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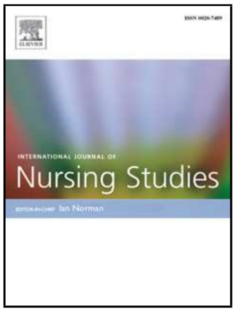

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SELF-MANAGEMENT SUPPORT AT THE END OF LIFE: PATIENTS', CARERS' AND PROFESSIONALS' PERSPECTIVES ON MANAGING MEDICINES

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ABSTRACT

Background: Pain is a frequently reported symptom by patients approaching the end of life and well-established that patients and carers hold fears relating to opioids, and experience side effects related to their use. The management of medicines is intrinsic to achieving effective pain relief. The concept of self-management support whilst well characterised in the context of chronic illness has not been elaborated with respect to end of life care.

Aim: To identify patient, carer and professional views on the concept of self-management support at end of life, specifically in relation to analgesia and related medicines (for side-effect management) in order to describe, characterise and explain self-management support in this context.

Methodology & Methods: Qualitative design, data collection methods involved focus groups and interviews. Topics included the meaning of self-management support in this context, roles and behaviours adopted to manage pain-related medicines, and factors that influence these. A largely deductive approach was used, involving verification and validation of key frameworks from the literature, but with capacity for new findings to emerge.

Setting: Participants were drawn from two different localities in England, one North, the other South. Interviews with patients and carers took place in their own homes and focus groups with healthcare professionals were held at local hospices.

Participants: 38 individuals participated. 15 patients, in the last year of life, and 4 carers under the care of community-based specialist palliative care services and 19 specialist palliative care health professionals (predominantly community palliative care nurses).

Findings: The concept of self-management support had salience for patients, carers and specialist nurses alongside some unique features, specific to the end of life context. Specifically self-management was identified as an ever-changing process enacted along a continuum of behaviours fluctuating from full to no engagement. Disease progression, frequent changes in symptoms and side-effects, led to a complex web of roles and behaviours, varying day by day, if not hour by hour. Data confirmed previously proposed professional roles were enacted to support self-management. Furthermore, as patients, carers and clinical nurse specialists worked together to achieve effective pain management, they enacted and inter-acted in the roles of advocate, educator, facilitator, problem solver, communicator, goal setter, monitor and reporter.

Conclusions: The study has demonstrated what self-management support at end of life entails and how it is enacted in practice.

KEYWORDS

Analgesia
End of life
Opioids
Pain management
Palliative care
Qualitative
Self-management

WHAT IS ALREADY KNOWN ABOUT THE TOPIC?

- Pain is a frequently reported symptom by patients who are approaching the end of their lives.
- It is well-established patients and carers hold fears that relate to opioids, and experience side effects related to their use.
- The concept of self-management support is well elaborated in the context of chronic illness
- Through the technique of concept analysis Johnston and colleagues (2014) have defined the concept of self-management support from a palliative nursing perspective and outlined the range roles adopted by nurses to support self-management.
- How self-management is operationalized in the practice context at the end of life remains little understood

WHAT THIS PAPER ADDS

- An empirically grounded description of self-management support at end of life, in the context of analgesia management from the perspective of patients, carers and healthcare professionals.
- Characterisation of the roles undertaken by patients, carers and clinical nurse specialists to support opioid management and how these roles are enacted in the context of specialist palliative care.
- Demonstration of the salience of the concept of self-management support as the end of life approaches.

INTRODUCTION

Self-management support has been well elaborated and tested, and programmes of support offered in the context of chronic illness (Taylor et al 2014). In contrast, in the situation where someone is rapidly approaching the end of life there is much less evidence of if and how this concept applies (Hughes et al 2016). Johnston is one of a handful of authors to have addressed this, who along with colleagues (2009; 2012), argued that benefits of self-management focused symptom control include improved health status, reduced hospital admission, reduced pain and symptom distress, and can result in people feeling in more control with respect to pain and more prepared for end of life. Through recourse to concept analysis self-management support in palliative nursing has been defined as: ***"assessing, planning, and implementing appropriate care to enable the patient to live until they die and supporting the patient to be given the means to master or deal with their illness or their effects of their illness themselves"*** (Johnston et al 2014, p8)**.** Eight professional nursing roles that support self-management: **advocate, educator, facilitator, problem solver, communicator, goal setter, monitor and reporter** were outlined. Whilst these nursing roles were depicted they were neither described nor characterised and little is understood about how they are operationalised in the context of practice. Hence there is a lack of knowledge about self-management support in the context of end of life care with little evidence with which to underpin practice.

In one of the only studies in this area, Schumacher and colleagues in the US (2014a&b) have studied the self-management work that goes on in relation to pain medication management in cancer patients. Their research revealed that much of what goes on involves work that is challenging and frustrating for patients and could be alleviated by better information, skills and health services co-ordination to *support* patient self-management. The work of **getting prescriptions, obtaining medications, understanding, organising, storing, scheduling, remembering, and taking** was perceived to be "*unending*" and required a huge amount of effort in order to navigate healthcare systems and often resulted in frustration and anxiety. As the sample consisted of oncology out-patients whether these findings might transfer to the specific context of end of life care was not clear.

Given there is limited understanding of if and how the concept of self-management support might be applied in the context of end of life care we set out to investigate the concept further, exploring its application through accessing the perspectives of patients, carers and health professionals. We defined carers as anyone who cared, unpaid, for a friend or family member due to their end of life illness.

AIMS/OBJECTIVES

The study aimed to describe, characterise and understand the concept of self-management support as the end of life approaches, in the specific context of managing analgesia and related treatments. This work formed part of a larger study involving intervention design and a feasibility trial of self-management support in relation to opioid medications for pain relief, and the associated side-effects of nausea, constipation and drowsiness at the end of life (Bennett et al 2016).

The objectives were to:

- Characterise the nature of self-management support regarding analgesia and related treatments at the end of life

- Explore in-depth the views of patients, carers and healthcare professionals regarding the components of self-management support in this context
- Reveal self-management promoting behaviours and roles used by patients, carers and healthcare professionals

METHODOLOGY & METHODS

Study design

A qualitative approach was used and data collection comprised focus groups and interviews, held within two geographical regions in England (one North and the other South).

Participants

Participants included patients, their carers and specialist, largely community based, palliative care health professionals (including service managers and commissioners).

