

## QUALITATIVE PAPERS

# Health professional perspectives on the management of multimorbidity and polypharmacy for older patients in Australia

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## Abstract

**Background:** delivering appropriate care for patients with multimorbidity and polypharmacy is increasingly challenging. Challenges for individual healthcare professions are known, but only little is known about overall healthcare team implementation of best practice for these patients.

**Objective:** to explore current approaches to multimorbidity management, and perceived barriers and enablers to deliver appropriate medications management for community-dwelling patients with multimorbidity and polypharmacy, from a broad range of healthcare professional (HCP) perspectives in Australia.

**Methods:** this qualitative study used semi-structured interviews to gain in-depth understanding of HCPs' perspectives on the management of multimorbidity and polypharmacy. The interview guide was based on established principles for the management of multimorbidity in older patients. HCPs in rural and metropolitan Victoria and South Australia were purposefully selected to obtain a maximum variation sample. Twenty-six HCPs, from relevant medical, dentistry, nursing, pharmacy and allied health backgrounds, were interviewed between October 2013 and February 2014. Fourteen were prescribers and 12 practiced in primary care. Interviews were digitally audio-taped, transcribed verbatim and analysed using a constant comparison approach.

**Results:** most participants did not routinely use structured approaches to incorporate patients' preferences in clinical decision-making, address conflicting prescriber advice, assess patients' adherence to treatment plans or seek to optimise care plans. Most HCPs were either unaware of medical decision aids and measurements tools to support these processes or disregarded them as not being user-friendly. Challenges with coordination and continuity of care, pressures of workload and poorly defined individual responsibilities for care, all contributed to participants' avoiding ownership of multimorbidity management. Potential facilitators of improved care related to improved culture, implementation of electronic health records, greater engagement of pharmacists, nurses and patients, families in care provision, and the use of care coordinators.

**Conclusion:** extensive shortcomings exist in team-based care for the management of multimorbidity. Delegating coordination and review responsibilities to specified HCPs may support improved overall care.

**Keywords:** multimorbidity, polypharmacy, care coordination, primary care, older patients

## Background

The majority of older adults have multimorbidity, defined as experiencing two or more long-term health conditions [1]. A rapid increase in multimorbidity research has occurred over the past decade, linked to an increasing prevalence of multimorbidity and increasing challenges in areas such as workforce redesign and appropriate funding mechanisms to deliver appropriate care for such patients [2, 3]. The contiguous phenomenon of increasing polypharmacy—using multiple medications—has received similar attention [4]. Patient-reported challenges to optimising medication management in the context of multimorbidity and polypharmacy include out-of-pocket costs, care coordination, conflicting therapeutic advice from prescribers, low levels of engagement in decision-making and knowledge or skills deficits [5–7].

Challenges with care delivery for multimorbidity arise from factors such as limited consultation time, inadequate service coordination, lack of evidence, inadequate consideration of multimorbidity in clinical guidelines, inadequate medication review and multiple prescribers acting independently [8]. Most older people experience multimorbidity, but guidelines often focus on individual conditions and thereby have uncertain applicability for many patients [9]. Applying multiple individual guidelines can lead to complex medication regimens and treatment conflicts [10]. Emerging evidence suggests that multimorbidity and associated challenges with providing appropriate care may increase treatment burdens, reduce quality of life, diminish medication adherence and cause adverse drug events, unnecessary hospital admissions and unnecessary health-care expenditure [11, 12].

To support best practice for multimorbidity [13], the American Geriatrics Society (AGS) published Guiding Principles for the Care of Older Adults with Multimorbidity (2012) [14]. It is unclear if these generic principles are being applied in different health systems to support multimorbidity management. Multimorbidity management has largely been explored among a small number of primary care professions, particularly general practitioners (GPs) [8, 15–18]. The application of AGS principles for multimorbidity is also largely unexplored from the perspective of an often diffuse healthcare team. This is despite the increased likelihood of hospital admissions and transition between different care settings for patients with multimorbidity [12], and their greater susceptibility to fragmented care, inappropriate polypharmacy and the adverse consequences of polypharmacy [19]. The objective of this study was to explore current approaches to multimorbidity management, and perceived barriers and enablers to appropriate medications management for community-dwelling patients with multimorbidity and polypharmacy, from the perspectives of Australian HCPs.

## Methods

### Design and setting

Semi-structured interviews were undertaken with HCPs working in metropolitan and rural areas of Victoria and South Australia. The healthcare structure is similar in each Australian state, with nationally funded primary care services and state-funded hospital care. The primary source of universal healthcare is typically a GP. GPs also act as gatekeepers to other government-funded health services. The interview guide was based on the AGS Guiding Principles for the Care of Older Adults with Multimorbidity [14]. These principles align with recommendations from several Australian policy documents, but there is no single Australian report that comprehensively frames the same issues. The study was approved by the Monash University Human Research Ethics Committee.

### Study sample

A maximum variation sample of participants from a diverse range of HCPs in primary, secondary and tertiary care settings was purposively recruited through investigator networks. Potential participants were identified according to their professional background and experience in managing multimorbidity. Because a wide range of individuals influence prescribing and support for patients around medications, the sample included a range of medical and non-medical prescribers and non-prescribers to ensure a broad understanding of perceived roles, responsibilities and challenges experienced with multimorbidity and medication management.

### Overview and health professional characteristics

Overall, 26 HCPs were recruited from relevant medical, dentistry, nursing, pharmacy and allied health backgrounds, and almost half worked in primary care settings (Table 1). Participants were aged from 29 to 70 years and more than half (14/26) were prescribers (Table 1).

### Data collection

The semi-structured interview guide was designed around six domains relating to current multimorbidity management, individual strategies for patient-centeredness, barriers to AGS-defined best practice and how they think the healthcare team should function to improve care. Five of these domains aligned with AGS principles [14]: elicit and incorporate patient preferences; recognise limitations of the clinical evidence base; frame treatment decisions in the context of risk, benefit and prognosis; assess the clinical feasibility of treatment options and use strategies to ensure that treatments optimise benefit, minimise harm and enhance quality of life for older adults with multimorbidity. Because these principles focus on individual care, a sixth domain was added to explore care coordination.

To facilitate consistent interpretation, commonly used definitions were provided before interviews. Polypharmacy was

**Table 1.** Healthcare professional characteristics

Social demographics	N = 26	%	Details
<b>Age</b>			
20–40	8	30.8	
40–60	15	57.7	
>60	3	11.5	
<b>Area</b>			
Rural	9	34.6	
Metropolitan	17	65.4	
<b>Setting</b>			
Community	12	46.2	
Hospital	14	53.8	
<b>Prescribing status</b>			
Prescriber	14	53.8	
Non-prescriber	12	46.2	
<b>Field of practice</b>			
Acute care medical speciality <sup>a</sup>	6	23.1	Three general medicine consultants, two geriatricians and one clinical pharmacologist
General practice <sup>a</sup>	5	19.2	Five GPs
Nursing	6	23.1	Two practice nurses, two nurse practitioners <sup>a</sup> and two hospital nurses (including one transition of care coordinator)
Pharmacy	6	23.1	Four hospital pharmacists and two community pharmacists (including three home medication review accredited pharmacists and one transition of care coordinator)
Dentistry	2	7.7	One dentist <sup>a</sup> and one dental hygienist/centre coordinator
Physiotherapy	1	3.8	One physiotherapist

<sup>a</sup>Denotes disciplines/subdisciplines with prescriber authority.

defined as the use of five or more different medications [20]. Multimorbidity was defined as an individual having two or more chronic conditions [13]. It was clarified that the interview focus would be medication management for community-dwelling patients with both multimorbidity and polypharmacy. The interview guide was pilot tested for face validity by conducting interviews with two pharmacists and a physician.

