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Hughes, ND, Closs, SJ [orcid.org/0000-0002-3257-5277](https://orcid.org/0000-0002-3257-5277), Flemming, K et al. (1 more author) (2016) Supporting self-management of pain by patients with advanced cancer: views of palliative care professionals. *Supportive Care in Cancer*, 24 (12). pp. 5049-5957. ISSN 0941-4355

<https://doi.org/10.1007/s00520-016-3372-2>

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**Supporting self-management of pain by patients with advanced cancer: Views of palliative care professionals**

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## **Supporting self-management of pain by patients with advanced cancer: Views of palliative care professionals**

### **Abstract**

**Purpose:** To ascertain the views of specialist palliative care professionals on patient self-management of cancer pain in order to inform the development of a new educational intervention to support self-management.

**Methods:** Qualitative research using focus group interviews.

**Results:** Participants viewed self-management of cancer pain as desirable and achievable but also as something that could be problematic. Challenges to self-management were perceived in: patient attitudes and behaviours, professionals' own beliefs and actions, the wider social system. Practitioners showed awareness of potential tension between their espoused views (the desirability that patients manage pain autonomously) and their tacit views (the undesirability of patients managing pain in ways which conflict with professionals' knowledge and identity).

**Conclusions** Practitioners espoused patient-centred professional practice which inclined them towards supporting self-management. They showed awareness of factors which might inhibit them from effectively incorporating education and support for self-management into routine practice.

**Keywords:** Self-management; self-care; cancer; pain; education; specialist palliative care; focus group interview.

## **Introduction**

Self-management of chronic illness has been investigated over several decades in numerous countries [1-7]. It includes day to day activities designed to control and limit the impact of a long-term condition on both physical and emotional health [8].

Specifically, self-management requires ‘an ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life’ [2 p178]. While the approach has been actively promoted on the basis of research findings which support its utility [9], claims for the benefits of promoting self-management, at both the individual and health system level, have also been subjected to critical scrutiny [10-12].

‘Self-management’ has been used interchangeably with other terms such as self-care, self-monitoring and self-efficacy [13]. It is a relatively well-defined concept in long-term conditions such as arthritis, diabetes and asthma; but self-management of a long-term condition has been seen as very different from self-management of a life-shortening illness [14]. Understanding of self-management in people with advanced cancer has been developing over the last decade or so [15-20]. For example, research has shown that ‘self-action strategies’ to manage the effects of advanced cancer on

appetite and eating can lead to changes in patients' thinking and behaviour which enhance well-being [17]; the importance of recognizing and supporting patients' self-management strategies in regard to medicines taking when their life expectancy is reduced by advanced cancer has been demonstrated; and, importantly, self-management has been shown to fluctuate during the trajectory of an illness, with advancing metastatic disease and/or feeling more ill prompting changes in how actively individuals self-manage [19]. Supporting self-management has become a standard approach for health care professionals working with people who experience chronic non-cancer pain [21, 22] and many studies and reviews have reported that patient-focused educational interventions, including self-management, can also improve pain control in patients with advanced cancer [23-30].

The aim of the present study was to ascertain the views of specialist palliative care professionals on patient self-management of pain from advanced cancer in order to inform the development of a new educational intervention to support self-management. Based on our extensive reading of the literature, we defined 'self-management' as any behaviour which an individual engages in specifically to try and relieve, minimise or prevent pain; or more broadly to cope with their illness. We use the term 'supporting self-management' to refer to actions by health care professionals which provide information or teach skills that can underpin patients' self-management behaviours. This study was part of a larger programme of work, funded by a National Institute for

Health Research Programme Grant for Applied Research (RP-PG-0610-10114), designed to improve the management of pain from advanced cancer in the community ('IMPACCT').

## **Materials and Methods**

### **Design, sample and setting**

We conducted a qualitative descriptive study using focus group interviews with a purposive sample of health and social care professionals working in specialist palliative care services in a large city in the North of England. We chose this setting because these staff have the most frequent interaction with patients who have advanced disease and we thought they would be best placed to comment on the concept of self-management in this population. We recruited participants from a variety of occupational groups through local clinical networks, personal contacts and professional email discussion boards. Seventeen individuals took part in four focus group interviews, which took place in November and December 2013. All participants received written information about the study and gave written consent to participate. The study received ethical approval from the NRES Committee East Midlands – Nottingham.