Sampling Strategy and Recruitment

Inclusion criteria

Patients were included if they were:

1. Aged over 25 and considered (by their specialist palliative care team) to be in the last year of life
2. Experiencing pain
3. Being treated with, or starting, opioid analgesia
4. Experiencing, or anticipating, adverse effects of nausea, constipation and drowsiness
5. Living at home
6. Being cared for by specialist community based palliative care services in the 2 study regions
7. Had capacity to consent

Carers were included if they were:

1. The primary carer of a patient meeting the above inclusion criteria
2. And, the patient gave consent to their involvement

Healthcare professionals were included if they were:

1. Clinical Nurse Specialists (CNSs) or doctors who were part of specialist palliative care teams or
2. Service providers or managers of specialist palliative care services or
3. Local commissioners of palliative care services

In order to access a range of individuals (patients, carers and healthcare professionals) recruitment occurred via various strategies across four hospices and two acute Trusts. In the Southern region palliative care specialist healthcare professionals at two acute Trusts and two hospices were informed about the study via staff meetings attended by a researcher (NC), supplemented by email invitations, and invited to participate in a focus group. Patients and carers attending group sessions at two day hospices in the region were informed about the study by a researcher (NC) and able to ask questions about participation; all specified a preference for taking part in interviews (rather than a focus group). In the Northern region a community palliative care CNS team were invited (by MM) to take part in a focus group; and patients and carers were approached by a research nurse via the out-patient clinic at the respective hospice, and invited to a focus group.

Focus Group and Interview Guides

Topic/interview guides were developed to meet the study aims. Largely semi-structured, interview topics included: self-management of analgesia and related side-effects of nausea, constipation and drowsiness; roles played in managing medicines; processes involved in accessing, obtaining and understanding medicines in order to safely store, organise and take them. Guides were constructed and materials used to explore and elaborate on the following concepts:

- Definition of self-management support in the context of palliative care (Johnston et al 2014)
- Professional roles adopted in support of self-management in the context of palliative care (Johnston et al 2014)
- Processes involved in managing supply and medicines-taking encountered by patients and carers (Schumacher et al 2014a & 2014b)

Interviews and focus groups were conducted by the study's research fellows (MM & NC). Focus groups took place at hospices, whilst interviews occurred in participants' homes. Where carers participated in interviews all patients expressed a wish to be interviewed with their carer (dyadic interviews). After obtaining informed consent all interviews and focus groups were digitally-recorded. Focus groups were conducted with a co-facilitator present, in this case another researcher with expertise in the field, to aid moderation (Krueger & Casey 2014).

Data Analysis

Audio files from the interviews and focus groups were professionally transcribed and listened to alongside the transcripts to check for accuracy. Researchers (NC, MM) familiarised themselves with data by reading and re-reading the transcripts and identifying key issues, concepts and themes. Initial coding occurred via indexing on the transcripts and each researcher summarised key themes arising from the data separately. Themes were subsequently discussed for comparative purposes. The entire dataset was then coded for all issues, aspects and themes relevant to self-management support (NC) within NVivo software (version 11). A deductive-driven approach was used, verifying and validating key frameworks from the literature, but with capacity for new findings to emerge

Ethical and Research Governance Considerations

NHS research ethics and governance approvals were obtained from an NHS Research Ethics Committee (North East – Tyne & Wear South 14/NE/1155) and the respective NHS Trusts and independent hospices. Written informed consent was obtained from all participants.

FINDINGS

The sample comprised 38 participants recruited across the two regions: 15 patients, 4 carers and 19 healthcare professionals (Table 1). The findings are presented in two discrete sections. The first section characterises the range of self-management and self-management support roles adopted by patients, carers and nurse specialists as they relate to pain medicine management. Secondly, these data are incorporated into a model of self-management support, alongside a description of the continuum of self-management behaviours in the context of the end of life.

Self-Management and Self-Management Support Roles

Data supported the eight roles proposed by Johnston et al (2014) and furthered understanding by revealing the roles were not confined solely to nurses (see Table 2). Patients, carers and CNSs enacted these roles in various ways (Table 2).

The labels used by Johnston et al (2014) to refer to roles were presented to healthcare professionals during the focus groups. They were asked for their views on these roles, whether they believed they occurred in practice, if anything was missing and what examples they could provide to illustrate the roles in action. As a result the roles were both delineated and defined by the professionals in this study. These were generated from accounts involving a preponderance of community-based healthcare professionals, but it could be argued the roles could equally apply to those in other practice settings.

Descriptions from patients and carers confirmed the range and types of roles adopted and the part they played in managing their own or supporting the management of their relative's opioid medication (and medication for nausea and constipation). The roles that patients and carers took on could be categorised in the same way as those undertaken by CNSs, but often implemented and enacted in different ways. Some patients in the study managed their medicines almost entirely by themselves, however this occurred only for a minority. Where patients had visits from a palliative care nurse specialist they highlighted the importance and value of their nurse input in relation to medicines management. For example one patient said: "*she's the one I'm looking to for answers*" (H1Pt001). The self-management support roles of carers fluctuated in relation to changes in the competence and engagement of the patient. Some patients leant on their carers very little even where they were available: "*he's managed all of it very well, I'm not involved at all*" (Carer-H1Pt002), but again this was confined to the minority. In the case of a few patients they had always sought to hand over responsibility for medicines management to their carer: "*she just always did it… I tend to be… not worried enough about it you know. I basically need looking after that's the truth of the matter*" (H1Pt004).

To evaluate which roles were required of them, and at what point, nurses assessed the competence of not only the patient but also the carer. It was recognised that self-management support roles would fluctuate in relation to patient and carer needs and, at times, be challenging to undertake.

> *"…All of these (roles) will probably peak in difficulty, at times depending on the situation. As a professional, there could be a nightmare sometimes, in a person's home advocating for that patient, if… you have a family who have distinct feelings that are opposing the patient, that's really… difficult…" (H2HCPfocusgroup)*

Advocate

Patients often played an advocacy role on their own behalf, for example requesting alternative analgesics/opioids where they found side-effects to be unacceptable and were unable to manage these.