Twenty-four interviews were conducted face-to-face at the participant’s practice setting or another mutually convenient location, and two were conducted by telephone. The average interview duration was 45 minutes (range 25–61 minutes). Written informed consent was obtained to audiotape interviews. Interviews were conducted until data saturation occurred, where no new data, themes or coding emerged. To ensure data saturation, independent coding of transcripts by multiple researchers was employed, and interviews were structured to ensure continued exploration of key issues with multiple participants (minor amendments to the interview guide were introduced after pilot interviews to further explore, confirm or contest issues of interest identified from previous interviews).

**Data analysis and synthesis**

Interviews were digitally audio-taped and transcribed *verbatim*. After familiarisation with all interviews, two researchers

(B.B. and H.A.) carefully read all transcripts line by line and independently coded data using a constant comparison approach. Conflicting codes were discussed until consensus was reached: first by the two coding researchers and then with other authors when required. B.B. and H.A. agreed, after discussion with other authors, on a set of codes to apply to all subsequent transcripts. These codes were then aggregated into themes using AGS Guiding Principles as a framework for analysis [14, 21]; any conflicts were again discussed for consensus.

**Results**

**Incorporation of shared decision-making and patient preferences**

All HCPs perceived shared decision-making as important to improve medication adherence and maximise treatment benefits. Apart from geriatricians, most prescribers either recognised that they did not routinely practice shared decision-making or sidestepped the subject, when asked how they incorporated shared decision-making into routine care. Somewhat related to shared decision-making, nursing and pharmacist participants described filling gaps in patient knowledge or addressing patient concerns and preferences after medical decisions had sometimes been made without adequate patient engagement.

I spend a lot of time doing and getting complete medical history and medication reconciliation. Then the next thing is making sure they [patients] really want to be on the medicine. Because if they don’t want to be on the medicine there is no use in me prescribing the medicine.

Geriatrician 2

The big thing which I think sometimes the doctors forget is consent...you go in there [to the patient and say], ‘Hi XXXX, doctor XXXX has requested that you do cardiac rehab’, and he said ‘I am not going to cardiac rehab. I did it two years ago, I’ve got a sore hip, I have got pain [in] the guts, I don’t wanna. I don’t drive, my wife has to bring me in, once a week, I can’t do it and he didn’t even ask me.

Registered nurse 1

Prescribing HCPs, particularly GPs, described how the limited time available for care episodes reduced the likelihood of incorporating patients’ preferences into treatment decision-making for multimorbidity. While exploring or confirming patient acceptance of ‘clinical’ goals was commonly mentioned, no participant made reference to exploring goals for daily living as a means of eliciting patient preferences.

Cognitive impairment, hearing problems and poor health literacy were cited as prevalent additional challenges. Several pharmacists and nurses suggested that patients are also often reluctant to ask physicians questions, fearful of consuming physicians’ valuable time.

## Evidence base

Prescribing HCPs questioned the applicability of clinical guidelines when making decisions for patients with multimorbidity.

Guidelines that have been developed for individual diseases are based on research that excluded patients with multimorbidity [...] we try and follow those [guidelines] where they are applicable but otherwise I guess it is just having the experience of working with these patients and working out what works and what doesn't.

Geriatrician 1

...general guidelines don't work very well for complex poly comorbid patients. In fact, the general guidelines [...] have got information that's [...] wrong and dangerous and risky if you actually follow them. [...] The heart failure, the cardiology guidelines still recommend very restricted diets for patients with heart disease and those guidelines are appropriate for 50 year old overweight patients, but 85 year old patients with multiple chronic diseases they are very at risk of malnutrition so those guidelines are really not appropriate for these common patients particular as they start to age.

Clinical pharmacologist

HCPs more often relied on personal clinical judgement and experience. Lacking this experience, junior doctors reported being dependent on advice from senior colleagues. Nurses reported major problems with conflicting advice from different prescribers, leading to patient uncertainty.

## Patient prognosis

All HCPs reported problems with incorporating patients' prognoses into decisions about therapy appropriateness. Most were unaware of available prognostic tools. The HCPs who were aware of these tools considered them unhelpful because they presented probability of mortality rather than life expectancy. Therefore, likelihood of benefits from treatment is only clear for patients with very high or very low estimated risks of mortality. Conversely, unvalidated mortality predictors such as longevity of patients' family members were reported for estimating patients' life expectancy and deciding the appropriateness of therapies. Some HCPs reported ethical concerns around denying treatments and litigation fears if, after withholding preventative medications, a related clinical event occurred (e.g. stroke after statin withdrawal). Prescribing of potentially inappropriate preventative medications was a concern, but no HCP could suggest how to resolve this issue.

If something estimates a risk of death in five years of 20% or 40 [...] it doesn't really help me (to decide if I should) prescribe a statin or not. If someone's risk of death is 80% within a year, I wouldn't prescribe that person a statin.

Clinical pharmacologist

You need to have an idea of obviously what their life expectancy is, their quality of life, all those things, their genetics, 'cause if they come from a family where they live a long time that might make you prescribe something that is prophylactic.

GP 2

## Clinical feasibility of treatment plans

There appeared to be no clear method for assessing patients' likely adherence to treatment plans if modified. HCPs also struggled to articulate how they assessed the likely impact of changes to treatment and care plans on patients' capacity to adopt recommendations. None mentioned using available tools to measure medication management capacity or seeking patient feedback about self-management capacity. Hospital-based HCPs reported that treatment plans are often changed during admissions, but that they do not have sufficient information or time to assess patients' adherence capability. Post-discharge appointments in primary care were considered by these HCPs as the most appropriate setting to assess patient adherence to treatment plans and self-management.

I might see a patient once, maybe twice or thrice, and then I might never see them again. Cause my, I am there to just give the GP advice, so in the end of the day I have to hope that wherever else they go, people are also giving them the same information, doing the same things, checking and educating.

Geriatrician 1

(There's) not many (steps I can take to assess feasibility) [laughing], uhhhhh...there is probably not very much we can do other than talk to them and say it (adherence) is important [...] I don't tend to see patients on a regular ongoing basis. I see them in you know an acute setting in emergencies [...] I am not sure that there is a great deal that we can do that actually improves compliance.

General medicine consultant 2.

## Optimising therapies and health management plans

Participants commented most extensively on issues around optimisation of care plans and therapies, and related difficulties with continuity of care. Supplementary quotes for these two issues are provided in Box 1. Most participants admitted, some with embarrassment, that they should, but do not, routinely engage in optimisation of care plans and complicated medication regimens. It was not a priority for time-limited patient encounters.

Oh deprescribing! Yes, I'd like to do that more than I do, yeah we sort of scratch things off and delete things, we do that too. One of the last things you would do when it comes to the medication is to cease certain things.