The following professional disciplines were represented by participants in the focus group interviews: community clinical nurse specialists (6); complementary therapists (3); hospice nurses (5); hospice social worker (1); hospice spiritual care coordinator (1); palliative care consultant physician (1). One palliative care consultant physician and one hospice pharmacist who agreed to participate were unable to attend the scheduled interview. Sixteen of the participants were female and one male with a mean age of 47 (30-57 years). The time they had been in their current role ranged from 2 months to 11 years. We sought to interview as many locally-based practitioners as possible, aiming to conduct at least one focus group of 8-10 participants at each of two (hospice) sites. Pragmatic considerations meant that although we recruited sufficient for two groups, we actually conducted four group interviews.

Interviews took place in hospice meeting rooms (two sites) during working hours. The number of participants in each group ranged from two to eight. Two focus groups were conducted with professionals from the same discipline (clinical nurse specialists and day hospice nurses) and two with a mixture of participants from different professions. The strength of conducting focus group interviews, in this context, was the opportunity to hear a diverse range of views among a group of practitioners who share a field of expertise. The group interview necessarily leads to the sacrifice of more in-depth individual experiences and perspectives.

## **Data collection and analysis**

We conducted a single interview with each focus group, exploring participants' experiences and perceptions of what patients with advanced cancer do to manage their pain. Discussion topics included patients' use of medications and of non-pharmacological methods of pain relief, ways in which patients communicate about pain and participants' views about potential barriers to learning new methods of self-management. The average length of the interviews was seventy minutes. Interviews were conducted by the first author, an experienced qualitative researcher. In three of the four interviews a research nurse assisted the interviewer as co-moderator. One of the interviews comprised two participants only and we thought that the presence of a co-moderator would unbalance the dynamic of the interview. Field notes from the other three interviews were recorded by the co-moderator, noting participants' body language and interactions. Interviewer and co-moderator debriefed after each session. Interviews were digitally audio-recorded and transcribed verbatim by an administrative member of the research team. The first author checked the accuracy of the transcriptions.

We examined the data using latent content analysis [32], identifying all occurrences of statements about self-management and attaching them to inductively-derived concepts which we then explained and illustrated from the data (see Table 1) We did this by first listening to the interviews and reading the transcripts several times to reinforce familiarity with the material. We then extracted sections of the interviews in



which participants talked about any aspect of self-managing cancer pain. The first author coded each of the twenty-seven data extracts line-by-line using participants' own words (in vivo coding) [33]. A descriptive summary of each extract was written, based on the in vivo codes, with the addition of analytic memos which recorded first impressions and thoughts about the context and meaning of the data. The descriptive summary and analytic memos informed the next level of analysis whereby concepts embedded in the summaries were identified, extracted and discussed by the first and second authors. We identified illustrative quotations from the data which reflected each summary (see Table 1).

[Insert Table 1 about here, please]

## **Results**

We identified nine overarching concepts that related to health and social care professionals' views of the influences on patients' self-management of advanced cancer pain: autonomy, capability, control, education, identity, motivation, ownership, responsibility and resources. Taken together, these concepts informed three central perspectives in which participants viewed self-management of cancer pain as a) desirable, b) achievable and c) sometimes problematic (see Fig. 1).

[Insert Fig. 1 around here, please]

### **Self-management of cancer pain is desirable.**

Participants regarded self-management of cancer pain as an important way for patients to have a measure of control over what is happening to them. They viewed patients' ways of expressing control as a spectrum ranging from exercising total autonomy and refusing offers of professional help, through negotiated, collaborative decision making, to the apparently passive acceptance of help when too fatigued to act independently.

