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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. 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 ≥65, informal caregivers, specialist palliative care staff, and other clinicians who cared for older adults with advanced disease, and field work. Data were analysed using directed thematic analysis.

Results: Analysis of 91 interviews and 340 hours 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. Specialist palliative care 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, and appropriate access to specialist palliative care. Findings have relevance for many high- and middle-income countries with a growing population of older patients with advanced disease.

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 co-morbidities 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 field work (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 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: 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, ≥65 years,

hospitalised for ≥24 hours, 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 ≥65 years who had been hospitalised for ≥24 hours 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 (MS, BJ, LS) 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 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.

[INSERT BOX 1]

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 field work data (field notes and artefacts) were imported into NVivo v10.0 for analysis. Directed thematic analysis[16], concurrent with data collection, was used to identify instances and reports of challenges to and facilitators of patient empowerment. Data analysis occurred in 4 steps*:* 1) *Analysis by site:* Using deductive and inductive line-by-line coding, coding frames were constructed for each of the five datasets (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[17]. This reflects the therapeutic needs of our population[18]. (2) *Narrative summaries* were produced for each dataset at each site and tabulated alongside themes and sub-themes, identifying challenges and facilitators. (3) *Integration of site-level findings:* Country-level findings were compared and synthesised: themes across datasets were charted by site, categorised and tabulated to summarise cross-site findings. (4) *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).

[INSERT 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; one patient nominated two carers who both participated; 6 carers participated on their own. Thirty three staff were interviewed: 11 doctors, 15 nurses and seven from other professions. Most (66%) had ≥10 years of experience. Please see Appendix 2 in the supplementary data on the journal website for details of staff participants *http://www.ageing.oxfordjournals.org/*. 340 hours 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 on the journal website for details of the observational data http://www.ageing.oxfordjournals.org/. The project team judged that saturation had been reached.

[INSERT TABLE 1]

Findings

Three interrelated themes capture the cross-site findings: *Staff-patient communication and information; Hospital environment, systems and resources;* and *Attitudes to patient involvement and the tone of care.* Please see Appendix 4-6 in the supplementary data on the journal website for

challenges to and facilitators of empowerment by site and dataset *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).

<u>*In the USA, health financing and reimbursement disincentivise good communication*</u>

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, routinized 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 co-morbidities were perceived as a poor fit with the hospital system owing to the complex and time-consuming nature of their care: *'[NSPC 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, 13.05.2014). 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 care) 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 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 focused on promoting patient-centredness in end of life care had 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 health care requires the power to do so[19]. 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[20], 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, 21]. 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[22]. These patients may participate in care through discussions with clinicians and receiving information in line with their wishes rather than by directing decision-making[23]. 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 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[24]. The current organisational structure of hospitals, which emphasises medical specializations and is oriented towards acute care, is unsuitable for patients with advanced or chronic disease[25]. 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[26]. 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[27]. Palliative care is central to translating this model[28], yet access to SPC is variable[29, 30]. 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 focused 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 specialist palliative care.

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Authors' contributions: BD, IH, CN, PL, SM, DM, RM, KR conceived the study. BD and IH oversaw the research internationally. CN, KR, RM, SP, LS, BD and IH oversaw the research at each site. LS, BD, MS, BJ, LK, KT, CP, SdWL, PK and SP collected, managed and/or checked data. LS, BD, MS, BJ, CP, LK and KR analysed data. LS was responsible for cross-country analysis and conceived the idea for the paper. LS led on writing the paper, with input from all authors.

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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 information is conveyed by clinicians, 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 you feel empowered/disempowered in hospital, How empowering and disempowering has palliative care been
Unpaid caregivers	Account of patient's time in the hospital, Experience of care in the hospital, Experiences accessing care (including inpatient specialist palliative care) 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
Specialist palliative care providers	Summary of career to date, training, patients worked with and role, Organisation and delivery of specialist palliative care in the hospital, Referral processes and their adequacy, Barriers and facilitators of accessing specialist palliative care, Meaning of patient empowerment, How care empowers/disempowers patients

Hospital clinicians who care for older adults with advanced disease but whose substantive role is to provide a service other than 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 specialist palliative care team, Referral processes and their adequacy, Barriers and facilitators of accessing specialist palliative care, Meaning of patient empowerment, How care empowers/disempowers patients

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 = care provider for older adults with advanced disease whose substantive role is to provide a service other than palliative care (generalist in end of life care); SPC = specialist palliative care provider; D = doctor; N = nurse; O = allied health or another type of staff other than a physician or nurse (for example, chaplains, social workers, therapists)
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 is dated rather than numbered.