GP 1

**Box 1. Summary of themes relating to optimisation of therapy and care coordination identified from participants**

Theme	Quotes
Optimising therapies and health management plans	<p><b>GP 2:</b> Oh deprescribing! Yes, I'd like to do that more than I do, yeah we sort of scratch things off and delete things, we do that too. One of the last things you would do when it comes to the medication is to cease certain things</p> <p><b>Interviewer:</b> in what kind of situations do you do that?</p> <p><b>GP 2:</b> usually the true answer, you want the truth? The truth is when you remember, when you are not rushed, then you can do that. Because that is the next thing on your list, the last thing you would do. One of the last things you would do when it comes to the medication is to cease certain things.</p> <p><b>Nurse 1:</b> But sometimes there is such a discrepancy they get to the GP and they might have been discharged on Friday and then come and see the doctor and the appointment was made by the hospital on the Monday or Tuesday. The GP doesn't have a discharge summary, does not have an updated medication list and the patient turns up at the appointment that was made by the hospital and they go 'why are you here?' and the patient goes 'well don't you know?! I've been on the waiting list because I've been in the hospital last week' and that gets them cross which is fair enough, they are paying good money to follow up for their condition for what they are in hospital for and the GP is not even aware of it. Because I guess there is a time lag between the discharge summary being done and actually the GP receiving it. So here you've got the patient trying to explain to the GP what happened to them in hospital to fill in the picture and tell them something while they are at the appointment.</p> <p><b>Geriatrician 2:</b> Or there is often a view that I hear from patients is well my doctor prescribed this for me therefore it must be appropriate therefore I must keep taking it, even when it is clearly not appropriate.</p> <p><b>GP 2:</b> Because I can't usually just ring up and talk to the (hospital) doctor who wrote the prescription, I have to go through the health information service and sometimes they are more and less helpful cause sometimes they won't tell you because they are worried about privacy so then you have to go through a process to get it, to have your signature to say are you happy for me to have that information. But that delays things; it means I can't make a decision now.</p> <p><b>Clinical pharmacologist 1:</b> I think people do practice very defensively because they fear lots of things, they fear criticism by their colleagues as well as litigation, litigation is actually very rare in terms of being sued. There is other things as well, the fact that we work in a public health system, and it is perceived that you might be ignorant of new treatment or negligent if you don't offer it and someone isn't offered treatment. So it is not just the fear of litigation that drives people to offer treatment.</p> <p><b>General medicine consultant 3:</b> I think it is quite important. I have to be honest I don't do that myself. I think it's when, uhmm, as people age I think that a lot of doctors forget that you know, because we see them so often we forget that they actually are getting older now. The benefits of certain medications may not be actually effective, say when they are aged 80 years old compared to when they are 40 years old and I think that is a big problem in doctors that don't work in aged care. I think a lot of the doctors forget that you know, maybe we should start weaning of medication.</p>
Coordination of care	<p><b>GP 2:</b> Because I can't usually just ring up and talk to the doctor who wrote the prescription, I have to go through the health information service and sometimes they are more and less helpful cause sometimes they won't tell you because they are worried about privacy so then you have to go through a process to get it, to have your signature to say are you happy for me to have that information. But that delays things; it means I can't make a decision now. So I have to wait for that information to come back. It might be today, it might be tomorrow or it might be the next week, so it is difficult for those people who are in transit.</p> <p><b>Community pharmacist 2:</b> One of the issues with just chemotherapy in general is that GPs will prescribe cardiovascular medicines for diabetes or whatever it might be, but they don't want to get involved in oncology they go 'oh! I don't know anything about it' so they let that happen. When we speak to our oncologists they go I have not a clue about cardiovascular drugs, 'I just know about oncology', so they don't worry about that and that is where you get the complexity because not everyone is across (everything) and they are not willing to step in [...] The scope of practice doesn't allow them to so who is looking after the patient across the board. And that's when I think pharmacy comes in I guess is that we've got an opportunity to at least address that and be a bit of a middle man to help pull it together.</p> <p><b>Nurse practitioner 1:</b> They get some contradictory information for example patients might be told to drink a lot of fluid if they are diabetic and to help improve their renal function but if they've got poor left ventricular function because they've got a cardiomyopathy or just a tricky heart really they will be told to limit their fluid intake to 1.5 litres a day. So then they get in a conflict like 'my endocrinologist and renal doctors say I've got to drink three litres a day and you're telling me 1.5 and now I don't know what to do'. So I think sometimes there is a conflict in the messages, they may get a conflict and don't quite know how to understand. Or you know which track that they need a pathway down the middle and who do they need to believe?</p> <p><b>GP 2:</b> Private hospitals have no access to discharge summary system whereas the public hospitals do have a discharge summary. And it gets faxed to me. Usually within 2 or 3 days when the patients have been discharged unless it is a complicated and difficult inpatient admission with lots of changes. Then the discharge summary can often take 2 or 3 weeks [...] before we get the information. So for the most important one there is a bigger problem.</p> <p><b>Dental centre coordinator:</b> We rely on the patients themselves in providing their medical history and their medications and we get given all sorts of small papers with handwritings of medications and so on [...] GPs are not easy people to deal with and communicate due to shortage of time, not criticising them and sometimes they are hard to get in touch with.</p> <p><b>Dentist 1:</b> I have had issues with GPs, they don't want to answer questions about a patient's history. They say if you want to do a procedure, why should I get involved? They misunderstand their roles and responsibilities, that is not the norm, but it has happened when the GP would refuse to cooperate.</p> <p><b>Practice nurse 1:</b> ...there's not a lot of communication between the hospital and us here, and I think a lot of that is to do with time constraints as well. The discharge summaries from the hospital aren't very user friendly but that is a working thing in progress, we are looking at, at the moment, a whole new process with IT and that sort of thing that we will be able to access all of that information as well. So we'll see with the new collaborative programme that's out, we're very involved with that, with patient hand held records and things like that. So that's all in the process and I think in five years' time it will be wonderful but at the moment it's not.</p>

There was also a reluctance to ‘interfere’ with other HCPs’ prescribing driven by fear of disturbing therapeutic relationships, hesitation to contradict prescribing by other HCPs and among junior doctors, poor confidence to change treatment plans stemming from inadequate knowledge and experience. Some geriatricians and pharmacists mentioned that some patients ‘love taking medicines’, making it difficult to initiate conversations about deprescribing.

Some patients are, if they have been told once, you have to take this medication for the rest of your life, they really hang on to that view, even when it becomes inappropriate for them to continue on that medication.

Geriatrician 1

Prescribing HCPs reported not having a systematic approach to deprescribing or optimisation of care plans. Many of the community-based HCPs were unaware of tools to address potentially inappropriate polypharmacy (e.g. START/STOPP, Beers Criteria). Some of those hospital-based HCPs, who were familiar with these tools, considered them outdated, containing obvious interventions or too lengthy. Most participants reported awareness of potentially inappropriate key medications for older people, such as benzodiazepines and anticholinergic medications.

### Coordination of care

Some HCPs, particularly GPs, acknowledged that when multiple prescribers provide care in silos for the same patient with multimorbidity, overly complex medication regimens result that adversely affect patient adherence to treatment plans. Conflicting opinions existed regarding the optimal time to review and optimise medication regimens. Some HCPs believed that the best time is during a hospital admission because all specialists are available in one place for discussions. Hospital-based HCPs were considered more accessible for consultation compared with community-based counterparts because of perceived better collegiality, respect for each other’s profession and the opportunities to discuss issues in person.

...hospital is a very supportive environment and is very collegial, why is suppose, you know, you have, you don’t feel like you are alone so much. Where I imagine if you work in at the community pharmacy it would be very difficult to have that ..

Hospital pharmacists 1

Other HCPs reported trying not to adjust medication lists in hospital to avoid errors and confusion for both patients and GPs at discharge and post-discharge.

...no bits of the list of responsibilities and roles for management of polypharmacy for elderly people can be done successfully by any other profession other than general practitioners in my opinion

GP 2

In non-medical settings such as dental clinics, HCPs similarly felt that there were considerable difficulties with acquiring the necessary information to make treatment decisions from GPs.

Hospital-based HCPs acknowledged the importance of arranging post-discharge appointments, but many reported not doing enough themselves to ensure appropriate post-discharge care coordination. They cited time constraints and reluctance to assume responsibility as key factors and concluded that primary care is the most appropriate setting to evaluate treatment plans and patient adherence. Community-based HCPs argued that delayed, lost or vague discharge summaries or medication lists make it equally impossible for them to coordinate post-discharge requirements.

Hospital-based HCPs complained of limited abilities to meet care planning responsibilities because of inaccurate and outdated medication lists provided by GPs. Transition of care problems were reportedly far more common among patients with multimorbidity, since updating the more complex medication lists and writing discharge summaries for these patients takes a lot more time and has greater potential for delays and mistakes. Difficulty or inability to contact HCPs in other settings contributed to transitional care challenges. HCPs relied heavily on patients’ self-reported information to clarify ambiguities, which was considered error-prone to error and very time-consuming.

The GP doesn’t have a discharge summary, does not have an updated medication list and the patient turns up at the appointment that was made by the hospital and they go ‘why are you here?’ and the patient goes ‘well don’t you know?!..’ [...] Because I guess there is a time lag between the discharge summary being done and actually the GP receiving it. So here you’ve got the patient trying to explain to the GP what happened to them in hospital to fill in the picture and tell them something while they are at the appointment.