I sometimes think it's to do with control isn't it? It's asserting control of the situation, you know, you can understand why someone would want to. And the side effects of medication as well, they are often afraid of that, if they have had bad experiences in the past, and, yes, they want to keep themselves safe don't they, and symptom free? And sometimes I think that they know how to do that better than anyone else. (P1, Int.2)

I think it's always appropriate [self-management] because you want the patient to still be in control. They have got no control of their cancer, have they? So they still need to be in control of something. So I suppose some self-management is there – but it depends on how you define self-management doesn't it, and what

your concept of self- management is for them at that stage. Self-management might be just for them to say that they have got pain. That might be all the energy they've got is to say, "I've got pain" and to describe it very briefly. (P4, Int.1)

Palliative care professionals also considered self-management to be desirable because they believed it is unrealistic for them to provide comprehensive and complete solutions to the patient's pain problems. Practitioners expressed the view that self-management works best when patients act autonomously, but in partnership with a health professional. When patients' autonomous decisions were based on information, dialogue, and reflections on experience, they were more readily supported by practitioners.

It's about getting an understanding of what the patient wants. One codeine at night-time is unconventional but, for her, it works. (P4, Int.1)

I said perhaps we need to increase it [analgesic dose] but she doesn't want to at the moment. I thought it was interesting that she still wanted to mention it to me but she doesn't want me to do anything about it. (P2, Int.2)

### **Self-management of cancer pain is achievable**

Professionals identified a number of factors which enabled patients to self-manage their cancer pain. First, they viewed self-management as achievable if patients took

responsibility for ownership of their pain. Secondly, they believed that successful self-management was more likely to occur if professionals provided education for patients and carers on the purpose and role of their medications, and how to use them, alongside non-pharmacological approaches to pain management. Finally, they regarded it as very important that professionals introduce self-management options early in the disease trajectory when patients are well enough to learn about self-management and act upon it.

Participants considered self-management to be more achievable when patients were motivated to try it. Being motivated towards self-management could mean taking pain killing drugs as prescribed, or negotiating for alternative ways of using them. Participants reported that, for some patients, engagement with non-pharmacological methods of pain relief was an active and productive means of self-management. For other patients, religious and spiritual practices were seen to form an important part of coping independently with their experience of pain.

Self-management was seen to be achievable when patients responded to health providers' initiatives to enhance abilities for self-care. Day hospice nurses saw themselves and their service as supporting patient self-management by giving information and education:

We promote and teach relaxation, and distraction, to reduce pain and anxiety.

Most people take to it, even those who you think might not. Some people are a little bit sceptical about it at first. But it is about promoting self-help as opposed to us taking over and doing it all for them. They're going home after they've spent the day with us, so we're trying to get them to manage it at home. (P2, Int.3)

Other hospice nurses suggested the use of a smart phone app, and a website which 'would be open for family members to join in with the information and decision-making. [They would] feel more empowered to ask questions of the professionals' (P2, Int.4).

### **Self-management of cancer pain is sometimes problematic**

Practitioners sometimes regarded self-management behaviours as dysfunctional and potentially damaging, if they believed patients were acting on the basis of limited knowledge. This included when patients took random amounts of liquid morphine for breakthrough pain, took their partner's medication or, as reported above, used non-conventional medications whose properties were unknown to them. Some lifestyle adaptations were seen as counterproductive, too; for example, restricting movements which caused pain, for understandable reasons, then suffering the painful consequences of stiff and immobile joints. Even simple, tried-and-tested self-management strategies

could go wrong; for example, using a hot water bottle that was too hot and caused burns.

One participant (P3, Int. 2) spoke of ‘always trying to get the balance’ between supporting patients’ autonomy and expecting that patients will follow professional advice: ‘That can be a challenge, because I think sometimes we have our own agenda for things we want to treat and we want to come away feeling we have done something.’ When patients exercised complete autonomy and rejected their advice, professionals’ identity as expert problem-solvers could be compromised. One group of clinical nurse specialists reported that they were sometimes wary of recommending or supporting ‘alternative’, or complementary methods of pain control because of what they described as the ‘medical model’ of training they had received. They suggested that this form of professional education led them to prioritise scientifically validated knowledge. Their belief that complementary methods may lack such validation made them cautious about interpreting these approaches positively.