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

	UK	Ireland	USA	All countries
Patients n=	**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)*	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 n=	**10**	**11**	**11**	**32**
Sex (male/female)	5/5	4/7	1/10	10/22
Age: years; median (range)†	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)†	3/6	6/5	10/1	19/12

*****Data missing for one participant in the USA (preferred not to say). †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 (National Statistics, 2003) in England and Ireland; and Guidance for Industry: Collection of Race and Ethnicity Data in Clinical Trials (U.S. Department of Health and Human Services, 2005) in the USA.

Supplementary data

Appendix 1: Details of participating hospitals

1. All six participating hospitals provided acute and tertiary specialist services and had a consultant interdisciplinary SPC service.
2. The hospital and administrative trust (comprising two hospitals) in London had 974 and 1,175 beds respectively, an average length of stay (LOS) of six/four days, and 57,000/83,000 admissions.
3. The hospitals in Dublin had 600 and 820 beds each, an average LOS of nine days, and 21,000–25,000 annual admissions.
4. The 600-bed hospital in San Francisco had an average LOS of six days and 38,000 admissions.

Appendix 2: Characteristics of the 33 staff members interviewed by site

	UK	Ireland	USA	All countries
Specialist palliative care staff n=	**5**	**5**	**5***	**15**
Sex (male/female)	1/4	0/5	1/4	2/13
Professional group				
Doctor	1	1	2	4
Nurse	3	3	1	7
Other e.g., allied health professional	1	1	2	4
Years of experience				
≤10 years	2	3	0	5
>10 years	3	2	5	10
Generalist staff n=	**5**	**6**	**7**	**18**
Sex (male/female)	0/5	2/4	1/6	3/15
Professional group				
Doctor	1	2	4	7
Nurse	3	3	2	8

Other e.g., allied health professional	1	1	1	3
Specialty				
Internal/general medicine	2	0	2	4
Oncology	0	1	0	1
Gerontology	1	2	0	3
Urology	0	1	0	1
Cardiology	0	1	0	1
Renal	1	0	0	1
Dementia	1	0	0	1
General surgery	0	0	1	1
Heart failure & transplant	0	0	1	1
Hepatology & transplant	0	0	2	2
Patient services	0	1	1	2
Years of experience				
≤10 years	4	1	1	6
>10 years	1	5	6	12

* One staff member interviewed twice

Appendix 3: Details of observational data

	England	**Ireland**	**USA**	**Total**
Participants observed (staff types)	SPC staff: consultant, nurse, social worker, chaplain NSPC staff: consultants in elderly care, ward nurse, charge nurse, physiotherapist and occupational therapist in elderly acute medicine ward	SPC staff: registrar, consultant, clinical nurse specialist, social worker, occupational therapist, pharmacist NSPC staff: health failure clinical nurse specialist, heart failure consultant, consultant in geriatrics, nursing aide in geriatrics, member of COPD outreach team	SPC staff: nurse, consultant, chaplain, social worker, case manager NSPC staff: case manager, intensive care unit physician, intensive care unit nurse, haematological oncology physician, ward nurse, social worker, internal medicine physician	N/A
Number of hours of participant observation	70.5	85	69.25	224.75
Locations of non-participant observations	Elderly care wards, myeloma clinic, SPC multi-disciplinary meetings, palliative care research translation/ dissemination events, training course on end of life care for non-specialist palliative care providers	General wards, oncology ward, respiratory ward, outpatient clinic, multi-disciplinary meetings (SPC, geriatrics)	SPC team multidisciplinary meetings, intensive care unit ward round, haematological oncology ward round, internal medicine team meeting, case management meeting, neurological intensive care unit, ward nurses' station, palliative care training session for medical students, wards, family meeting	N/A
Number of hours of non-participant observation	29.75	45.5	39.5	114.75

Specialist palliative care (SPC), non-specialist palliative care (NSPC)

Appendix 4: Staff-patient communication and information provision: findings by site and dataset

Theme: Staff-patient communication and information provision		**London**	**Dublin**	**San Francisco**
Challenges to empowerment	Poor communication and information provision by HCPs: insensitivity, rushing, pushing an agenda, not listening to patients, avoidance of difficult conversations e.g. about prognosis, providing conflicting information, providing too much information too soon, not providing enough information	**✓ O, C**	**✓G, C**	**✓SPC, G, P, C**
	Poor coordination/continuity of care, fragmented care, frequent staff rotation, too many staff involved in care of one patient, patients not knowing staff, miscommunication between teams, conflicts of medical opinion	**✓SPC, P, C**	**✓SPC, O, P, C**	**✓ P, C, G, SPC**
	Patients/caregivers not wanting to burden staff, difficulty questioning/ communicating with authority	**✓P**	**✓SPC, P**	**✓C**
	HCPs lack of confidence/skills/training in communicating with patients with advanced disease and their families	**✓ SPC**	**✓SPC**	**✓SPC, G**
	HCPs' deprioritisation of communication/relational care		**✓C, SPC**	**✓ G, SPC**
	Curative focus of hospital care: HCPs' personal inability to accept deterioration and avoidance of patients/families as patient gets sicker/care is more complex, death seen as a failure, palliative care approach seen as 'giving up', focus on intervention/treatment	**✓G, SPC, O**	**✓O, SPC, G**	**✓SPC, G, C, O**
	Inadequate staffing levels, staff over-stretched, lack time	**✓G, O**	**✓P, G, SPC, O, C**	**✓G, SPC, O, P**
	Lack of/inadequate communication aids for non-English speaking patients e.g. translators			**✓G, O**