Registered nurse 1

Overall, participants reported that the problems described above evolve because nobody assumes responsibility for optimising care plans and because of poor coordination of care. After reflection, many participants concluded that their current situation did not allow them to shoulder these responsibilities. Only GPs asserted themselves as being the key care coordinators for patients with multimorbidity. However, because of previously described challenges, they also often reported not meeting this responsibility. Geriatricians felt their role was more to support GPs’ optimisation of care, and that potential input to ongoing care coordination was limited due to the short duration of their interaction with these patients.

GPs and nurses found that home medication reviews undertaken in collaboration with pharmacists were helpful to optimise treatment.

I know through my other role, district nursing out at [rural town] – community pharmacist had just recently

been to a home to go through all the medications and the patient was really happy and really pleased and really understood things so much better. So absolutely, the community pharmacist is fantastic.

Practice nurse 2

Both GPs and pharmacists complained about the level of government remuneration provided. Pharmacists criticised the standard remuneration for home medication reviews regardless of workload (AUS\$210.93 at 2 July 2015). Patients who are most in need of a home medication review and most complex were considered less likely to receive equally detailed reviews because pharmacists seemed unwilling to substantially extend the review duration without additional remuneration.

Potential enablers for improving the quality of care for patients with multimorbidity are presented in Box 2. Issues around team structure, electronic health and IT, proper resourcing and generation of better evidence were prominent.

### Discussion

This study provides a comprehensive account of the challenges for healthcare teams in attempting to optimise medication-related aspects of multimorbidity management. While many previous studies identify shortcomings with care for community-dwelling patients with multimorbidity, our findings provide a new multidisciplinary and system-wide perspective. Some challenges with medication use related specifically to potentially inappropriate polypharmacy (e.g. unnecessary adverse outcomes), while others had general relevance to polypharmacy (e.g. difficulty with medication reconciliation). Widespread personal reluctance to assume the responsibilities of multimorbidity management

and poor coordination of care was the key challenge identified from a team perspective. Only GPs asserted their responsibility for ensuring care coordination among patients with multimorbidity but often could not meet the relevant responsibilities due to workload pressure and poor communication from the hospital.

Despite growing consensus about the value of patient-centred care and stepwise management of multimorbidity [14], our findings suggest that considerable system-wide implementation gaps remain. The lack of individuals systematically taking responsibility for key aspects of multimorbidity care and the absence of coordinated care emerged as dominant issues. Addressing these issues is not emphasised in AGS guidelines. The Ariadne principles were published subsequent to our research, with extensive input from experts internationally [22], and build upon AGS principles to make recommendations about multimorbidity management with specific reference to primary care. Care coordination and the effects of referral on burden of treatment are given considerable emphasis in the Ariadne statement, possibly validating our decision to add a domain around care coordination.

Findings such as reluctance to ‘interfere’ with prescribing by other HCPs, resulting in treatment inertia, and incomplete medical history may disproportionately affect patients with multimorbidity because they are more likely to require multiple prescribers. Participants relied on patient recall for medical histories, which may be less reliable for more complex multimorbid cases. Likewise, HCPs appeared to restrict their focus of care to acute presenting issues as a means of avoiding complex multimorbidity challenges related to inadequate documentation of care or ambiguity around management decisions.

Previous research has explored perspectives of GPs and practice nurses regarding multimorbidity [8] and to a lesser

### Box 2. Recommendations made by healthcare professionals to improve care for patients with multimorbidity and polypharmacy

Working as a close healthcare team and removing the hierarchical structure that puts specialists above generalists.

To overcome the time constraints of medical consultations, nurses reported their willingness to continue working closely with patients to help them prioritise problems and empowering them to take responsibility for their conditions.

Geriatricians recommended greater family involvement to elicit patients’ problems and preferences and ensure that information is communicated correctly to prescribers and the patient.

Most HCPs expressed the view that pharmacists could play a bigger role in continuously reinforcing information to patients in both the hospital and the community setting.

Community pharmacists mentioned they are ideally situated to reinforce information as the last in line before patients are given medications but needed to take more responsibility to ensure delivery of information with every script.

Practical suggestions were raised to overcome the shortcomings of clinical guidelines. These include: addition of warning sections in every guideline detailing if extra attention should be paid when patients are above a certain age or when certain comorbidities exist; software programmes to send out warnings about, e.g. renal impairment, anticholinergic load or interactions; an extension of the evidence base with numbers needed to treat or risks versus benefits in this specific patient population.

More involvement of the hospital pharmacists was identified as helpful for facilitating faster processing of medication lists at discharge. Another highlighted enabler to overcome the problems in transition of care was the development and improvement of communication systems, including the use of e-health systems. To overcome the lack of optimisation of care plans by prescribers, participating GPs tended to refer patients to pharmacists for a medication review when they use a certain number of medications, when optimisation of medication regimens seems necessary or when patients are confused or in need of education about their medications.

HCPs pointed out that there needs to be one key carer who should be involved in optimising care plans and coordination of care.

In some of the explored practices in rural areas, nurses were involved in identifying patients to relieve the burden for GPs.

extent those of pharmacists and hospital physicians [15, 18]. Our findings add an important system-wide and multidisciplinary perspective. For example, seeking the view of multiple HCPs allowed an understanding of how the absence of coordination or leadership led to general inaction on multimorbidity. These problems are largely not amenable to resolution by individual HCPs. They need macrosystem-level changes for guideline implementation to support clinical teams. Recent initiatives such as the Australian Deprescribing Network may provide necessary leadership.

Primary care capacity to accommodate the needs of patients with multimorbidity and polypharmacy must be increased in light of the growing prevalence of this patient group [23]. Overall, the evidence base for interventions to improve management of multimorbidity is limited [13]. A systematic review posits that multifaceted organisational interventions involving dedicated care coordinators may be beneficial, but these benefits appear more clearly established for the management of specific comorbidities rather than general management of multimorbidity [13]. Our participants recommended the appointment of care coordinators to facilitate better communication between settings, an innovation that seems both feasible and effective in primary care [24] and a preferred option for older people with multimorbidity [7].

Our study suggests that pharmacist-delivered clinical medication review may be acceptable to support patient coordination from a medication perspective, but remuneration systems may require amendment to optimise care of complex cases. Studies exploring health outcomes following medication reviews have conflicting results [25], possibly explained by variation in the interventions and patient groups investigated. Interestingly, our participants did not cite examples of other available services potentially suited to addressing polypharmacy. Options included geriatrician-led comprehensive geriatric assessment [26], GP health assessments for people aged 75 years and older [27] and home nursing programmes.

Patients' experiences of models for multimorbidity management also remain poorly understood and warrant extensive exploration for health system redesign [6]. In keeping with literature, patient preferences and capacity to implement recommendations did not appear to strongly influence HCPs where clinical uncertainty exists as to the preferred course of action [28]. Our findings that patient difficulties, concerns and conflicting prescriber instructions more commonly become apparent in downstream settings during discussions with other HCPs have been reported previously [29]. Developing mechanisms to ensure that prescribers have the resources, skills and motivation to engage patients at the point of making treatment decisions might therefore deliver more efficient healthcare processes as well as improving patient-centeredness.

### Strengths and limitations

Further research is needed to investigate the generalisability of our findings and system-wide strategies needed to promote

the uptake of best practice for multimorbidity management. This is particularly relevant in light of widely varying models for care and care coordination, both in Australia and internationally. In line with the qualitative methodology, sampling strategy was designed to achieve a maximum variation of participants rather than being numerically representative. The pharmacy background of the interviewer might have biased the direction of conversations or promoted socially desirable responses regarding pharmacist-delivered services.

