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

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Acknowledgements and declarations	***WHY: So readers understand the context of the research*** Have you included a funding declaration according to the SAGE format? Are there acknowledgements to be made? Have you stated where data from the study are deposited and how they may be available to others? Have you conflicts of interest to declare?	Yes acknowledgments and declarations included. We have commented that a data repository is currently under

		construction and details will be provided for publication if paper accepted.
Supplementary data and materials	***WHY: So the context is clear, but the main paper succinct for the reader*** Is there any content which could be provided as supplementary data which would appear only in the online version of accepted papers? This could include large tables, full search strategies for reviews, additional data etc.	No supplementary materials supplied.
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How much information is 'reasonable'? A qualitative interview study of the prescribing practices of palliative care professionals

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Abstract

Background: While professional guidance regarding information provision and consent for medications is available and recently updated by the General Medical Council, there remains a degree of ambiguity that clinicians have to negotiate on a regular basis.

Aim: This study aims to explore some of the many factors clinicians 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: A purposively-selected sample of 10 prescribing clinicians (doctors and nurses) from a large combined team of National Health Service 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, Communication, Scope of Practice; Patient Medication Knowledge; Decision Making, United Kingdom

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]** As part of this, The General Medical Council (GMC) developed guidance about how information should be given to patients about the medication they are given, and the extent to which risks and side-effects of treatments need to be openly discussed**[5**,**6].** The primary focus of early iterations of the GMC guidelines was to ensure a prescriber had sufficiently warned a patient of known

risks, as judged by a responsible body of medical opinion, and hence were driven largely by a concern to avoid potential clinical negligence.

The landmark 2015 UK Supreme Court case Montgomery vs Lanarkshire Health Board outlined further parameters regarding information provision.**[7]** Although some hailed this judgment as ground-breaking,**[8]** others have argued it merely exemplified the law catching up with professional guidance.**[9]** The 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. It also emphasised that a 'reasonable person in the patient's position' should be able to recognise those risks as significant. This double evocation of the threshold of reasonableness, which underpins much of UK law**[10]**, is telling; applying it to both clinicians and patients in parallel, the ruling reflects how the provision of clinical information can rarely be a singular and straightforward matter. Therefore, 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 current GMC guidance reflects a further concern with patient perspectives, and what individual understanding of risks might be.**[11]** It notes that providing too much information, as well as too little, may sometimes be problematic. It also acknowledges that clinicians inevitably need to apply their own judgment, which means that clinicians may come to different conclusions about the same situation. However, the guidelines nevertheless emphasise certain legal and moral obligations: some sections maintain that a clinician *should* assess how to meet a duty or principle, while others emphasise clinicians *must* fulfil certain legal obligations and ethical standards, and that, if necessary, they should be able to provide justifiable evidence for their decisions.**[12]** Consequently, although GMC guidelines support tailoring to individual patients in order to support shared decision-making, doing so is potentially at odds with the stated legal and moral imperatives.

Little is known about how professionals navigate this ambiguity about what information to give, or how they reconcile their independence to make a judgement with the need to follow professional and legal requirements and the possibility of having to justify their choices. Medical literature often represents decision-making as the logical assessment of different elements, such that they can be compared and weighed against each other.**[13]** 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.**[14,15]** 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.**[16,17]**

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]** 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]**

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

Guided by a grounded theory approach, our theoretical framing was that decisions are not the result of simple calculation of competing factors, but rather emerge from a range of diverse and sometimes incommensurate considerations.**[12,25]** Decisions may appear rational and logical in retrospect, but this fails to acknowledge the many diverse factors that are actually drawn on and responded to. For this reason, caution should be adopted when eliciting clinicians' personal accounts of what they do. In-depth interviews were semi-structured and 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 a large acute secondary, tertiary and quaternary hospital (including oncology and neurology) team. Only those professionals qualified to prescribe were invited to participate. Both doctors or nurses are referred to as clinicians in the following sections as comparison between professions was not a study aim. The study received formal research and ethics approvals (IRAS 239197 and Camden & Kings Cross Research Ethics Committee review), and permission granted by the R&D service of the hospital.

Recruitment

To achieve purposive sampling an email was sent in July 2019 to all prescribing clinicians (n=17) within the palliative care service inviting them to participate in the study. 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. There were no other individuals present during the interviews. This study was part of a wider research project (Forms of Care) by the same research team being undertaken in the service. 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 (Table 1), which had been refined after pilot testing with the other authors and two external colleagues. 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 own 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 ensure participants felt 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 anonymised. The average duration of interviews 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 in Microsoft Word and Excel.

