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A critical exploration of professional jurisdictions and role boundaries in inter-professional end-of-life care in the community

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Abstract

This article critically examines how professional boundaries and hierarchies influence how end-of-life care is managed and negotiated between health and social care professionals. Our findings suggest there is uncertainty and lack of clarity amongst health and social care professionals regarding whose responsibility it is to engage, and document, the wishes of patients who are dying, which can lead to ambiguity in treatment decisions. We go on to explore the potential role of a new electronic system, designed to facilitate information sharing across professional boundaries, in shaping and bridging professional boundaries in the delivery of end-of-life care. We highlight potential negative impacts that may arise when health and social care groups are permitted varying levels of access to the system, and how this may be seen to reflect the value placed on their role in end-of-life care.

Key words

United Kingdom; Advance care planning; End-of-life; Boundaries; Palliative Care

Introduction

End-of-life care, defined as ‘care for patients that are considered to be in the last stage of their lives’(Hunter and Orlovic, 2018p5) is an inter-professional activity. This article discusses the management of patients at the end-of-life through the lens of boundary work. We specifically focus on the delivery of end-of-life care for persons living in the community, defined as usual place of residence (whether this is the individual’s own home or a care home). Within a United Kingdom context professions involved in the delivery of end-of-life care in the community may include: general practitioners (GPs), out-of-hours services, district nurses, palliative care nurses and physicians, Macmillan/Marie Curie/Admiral nurses (specialist cancer and dementia nurses), care homes nurses and carers, social workers, and paramedics (emergency medical technicians). Additionally, these professional groups may work alongside informal care providers (those who provide unpaid care to older or sick family members (The Kings Fund, 2020)). Whilst the professionals involved in the care of patients nearing end-of-life living in the community may not consider themselves a team as such, and their involvement may occur at different times and settings, there is a need for coordination and cooperation to ensure care is coherent and aligned with patient preferences.

Delivery of high quality safe care within an inter-professional environment has been highlighted as one of the biggest challenges facing the health care system (Powell and Davies, 2012, Kreindler et al., 2012). Inter-professional working can be a complex endeavour, where it is suggested potential problems fall into four categories: ideological differences; unequal power; communication; role overlap and/or confusion (Caldwell and Atwal, 2003). Inter-professional working does not necessarily come naturally to health and social care professionals, and there is a tendency to work in ‘tribal silos’ (Braithwaite et al., 2016). Furthermore, the provision of care may be a collective activity, but the division of power between those delivering the care is unequal (Petrakaki et al., 2016), and some groups may feel that their role is undervalued (Fryer et al., 2016). Healthcare operates within a hierarchy (Cramer et al., 2018), where established professional jurisdictions and role boundaries can be helpful (Strauss et al., 1985, Fournier, 2000). Inter-professional working may be facilitated when every team member has their own distinct role, and an awareness of the roles of other team members (Reeves et al., 2011). However, ambiguity in professional boundaries is often apparent, related to confusions about responsibility for some aspects of work (Strauss et al., 1985), and challenges in the identification of distinct roles (Cipolletta and Oprandi, 2014). Indeed, healthcare roles and responsibilities often overlap, shift and change over time.

Professional boundaries and boundary work

This article uses the concept to boundary work to explore some of the challenges that arise in inter-professional working in the management of end-of-life care. Boundary work has been used by sociologists to highlight how professional groups seek to establish a privileged position for themselves by setting a boundary around their work (Lamont and Molnár, 2002), a phenomenon Weber terms as ‘social closure’ (Weber, 1978). This process enables one group to gain privileged access to scarce resources by excluding those outside of the boundary they have created. Boundary setting can have dual opposing functions: as a facilitator connecting multiple entities together, or a barrier which protects autonomy, professional standing, and the control of resources (Chreim et al., 2013, Lamont and Molnár, 2002). Classic sociology, alongside a growing body of more recent work, draw attention to the socially constructed nature of professional identity and how boundaries between professionals are not fixed, rather locally determined and negotiated (Svensson, 1996, Allen, 1997, Allen, 2009). Boundaries are a powerful, yet vague, construct for understanding organisational work; they capture the fundamental social processes of relationality which is central to inter-disciplinary working (Lamont and Molnár, 2002).