In conclusion, participants perceived multimorbidity management including medication use as important but it was typically relegated to a secondary priority in the face of more acute patient needs. Interprofessional communication seemed to be better coordinated within hospitals but less likely to focus on the ongoing patient needs compared with primary care. GPs were concerned by continuity of care, but time pressures and siloed care appeared to inhibit translation into practice. System-wide initiatives to resource care coordination may support leadership and increase capacity in this area.

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### Key points

- Multimorbidity is acknowledged by healthcare professionals as important but acute issues take priority more often than not.
- Healthcare professionals do not regularly use recommended strategies for optimising management of multimorbidity.
- The inherently complex nature of multimorbidity increases potential for communication problems and inadequately resourced care.
- Poorly defined roles and responsibilities for the management of multimorbidity engender reluctance to assume clinical leadership.

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### Authors' contributions

All authors made significant contributions to the study concept and design, and reviewed several manuscript drafts. B. B. conducted all interviews. B.B. and H.A. independently coded data, and K.P.M.N. facilitated resolution of coding issues. B.B., K.P.M.N. and H.A. led the initial drafting of the paper.

### Conflicts of interest

None declared.



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# How empowering is hospital care for older people with advanced disease? Barriers and facilitators from a cross-national ethnography in England, Ireland and the USA

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## Abstract

**Background:** patient empowerment, through which patients become self-determining agents with some control over their health and healthcare, is a common theme across health policies globally. Most care for older people is in the acute setting, but there is little evidence to inform the delivery of empowering hospital care.

**Objective:** we aimed to explore challenges to and facilitators of empowerment among older people with advanced disease in hospital, and the impact of palliative care.

**Methods:** we conducted an ethnography in six hospitals in England, Ireland and the USA. The ethnography involved: interviews with patients aged  $\geq 65$ , informal caregivers, specialist palliative care (SPC) staff and other clinicians who cared for older adults with advanced disease, and fieldwork. Data were analysed using directed thematic analysis.

**Results:** analysis of 91 interviews and 340 h of observational data revealed substantial challenges to empowerment: poor communication and information provision, combined with routinised and fragmented inpatient care, restricted patients' self-efficacy, self-management, choice and decision-making. Information and knowledge were often necessary for empowerment, but not sufficient: empowerment depended on patient-centredness being enacted at an organisational and staff level. SPC facilitated empowerment by prioritising patient-centred care, tailored communication and information provision, and the support of other clinicians.

**Conclusions:** empowering older people in the acute setting requires changes throughout the health system. Facilitators of empowerment include excellent staff–patient communication, patient-centred, relational care, an organisational focus on patient experience rather than throughput, and appropriate access to SPC. Findings have relevance for many high- and middle-income countries with a growing population of older patients with advanced disease.

**Keywords:** empowerment, inpatients, hospitals, aged, palliative care, older people

## Background

Patient empowerment is now embedded within healthcare policy globally [1–4]. Tools to measure patient empowerment have been developed [5], and there is evidence it is associated with more cost-effective use of health services [6], healthier behaviours [7], and improved quality of life and clinical outcomes [8]. Consequently, patient empowerment may help health systems cope with the growing burden of chronic disease [9].

Patient empowerment is often poorly defined [10], but theoretical and empirical research has identified its specific features. Empowerment is a process through which patients become self-determining agents with some control over their own health and healthcare, rather than being passive recipients of healthcare [11]. Empowered patients exhibit self-efficacy (confidence in their ability to exert control) and engage with clinicians, make decisions and manage their illness in line with their preferences and values [8]. Properly defined, patient empowerment is determined by the patient, not the clinician: empowerment relates to the extent to which patients' decision-making and engagement meet their own preferences and values [10, 12], not an externally stipulated level of engagement or type of decision-making involvement, as is sometimes suggested [13].

Current research on empowerment has focussed on community-based interventions [8], not acute care settings. Yet hospitals are the primary location of care for the growing population of older patients, many of whom have long-term conditions, multiple comorbidities and complex needs [14]. We aimed to identify and explore challenges to and facilitators of empowerment for older adults with progressive, life-limiting disease in inpatient settings in England, Ireland and the USA. Empowerment is a core principle of palliative care, which prioritises attention to patients' preferred level of involvement in decision-making. As a secondary aim, we therefore explored the impact of inpatient specialist palliative care (SPC) involvement on patient empowerment.

## Methods

### Design

As part of a study examining end of life care, we conducted an international ethnography in London (England), Dublin (Ireland) and San Francisco (USA). We conducted in-depth interviews with patients with advanced disease, family caregivers, SPC staff and other health professionals caring for older adults with advanced disease in hospital settings, and fieldwork (participant and general observation and collection of artefacts).

### Setting

The study reported here was conducted in 2012–2014 in six urban university hospitals, three in England (two of

which were part of the same administrative trust), two in Ireland and one in the USA. The study was component 2 of International Access, Rights and Empowerment (IARE), a mixed-methods study examining palliative care for older people; further details regarding IARE are available at <http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/buildcare/iare.aspx>. We selected these countries as all face the challenges of an ageing population and have integrated palliative care within their health systems, yet do so via different approaches to the provision of healthcare. They are also committed to patient empowerment as a cornerstone of healthcare [2–4]. Please see Appendix 1 in the supplementary data available in *Age and Ageing* online on the journal website for details of the participating hospitals <http://www.ageing.oxfordjournals.org/>. Ethical approvals were obtained [NRES: 12/L0/0044; Ireland: 1/378/1456; 12/07; USA: 13-1099].

### Participants and sampling

Participants were the following: patients, unpaid caregivers (family members or close friends), SPC staff and other hospital clinicians who cared for older adults with advanced disease but whose substantive role was to provide a service other than palliative care. Eligible patients were English-speaking,  $\geq 65$  years, hospitalised for  $\geq 24$  h, receiving SPC and able to complete an interview. Patients in England and Ireland were recruited consecutively through component 1 of the IARE study, which had the same eligibility criteria. Each patient who participated in the survey was invited for interview, until data saturation. Purposive sampling (by patient age, diagnosis and gender), guided by a sampling frame, was used in the USA as the larger survey was not conducted in San Francisco.

Eligible caregivers were English-speaking, cared for a patient  $\geq 65$  years who had been hospitalised for  $\geq 24$  h and was receiving SPC, and were able to complete an interview. Patients interviewed were asked if they wished to nominate an unpaid caregiver for interview; if so, the caregiver was also invited to participate. In addition, caregivers of patients who were too unwell to take part or did not speak English were also interviewed; these were identified by clinical staff and researchers.

Theoretical sampling, on the basis of emerging findings and the research question, was used to select staff to invite for participant observation and/or interview, ethnographic artefacts and locations for general observation. Palliative care staff of different professions were approached initially, followed by other staff who cared for older patients with advanced disease, who may have different perspectives on patient empowerment. Clinical members of the project team based at the participating sites introduced researchers to potential staff participants via email or face to face. In line with ethnographic methods, the artefacts collected were man-made objects which provided information about the

culture of their creators and users and were relevant to the study aims.

Data collection continued until data saturation [15], i.e. no new themes were emerging from the data and the research team judged a rich account of patient empowerment at each of the sites to have been obtained.