Table 1. Case Vignette

<table>
<tr><td colspan="2">67yr Female
New referral to Community Palliative Care team for symptom control from Oncology team</td></tr>
<tr><td>Background:
Metastatic ovarian cancer with liver and peritoneal metastases.
Recent disease progression despite chemotherapy, and chemotherapy has now been stopped.</td><td>Past medical history:
Nil</td></tr>
<tr><td>Social history:
Lives with husband in own home.
Independently mobile
Husband does all shopping/cleaning</td><td>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</td></tr>
<tr><td colspan="2">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.</td></tr>
<tr><td>Examination:
Abdomen is soft & non tender, bowel sounds present, liver edge non tender and palpable 3 cm.
Chest clear.
No signs of opiate toxicity.</td><td>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.</td></tr>
<tr><td colspan="2"><u>Starter Questions</u>
1. How would you approach addressing the nausea in this case?</td></tr>
</table>

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

KD and AD separately read three interview transcripts, inductively thematically coding the data. They discussed themes and consistency, refining themes where necessary. They coded a further five interviews, before discussing additional themes and refinements, which were 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.

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 different themes 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

Participants all 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 them to 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 judge this according to a patient's level of anxiety and fear. Frequently this was not explicitly articulated, so they must 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 following participant comparing their assessment with the more hesitant interactions of junior colleagues:

> It's about confidence in picking up non-verbal cues… that 'green fingers' of communication which I think I suppose you get with age or with seeing loads of patients. (Interview 5)

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 when they are in earlier stages of their career or when they are out of practice. For example, one participant described the importance of 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 incidence:

> 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 getting 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, 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 think if we warned every patient of every side effect of every medication, we would end up doing more harm than good. (Interview 5)

Participants said that in practice 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 had. By drawing on these different components, they 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 stated 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 how the imperative to give greater information was generally a way to pre-empt any possible misunderstandings or conflict. Sometimes this was to counter patient preconceptions – such as morphine, oxycodone and pregabalin, which all have negative social connotations and alarmist representations in the media. In other instances it was because the drug in question was originally given for a different purpose, which 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 a range of 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 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 curtained 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 reflecting on how they made decisions regarding the medication information they give patients. Every participant felt it was not always appropriate to share all the 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.

We summarised three areas participants considered when doing this: 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', but instead a mix of clinical knowledge, sensitivity and professional experience.

Implications for practice/further research

Our findings align with previous research about the importance of rapport-building, shared decision-making and the role of clinicians, and the need to tailor information provision.**[26]** It is clear that maintaining a good, trusting relationship does not always depend on providing all the information, but instead information that is relevant and suitable for the patient's current situation. Clinicians valued being able to exercise personal judgment, especially since symptom management in palliative care is considered both an art and a science.**[27]** 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.

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,**[28-30]** 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 clinicians' perceptions rather than being based on observational data; this could potentially be elicited through ethnographic fieldwork and incorporating patients' perspectives. Additionally, the study is based on one clinical service which has its own set of practices that may 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 both simultaneously prescriptive yet also allows for variation.

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 initial 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:
Research and Ethics approvals are from the London - Camden & Kings Cross Research Ethics Committee. IRAS project ID: 239197. HRA favourable opinion (REC reference: 18/LO/0871) received on 29 August 2019, and CAG Approval (CAG reference: 18/CAG/0203) received on 28 January 2019.