I’ve had a patient that wouldn’t use any traditional medication, would only use alternative and we all found that very difficult to deal with. He would only use alternative...and he died having nothing [to relieve pain]. We found it difficult because we are so geared up to giving people something to make them comfortable. (P3, Int.1)

I think it's really difficult to manage somebody's pain when they are buying things off the internet, which they have seen in journals or research, whatever. So families are buying it, giving it to them, but you are trying to do other methods down the same line and it muddies the water [...] Because you are fighting against their beliefs [with] modern medicine, I suppose. (P2, Int.1)

For some participants self-management was conceptualised more directly as the patient's willingness to accept professional advice, when necessary:

It's about being willing to seek advice if something goes wrong because many a time we'll pick up difficult situations that could have been avoided had somebody picked up the phone and said, 'This isn't working, can I do [something else]...?' (P1, Int.4)

For this practitioner it was important to 'guard against patients who self-regulate their doses' and to promote 'willingness to engage with a plan and stick to the plan and seek advice if that plan starts to go wrong'. Another practitioner suggested that patients who were deemed to be 'competent' could be taught to titrate their medicines within a pre-specified dose range, to avoid problems posed by ill-informed self-regulation. Professionals sometimes perceived that patients handed over control to them, for a variety of reasons, and expected them to provide all the solutions. This made it difficult to engage them in self-management: 'If you say, 'This is your pain, your body, you

make the decision,' it's hard because they've handed their bodies over to the medical profession.' (P3, Int.1)

Self-management was also seen as difficult to achieve when professionals took too much control away from patients; for example, by introducing new medication regimens during hospice admissions without full explanation: 'I think sometimes we do have a tendency to take over and that doesn't allow them to be in charge of their pain' (P4, Int.2). In such situations, this nurse explained, it is necessary to help the patient, and their relatives, to understand their new medication. She recommended education via practical demonstrations, for example, helping patients to practise drawing up liquid medications in a syringe before they go home, to relieve anxiety and promote effective self-management. At the same time, practitioners observed that some patients seemed content to hand over control, giving them respite from carrying a burden of responsibility for managing their pain.

Some participants reflected on the socio-demographic context of providing educational material for self-management. They suggested that different populations have different capacities to 'take up information' depending on how it is presented – for example, written materials have limited utility among people with low level literacy. The conclusion here was that self-management education needs to be made available to all, by providing it in a range of formats.



I would worry that you will be targeting the middle class articulate patients, not the ones who can't read or write. I've got many who can't read or write. I've got many that can't speak English. I've got many that have got no concentration to watch a DVD, who can't even afford to buy a DVD player to watch the material that you are giving them; so I would worry that if we are looking at giving them educational material that it's got to be targeted at everybody so there is not an inequality. (P4, Int.1)

## **Discussion**

Our findings suggest that health and social care professionals working in specialist palliative care have a nuanced and subtle understanding of patient self-management in the context of advanced cancer pain. Taking a person-centred perspective [34, 35] they viewed self-management as, broadly, desirable – particularly as a way of patients maintaining some control over their lives [30, 36]. Participants described conditions under which self-management can be achieved when patients are motivated towards self-action and capable of it; and they reflected on challenges surrounding self-management which they saw located in patient behaviours, in their own actions and beliefs or in the wider social system. With regard to the wider social system, lower social class along with lower levels of literacy were seen to have a potentially negative

impact on capacity for making use of educational materials which support self-management. This concurs with findings from a sociological study of self-management in people with coronary heart disease which suggested that individuals with limited personal resources or life-choices were less likely to engage with self-management [38].

Professionals considered that their role in educating patients and their carers made an important contribution to successful self-management. A key finding from studies in this field is that education for self-management of cancer pain should be integrated into routine practice [29, 19, 30]. Despite optimism that this can be achieved ‘without undue extra resources or time’ [14, p393] there are numerous factors, often presented as barriers, which influence the implementation of patient education for self-management – including health professionals’ knowledge, attitudes and beliefs [26, 30]. Findings from our study extend our understanding of the type of factors which can inhibit practitioners from effectively incorporating education and support for self-management into their routine practice. Our sample included a range of health and social care professionals who offered different perspectives on self-management. However, most of the participants were nurses which may have led to a dominance of nursing discourse in the data and in our interpretation.