## Data collection

Experienced qualitative researchers (M.R.S., B.J. and L.E.S.) collected the data. Interviews were guided by semi-structured interview schedules (Box 1), and were face to face, except one caregiver interview conducted by telephone as this was more convenient for her. Interviews were audio

**Table 1.** Characteristics of the 26 patients and 32 unpaid caregivers interviewed for the study

	England	Ireland	USA	All countries
Patients, <i>n</i>	10	10	6	26
Sex (male/female)	4/6	7/3	3/3	14/12
Age: years; median (range)	70 (65–85)	70 (65–82)	74 (67–81)	70 (65–85)
Marital or spousal status				
Married or with a partner	2	4	4	10
Widowed	4	3	1	8
Divorced or separated	3	1	1	5
Single	1	2	0	3
Living situation				
Alone	5	5	1	11
With spouse and/or children, with others	5	5	5	15
Has a primary caregiver (yes/no)	9/1	6/4	6/0	21/5
Diagnosis group				
Cancer	7	9	4	20
Lung and respiratory	1	2	0	3
Breast	0	1	1	2
Genitourinary	2	3	1	6
Digestive	1	2	2	5
Other	3	1	0	4
Non-cancer	3	1	2	6
Education				
Did not go to school or pre-primary	0	3	0	3
Primary	0	2	0	2
Secondary or higher	10	5	6	21
Race				
White	9	10	3	22
Black	0	0	0	0
All other races	1	0	3	4
Religious (yes/no) <sup>a</sup>	5/5	8/2	3/2	16/9
Financial hardship				
Living comfortably on present income	5	3	4	12
Coping on present income	3	5	1	9
Difficult or very difficult on present income	2	2	1	5
Unpaid caregivers, <i>n</i>	10	11	11	32
Sex (male/female)	5/5	4/7	1/10	10/22
Age: years; median (range) <sup>b</sup>	61 (23–68)	52 (30–63)	54 (34–84)	53 (23–84)
Relationship to patient				
Spouse or partner	2	4	5	11
Son or daughter	6	5	5	16
Brother, sister or other relative	0	2	1	3
Friend or neighbour	2	0	0	2
Working status				
Working	4	7	4	15
Student or unemployed	1	4	1	6
Pensioned	5	0	6	11
Race				
White	9	11	4	24
Black	1	0	1	2
All other races	0	0	6	6
Religious (yes/no) <sup>b</sup>	3/6	6/5	10/1	19/12

<sup>a</sup>Data missing for one participant in the USA (preferred not to say).

<sup>b</sup>Data missing for one participant in England (preferred not to say). Education was assessed with ISCED (International Standard Classification of Education); race was assessed in accordance with Ethnic group statistics: a guide for the collection and classification of ethnicity data [16] in England and Ireland; and Guidance for industry: collection of race and ethnicity data in clinical trials [17] in the USA.

**Box 1. Interview schedule**

Participant group	Topics in interview schedule
Patients	Overall impressions of hospital care, Engagement in care (e.g. preparation for palliative care consultations), How they access information, How clinicians convey information, Information availability and adequacy in hospital, Preferences regarding involvement in clinical decision-making and extent to which these have been met, Advice received from clinicians and how easy it has been to follow, Independence and dependence in hospital setting, Meaning of empowerment, What makes them feel empowered/disempowered in hospital, How empowering and disempowering palliative care has been
Unpaid caregivers	Account of patient's time in the hospital, Experience of care in the hospital, Experiences accessing care (including inpatient SPC) here compared with other settings, Experience of the hospital system, Barriers to accessing care, What has worked well in hospital, What has not worked so well/could be improved
SPC providers	Summary of career to date, training, patients worked with and role, Organisation and delivery of SPC in the hospital, Referral processes and their adequacy, Barriers and facilitators of accessing SPC, Meaning of patient empowerment, How care empowers/disempowers patients
Hospital clinicians who care for older adults with advanced disease but are not specialists in palliative care	Summary of career to date, training, patients worked with and role, Understanding of and training in palliative care, Experiences of working with the SPC team, Referral processes and their adequacy, Barriers and facilitators of accessing SPC, Meaning of patient empowerment, How care empowers/disempowers patients

SPC = specialist palliative care

recorded and transcribed by a professional transcriber, except for one staff interview in which detailed notes were taken as the participant preferred not to be recorded. Patients and caregivers were interviewed separately. Informed consent was obtained prior to interview.

Participant observation was conducted by following and observing SPC and other staff caring for patients with advanced disease. Researchers had minimal contact with patients and were introduced to them as researchers working in the hospital. General observation was conducted in multidisciplinary meetings and wards providing care for this population, by agreement of the ward managers and other clinical leads. All observation was recorded in detailed field notes, anonymised prior to analysis. Artefacts were anonymised and scanned.

**Analysis**

Interview transcripts and fieldwork data (field notes and artefacts) were imported into NVivo v10.0 for analysis. Directed thematic analysis [18], concurrent with data collection, was used to identify instances and reports of challenges to and facilitators of patient empowerment. Data analysis occurred in four steps: (i) *Analysis by site*: using deductive and inductive line-by-line coding, coding frames were constructed for each of the five data sets (patient, caregiver, SPC and other staff interviews, plus fieldwork data). Deductive coding was informed by Aujoulat et al.'s conception of empowerment as involving both taking control of disease/treatment and relinquishing control so as to integrate illness [19]. This reflects the therapeutic needs of our population [20]. (ii) *Narrative summaries* were produced for each data set at each site and tabulated alongside themes

and sub-themes, identifying challenges and facilitators. (iii) *Integration of site-level findings*: country-level findings were compared and synthesised: themes across data sets were charted by site, categorised and tabulated to summarise cross-site findings. (iv) *A cross-site narrative summary* was developed, drawing out the main findings and highlighting similarities and differences. Illustrative data extracts were tagged using ID codes (Box 2).

Triangulation and deviant case analyses were used to enrich findings, inform sampling and enhance credibility. Regular meetings to discuss data collection, sampling and emerging findings and refine analysis enhanced reflexivity and ensured consistency.

**Results**

**Participants, observations and artefacts**

Twenty-six patients and 32 caregivers were interviewed (Table 1). There were 25 patient–carer dyads interviewed; 1 patient nominated 2 carers who both participated; 6 carers participated on their own. Thirty-three staff were interviewed: 11 doctors, 15 nurses and 7 from other professions. Most (66%) had ≥10 years of experience. Please see Appendix 2 in the supplementary data available in *Age and Ageing* online on the journal website for details of staff participants <http://www.ageing.oxfordjournals.org/>. Of note, 340 h of observational data and 50 artefacts were collected (including consult lists, leaflets for hospital users, quality assessment documentation and photos of wards). Please see Appendix 3 in the supplementary data available in *Age and Ageing* online on the journal website for details of the observational data <http://www.ageing.oxfordjournals.org/>. The project team judged that saturation had been reached.

**Box 2. Conventions used to assign data ID codes**

ID element	Convention
Location code	L = London; D = Dublin; SF = San Francisco
Participant code	P = patient; UC = unpaid caregiver; G = generalist end of life care provider (provides care for older adults with advanced disease but is not a specialist in palliative care); SPC = specialist palliative care provider; D = doctor; N = nurse; O = allied health or another type of staff other than a physician or nurse (e.g. chaplain, social worker, therapist)
Observational data code	PO = participant observation; MDT = multidisciplinary observation; GO = general observation
Number	Consecutive numbers assigned for each participant interviewed, by city and participant group. Observational data are dated rather than numbered

**Findings**

Three interrelated themes capture the cross-site findings: Staff–patient communication and information provision; Hospital environment, systems and resources; and Attitudes to patient involvement and the tone of care. Please see Appendices 4–6 in the supplementary data available in *Age and Ageing* online on the journal website for challenges to and facilitators of empowerment by site and data set <http://www.ageing.oxfordjournals.org/>.

**Staff–patient communication and information provision***Clinicians' inadequate communication skills and deprioritisation of relational care hinder patients' self-management*

At all sites, a lack of information from staff and poor communication with staff, particularly regarding end of life issues, prevented patients from taking a more active role in managing their disease and treatment, making decisions and planning for the future: 'The whole journey... we've felt in the dark... there's been no long-term plan, no guided plan, no information actually specifically provided for us' (LUC07). Poor continuity and coordination of care ('Trying to treat people like pieces of metal in a factory' (LP08)) was evident and made communication difficult. Researchers documented the large numbers of staff entering and leaving patients' rooms/berths, with many patients unsure of their role and which teams they represented. A caregiver remarked: 'What is lacking is continuity and a place that you can... anchor your questions... There was information from the pathologist, general medicine, surgery and three different ICUs [intensive care units] on three different occasions and with a new nurse every twelve hours... we're talking 120 nurses in the time he was there' (SFUC10). Patients at all three sites feared burdening staff or for cultural reasons did not want to ask for help ('I'm from the old school. We didn't ask for things, they were either given to you or you did without them' (DP06)), so if information and support were not provided proactively by staff then patients often missed out. Information provision needed to be tailored to the individual: one patient in London did not want full information ('If I need more information I could get it, but I'm happy with what information I've got' (LP01)), and

in Dublin some patients and families preferred to use euphemisms than communicate directly regarding diagnosis and prognosis ('They talk about the lump, the bump, the shadow' (DSPCN01)). In San Francisco, staff reported that a lack of translators hindered communication with patients and families.

