristics of Participants:

Participant Information		Study Participants (N=10)	Total Prescribers in Clinical Service (N=17)
Sex	Female	8	14
	Male	2	3
Current Clinical Role of Prescriber	Palliative Medicine Consultant	4	9
	Palliative Medicine Registrar	1	3
	Palliative Medicine Clinical Nurse Specialist	4	4
	Palliative Medicine Speciality Doctor	1	1
Main palliative care work setting	Community	1	2
	Hospital inpatient	4	8
	Hospital & Community	3	5
	Oncology Outpatient Clinics	2	2

We identified three core areas that capture prescribers' priorities when considering what information to give a patient: 1) assessing the individual patient; 2) tailoring the provision of information; 3) jointly forming a plan. We present a summary of each of these below, with representative quotes for illustration.

1. Assessing the individual patient

All participants emphasised the need to ensure each patient was considered on an individual basis. As part of this, they talked about the need to establish a patient's 'back story', establishing a general timeline of symptoms, and ascertaining how severe they had been:

I spend a fair bit of time trying to get to know her, trying to attune to her needs, very conversational in that way I think, most of the time. [...] So a lot of talking, a lot of trying to elicit her understanding, and then I'll get down to the specifics of what really her current concerns are. (Interview 1)

Although the focus is ostensibly on clinical concerns about symptoms and health status in order to assess which medicines or interventions may help, these conversations also provide an opportunity to gain a more general sense of the patient and begin to build a relationship with them.

Participants broadly categorised patients into those who wanted to know everything, those who wanted an average level of information, and those who did not want to know much detail at all. Although somewhat crude, these groupings helped the clinician make an assessment relatively rapidly. As one of the participants said:

It's often a judgment of the individual patient. Some people are very, you know, very willing to see... But I think it'd be very much patient led. Because some people, they then freak out and... you know, I don't say 'oh don't read it'. Because actually it *can* help; proactively saying, okay these are all the side effects... (Interview 2)

Interviewees talked about having to also assess this according to a patient's level of anxiety and fear. Frequently this was not explicitly articulated, so they need to be sensitive to body language, eye contact and other non-verbal cues. It was felt that these skills could only be gained from clinical experience, as in the words of the following participant:

I think once you have been assessing patients like this all the time, you know where you need to pitch it and what they're reflecting back to you...it's hard to pin down exactly what that is, that combination of experience and intuition that you gain over time. (Interview 7)

Participants also expressed how confidence in their assessment and prescribing skills can have an impact on the information they give, and that they can feel more vulnerable at earlier stages of their career or when they are out of practice. For example, one participant described the importance of experience when communicating information clearly and with conviction as follows:

I'm very concerned when I see CNSs [clinical nurse specialists] and junior members of staff being... you could call it paternalistic, or maybe too frightened ... to be able to give information confidently. (Interview 5)

They went on, recalling how a particular patient reacted to one such incident:

And I could see he [the patient] was looking a bit quizzical, and I was thinking, well blimey. I'd be quizzical, by what I had just been told... 'we'll stop this and start that.' Well how? And what if? (Interview 5)

Overall, this process of gaining a sense of the patient relied on a wide range of tacit knowledge and accumulated skill, not only to assess how they might relate to clinical information, but as the basis for considering what might be the most appropriate next steps.

2. Tailoring the provision of information

In line with current guidelines, participants recognised that in principle it was always important to explain possible medication side-effects. These might range from common and relatively minor ones – for example, increased likelihood of constipation from taking morphine – to rarer, more severe, or life-threatening risks such as seizures from levomepromazine for those patients who already had a low threshold. However, many commented that in practice not only was there rarely enough time to give all relevant information, but that this was often not helpful:

I have...worked with patients who...every drug is like , so what are the possible side effects? And for that person I have sat down with the BNF (British National Formulary) on my phone and said...this is the list of things...but I think this is quite an unusual person in wanting that level of detail, and that level of detail helping them...most people don't want that level of information. (Interview 6)

Participants said that they consequently drew on what they had established about the patient in order then to decide precisely how much to say, and when. Choosing appropriate language was key to this and entailed pitching information in a way an individual patient would understand, and in a manner that allayed any fears or anxieties they might have. By drawing on these different components, participants described how they tailored what information might be conveyed, and in what way:

I would be balancing as we talked... I would then say 'this is what I think we should do about those three options, for these reasons' and then 'these are the drugs we should use'... I don't think many patients really want to hear: 'oh, there's a list of five different antiemetics'... So, I suppose that would be my sieve. (Interview 8)