	Skills in end of life care (e.g. spending time talking to patients) not emphasised/ rewarded in medical education		✓**G**	✓**G**
	Heath financing and reimbursement system biased against talking with patients and families towards procedural care			✓**G**
Facilitators of empowerment	Good communication: HCPs explaining staff role, encouraging openness, exploring needs/preferences, honesty e.g. about limitations of care, not having an agenda, listening, inviting questions, providing opportunities for patients/families to speak, tailoring information provision to the individual	✓**P, G, SPC**	✓**SPC, G, O, P**	✓**SPC, O, P**
	HCPs have expertise in care for patients with advanced disease, and make enough time for communication and relational care	✓ **SPC, P**	✓**SPC, G, O, C**	✓ **SPC, G, P**
	Improving continuity of care and HCP communication visually (e.g. white boards, posters) or through staff rostering			✓**SPC, O, G**
	Specialist palliative care providers educating and supporting non-specialist palliative care providers in palliative care, communication and culturally complex care; non-specialists drawing on specialist team's expertise	✓**SPC, G**	✓**SPC, G**	✓**SPC, G, O**

HCP=health care professional; P=patient interview, C=unpaid caregiver interview, SPC=specialist palliative care provider interview, G=generalist (non-specialist palliative care provider) interview, O=observational data

Appendix 5: Hospital environment, systems and resources: findings by site and dataset

Theme 2: Hospital environment, systems and resources		**London**	**Dublin**	**San Francisco**
Challenges to empowerment	The environment hinders independence/control, is hierarchical, difficult to navigate, encourages compliance, makes patients vulnerable	✓**SPC, C**	✓**P, C, O, G, SPC**	✓**SPC, P, C**
	Lack of privacy and space (including shortage of beds), noisy	✓**C, P**	✓ **P, SPC, G, O, C**	✓**SPC, P**
	Hospital procedures, routines, rules and systems		✓**O**	✓**SPC**
	Evaluation of quality of care based on mortality statistics/patient throughput, not patient experience			✓**SPC**
	Emphasis on discharge and hospital discharge protocols/case management procedures	✓**C, SPC**	✓**O**	✓**SPC, P, G, O**
	Reliance on private insurance system with restrictions on accessing care			✓**SPC, G, O**
	Lack of access to/delayed access to specialist palliative care in hospital due to reluctant/late referral, curative focus of HCPs, medical consult model of specialist palliative care or over-stretched specialist team	✓**G, SPC**	✓**O, SPC**	✓**SPC, G**
Facilitators of empowerment	Well-resourced hospital with access to equipment to support needs and a peaceful, attentive environment	✓**C**	✓**C**	✓**P, O**
	Systems and initiatives that enable flexible, responsive, timely care	✓**O**		✓**O, G**
	Quality improvement initiatives focused patient satisfaction measures and palliative and end of life care		✓**G, C**	✓**SPC**

	Non-hierarchical, interdisciplinary MDMs which explore psychosocial and end of life issues	✓**O, G**	✓**O, G**	✓**G, SPC**
	Transparency and dignity-promoting initiatives	✓**P, O**		
	Appropriate, timely access to specialist palliative care	✓**SPC, G, P, C, O**	✓**G, C**	✓**SPC, P**