Overall, participants’ accounts reveal a positive and sophisticated attitude towards self-management which does justice to the complexity of the concept. Practitioners showed awareness of potential conflicts between their espoused views (it

is desirable that patients manage their own pain) and their tacit views (it is not desirable that patients manage their own pain in ways which conflict with professionals' knowledge and problem-solving recommendations). Having said this, there is some evidence in our study of unconsciously held paternalistic attitudes towards self-management, expressed by one practitioner as the need to 'guard against' patients' self-regulation of medication doses. Previous research also suggests that health care professionals do not always recognise or understand patients' self-management behaviours – for example, the self-regulation of prescribed medication dosage and timing in order to trade-off pain intensity against the impact of side-effects [37] – and thereby miss opportunities to create supportive self-management partnerships with patients.

Health care providers require a sophisticated understanding of self-management in the context of health-care systems where self-management is increasingly promoted as a means to optimise patients' health whilst also looking for a reduction in their use of health services [10]. Both of these can be seen as reasonable aims. Management of long-term health conditions must, by their very nature, be incorporated into the person's daily life and only a limited part of that life will include contact with health care professionals. Whatever a person can be taught and encouraged to do by way of maximising their health in these circumstances can be seen as beneficial to them. Even in a condition such as advanced cancer, where there may be a shortened lifespan and

more frequent interaction with health care professionals, self-care behaviours may contribute to reduced symptom burden and improved quality of life [14]. In a health system with finite resources it is rational to find ways to reduce utilisation of services, and hence lower expenditure, where those reductions do not compromise an individual's health status.

At the same time, individual capacities and preferences for self-management are likely to vary according to health status [14, 19], learning styles [24] and socio-demographic profile [1, 38]. Over-enthusiastic and simplistic promotion of self-management might risk reinforcing inequality in favour of those individuals and groups with greater resources for self-care. As some participants in our focus group interviews argued, the 'articulate middle-class' may access self-management support disproportionately while those with fewer resources and, arguably greater need, might receive less support [39].

## **Conclusion**

Health and social care professionals working in specialist palliative care viewed self-management of cancer pain as desirable and achievable, but sometimes problematic. They described challenges to self-management which they saw located in patient behaviours, in their own beliefs and actions and in the wider social system. Participants'

accounts revealed a positive and sophisticated attitude towards self-management. Their discussions suggested they espoused a person-centred form of professional practice which inclined them towards supporting self-management. They also indicated awareness of factors which might inhibit them from effectively incorporating education and support for self-management into their routine practice.

### **Practice Implications**

Education to support self-management of cancer pain in advanced disease should incorporate practitioner, patient and family caregiver perspectives. We have used this model – including the findings from this study – to inform the development of a multi-media educational resource to support self-management of pain in advanced cancer. This is currently being evaluated, along with other interventions to improve the management of cancer pain in community-dwelling adults, in a multicentre feasibility randomised controlled trial. Findings from this study also suggest that it may be helpful for practitioners to reflect on, and discuss with others, their beliefs and attitudes about self-management so that they can create the best possible synergy between their espoused (consciously acknowledged) and their tacit (subconscious) views. Care teams could then develop agreed approaches, underpinned by evidence, to supporting patient

self-management. Written care plans should include reference to measures taken to support self-management.

**Acknowledgements** We are grateful to the patients, caregivers, health and social care professionals who participated in this study. Thanks also to Kathryn Black for assistance with preparation for ethical and governance review and for help with recruitment and data collection. Thanks to Faith Jacob for help with recruitment and data collection.

**Author roles** MB and SJC conceived and designed the study. NH contributed to the study design, conducted the interviews, analysed the data and drafted the manuscript. KF contributed to study design. SJC contributed to data analysis. SJC, MB and KF revised the manuscript for important intellectual content. All authors have given final approval for publication of the article.