> *"…I was getting really bad pains and it (morphine) didn't seem to be controlling it. I mentioned it to X who is the nurse that looks after me, and she just said "do you want me to ring Dr X or will you?" so I said "I'll give her a buzz"… You've got to do things…if you are able to, you've got to look after yourself quite a bit, and then know who to turn to if you can't find the answer…"* (H2Pt005)

Where advocating on their own behalf was not possible carers took on this role for patients, especially when difficulties arose with challenging side-effects or poorly controlled pain.

> *"…He was determined to get me into the hospice, and in the end he went over himself. And I said to Sister X "I've got such a pushy –" and she said "that's just what you need, you've got to have a pushy friend…"* (H2Pt001)

Nurses emphasised the importance of ensuring patients had the right drug, via the right route. For them this was a clear example of the advocacy role:

> *"…I met a lady with head and neck cancer that was really compromising her mouth and she was just starting on opiates, thought patch that's going to be the best way to go… then the relative rings up we've just gone to collect the patches and it's tablets so I'm like "Oh god" ring up again, "there is a reason why we said patches, I know they're expensive but she can't open her mouth…"* (H2HCPfocusgroup)

Educator

Patients educated their carer, if they had one, regarding their medicines so if their condition changed or they had a bad day they could rely on them to safely administer their medications for them. This often took the form of listing their medications and creating a simple timetable of what they took and when, and keeping this in a location in the home that could be easily referred to by others if needed. Equally, carers could play an educator role of both the patient and CNS via astute monitoring of side-effects and the effectiveness of medicines, highlighting changes.

The role of educator was viewed by nurses as one that involved providing *"instruction and information regarding medicines"* (H2HCPfocusgroup) to patients and carers. This was valued strongly by patients:

> *"…She (the specialist nurse) came and said "actually the reason that (medicine) is not working is because that works in this way" and she talked about the medication, and I just found it so, so helpful. That was the first time that I felt like I'd been given a lifeline that I could just hang onto…"* (H3Ptfocusgroup)

The increasing role of the internet as a source of information for patients and their families was also recognised so that the supportive role of nurses was seen as one of helping to "*refine*" and apply this knowledge to individuals. The need to provide education for carers specifically was recognised to be important as many had unmet information needs and knowledge gaps:

> *"…You get carers who the knowledge gap is so huge for them, they want to help, they want to know what to do and we need to be filling that knowledge gap for them appropriately… I think for the carer what they want is the right information and we don't currently meet that need I don't think. We try…"* (H1HCPfocusgroup)

To meet the informational needs of patients (and their carer) in the context of their educational role nurses recognised a number of key areas that needed to be addressed. These included:

- The starting point - working out how an individual best learns and then tailoring information to this. Verbal information reinforced by written information (+ technological alternatives if possible) at the right pace, via step wise provision
- Identifying types of pain and which medications are best suited for that individual
- Outlining each medicine, what it is, what it's for and how to take it
- Explaining the requirement to adjust medications on an on-going basis. Highlighting there are alternatives if pain remains uncontrolled or side effects are intolerable.
- Information about side-effects – benefits vs. burdens and likelihood of an individual experiencing them
- Outlining need for laxatives and working out the balance between opioid dosage and laxatives required
- Revealing and discussing an individual's fears, challenging and correcting opioid related preconceptions
- Explaining lack of dosing ceilings for opioids, being clear regarding relative lack of required dosing intervals for 'as required' doses for breakthrough pain
- Highlighting importance of monitoring effectiveness of medications (especially in relation to the pain experience). Need to record breakthrough doses so that regular opioid doses can be increased/altered if required
- Signposting individual and carer to contacts for concerns/questions, outlining the most suitable contacts for specific situations an individual may encounter

Communicator

The patient's educator role aided their communicator role whereby they transferred relevant information regarding their medicines, their effectiveness and their experience of side-effects to respective healthcare professionals (particularly general practitioners and CNSs). Carers encouraged communication and discussion with the patient, asking questions about whether specific medications were working:

> *"…Every so often, I say to you don't I "How are you on the laxatives?" And it seems ridiculous doesn't it, because… that's the best (thing) that's happened, that you've managed to get it (opioids + laxatives balanced) at a level which is not a problem for you…"* (Carer-H2Pt004)

The supportive role of communicator was seen as vital by nurses and they emphasised the complexities involved in communicating well and aligning this with "*the agenda of the patient*" , using language that would be understood, highlighting "*what they need to know, because they might not be interested in all the things that you want to say*" (H2HCPfocusgroup).

> "*…I think you have to really pick your style of communication with each individual, this is what (participant's name) was saying about knowing your family, knowing your patient, 'cos sometimes you are as much a mediator as communicator. We can sometimes have a relative*

> *that just simply doesn't believe in morphine… they will withhold it from them… And then others where they will perhaps give a little too much, then you have to sort of be kind in how you say these things, because they want to make it better… so communication is quite hard; you have to get that right, don't you…*?" (H2HCPfocusgroup)

Goal-setting

For those patients who were under the care of community palliative care CNSs this often involved developing "*joint plans*"/goals with them. Whereas patients not under the care of a CNS made their own plans and goals, and/or negotiated these with their general practitioner (for example coming off a neuropathic agent because of unacceptable side-effects).

Carers often took a lead in establishing small goals for a patient when they aware these were of particular importance to the individual. With effective medicines management and particularly side-effect management, frequently goals involved getting out and about, and visiting favourite places.

With respect to professional involvement in goal-setting this would often involve proposing different options to a patient in relation to their medicines management, allowing an individual to decide between different proposed courses of action and then putting a joint plan together based on an individual's preferences.

> *"…It's good when you are given a choice and they say "well it's up to you, we could do this, or we could do this, which would you like to try? That is helpful…"* (H3Ptfocusgroup)

Facilitator

Patients facilitated relationships with their healthcare professionals and carers so as to aid access to their medicines. Patients worked at developing and maintaining relationships with those that were key to managing their medicines and supporting their self-management. Generally this involved CNSs and general practitioners but also community pharmacists. They often found that knowing their pharmacist, and the pharmacist knowing them, aided the supply and stocking of their medicines, and affected their ability to obtain their medicines quickly and without delays in the system. At times pharmacists put in repeat prescription requests for patients because of these relationships, meaning a patient then just had to arrange to collect the medications from the pharmacy or they could use the pharmacy delivery services, where they were available.