Interestingly, participants said that prescribing a controlled drug did not necessarily mean they were more likely to give greater detailed information, even when associated with more rigorous guidance. Instead, they described the more relevant imperative was to pre-empt any possible misunderstandings or conflict, whatever the medication. Sometimes this was to counter patient preconceptions – such as morphine, oxycodone and pregabalin, which all have negative social

connotations and often alarmist representations in the UK media. In other instances, the potential area of confusion was because a drug might originally have been developed for a different purpose, and this might cause alarm if a patient looked it up on the internet (such as gabapentin for neuropathic pain rather than its original use in epilepsy management).

There were also situations when the clinical priority to prevent harm was felt to override the commitment to provide detailed information; in particular, when a patient was experiencing multiple severe symptoms, or during their last days of life. Providing new or complex information was felt to be add an unnecessary burden and potential cause for worry. For example, one participant recalling a man dying of a bronchial artery haemorrhage who was clearly in distress, reported:

I simply said, have you got any pain? Yes. Where is it? In your head? Would you like to be more sleepy? I can see that this is very distressing. He nodded. I went to the drug rooms. I got the drugs. I could see he was dying. There was no more information that that man needed at that point. I needed to palliate him. [...] It was totally clear to me that any further conversation would be entirely inappropriate. He was scared witless (Interview 5).

An important part of ensuring information provision was tailored to a specific patient was establishing trust with them; clinicians have to be confident that a patient not merely complies with medication adherence, but that they are sufficiently aligned with the medical reasoning that they can work together:

I need to make sure that [the patient] has that relationship with me, that he [sic] trusts me, and that he understands where I'm coming from.... So when I start to say, "Actually, why don't we... let's think about..." it's not going to be a question of 'I'm going to do this, this and this', it's going to be, 'let's think about this' *with* him.. (Interview 7)

However, prioritising the need to establish trust was often felt to be in tension with more stipulated processes and procedures, such as obtaining formal consent. A general concern was that these requirements tended to be based on assumptions about what was appropriate or necessary for patients *in general*, and that these could be at odds with the circumstances of a particular patient.

3. Jointly forming a plan

Like many other areas of medicine, jointly making treatment plans with patients was regarded as empowering. For instance:

When I'm doing any home visits, even if they're really sick, I'll always give them something to do ... to give a sense that actually we're working on this together... they've got to be able to cope... (Interview 1)

Participants felt providing information about the medication was key to encourage patients to share some of the responsibility and be committed to the treatment. This enabled patients to monitor their own side effects and relay this to their clinical team. In this way, providing an appropriate amount of information was seen as a way to consolidate a collaborative, ongoing relationship.

Nevertheless, participants acknowledged there were occasions when a patient simply did not want to know any details. As one participant said, 'you can't force information on somebody' (interview 8). This lack of patient involvement can be difficult to manage, especially if it is felt to potentially impact safety. Compensatory strategies included increased monitoring, more regular follow-up telephone calls, speaking to a carer or directly involving the General Practitioner or District Nurse.

Comments from all the participants reflected the reality that while providing information about medication was a central aspect of building an ongoing relationship with patients, this was invariably curtailed when death was imminent. The urgency which often accompanies an assessment that death is near further shifts priorities; the commitment to plan things jointly is superseded by the duty to quickly control symptoms to improve the quality of remaining life. This included not burdening patients or their relatives with information about a drug which might just add further distress or confusion:

I suppose I'm making the decision given the time that is left. What is the information that relatives would most value, what is the support that they need? ...I don't think I have an algorithm for that, I really don't. I think that's a case ... where one has hopefully built a rapport, and works out what the needs are...
(Interview 3)

From this point on, the commitment to the patient included recognition that an aspect of care was not to saddle them with information that was no longer a central concern.

Discussion

This article presented interview data from palliative care professionals based in the UK reflecting on how they made decisions regarding the information they give patients about medication. All participants felt it was not always appropriate to provide extensive information about material risks. This is particularly foregrounded in situations where patients are coming to terms with life-limiting diagnoses or are close to death.

Clinical consideration of how much information to give patients fell into three general areas : assessing the individual patient, tailoring the provision of information, and jointly forming a plan. These represent overlapping areas of concern, where personal judgement is reconciled with professional guidance and legal requirements. A central feature of the accounts was that ultimately making an assessment was not derived from a process that employed objective 'reason' to come to a calculated decision, but instead drew on a mix of clinical knowledge, sensitivity and professional experience.