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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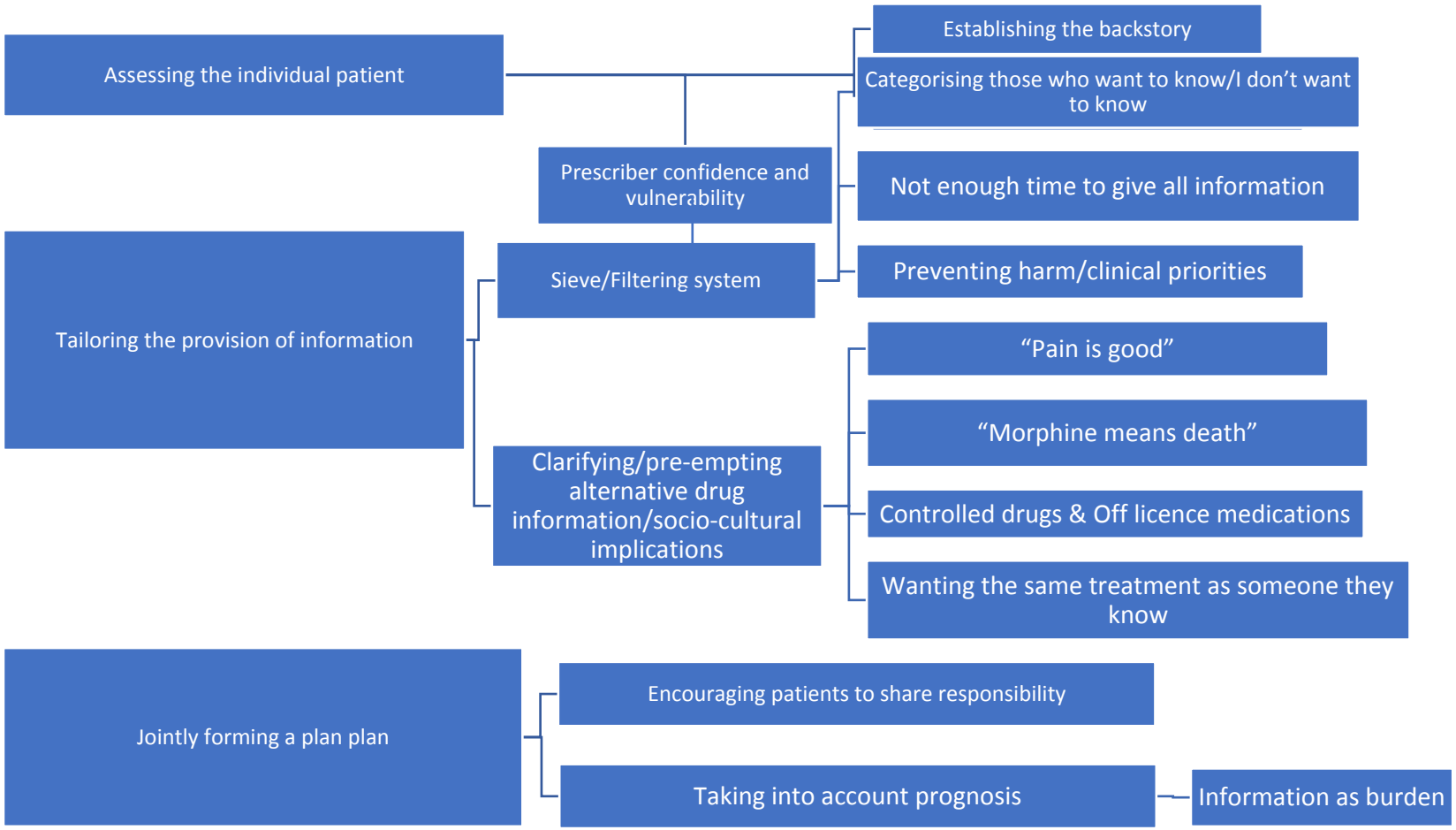
References

1. Ham C and Alberti KGMM. The medical profession, the public, and the government. *British Medical Journal* 2002; 324: 838–842.
2. Waitzkin H. Information giving in medical care. *J Health Soc Behav* 1985 Jun 1:81-101.
3. Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: Consider all the consequences. *Implement Sci* 2016; 11: 114.
4. Madsen C, Fraser A. Supporting patients in shared decision making in clinical practice. *Nurs Stand* 2015; 29: 50–57.
5. General Medical Council. Good Medical Practice, 1st edn. London: GMC, 1995.
6. General Medical Council. Good practice in prescribing and managing medicines and devices. https://www.gmc-uk.org/-/media/documents/Prescribing_guidance.pdf_59055247.pdf (Published January 2013, accessed 4 May 2021)
7. Montgomery v Lanarkshire Health Board [2015] SC 11 [2015] 1 AC 1430
8. Dyer O, White C and García Rada A. Assisted dying: law and practice around the world. *BMJ* 2015; 351: h4481.
9. Chan SW, Tulloch E, Cooper ES, et al. Montgomery and informed consent: Where are we now? *BMJ* 2017; 357: j2224.
10. Daniels N, Sabin JE. Accountability for reasonableness: an update. *BMJ* 2008 Oct 9;337.
11. General Medical Council. Guidance on professional standards and ethics for doctors: Decision making and consent. London, https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf (Published 30 September 2020, accessed 4 May 2021).
12. Bester J, Cole CM and Kodish E. The limits of informed consent for an overwhelmed patient: Clinicians' role in protecting patients and preventing overwhelm. *AMA J Ethics* 2016; 18: 869–886.
13. Rycroft-Malone J, Fontenla M, Seers K, et al. Protocol-based care: the standardisation of decision-making? *J Clin Nurs* 2009; 18: 1490–500.