The study of boundaries has been used to understand differences (and consensus) between professionals and lay public, between different professional and scientific disciplines and how different systems of classification can provide order and structure in professional and lay work. Boundary work enables professionals to claim authority over certain aspects of practice (Saario et al., 2015), which may facilitate a sense of ownership over one's work. Within healthcare, boundary work is suggested to be an ongoing process where boundaries are frequently drawn and redrawn as professions question the jurisdictions of their work (Cramer et al., 2018). Renegotiation of professional boundaries may be necessary in order to achieve person-centred care (Omori et al., 2019), which is a strategic ambition for end-life-care (National Palliative and End of Life Care Partnership, 2015, NCPC, 2015)

Communication and information sharing across boundaries

Communication and information sharing across professional boundaries are key to inter-professional working, yet are consistently highlighted as problematic areas of practice (Kimble et al., 2010). Indeed, poor coordination between primary and secondary care providers has been identified as a major challenge to the delivery of high quality end-of-life care in the community (Department of Health, 2008). Advance Care Planning (ACP) documentation has the potential to be a key source of information for the management of patients approaching the end-of-life in the community. ACP is the process of engaging patients with a palliative diagnosis in discussions and documentation of their preferences for future treatment to help ensure that the care provided aligns with their wishes (National Gold Standards Framework Centre, 2018). Typically, ACP in the UK includes: a written summary of care preferences, Do Not Attempt Cardio-Pulmonary Resuscitation order, Emergency Health Care Plan, and Advance Decision to Refuse Treatment form (Northern Cancer Alliance, 2019). In the USA Physician Order for Life Sustaining Treatment is used to document and communicate patient treatment preferences. ACP has been found to improve clinician confidence in end-of-life care,(Kirk et al., 2017a, Murphy-Jones and Timmons, 2016) patient and family satisfaction with end-of-life care and reduce negative impacts experienced by surviving relatives, such as anxiety and depression (Detering et al., 2010). However, sharing ACP documentation across health and social care can be challenging (Bellamy et al., 2018).

New Information Communication Technology (ICT) innovations are being developed to improve access to and communication of patient health information, including ACP documentation. Electronic Palliative care Co-ordinating Systems (EPaCCS) are electronic solutions designed to capture patient care preferences to improve co-ordination of care between health and social care services involved in end-of-life care (Petrova et al., 2016, Smith et al., 2012, Wye et al., 2016). Improved care coordination and shared patient records are ambitions for improvements in end-of-life care (National Palliative and End of Life Care Partnership, 2015). Indeed, a Framework for Action developed by the NHS cites 2020 as the target for digital, real-time, and interoperable health records being rolled out across the UK (NHS National Information Board, 2014). In spite of this target, little is known about the impact of an EPaCCS on organisational, professional and individual networks and the distribution of power within them. The introduction of new practices and systems has implications for the social order (Strauss et al., 1985) and may necessitate the renegotiation of boundaries (Håland, 2012, Huby et al., 2014, Fournier, 2000, Timmons and East, 2011), to avoid conflicting expectations and uncertainty (van Bochove et al., 2016). In contrast to the earlier conceptualisation of boundary work as a means of social control (Gieryn, 1983), it has been argued that boundaries are useful for communication, exchange, bridging and inclusion (Star, 2010, Star and Griesemer, 1989). This article critically examines how end-of-life care is currently negotiated and managed between health and social care professionals, highlighting the decidedly inter-professional nature of this area of practice and how professional boundaries and jurisdictions influence the delivery of care to patients at the end-of-life. We go on to explore the potential role of an EPaCCS in facilitating communication and information sharing across professional boundaries.

Methods

Study design

Data presented in this article are from the pre-implementation phase of a trial of an EPaCCS within the North of England. Interviews and focus groups explored current approaches to end-of-life care management, the state of information sharing in end-of-life care, and the potential utility of an EPaCCS system to facilitate sharing patient data across organisational and professional boundaries.

Procedure

Ethical approval for this study was obtained from the Health Research Authority (REC reference: XX/XX/XXXX). Data collection took place from March to October 2018.