Implications for practice/further research

Whilst this qualitative study was situated in the UK context, as we noted in the Introduction, the question of how much information should be given to patients, and whether it is invariably beneficial to do so, is relevant everywhere. It is likely that different national contexts will raise somewhat different issues, depending on such things as the role and authority of the prescriber, the expectations of the patient, and nature of the clinician-patient relationship. Nevertheless, our findings align with previous research about the importance of rapport-building in general, the nature of shared decision-

making and the role of clinicians, and the need to tailor information provision.[33] We have shown that it is clear maintaining a good, trusting relationship with a patient does not always depend on providing all the information, but instead information that is pertinent and suitable for the patient's current situation. In our study, clinicians valued being able to exercise personal judgment, especially since symptom management in palliative care is considered both an art and a science.[34] Any requirement to offer a justifiable defence if ever a decision is disputed needs to acknowledge the non-clinical as well as clinical criteria a professional often has to consider.

Additionally, while current clinical guidelines recognise the importance of individual professional judgment, they do not acknowledge the amount of work required by clinicians to continuously appraise each patient and respond to their changing circumstances. The diverse and often competing factors mean making a simple calculated decision is often impossible. Instead, determining what is 'reasonable' information provision is part of a demanding and continuous set of practices that include building trust, communication skills, making clinical judgements and care planning. The recognition of these practices will be applicable in all national healthcare systems and when responding to different cultural ideas about medication use.

Furthermore, awareness that these assessments are regularly made by clinicians without institutional recognition or explicit guidance can make them feel vulnerable – especially if decisions are ever disputed. This is particularly true for those who are less experienced and have not yet developed their own strategies to deal with difficult situations. Senior clinicians suggested that relevant skills could be gained through formal training and informal learning, such as during ward rounds, senior mentoring,[35-37] and learning from other peers to establish a sense of shared practice. This paper supports further evolution of guidelines to establish a more sophisticated way to acknowledge professional and legal requirements, whilst also promoting professional autonomy and judgement.

Strengths and Limitations

The study is limited in that the data focuses on a small number of UK clinicians' reflections. Observational data, for example collected through ethnographic fieldwork, may well add further considerations that only emerge in practice, as would data drawn from patients' about their own perspective on the topic. Further studies conducted within other healthcare systems internationally would allow for a comparison of issues, and potentially might lead to a map of those considerations that are common and those that are specific to a particular healthcare system.

Additionally, the study is based on one clinical service, palliative care, which has its own set of practices that emerge from the heightened consideration of the patient's experience at a time when there is often a high degree of uncertainty and distress. This may well differ from other services. Nevertheless, the methodological design enabled the identification of general themes, rather than specific issues, to illustrate how professionals engage with current official guidance concerning information provision that is prescriptive yet also allows for variation.

The first author had a prior professional relationship with the participants. Participants may have assumed the author would know what they were referring to and so may not have articulated their thought processes as clearly. The author was cautious in her interviewing technique and aimed to help the interviewees articulate their views clearly for the purpose of analysis. The study may also be

limited by the self-selecting participation of interviewees. It is unknown whether the seven prescribing clinicians who chose not to participate may have expressed different views or rationales to the clinicians interviewed.

Summary

We have described how palliative care clinicians assess what is a reasonable amount of information on an individual basis, and found that although the current ambiguity inherent in professional guidelines and the law allows for flexibility, this can make them feel vulnerable and not fully supported. Furthermore, and potentially more significant, devolving judgment and decisions in this way means that the complex, demanding and ongoing work to assess each situation – that includes getting to understand the individual patient, their ever-changing health status, and assessment of how things might unfold over time – is routinely made invisible and consequently unacknowledged in formal systems and current documentation.

Authorship

All co-authors contributed to the concept, study design, reviewing the article critically for important intellectual content, revising draft manuscripts and approved the near-final version to be published. K.D was responsible for the study design, data collection, drafting and revising the final manuscript. Data analysis and initial interpretation was done by K.D and A.D. Further interpretation and draft revisions done by A.D, S.C and E.B.

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Declaration of Conflicts of Interest

The authors declare that there is no conflict of interest.

Research/Ethics:

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Data Management and Sharing

The data repository is currently being readied for uploading, and may be ready for inclusion if and when this paper is published.

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