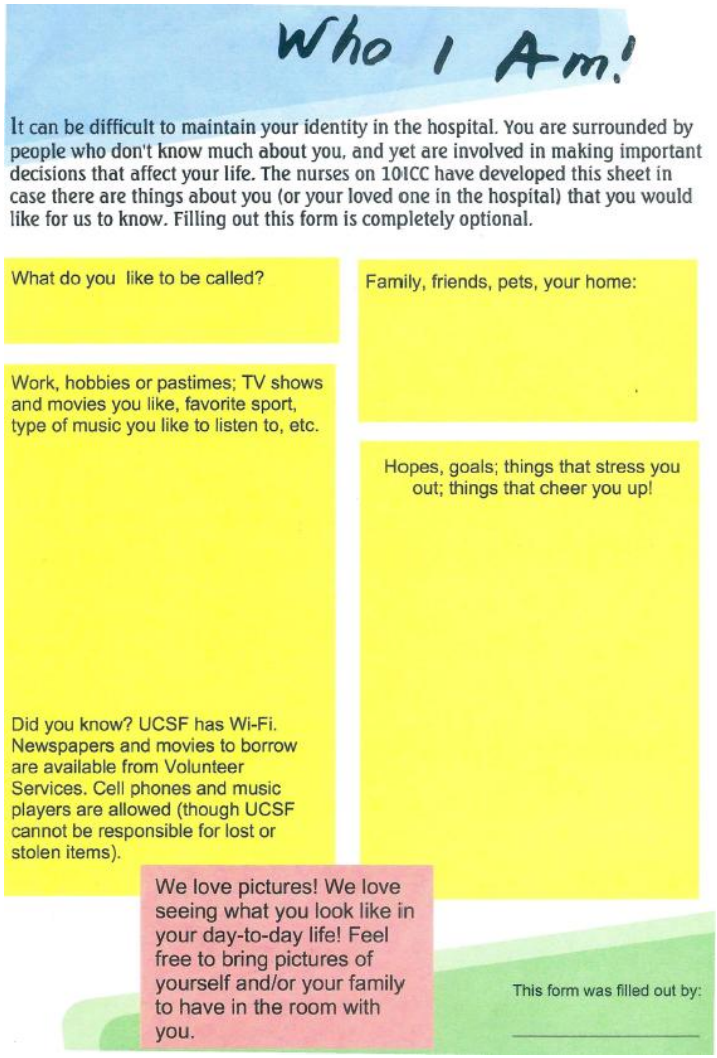
HCP=health care professional; P=patient interview, C=unpaid caregiver interview, SPC=specialist palliative care provider interview, G=generalist (non-specialist palliative care provider) interview, O=observational data, MDMs= multi-disciplinary team meetings

Appendix 6: Attitudes to patient involvement and the tone of care: findings by site and dataset

Theme 3: Attitudes to patient involvement and the tone of care		**London**	**Dublin**	**San Francisco**
Challenges to empowerment	Over-emphasis of patient autonomy means patients left to make decisions alone, HCPs are passive and defer to patient/withdraw from responsibility	✓ **P**		✓**SPC**
	Lack of patient-centred care, e.g. formulaic approach to care, HCPs not acknowledging what is important to patient or imposing own values, lack of respect for patient autonomy and dignity, complaints/concerns about care provision ignored/dismissed, HCPs dismissive of patient's attitude/fear	✓**C, P**	✓**O, C**	✓**C, G, O**
	Perception among service users that HCPs aren't adequately trained, are unreliable/too busy	✓**P, G**	✓**P, C, O**	✓ **C**
Facilitators of empowerment	Patient-centred, holistic care e.g. HCPs thinking beyond routines/tick boxes, focusing on quality of life, protecting patient dignity, respecting privacy, including patient and family as part of the team, providing kind, attentive care	✓**P, G, C, SPC, O**	✓**SPC**	✓**SPC, O**
	HCPs advocating for patient, protecting dignity, respecting preferences, goals and values, being attuned to changes in circumstances, facilitating patients to help themselves and be informed, promoting self-efficacy, respecting autonomy	✓**O**	✓**SPC, O**	✓**SPC, G, O**
	Perception among patients that they are acknowledged, respected and valued; patients feel comfortable asking for HCPs' help/time	✓**P**	✓**P**	✓**P**

HCP=health care professional; P=patient interview, C=unpaid caregiver interview, SPC=specialist palliative care provider interview, G=generalist (non-specialist palliative care provider) interview, O=observational data

Appendix 7: Artefact: leaflet collected from ward in San Francisco



Who I Am!

It can be difficult to maintain your identity in the hospital. You are surrounded by people who don't know much about you, and yet are involved in making important decisions that affect your life. The nurses on 10ICC have developed this sheet in case there are things about you (or your loved one in the hospital) that you would like for us to know. Filling out this form is completely optional.

What do you like to be called?

Family, friends, pets, your home:

Work, hobbies or pastimes; TV shows and movies you like, favorite sport, type of music you like to listen to, etc.

Hopes, goals; things that stress you out; things that cheer you up!

Did you know? UCSF has Wi-Fi. Newspapers and movies to borrow are available from Volunteer Services. Cell phones and music players are allowed (though UCSF cannot be responsible for lost or stolen items).

We love pictures! We love seeing what you look like in your day-to-day life! Feel free to bring pictures of yourself and/or your family to have in the room with you.

This form was filled out by:

_____