A combination of convenience, snowball and purposive sampling (Marshall, 1996) was used to recruit a variety of health and social care professionals to explore their perspectives on inter-professional management of patients at the end-of-life. A variety of recruitment methods were employed to maximise the range of health and social care professionals recruited: calls for volunteers were circulated by email through professional networks; the trial management team provided contact details of GP practices and care homes which were directly contacted with invitations to participate through both email and telephone; researchers attended events related to the EPaCCS trial where the qualitative study was promoted and requests for participation were made; and finally, researchers also promoted the study at local professional and commissioning meetings.

Table 1 details participant demographics. Data were generated through interviews (n=24) and focus groups (n=5 involving 38 health and social care professionals). Two of the focus groups were conducted with a mix of professionals, including hospital doctors, pharmacists, out-of-hours GPs (n=9, n=10), and three with a single group of health and social care professionals (care home staff n=5, social workers n=5, nurses n=9). Interviews and focus groups were conducted by A1, A2 and A5, skilled qualitative researchers who have experience of conducting interviews around end-of-life issues. Participants were given the opportunity to withdraw from the study at several time points.

Table 1: Participant demographics

Health and social care professional role	**No.**
GP	7
Out of hours GP	2
Nurse (including: care home, district, Admiral nurse)	10
Specialist end-of-life nurse (including: MacMillian, Marie Curie, palliative care)	11
Formal carer (care home)	3

Paramedic	10
Social worker	6
Pharmacist	4
Hospital doctor	4
Other supporting professions (including: care coordinator, health care assistant Macmillan manager, physiotherapist, coroner)	5
Total	**62**

Interviews and focus groups were conducted at the interviewee's place of work, at the university, in cafes and community venues, or over the telephone, according to participant preference. A topic guide was developed by A1, A2, and A5 following a review of the literature, this was revised after each interview to allow for investigation of new areas of enquiry. Questions were open ended, issues explored in the interviews and focus groups included: experiences of managing patients approaching the end-of-life in the community; experiences of sharing patient information between professionals; attitudes towards an electronic system to coordinate palliative care. An example interview schedule is provided in the supplementary material. The topic guide was not prescriptive, interviews and focus groups also allowed participants to raise issues of interest to them. A video demonstration of a draft version of the proposed EPaCCS was also used as a prompt during the later stage of the interviews. All participants were provided with opportunities prior to the interview to ask questions about the study. Informed consent was given by all participants. Interviews and focus groups were digitally recorded and field notes of interviewer observations were recorded before, during and after the interview. Eight of the 24 interviews were conducted over telephone, the remainder were face-to-face. Interviews lasted between 28-93 minutes, and focus groups between 39-63 minutes.

Data analysis

Audio recordings of interviews and focus groups were transcribed verbatim by an independent transcription company, pseudonymised and checked for accuracy by the researcher who collected the data. As data collection and analysis occurred concurrently, preliminary analysis of early transcripts informed the topic guide for later interviews and each transcript was re-analysed following subsequent interviews. Our approach to analysis followed the five step process of thematic analysis, as outlined by Braun and Clarke (2006). Firstly, transcripts were read and re-read to achieve familiarisation with the data; this was followed by the generation of preliminary codes; searching for themes; reviewing the themes, and finally defining and naming the themes. Field notes taken during data collection were utilised in data analysis to enhance the reflective process. The data management software NVivo 12 was used to develop and refine a coding scheme. Several credibility measures were employed to ensure trustworthiness of the data. 20% of the transcripts were coded independently by three researchers who compared their analysis, and themes derived from the data were discussed at wider team meetings where clinical and patient representation was included.

Findings

Professional jurisdictions in end-of-life care

Arbitrary jurisdictional boundaries

Arbitrary geographical boundaries which are applied to health and social care services and control the flow of patient information were identified as a barrier to effective management on patients approaching the end-of-life in the community. Due to the way in which Health and Social care is organised in the UK, NHS services are devolved into separate Clinical

Commissioning Groups (CCGs) each with their own budgets and systems of working. CCGs cover defined geographical areas, however patients, and their care, are not necessarily confined by these arbitrary boundaries. Problems can arise when patients physically move between these boundaries, but their information does not.

> *That's a major problem for me. I cover close to Area 1, and a lot of my patients don't access services within Area 2. So, getting information and letters, I can't access them when they're not on a central system.* (Nurse8)

Due to the fragmentation of health and social care services in the UK, services utilise different ICT systems for their electronic patient record (EPR), lacking interoperability, which may be a barrier to effective, safe, high quality healthcare (Hignett et al., 2018).