Poor communication and information provision was related both to inadequate communication skills among some healthcare professionals ('The staff have been very anxious when they've someone dying on the ward; they'd be afraid of what questions family would ask' (DGN05)), and the extent to which staff prioritised providing relational care in busy inpatient environments: 'Every moment, they are prioritising how to use their time most wisely' (SFGD03). Primary doctors, SPC providers and nurses alike reported that nurses and SPC staff generally had more time and inclination than other doctors to establish relationships with patients and discuss their wishes: 'I hate to say this, but my relationship with patients is far more superficial than it was when I was a medical student.. it's amazing what [the nurse practitioners] know that I have no clue' (SFGD03). Some staff avoided, delegated or deprioritised conversations with patients with advanced illness owing to personal discomfort discussing death and dying or because, in the curative culture of hospital care, death is perceived as a failure: 'I think they sort of feel they've failed, so it's sort of like they don't want to talk to you' (LUC04). The emphasis on curative care and devaluing of communication were reportedly reflected in medical education: 'Their model of training is very much "treat, treat, treat"' (DGN03); '[Spending time on communication] is not rewarded [or] seen as valuable because it doesn't fit in with the ACGME [Accreditation Council for Graduate Medical Education] guidelines' (SFGD03).

*In the USA, health financing and reimbursement disincentivise good communication*

In San Francisco, health financing and reimbursement compounded the problem, preventing good staff–patient communication: 'Right now with our fee-for-service payment system, if you do procedures, you do something with a patient, you get reimbursed more heavily than if you just talk to them' (SFGD01). A perceived consequence was clinicians valuing and prioritising interventionist care over

relational care, and lucrative care being placed at the top of the hospital hierarchy: ‘The specialties that are going to make a lot of money for the hospital, the hospital has to treat them better at some level because that’s where the revenue is... Orthopaedics, neurosurgery’ (SFSPCD01).

### *Open, tailored communication facilitates collaborative healthcare and decision-making*

Conversely, effective staff–patient communication in line with patient wishes universally supported empowerment by enabling collaborative relationships and facilitating informed decision-making. A patient described what good communication looked like: ‘They come in and they sit down... and oftentimes they will put communication before medical [issues]. It is more total. They want to know the intimacies of you’ (SFP01). In London, practices promoting open communication were evident and appreciated by patients: ‘One of the good things now is you can actually see your notes... at one time they stayed secret even though it concerned you and your illness and your body’ (LP09). Staff across the sites valued communication skills training: ‘It gave us a language to be able to speak, because before, you might have been sort of thinking oh, how am I going to approach this, do I use this word...? People felt very uncomfortable’ (DGN03). Palliative care specialists were recognised as experts in communication and patient and family involvement, ‘explaining things very gently so that patients really understand, removing any jargon and removing complex medical words... checking understanding as well’ (LGN05). The SPC teams’ education and support of staff from other specialities played an important role in enabling good staff–patient communication: ‘They are present as a coach... a support network... It is very positive from a learning, experiential standpoint’ (SFGD01).

### **Hospital environment, systems and resources**

#### *Busy, routinised inpatient care restricts patients’ choice and control*

Hospitals are ‘bewildering’ (SFP06) places, ‘where it’s all about getting patients in, getting them treated, getting them out’ (DGN03), and staff are ‘running, running all day’ (DGO06). Inpatient care follows institutionalised routines, ‘a fixed pathway that the patient is on...: op day; post-op day, this is what you do; day two post-op, this is what you do’ (LSPCN05), which conflict with the needs of patients with advanced disease (‘Things happen... it’s not a linear process at all’ (LSPCN05)). Patients with comorbidities were perceived as a poor fit with the hospital system owing to the complex and time-consuming nature of their care: ‘[Non-SPC doctor] remarked that the more complex the illness, the less forward people are to fixing it: “They fix one problem but then find 10 others, [so] people often don’t go and visit them at all. Nothing is done for the people who are most in need”’ (LGPO, 13 May 2014). In San Francisco, the use of highly technological interventions

such as high flow nasal cannula was reportedly routine in the ICU. This impacted on empowerment by restricting patients to specific wards, in which nurses had not received palliative care training, and limiting discharge options: ‘[Patients] can’t leave the hospital because they have that technology in place, because they can’t be transported. And even if they could, there’s nowhere that would be able to provide it other than here’ (SFSPCD01). At all sites, a lack of space and privacy impacted on patient empowerment by preventing therapeutic communication: ‘To be told that information in a ward with six other people with curtains around... was quite horrific’ (DUC08).

#### *Patients’ lack of control and choice at discharge*

Observations of team meetings and patient care across the sites highlighted an institutional emphasis on freeing up beds as quickly as possible, which could be depersonalising for patients: ‘They want to get you out within four hours and whether you should be out of casualty in four hours or not doesn’t matter... they shove you on any ward’ (LUC04); ‘To really pay attention to what the issues are and the problems are, that’s going to get in the way of their goal of... ‘let’s discharge everybody by 11 o’clock”’ (SFSPCN04). Experiences of discharge demonstrated patients’ and families’ lack of power: ‘It’s as if you’ve fallen off the end of a chute... It feels as if they don’t care about you anymore, and you’re shoved out the door’ (LP08). Patient wishes were just one of several factors taken into account in planning discharge: ‘It is a kind of a three way process. [One,] it is what the patient wants... Two, it is the needs required to care for the patient safely and then three, the insurance and financial piece’ (SFGO07). In the USA, the private insurance model curtailed empowerment by restricting treatment choices and access to care for patients with limited insurance.

#### *Continuous, flexible care provides patients with choice and facilitates communication*

Strategies to counter the fragmentation of care, such as staff rostering to support continuous care and having a key contact person to signpost and organise care, were supportive of patient empowerment. Nurses played an important role in maintaining continuity: ‘keeping track of the big picture of what’s going on with that patient... as the different residents rotate through’ (SFGN02). Flexibility in care was also important; for example, in London patients could choose to be seen in the SPC clinic or at home, providing the patient with some control. Appropriate referral to SPC contributed to empowerment by providing access to specialists in care coordination: ‘The palliative team were there the next day... making arrangements in terms of social workers, making assessments... Whenever I called, they were pretty much instantly available... Oh my God, I can’t tell you the difference that makes in helping you cope with everything’ (LUC07).

### Attitudes to patient involvement and the tone of care

#### *Simplistic attitudes to patient involvement disempower patients by depersonalising care*

The way staff approached patient involvement could be disempowering for patients. A simplistic over-emphasis of patient autonomy by clinicians was described by SPC staff in San Francisco: 'In the US... you really, really get it hammered into you that autonomy is the dominant principle that you want to really respect' (SFSPCD01). This was perceived to result in patients and families having to make difficult clinical decisions (e.g. regarding withdrawing aggressive treatment) with little guidance or support from their clinicians: 'I feel like we give people too many options... I feel exhausted just hearing everything... We ask too much of families' (SFSPCO03). One patient in London exemplified the need for decision-making involvement to be individualised rather than prescriptive, reporting that, for him, 'You feel less in control and have less confidence when... medical practitioners are coming and asking you what you would like for your care' (LP05).