**Declaration of conflicting interests** The authors declare that they have no conflicts of interest.

**Funding** This article presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research (Grant Reference Number: RP-PG-0610-10114). The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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Figure 1: Overarching concepts influencing practitioner perspectives on self-management of pain in advanced cancer

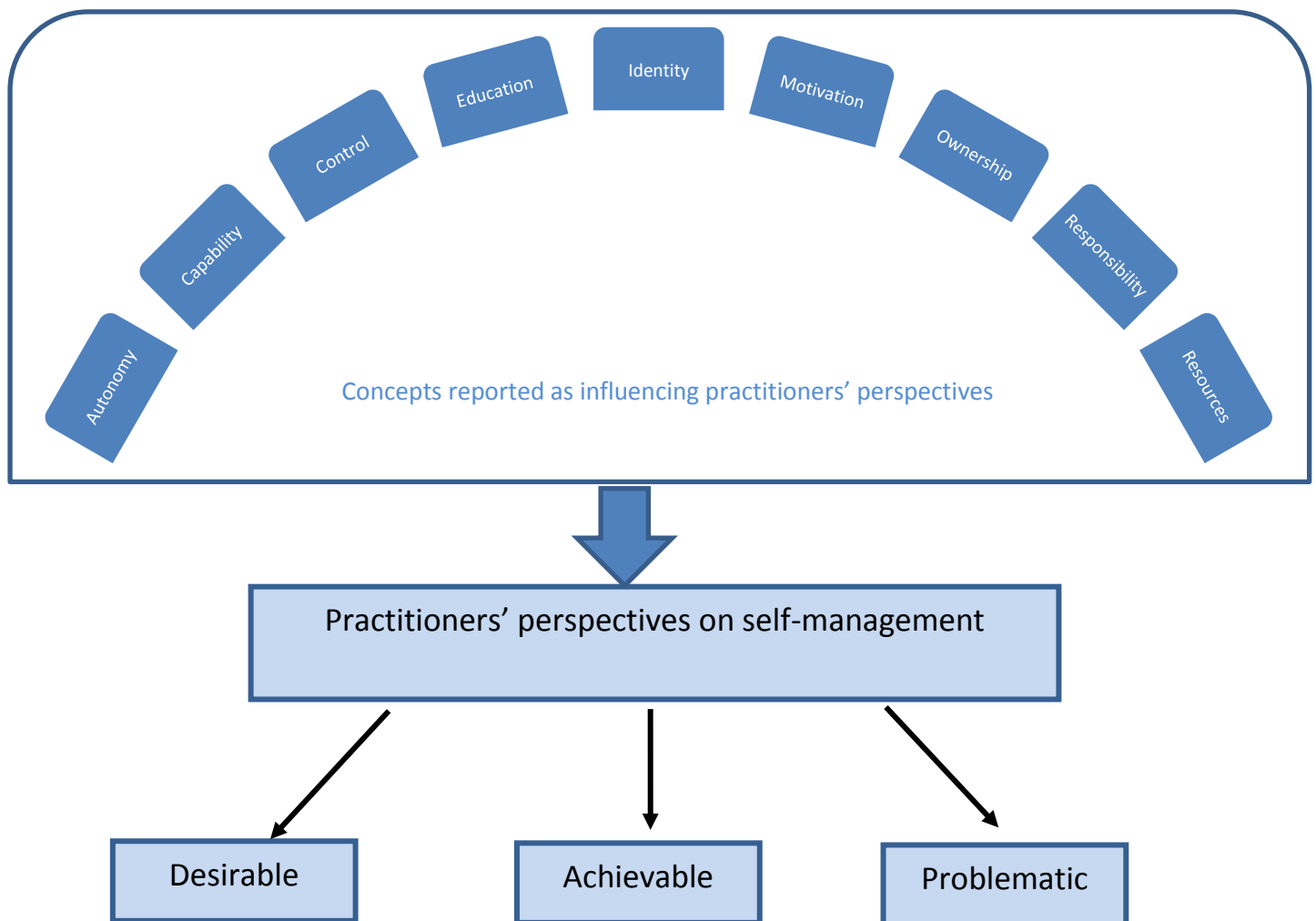


Table 1

Self-management: summary of overarching concepts with illustrative quotations and related themes