Responsive services, such as rapid response nurses and paramedics, reported having very limited access to patient information meaning they are often 'blind' to a patient's condition when responding to a call.

> *They're* [rapid response nurses] *literally going in blind to cases. You're really stripped bare, aren't you, having to start from scratch as well? I think the other things* [to] *add is that we provide specialist palliative care into the nursing home* […] *Very often, we're not updated because nursing homes* […] *don't have a system that talks to our systems, or the GP systems either. The information that we currently hold might be five days out of date, unless the nursing homes are ringing us, or whatever.* (Nurse9)

Care homes in particular were identified as a site of informational isolation, where information does not easily flow in or out. The patient record systems used by care homes were not interoperable with systems used by other services. Although care homes possessed valuable information that is wanted, and needed, by other services, systems did not facilitate a two-way exchange of information, in and out of the care home.

Responsibility for end-of-life care

In addition to the need for clear information exchange strategies, our findings suggest a degree of uncertainty and difficulty when working across professional boundaries in end-of-life care that can contribute to confusion in regards to the role that certain professions have, if any, in its delivery. For example, paramedics expressed a lack of confidence in managing patients at the end-of-life, which they believed fell outside of their professional jurisdiction, resulting in a default approach of transferring the patient to hospital. Receiving a call to attend a patient known to be end-of-life was seen to be indicative of a failure of other services to plan adequately – something they felt could have be avoided by the production of ACP documentation.

> *We tend to encounter it* [end-of-life care] *either when things have gone wrong or when families have panicked; or when things haven't been put in place that should have been* (Paramedic1)

Attending end-of-life calls was reported as a source of frustration due to the limits of their scope for action. Still, they felt compelled in these situations to at least offer emotional support.

> *If nothing else, the moral thing to do is sit and wait for these people* [other services] *to turn up* […] *Because you've got a green suit on, you can save the world, that's the general perception* […] *you can only verbally cuddle somebody for so long.* (Paramedic3)

This frustration reflected a perceived conflict between the general public's perception of paramedics as 'life savers', and their actual jurisdictional capabilities. Indeed, previous research indicates that paramedics struggle to deal with romanticised visions of their service

(Waldrop et al., 2015). A sense of failing to fulfil societal expectations of the role may result in frustration and concerns about letting people down. Further, paramedics' discomfort with attending end-of-life calls was compounded by concerns that patients' preferences to die at home, conflicted with their standard approach of transferring patients to hospital, causing uncertainty around the best course of action with fear of legal repercussions. Paramedics' fear of litigation following a failure to act, or being seen to act has been reported previously (Hoare et al., 2018, Kirk et al., 2017b, Dalkin et al., 2018, Patterson et al., 2019). Professional jurisdictions are shaped and constrained by legalities. Paramedics' uncertainty at dealing with end-of-life patients arises in part from the dilemma of wanting to do what is right for the patient and the necessity of protecting their career and livelihood.

Passing the parcel of ACP

Engagement of patients in, and documentation of, ACP can be subject to jurisdictional disputes. Although effective engagement in ACP can be key to understanding a patients' condition and their end-of-life preferences, debate about which professional group should bear responsibility for this process (Robinson et al., 2013) means the task does not fall explicitly within the jurisdiction of any single professional group. Participants expressed a lack of enthusiasm for assuming responsibility for ACP and there was a tendency for health and social care professionals to play 'pass the parcel' with this task. GPs were frequently identified by other health and social care professionals as most appropriate to take primary responsibility for ACP. Indeed, GPs may be well placed as they are most likely to have an established relationship with the patient, and patients and family members have been found to prefer discussions around end-of-life to be initiated by someone they trust (Hall et al., 2019). Yet, the GPs themselves appeared reluctant to accept this task fully within their professional boundary, and indicated a need for a more inter-professional approach.

> *as a GP* […] *you haven't got the time that the patient needs* […] *and that's why I guess it's good that you've got all the other multi-disciplines that can offer that.* (GP4)

The GP quoted above cites lack of time as a key barrier to assuming responsibility for ACP, their reluctance to accept responsibility for ACP could be interpreted as an attempt to protect their workload from further expansion. Professional boundaries may be highlighted when trying to avoid additional work (Conn et al., 2016).