The role of specifically facilitating/managing the practical issues related to supply and medicines-taking was frequently an onerous one for patients. They had to get prescriptions, obtain the medicines, understand them once they had been dispensed, organise the medicines at home to keep track of them, store them, schedule them around their routine, remember to take them and finally actually administer them.

> *"…I've had problems between the Chemist and the GP… one saying it's the other one's responsibility, and the other one saying it's the other. Nobody will take an overall responsibility for it (repeat supply), either prescribing it to the Chemist and then the Chemist gives it to me, or have I got to do it myself, or can they ring up and do it? And that's a kind of constant thing that's carried on…"* (H3Ptfocusgroup)

The implications of the supply system and the requirements for organising, storing, scheduling, remembering and administering were very significant in patient and carer accounts and Table 3 summarises the effects and impact of these issues (Table 3).

Carers facilitated the supply system by managing all the practical issues of: getting prescriptions, obtaining the medicines, understanding the medicines, organising the medicines in the home environment to keep stock of them, storing them safely, scheduling them around the patient's routine, remembering (i.e. reminding the individual to take the medicines) and administering medicines if required (Table 3):

> *"…I have a friend who does my patches for me. And between us, there is both of us to remember which night it is to change it and which it isn't…"* (H3Ptfocusgroup)

Facilitating on behalf of the patient in relation to obtaining medicines was complex, onerous and a hugely time-consuming process for many carers. Carers also pre-emptively facilitated stock management, requesting medicines before they ran out, and chased both GP practices for prescriptions and pharmacies if medications had not been dispensed as requested.

One patient outlined his difficulties (lengthy delays) in obtaining supplies of his fentanyl patches through a non-palliative care specialist pharmacy.

> *"…When I rang through (to the pharmacy) and said "Here look, what about these patches? And the woman said "What are they?"… She said "Yes, well we have got them down on the list, but I don't know where they are". On like that again…"* (H2Pt004)

This left his wife needing to make in person visits to the pharmacy, striving to facilitate supply on his behalf, only for her to be equally frustrated and leave without the patches in tears because she could not answer the question of "*who's prescribed this*?" (Carer-H2Pt004).

Nurses also acted as facilitators in relation to the practical issues of getting prescriptions, obtaining the medicines, organising the medicines at home, storing the medicines safely and scheduling the medicines around their daily routines (Table 3). For example:

> *"…Getting prescriptions… we spend a lot of our time trying to sort that out, and you can understand how patients really struggle with (it). I mean one chap… it has taken so many phone calls and so much of my time… a youngish intelligent chap and he has just really struggled with that. I think the other issue is sometimes they get 28 tablets and then you change them, then that knocks their whole sort of repeat prescription out of balance…"* (H1HCPfocusgroup)

This was a time consuming role for nurses as medication supplies often got "*out of sync*" for patients with alterations in a prescription. For example, doubling a dose then meant that supplies lasted for much shorter periods of time and ran out in advance of supplies of other medications.

Problem-Solver

Patients played a problem-solving role, often striving to navigate the difficulties posed by the medicines supply system. They also problem-solved the side-effects of their opioids making decisions to appropriately balance the benefits of pain control vs. a manageable level of side-effects for them personally. This was always a balance, for example titrating laxatives or anti-emetics on a daily basis to offset the common side-effects. Some individuals, whilst in the minority, made decisions regarding which dose of opioid to take, where a range has been prescribed from which they could choose.

The role of carer in relation to problem-solver was an influential one. In the words of one carer "*I try and stop problems happening*" (Carer-H2Pt004). This was in the main pre-emptive, resolving potential problems before they arose. This was particularly the case in terms of asking an individual about their pain, so as to be able to suggest and administer 'as required' analgesia.

Within their problem-solving role nurses sought to work out the best drug and dosage with the most tolerable side-effect profile for an individual, recognising that this necessitated fine-tuning over time, time which was by its very nature limited at the end of life. This problem-solving role was frequently implemented in a pre-emptive way, and referred to as "*mind-reading*" or being "*a problem solver in advance*", necessitating always having "*a plan B*" (such as knowing when and who to contact or the likelihood of a particular individual experiencing a crisis episode e.g. chest inflections or bowel obstruction and conveying information to support patient and carer recognition).

> *"…You're anticipating, you're pre-empting what might happen to be able to talk it through with that patient and to that carer to be able to give them you know a toolkit of who to ring, when to ring and why they might ring. How to deal with the uncertainties of do I ring now, do I ring later… the security of knowing that there is somebody to ring…"* (H1HCPfocusgroup)

Monitor

Patients monitored their symptoms, side-effects and the effectiveness of their medicines, often keeping their own records of this, particularly in relation to administration of 'as required' doses for breakthrough pain. This was often facilitated through the input of community palliative care CNSs or general practitioners who prompted patients to consider "*how much they were taking, when they were taking it, and how did they find it?*" (H2HCPfocusgroup).

Carers often played a monitoring role highlighting and watching for condition changes, symptom changes and alterations in side-effect management. Indeed, the monitoring they undertook was often extremely astute due to the fact they were the person who knew the patient best.

The CNS role of monitor was closely related in practice with the role of goal setter (involvement in decision-making and shared responsibility where possible). Nurses continually monitored "*how much the patient has understood*":

> *"…In terms of monitoring… it's about involving the patient in those decisions isn't it… having given them some education… when you're reviewing things… saying to them "So are you happy then that we're still on the same dose for now?"… They've got that involvement in that… it's like an agreed shared sort of responsibility…"* (H1HCPfocusgroup)

This monitoring role was seen as an imperative professional responsibility, particularly when starting individuals on new medications. This led nurses to frequently contact patients, either face to face or on the phone, often within 24 hours of starting a new drug. Nurses emphasised the value of face-to-face monitoring in the context of end of life. In the words of one:

> *"…It's a blended approach really, you know, just to phone them up, say "How are you doing?" and if you sense that… the things you are listening to aren't representative of somebody managing, then you actually go back and reassess them face-to-face; there is nothing quite like eyeballing a patient..!"* (HCPW001)

Reporter

As a result of the monitoring role patients undertook they were often in a position to accurately report their relevant symptom and side-effect experiences, and changes, to their healthcare professionals. Carers often aided monitoring of the effectiveness of the medicines by asking simple questions such as: "*Is it helping? Does that help?"* Consequently, carers encouraged discussion with the patient (within their communicator role) and could report this information to healthcare professionals. In addition, CNSs often relayed and discussed goal-setting plans with the wider palliative care team and general practitioners (to support medication changes) under the role of reporter.