14. Rapley T. Distributed decision making: The anatomy of decisions-in-action. *Sociol Health Illn* 2008; 30: 429–444.
15. Stevenson FA, Barry CA, Britten N, et al. Doctor-patient communication about drugs: The evidence for shared decision making. *Soc Sci Med* 2000; 50: 829–840.
16. Palmboom GG, Willems DL, Janssen NBAT, et al. Doctor's views on disclosing or withholding information on low risks of complication. *J Med Ethics* 2007; 33: 67–70.
17. Jenkins TM. 'It's time she stopped torturing herself': structural constraints to decision-making about life-sustaining treatment by medical trainees. *Soc Sci Med* 2015; 132: 132–40.
18. Bond C, Blenkinsopp A, Raynor DK. Prescribing and partnership with patients. *Br J Clin Pharmacol* 2012; 74: 581–588.
19. Härter M, Moumjid N, Cornuz J, Elwyn G, van der Weijden T. Shared decision making in 2017: International accomplishments in policy, research and implementation. Z Evid Fortbild Qual Gesundhwes 2017 Jun 1; 123: 1-5.
20. Alden DL, Friend J, Schapira M and Stiggelbout A. Cultural targeting and tailoring of shared decision making technology: a theoretical framework for improving the effectiveness of patient decision aids in culturally diverse groups. *Soc Sci Med*. 2014 Mar 1;105:1-8.
21. Culshaw J, Kendall D, Wilcock A. Off-label prescribing in palliative care: A survey of independent prescribers. *Palliat Med* 2013; 27: 314–319.
22. Hagemann V, Bausewein C, Remi C. Drug use beyond the licence in palliative care: A systematic review and narrative synthesis. *Palliat Med* 2019; 33: 650–662.
23. Fine PG. Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life. *Journal of pain and symptom management.* 2003 Apr 1;25(4):S53-62.
24. Johnson SB, Butow PN, Kerridge I, Tattersall MH. Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives. *Support Care Cancer*. 2018 Feb;26(2):565-74.
25. Bruch E, Feinberg F. Decision-making processes in social contexts. *Annu Rev Sociol* 2017 Jul 31;43:207-27.
26. Kunneman M, Gionfriddo MR, Toloza FJK, et al. Humanistic communication in the evaluation of shared decision making: A systematic review. *Patient Educ Couns* 2019; 102: 452–466.
27. Booth S. Science supporting the art of medicine: improving the management of breathlessness. *Palliat Med* 2013; 27: 483–485.
28. Hafferty W. Into the Valley. New Haven: *Yale University Press*, 1991.
29. Hafferty FW, Hafler JP. The Hidden Curriculum, Structural Disconnects, and the Socialization of New Professionals. In: *Extraordinary Learning in the Workplace*. Dordrecht: Springer Netherlands, pp. 17–35.
30. Staveley I, Sullivan P. We need more guidance on shared decision making. *Br J Gen Pract* 2015; 65: 663–664.


Assessing the individual patient
Establishing the backstory
Categorising those who want to know/I don't want to know
Prescriber confidence and vulnerability
Not enough time to give all information
Tailoring the provision of information
Sieve/Filtering system
Preventing harm/clinical priorities
"Pain is good"
"Morphine means death"
Clarifying/pre-empting alternative drug information/socio-cultural implications
Controlled drugs & Off licence medications
Wanting the same treatment as someone they know
Jointly forming a plan plan
Encouraging patients to share responsibility
Taking into account prognosis
Information as burden

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	n/a
Occupation	3	What was their occupation at the time of the study?	4
Gender	4	Was the researcher male or female?	4
Experience and training	5	What experience or training did the researcher have?	4
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	n/a
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	4
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	6
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	5
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	5
Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No.**

		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	6
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	5
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	7-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-10
Clarity of major themes	31	Were major themes clearly presented in the findings?	7-10
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7-10

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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