<b>Conceptual category</b>	<b>Example from summary based on in vivo coding</b>	<b>Illustrative quotation</b>	<b>Theme/perspective on self-management</b>
Autonomy	Self-management works well in negotiation with the patient.	<i>It's about getting an understanding of what the patient wants [...] one codeine at night-time is unconventional but, for her, it works.</i>	Desirable
Capability	You need to choose the right patients for self-management ie motivated (not wanting to hand care over to professionals) and competent (ie not cognitively impaired).	<p>I think there are a lot of parameters around self manage given what one of the things [P2] said earlier about the of our patients who have either temporary or permanent <i>deficit you've to be very careful that you choose the right</i></p> <p>A lot of the advice and support patients get out of hours from the hospice is really just guiding them through self-managing, facilitating them to manage their pain—and it usually is sufficient.</p>	Achievable

Control [1]	Self-management, variously defined, is an important way of patients having a measure of control over what is happening to them.	You want the patient to be still in control [...] <i>but it depends how you define self-management, doesn't it, and what your concept of self-management is for them at that stage. Self-management might be just for them to say that they have got pain. That might be all the energy they've got is to say, "I've got pain" and to describe it very briefly.</i>	Desirable
Control [2]	Some patients hand over control of their illness to the medical profession, so it is difficult to engage them in self-management.	<i>If you say, 'This is your pain, your body, you make the decision,' it's hard because they've handed their bodies over to the medical profession.</i>	Problematic
Control [3]	Professionals tend to take over when patients are admitted (to hospice). Can take away sense of control.	I think sometimes we do have a tendency to take over <i>(in hospice) and that doesn't allow them to be in charge of their pain.</i>	Problematic
Control [4]	Some patients are happy to hand over control, giving them respite from carrying responsibility for managing their pain.	<i>It's a relief if they have been carrying this (pain) for some time and they can feel 'I want to hand it over to you so it's your problem now.'</i>	Problematic

Education	Patients need education for self-management, including information and skills instruction.	I feel that sometimes we need to just sit with them and help them to understand their medication.	Desirable
Identity	Specialist nurses are sometimes uncomfortable with autonomous patient decision making that doesn't accord with their sense of professional identity as people whose job it is to help people reduce their pain.	<i>He would only use alternative [...] we found it difficult because we're geared up to giving people something to make them comfortable.</i>	Problematic
Motivation	Disease stage can have a marked impact on motivation for self-management.	[At a late stage of disease] patients are too fatigued. <i>The concentration's quite poor, they've got multiple symptom burden and just have not got the energy to do things on their own. They're not motivated enough because of the burden of the disease as a whole.</i>	Problematic
Ownership	Self-management depends on patients accepting ownership of their pain.	<i>That's when they can really start self-managing, if they realise the pain belongs to them, not to somebody else.</i>	Achievable
Resources	Both individualised and general information recommended, in a variety	If the patient was on a patch you would be putting the relevant information in [to educational resources] so	Achievable



	of formats that are accessible to patients and to family members.	<p><i>then you wouldn't be overloading them or having things that weren't relevant to them.</i></p> <p><i>If there's stuff on a website it's open for family members to be able to join in with the information and the decision-making and feel more empowered to ask questions of the professionals.</i></p>	
Responsibility [1]	Effective self-management is more likely when a) the patient takes responsibility for their pain and b) the nurse and patient negotiate ways of managing the pain together.	I said perhaps we need to increase it (analgesic dose) <i>but she doesn't want to at the moment...I thought it was interesting that she still wanted to mention it to me but she doesn't want me to do anything about it.</i>	Achievable
Responsibility [2]	Professionals are seen as having responsibility to be proactive in helping the patient to gain knowledge and skills for self-management.	<i>It's about thinking early enough in the course of somebody's illness about being proactive around what they will need later in their disease.</i>	Achievable
Responsibility [3]	Patients sometimes hand over responsibility for pain management to a spouse, who can feel it as a big responsibility, as though what they do	Some people will hand over to their spouse [and] they feel it as a massive responsibility, as if they are in charge of the pain relief.	Problematic

	can affect how the pain relief works, or not.		
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