Continuum of Self-Management Behaviours

Further inductive analysis led us to generate a model of self-management support pertinent to the end of life context (Figure 1).

Self-management support was conceived as a dynamic process, enacted through a continuum of behaviours and depended on the specific responsibilities and roles adopted by patients, carers and specialist nurses. This is context specific (end of life) and influenced by opioid-related fears.

At the centre of the model (Figure 1) is a continuum of behaviours that ranged from:

- ***Full engagement*** - with full responsibility chosen by an individual, with acceptance of the possibility of risk and requirements for complex decision-making, through to
- ***No Engagement -*** with reduced capabilities and willingness to engage in self-management behaviours, for example through individual choice (preference), the effects of uncontrolled pain, the side-effects of opioids (particularly drowsiness), clinical depression and memory loss, all of which lead to responsibilities being transferred to another (the carer and/or CNS)

Study participants highlighted variation in the range of self-management behaviours enacted.

> "*…You'll get some who don't want anything to do with their medicines…. and then people that want to know everything will… do their own thing as much as they can…*" (H1HCPfocusgroup)
>
> "…*Asking them to go through their medicines, some people haven't got a clue, and other people don't even need to get the boxes or list out and they can tell you absolutely everything they've had …"* (H4HCPfocusgroup)

When discussing the role patients' played in managing their medicines those who felt in control, often referred to how "*lucky*" they were in terms of being able to "*think about it and work it out*". These individuals accepted and preferred full responsibility and were "*doing it all*" themselves, but with backup strategies in place and knowledge of whom to contact should issues arise.

Healthcare professionals often spoke about individuals who were at polar ends of the continuum, but there was also evidence of wide intra-person variation in both behaviours and choices and these could and did continually fluctuate:

> *"…A man that's really angry and frustrated, he's young but he was diagnosed late. He's had lots of frustrations with chemo, and things like that. So he's quite resistant to changes, and that's fine, so we've just left him (medication wise) as he is; he's not managed quite properly, not adequately in our eyes, but he is doing what he wants to do at the moment…"* (H4HCPfocusgroup)

The degree of competency and degree of engagement in tasks involved, and preference in regard to accepting responsibility affected patients' enactment of self-management behaviours, and subsequently influenced the roles adopted by carers and CNSs. Nurses recognised the importance of assessing an individual's capabilities – and their potential for engagement (what the individual was currently doing vs. what they would like and had capacity to do).

End of Life Context

The fact patients were approaching the very end of their lives had a profound influence on the supportive self-management behaviours of patients, carer and CNSs. Continual disease progression led to rapid changes in symptoms and side-effects experienced from medication and treatment. This in turn led to fluctuations in behaviours. This context was overlaid with individuals and their families striving to deal with the psychological distress and high levels of carer strain that can accompany terminal decline.

> *"…So we started in January last year (date of palliative diagnosis). I've aged. Well, somebody asked me (my age) the other day, I said "I'm 95 next week!" they didn't argue (actual age 80), they could see I probably was! I crawl up the stairs some nights…And I'm gradually running out of energy; completely…"* (Carer–H2Pt004)

Individuals could be struggling to cope with a palliative diagnosis, and anxiety and clinical depression could be present in one or both patients and/or carers.

> *"…When I got very depressed, I had flu and (participant's name) was ill with his pleurisy thing and I, we were both very poorly and I got exceptionally depressed and wanted some help… The thing is that if I'm not well it affects (participant's name) and so I felt doubly bad…"* (Carer–H1Pt002)

As a result, the self-management capabilities of patient and carer could fluctuate greatly, and this in turn influenced the supportive self-management roles adopted by the CNS.

> *"…I have very clear memories of a lady being very competent and able with her medication, and then her disease progressed. And I arrived one day to see that she'd put all her tablets on to a tray, and mixed them, they looked like dolly mixtures. Because her condition had deteriorated so badly and because then she took the wrong medications at the wrong time, it exacerbated her condition. So it's that fine balance of monitoring, empowering people, giving them the information but actually responding very quickly when you see that things have changed, their abilities have changed. And this can be so with a carer. Because carers' conditions don't remain static…"* (HCPW001)

Opioid-Related Fears

Patient and carer behaviours in relation to opioid management were strongly affected by misconceptions such as: fear of addiction "*you hear of so many people get(ting) addicted to certain things*" (H1Pt004); assumption that there is a ceiling dose for opioids as with other medicines; fear of over-dosing; fear that these medicines are "*killers*" (H2HCPfocusgroup); assumption that the individual will develop a level of tolerance; fear that death of the individual is imminent i.e. "*I'm dying*" (H1HCPfocusgroup); and fear that in taking these medicines now then there is "*nothing later… so I'll avoid it if I can*" (H1HCPfocusgroup). Nevertheless, the most common fears related to opioids were about side-effects.

> *"…The greatest fears are not so much the addiction but sedation or constipation and again it's a reluctance, "I won't take it unless I need to 'cos I don't want those effects…"* (H1HCPfocusgroup)

Patients were reluctant to take opioids for fear of both constipation and drowsiness. The fear of constipation and subsequent difficulties in balancing doses of laxatives with opioid intake was particularly troublesome for some. Some had experienced faecal impaction requiring hospice admission; as a result the fear of constipation was profound.

> H2Pt004: *My main concern is that if I get some pain, I take extra morphine. I'm on a patch at the moment, so if I change the dose of the morphine, I have to change the dose that I take of the laxative. And of course, the first time "oh yeah, ok, let's bang it up by another one of the sachets". And of course I was then for the next two days on the loo! So "oh let's cut it down", by which time "Oh god I haven't been to the loo now for two days!"*
> Carer: *I've never before seen people so frightened of constipation, as he has been.*

DISCUSSION

The majority of end-of-life care takes place in the home, being undertaken by patients and carers and supported by health care professionals, often nurses. Effective management of medicines in this context is critical for symptom control, quality of life, avoidance of unplanned and emergency services and hospital admission. Equipping and supporting patients and carers to self-manage this important task is a key nursing responsibility. Yet little was known about how self-management is enacted in the home setting at the end of life. To our knowledge, this is the first UK study to characterise self-management and how it is supported in this context, providing a valuable understanding of the work and roles that patients and carers undertake and how nurses can and do support this.