#### *Patient-centred, holistic care empowers patients to participate in their care*

Across the sites, observational and interview data demonstrated how a patient-centred, holistic approach empowered patients by putting their perspectives, wishes and needs in relation to decision-making and information provision at the heart of care: 'You are consulted and your decisions are valid, and... your own perspective on your illness' (LUC07). A commitment to patient-centred care at an organisational and individual clinician level provided patients with the power to participate in their healthcare by legitimising a focus on patients as whole people rather than as mere illnesses or recipients of treatment. Regular, non-hierarchical and interdisciplinary meetings created the time and space for staff to explore patients' psychosocial concerns and end of life issues, helping to ensure care was holistic: 'We have a meeting every week where we discuss our patients... everyone – from the therapies, nursing, doctors – [is] there. Everyone has an opinion to be voiced and you're allowed to voice it' (LGD04).

SPC providers were observed empowering patients by acting as patient advocates, and emphasised in interviews their role in ensuring treatment was in line with patient goals: 'I'm the patient's advocate... if somebody is suffering I have a responsibility and a duty to help alleviate that suffering' (DSPCN03). Delays or barriers to accessing palliative care—for example, due to clinicians' perception that referral to SPC was 'a bit of failure' (LSPCN02) or 'a demonstration of.. hopelessness' (SFGD04)—prevented patients accessing the SPC teams' patient-centred approach. Failures in patient-centredness also occurred due to factors outside clinicians' control, with negative consequences for patients: 'Somebody who is palliative care, they don't

necessarily always get the attention they need, because the nurse is taking handover for her five [patients] or she is transferring them, or if we are short-staffed... ' (LGN02).

Specific interventions at the sites supported empowerment by facilitating patient-centred care. In London, 'dignity ambassadors' throughout the hospital trust promoted 'dignity and respect for patients and carers... troubleshoot[ing] to challenge poor practice' (LSPCPO 14.08.13). In San Francisco, photo cards, whiteboards and leaflets (please see Appendix 7 in the supplementary data available in *Age and Ageing* online on the journal website for an example <http://www.ageing.oxfordjournals.org/>) were used to personalise care and inform patients, families and staff: '[We have] photo cards to give to people so that they can see what we look like. We have whiteboards in the room. We write our names and goals... [get] the medical intervention and plan all... in one spot for people to visualise' (SFGO07). In Dublin, staff reported that quality improvement initiatives focussed on promoting patient-centredness in end of life care had system-wide benefits.

### Discussion

This study, the first cross-national examination of the empowerment of older patients in hospital settings, identifies significant challenges to patient empowerment. Across the sites, patients' participation in their care and self-management of their illness and treatment depended on communication, information and support tailored to their preferences, but hospital staff did not always meet their needs for relationship and information. Challenges in this area included poor communication skills among some clinicians, fragmented care and a deprioritisation of relational care. Yet while information and knowledge were for many patients necessary for empowerment, we found that they were not sufficient: fully participating in healthcare requires the power to do so [21]. In our ethnography, the power to participate depended on the principles of patient-centredness being enacted in the organisations, on the wards and by frontline staff. Efforts to support patient empowerment therefore cannot come from clinicians alone; the health system often prevents staff from providing the good-quality care they would like to give [22], and staff can be disempowered by the structures and cultures of the organisations in which they work. The way institutional routines and priorities disempower patients was particularly evident in relation to discharge. In the USA, health financing and reimbursement further restricted access to certain types of care and support, challenging patients' sense of self-efficacy. Across the sites, SPC made a positive difference to empowerment by being patient-centred and holistic, focussing on communication and information provision, coordinating a myriad of service providers, and training and supporting other staff. While there were examples of excellent communication skills among non-SPC staff, overall SPC staff were better at communicating and prioritising relational care. This is likely to be due to staff training, the philosophy or culture associated with specific specialisms, and organisational expectations of staff



(including time allocation), as well as individual staff factors. Our finding that good staff–patient communication and information provision were fundamental supports other studies of patient empowerment and involvement highlighting the importance of trusting, therapeutic relationships with staff, having enough time during consultations and acquiring knowledge [10, 17, 23]. We found a minority of patients did not want full information or to play an active role in decision-making; this aligns with other studies [24]. These patients may participate in care through discussions with clinicians and receiving information in line with their wishes rather than by directing decision-making [25]. Empowerment in this context means patients exercising their right not to be involved in decision-making; this should be recognised in models of shared decision-making. We also found that over-emphasising autonomy in clinical care could actually disempower patients by forcing unwanted decision-making on them and their families: upholding the principle of self-determination does not mean that patients and families should be left alone to decide what is best for them [10].

Our finding that continuity and coordination of care were poor concurs with Rothman and Wagner’s description of chronic disease care as a ‘poorly connected string’ of clinician–patient encounters [26]. The current organisational structure of hospitals, which emphasises medical specialisations and is oriented towards acute care, is unsuitable for patients with advanced or chronic disease [27]. Yet to say that hospitals are not the ‘right place’ for older people is wrong-headed; it is the hospital environment that should be changed, not the patient group [28]. Facilitators of empowerment identified in this study support the Institute of Medicine’s model of effective care as a collaborative process involving clear patient-provider communication, training and support to enable self-management, and coordinated, sustained follow-up [29]. Palliative care is central to translating this model [30], yet access to SPC is variable [31, 32]. The initiatives seen at the sites that are supportive of patient empowerment, such as the photo cards and leaflets used in San Francisco, could contribute to an empowerment tool kit for hospitals, subject to further research.

This study has both strengths and limitations. One of the strengths is the triangulation of multiple data sources to give a comprehensive picture of empowerment among patients with advanced disease. The observational and interview data complemented each other, with the former providing instances of empowering/disempowering care, and the latter enabling in-depth exploration of challenges to and facilitators of empowerment. However, we only interviewed patients receiving SPC, and challenges to empowerment faced by those not accessing SPC might be different from and perhaps more extensive than those we identified. As we recruited SPC staff to understand patient empowerment in advanced disease, it is possible that they were biased towards reporting the benefits of SPC, although the ways in which access to SPC could empower patients were also born out in patient, caregiver and generalist staff interviews and in observational data. Purposive sampling could have

been used at all sites rather than embedding patient recruitment in the larger survey in Ireland and England. While we achieved diversity in terms of patients’ marital status and living situation, our sample was predominantly white and had cancer. This reflects the palliative care population at the participating sites, but should be taken into account in judging the transferability of findings. Finally, we focussed on how hospital care empowers patients, not how patients empower themselves; this is an important topic for future research.

Across three high-income countries, there are significant, system-wide challenges to inpatient empowerment, including poor communication skills among clinicians, fragmented care and a deprioritisation of relational care. While information and knowledge are often necessary for empowerment, they are not sufficient: empowerment depends on patient-centredness being enacted in organisations and by staff. Facilitators of empowerment include improving staff–patient communication, prioritising patient-centred, relational care and ensuring appropriate access to SPC.

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### Key points

- In hospitals in three high-income countries, the empowerment of older people is threatened by poor communication skills among clinicians, fragmented care and a deprioritisation of relational care.
- Information and knowledge are often necessary for empowerment, but they are not sufficient.
- Empowering older people in the acute setting requires changes throughout the health system.
- Empowerment depends on good staff–patient communication, patient-centred care, an organisational focus on patient experience rather than throughput, and appropriate access to palliative care.

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### Supplementary data

Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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## Authors' contributions

B.A.D., I.J.H., C.N., P.L., S.M., D.M., R.S.M. and K.R. conceived the study. B.A.D. and I.J.H. oversaw the research internationally. C.N., K.R., R.S.M., S.Z.P., L.E.S., B.A.D. and I.H. oversaw the research at each site. L.E.S., B.A.D., M.S., B.J., L.K., K.T., C.P., S.dW-L., P.K. and S.Z.P. collected, managed and/or checked data. L.E.S., B.A.D., M.S., B.J., C.P., L.K. and K.R. analysed data. L.E.S. was responsible for cross-country analysis and conceived the idea for the paper. L.E.S. led on writing the paper, with input from all authors.

## Conflicts of interest

The authors declare that they have no competing interests.

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