Our findings highlight the variety of roles that nurses enact to support patients and carers self-managing medicines, and they confirm and embellish the role typology proposed by Johnston et al (2012). Additionally, we also discovered that patients and carers may assume these roles in pursuit of self-managing medicines, albeit with slightly different foci than that taken by the nurses. For example, the need to sometimes act as advocate, facilitator and reporter was common to all actors in this context. This also highlights the significant work that patients and carers were found to be undertaking in order to effectively self-manage. Similar to the context of long-term conditions (see Boger et al 2015), self-management here did not comprise patients and carers managing with complete autonomy however, but required a blend of autonomy balanced with input and support from health care professionals. The finding that self-management support in the end-of-life context involves the provision of information and education also chimes with key factors identified as necessary for self-management in other contexts (Taylor et al 2014).

The idea of self-management being a dynamic process, with shifts in patient preference for taking responsibility versus being a more passive recipient of care is not new. Brearley (1990) first proposed that patient participation in care will vary according to factors including acuity of illness and age. Protheroe et al (2008) also found that patients with long-term conditions need information for self-management at different stages in their illness trajectory and in a variety of formats, depending on the receptivity of the patient. However, what our findings indicate is that this inter- and intra-personal fluctuation also exists in the end of life context, and indeed is compressed and magnified due to the complex context in which self-management is enacted and supported. The end of life context, characterised by often rapid disease progression, difficult psychological states, medicines' side-effects and opioid-related fears, all contributed to the existence of a continuum of self-management behaviours ranging from full to limited or no engagement, and rapid changes in patient and carer competencies in, and preferences for, self-management. This is in contrast to long-term conditions such as diabetes or asthma, which, if well controlled, offer more stable conditions for supporting self-management over a longer period of time.

The study findings illustrate that effective nursing support for self-management in this context requires highly skilled, individualised and on-going assessment of patient and carer needs to detect changes in competencies and preferences for engagement and responsibility. Nurses must also adapt and assume roles that shift and complement these changing patient and carer competencies and preferences. The salience of opioid-related fears, in addition to frequent changes in medicines and polypharmacy, means that a key feature of self-management support is provision of information and education to allay fears, change misconceptions and enhance understanding of medicines' actions and side-effects. Together with experiences from previous research (Latter et al, under review), we used our identification of these central components of self-management support (assessment and education), along with goal-setting, monitoring and coaching to form the basis of an end-of-life analgesia and related treatments self-management support intervention delivered by nurses and tested in a feasibility trial (see Bennett et al 2016).

Finally, our findings identify the often-problematic issues that accompanied patients' and carers' experiences of medicines supply and medicines-taking. Our data confirmed that of Schumacher et al's (2014 a&b) study – that these processes exist in a UK context and are typically characterised by effort and burden for the patient and carer. Additionally, we suggest that many of the problems - such as those described in 'getting' and 'obtaining' medicines in Table 3 - are due to system or service organisation failure. For example, the dearth of nurse prescribing in palliative care has been noted elsewhere (Zeigler et al, under review) and appears to contribute to patients' experience of delayed access to medicines. Community pharmacy services might also require improvement, and new services in the UK such as community pharmacist palliative care medicines access services may be important in redressing the problems patients and carers experienced in our study. Further research is needed into patient and carer experience of accessing medicines in the end-of-life context.

CONCLUSION:

Our study has demonstrated for the first time what self-management support at end of life entails and how it is enacted in practice, in relation to analgesia and related treatments. The concept has highlighted the importance for specialist nurses of recognising the roles that patients and carers play, alongside their own, and the factors that impinge on them. Skilled on-going assessment is central to this, as well as the requirement for the specialist nurse to adjust his or her own roles and behaviours in line with this assessment, as preference and capability fluctuate.

Self-management support was enacted on a continuum of self-management behaviours. The enactment of behaviours was dependent upon where the interpretation of responsibility lay. This required an assessment (by the healthcare professional) of competencies held by the patient and carer. It was also dependent upon the acceptance (or not) of choice by the individual patient and/or carer, as well as the acceptance (or not) of risk by these individuals, and a degree of transfer of risk from the professional.

> *"…I think it's about accepting that patients do things the way they want to…, it's their journey… that they are going on, and it's not up to us to dominate… I'll often have that conversation… "They did it their way didn't they? It may not have been the way we'd have done it, but it's what worked for them…"* (H4HCPfocusgroup)

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References

Bennett M.I, Mulvey M.R, Campling N, Latter S, Richardson A, Bekker H, Blenkinsopp A, Carder P, Closs J, Farrin A, Flemming K, Galagher J, Meads D, Morley S, O'Dwyer J, Wright-Hughes A, Hartley S. (2016) Self-Management of Analgesia and Related Treatments at the end of life (SMART): a feasibility study. Final Report to NIHR HTA (under review).

Boger, E., Demain, S. & Latter, S. (2015) Stroke self-management: A focus group study to identify the factors influencing self-management following stroke. *International Journal of Nursing Studies*, 52(1), 175-187.

Boger, E., Ellis, J., Latter, S., Foster, C., Kennedy, A., Jones, F., Fenerty, V., Kellar, I. & Demain, S. (2015). Self-management and self-management support outcomes: a systematic review and mixed research synthesis of stakeholder views. *PloS one*, *10*(7), p.e0130990.

Brearley, S. (1990) Patient Participation: The literature. Royal College of Nursing Research Series. Harrow, Middlesex: Scutari Press.

Health Foundation (2015). *A practical guide to self-management support. Key components for successful implementation*. The Health Foundation, London.

Hughes, N.D., Closs, S.J., Flemming, K. & Bennett, M.I. (2016). Supporting self-management of pain by patients with advanced cancer: views of palliative care professionals. *Supportive Care in Cancer*, *24*(12), 5049-5057.

Johnston, B., Rogerson, L., Macijauskiene, J., Blazeviciene, A. & Cholewka, P. (2014). An exploration of self-management support in the context of palliative nursing: a modified concept analysis. *BMC Nursing* 13, 21.

Johnston, B.M., Milligan, S., Foster, C. & Kearney, N. (2012). Self-care and end of life care-patients' and carers' experience a qualitative study utilising serial triangulated interviews. *Supportive Care in Cancer*, 20(8), 1619-1627.

Johnston, B., McGill, M., Milligan, S., McElroy, D., Foster, C. and Kearney, N., 2009. Self care and end of life care in advanced cancer: literature review. *European Journal of Oncology Nursing*, *13*(5), 386-398.

Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. Thousand Oaks: Sage publications.

Latter, S., Hopkinson, J., Lowson, E., Hughes, J., Hughes, J., Duke, S., Anstey. S., Bennett, M., May, C., Smith, P. & Richardson, A. Supporting family caregivers to manage pain medication in cancer patients at end of life: a feasibility trial. *Palliative Medicine* (under review)

Protheroe, J., Rogers, A., Kennedy, A.P., Macdonald, W. & Lee, V. (2008). Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake. *Implementation Science*, *3*(1), 44.

Schumacher, K. L., Plano Clark, V. L., West, C. M., Dodd, M. J., Rabow, M. W. & Miaskowski, C. (2014a). Pain medication management processes used by oncology outpatients and family caregivers part I: health systems contexts. *Journal of Pain and Symptom Management*, 48(5), 770-83.

Schumacher, K. L., Plano Clark, V. L., West, C. M., Dodd, M. J., Rabow, M. W. & Miaskowski, C. (2014b) Pain medication management processes used by oncology outpatients and family caregivers part II: home and lifestyle contexts. *Journal of Pain and Symptom Management*, 48(5), 784-96.

Taylor, S.J., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, H.L., Schwappach, A., Purushotham, N., Jacob, S., Griffiths, C.J., Greenhalgh, T. & Sheikh, A., (2014). A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS–Practical systematic Review of Self-Management Support for long-term conditions. *Health Services and Delivery Research*, No. 2.53., NIHR Journals Library, Southampton.

Ziegler LE, Bennett MI, Mulvey MR, Hamilton T, Blenkinsopp A. Palliative care prescribing in England; analysis of medical and non-medical activity 2011-2015. Palliative Medicine (under review)

Figure I – Conceptual Model of Self-Management Support of Analgesia and Related Treatments at the End of Life

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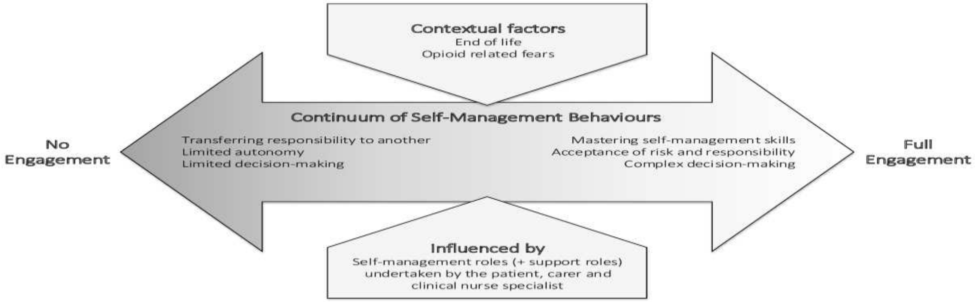

Table 1: The sample

Patient and Carer Sample	
Northern region	1 focus group n=4 patients
Southern region	11 interviews n=11 patients n=4 carers
Total	19 patients + carers
Healthcare Professional Sample	
Northern region	1 focus group n=4 clinical nurse specialists 1 face to face interview n=1 consultant
Southern region	2 focus groups n= 10: 9 clinical nurse specialists + 1 specialist registrar n= 3: 2 in-patient unit nurses, +1 lecturer/practitioner 1 telephone interview n=1 lead nurse/commissioner
Total	19 healthcare professionals
Overall sample total	38 participants
Healthcare Professional Demographics	
Gender	Female n=18 Male n=1
Professional background	Nursing n=17 Medicine n=2
Main working environment	Hospice in-patient n=4 Hospice education n=1 Community n=10 Hospital n=2 Community and day hospice n=1 Hospital, hospice + community n=1
Length of time in current post	Range 6 months - 24 years Mean 7 years
Length of time in palliative care specialism	Range 1 year - 27 years Mean 13 years
Patient Demographics	
Gender	Male n=8 Female n=7
Age	Range 47 - 84 Mean age 66
Cancer site	Bile duct, Breast, Colon, Lung n=3, Melanoma, Mesothelioma, Oesophagus, Pancreas, Prostate n=2, Uterus
Educational level	Degree level or above n=4 Below degree level n=6 No qualifications n=5
Carer Demographics	
Gender	Female n=4
Age	Range 52 – 80 Mean age 69
Educational level	Degree level or above n=2 Below degree level n=2

Table 2 – Self-management and self-management support roles adopted by patients, carers and nurse specialists

Roles	Patient	Carer	Clinical Nurse Specialist
Advocate	For themselves e.g. requesting alternative opioids/forms if side-effects are not acceptable	Total advocacy role where needed	Ensuring patients receive appropriate medicines to meet their symptom control needs
Educator	Of carer if required, anticipation of future changes (i.e. planning for worsening condition)	Of patient and clinical nurse specialist where needed	Refining knowledge for individuals, providing instruction
Facilitator	Of relationships (GP, healthcare professionals and carer, carer and community pharmacist) and access to medicines	Manager of the practical issues e.g. storing, organising and administering medicines, where needed	Assisting with the practical issues e.g. storing, organising and administering medicines as needed
Problem-Solver	Access to medicines and navigating the supply system, side-effects management and off-setting doses	Pre-emptive, for example regarding stock management or suggesting need for breakthrough analgesia	Best drug and side-effect profile for individual, sorting out when supplies get in a muddle, pre-emptive problem solving
Communicator	Of relevant information to all – family and health care professionals	Encouraging discussion with patient	Selecting the style of communication for individual, knowing the family and patient (mediator as well as communicator)
Goal-Setter	Self-planning, planning with a GP or joint planning with clinical nurse specialist	Often in relation to getting out and about e.g. getting out of the house for a coffee, going to a favourite place	Proposing options and allowing the individual to decide what they would prefer and putting a plan together
Monitor	Writing down of breakthrough doses and noting effectiveness	Pain diary recording	Assessing how much information has been understood. Monitoring involvement of patient in decisions and reviewing effectiveness of medicines
Reporter	Of relevant symptom experiences and side-effects	Evaluation of effectiveness of medications	To wider palliative care team and GPs

Table 3 – Summary of difficulties and impact of issues with medicine supply and taking

Medicines Supply and Taking Steps [1]	Specific Difficulties	Impact
Getting prescriptions • **New - initial prescriptions and changes to prescriptions** • **Repeat prescriptions**	Few clinical nurse specialists independent prescribers	Common requirement for patient to make an appointment with GP to gain new prescription (not all had the input of a CNS who could contact the GP on their behalf)
	Frequency of need for new prescriptions due to fine-tuning of pain medicines to meet changing needs	Time consuming process gaining new prescriptions
	Prescribing by different specialists	Patients/carers may not know who prescribed the medication and where this is queried by dispenser supplies may not be dispensed
	Need to physically collect prescription due to legal requirement for opioid prescription to be collected	Patient/carer asked to collect prescription from GP surgery, unless the GP practice and the pharmacist are willing and able to transfer the prescription electronically
	Lack of syncing of supplies - one medicine may last for two weeks or less, others for longer	Frequency of need for some repeat prescriptions. Need for request of some medicines but not others, often others are dispensed causing potential waste and costs. Difficulties with online GP practice systems for repeat prescriptions – slow and unstable platforms
Obtaining medicines	Having to get to the pharmacy	Carer or someone else having to go on individual's behalf, who may not know what should be dispensed
	Pharmacies offering a delivery service	Requirement to wait in to sign for receipt of the delivery
	Patients tend to use the nearest pharmacy rather than one that may be a 'palliative care specialist' pharmacy and more likely to stock these medicines	Delay in dispensing the prescription as the pharmacy may not stock the medicine or the prescribed dose
	Need to establish a relationship with the pharmacist	Patients encountered having to establish new relationships with pharmacists when there were changes in management
	Possibility of dispensing errors	Patients encountered medicines being dispensed that had not been requested, ones that had been requested could be missing or in a form not expected e.g. tablets rather than capsules

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[1] After Schumacher, K. L., Plano Clark, V. L., West, C. M., Dodd, M. J., Rabow, M. W. & Miaskowski, C. (2014). Pain medication management processes used by oncology outpatients and family caregivers part I: health systems contexts and part II: home and lifestyle contexts. *Journal of Pain and Symptom Management*, 48(5), 770-96.

Understanding	Individuals are faced with understanding the medicines once collected	Lack of understanding can result in uncontrolled pain and poor side-effect control of nausea and constipation
	Individuals usually receive information about their medicines but this may not be to the extent needed or in a helpful form or may not be retained	alternative forms required to backup initial verbal information-giving
	Confusion due to medicines with similar sounding names, abbreviations, maximum dose limits and intervals between taking medicines	Commonality of fears based on the misconception that opioids have dose ceilings and misconceptions about dosing intervals for breakthrough (as required) opioids
	Medicines may be recognised by their appearance rather than name, and pet names for the medicines may be used	Exacerbates difficulties in gaining repeat prescriptions – patients may be reliant on GP practice online systems recognising what they have previously requested
	Information printed on labels may be too small; lack of awareness even from specialists that the labels can be printed in larger font	Patients and carers unable to read labels, leading to confusion and / or lack of understanding?
	Wide range of potential information sources – GPs, nurses, pharmacists, the package inserts, the internet etc.	Patients did not report any contradictions in information given from the various sources but they reported fears being generated from the package inserts and the internet
Organising	Number and various forms of medicines prescribed within analgesic regimes (for regular and as needed use), including patches and liquids as well as pills precludes orderly arrangement	Orderly arrangement of numerous and various medicines at home can be difficult for many, preventing medicines from being easily remembered and kept track of
	Requires individuals to set up their own organisational strategies e.g. plastic boxes/tubs, cupboards, stacks of drawers	Wide range of individual strategies are used, which are not always orderly to allow stock levels to be monitored etc.
	Filling of a dosette box; lack of clarity for patients about who does this and which medicines can go in it. With supplies of pharmacy-filled dosette boxes e.g. NOMAD, the usual arrangement made is for opioids not to be dispensed in the boxes because of the likelihood of prescription changes	Where individuals purchase a dosette box and self-fill it they may not know which medications are suitable to be stored in it. Individuals have to remember to take their opioids in addition to the medicines in their dosette box.
Storing	Need to put medicines safely away, particularly from grandchildren; safe storage is often not addressed by specialists	Medications are not always stored in the safest location e.g. difficulties in shared accommodation
	Storage of 'old' medicines; many had relatively large supplies of out-dated (but not expired) prescription medications	These stores can add to the complexity for patients and they may not be able to return them to a pharmacy for disposal
Scheduling	Scheduling medicines according to the best time to take them in	Patients may need help to do this, but few patients had been aided by a

	relation to an individual's daily routine	medication chart that had been drawn up for them by their clinical nurse specialist
	Requires understanding of which medicines provide maximum benefit with a fixed schedule and which can be tailored to changing needs	This level of understanding may develop over time but for others medications are seen as something that requires a fixed schedule. Some may link their schedule to mealtimes, others at easy to remember times e.g. 8am and 8pm meaning medicines may not always be administered at appropriate times?
Remembering	Remembering to take the pills	Often complicated by a mind-set of taking medicine only when the symptom is present. Problems arise particularly when daily routines change e.g. with visitors or trips out of the house. Drowsiness, fatigue and memory loss exacerbate difficulties leading to medicines not being taken and questioning of whether they have been taken already
	Carers may be required to play a key role in reminding individuals to take their medicines	Some may use alarms to remind themselves to take their medicines
Taking	Nausea makes taking medicines problematic	Need for prophylactic anti-emetics where nausea is an issue
	There may be trouble swallowing large pills or opening tamper proof medicine bottles/filling syringes etc. Particular difficulties noted with the use of syringes for small doses of liquid opioids. Syringes not supplied routinely by pharmacies and on repeated use the markings may wear off	Medicines-taking a difficult experience for some. Potential for less than adequate symptom control
	Often requirements change, requiring review. Are the medicines being dispensed in the most suitable form and route for the individual?	Lack of review may lead to appropriate forms and routes of medicines, resulting in less than adequate medicine –taking and poorly controlled symptoms