Though all of our participants had contact with patients at the end-of-life, the frequency, and quality, of this contact varied according to role. A sense of resignation was evident amongst some out-of-hours and Accident and Emergency (A&E) doctors who were having to initiate ACP discussions, as it needed to be done. However, these doctors did not view themselves as the most suitable persons to be taking on this responsibility as they lacked an established relationship with the patient.

> *You always feel like it is someone else's responsibility, I guess when I'm meeting people, they're always a stranger to me and then they haven't had these forward planning conversations. You think 'well that's a shame'. Then it's falling on you, and you've never met them before, but it's my job to do it.* (Hospital doctor1)

Out-of-hours GPs were keen to emphasise the boundaries of their role, highlighting the distinctions between their professional remit and that of standard GPs; they are not a stand-in for regular services and should not be treated as such.

> *There's always this view that it shouldn't be an out-of-hours problem* […] *it feels a bit high-handed, as an out-of-hours doctor, to be doing that*

> [completing the emergency health care plan]. *There's also the situation of, what is our role? We are, really, a deputising service. You know, we're an emergency service. We're not there to be their regular GPs*. (Out-of-hours GP2)

Although engaging patients in ACP fell outside the remit of an out-of-hours GP's work, they would complete this work if necessary, but recognised that doing so was potentially encroaching on other professional jurisdictions and could cause tensions.

Failure to engage patients, and their families, in ACP can have negative impacts on experiences at end-of-life and after death. ACP allows the patient to make their preferences known, supporting health and social care professionals to meet these wishes.

> *We had one case of a young woman who was dying* […] *and they were asylum seekers, and there were a lot of people involved in their care. The social worker made the assumption* […] *that the Macmillan nurse had spoken to the family about what would happen when she died, around her body. So when she actually died, all hell broke loose because nobody knew where she wanted to* [go] […] *I think, is that a social care responsibility or is it the Macmillan or is it that of the family?* (Social worker1)

This social worker's account indicates a lack of initiative in professionals adopting ACP duties, each professional group involved assumed another was taking responsibility for this task, but none did. Such accounts demonstrate a need for clarity regarding responsibility for ACP, as the current approach risks health and social care professionals 'passing the parcel' of ACP and patients falling through the gaps.

Professional hierarchies and dismissal of expertise

Effective inter-professional working in end-of-life care requires a mutual understanding and appreciation of each other's expertise, roles, and responsibilities. Many of our interviewees felt that such a mutual understanding did not currently exist.

> *Professionals sometimes don't know what our role is and what we do. And a lot of the initial contact with GP surgeries was telling people about, "Actually, this is what Admiral Nursing is. We're here to complement your service. We don't take over district nurses, GPs, doctors, anything like that."* (Nurse21)

The necessity of having to define professional jurisdictions is perhaps unsurprising for Admiral Nurses, as although they have been in existence for around three decades there are only a small number of individuals working in this role in the UK (Evans et al., 2018). However, time that is devoted to drawing professional boundaries is time that cannot be invested in other aspects of end-of-life care. Lack of understanding of others' roles and professional jurisdictions risks potential duplication of work and possible encroachment upon ones' own professional jurisdiction, which may lead individuals to feel compelled to protect and reinforce boundaries. Accounts from some professional groups indicated that boundary work was utilised to reinforce hierarchies in health and social care and diminish or dismiss others' positions and professional expertise. Concerns about one's relatively low position in the professional hierarchy appeared particularly acute amongst care homes, and services who are episodically involved in care, such as paramedics, social workers, and out-of-hours services. This latter group spoke about being seen as the 'poor relation' to other NHS services and felt their expertise was sometimes overlooked or dismissed by other professionals.

> *These two nurses came out, totally ignored any handover from me, made me feel about two inches tall, and then one of these nurses turned round to the family and said, "Well, what do you want us to do?"*

> *I just looked at them and I thought, "I don't believe you've said that, like that." They* [family] *were all very clearly distressed and didn't know what to do. I sort of started explaining things, but this nurse just kept on knocking me down.* (Paramedic7)

The nurses' dismissal of the paramedic's handover and attempted input into the care of the patient can be seen as enacted boundary work. The end-of-life patient falls within the professional jurisdiction of the nurses, not the paramedics, and attempted input from the paramedic may be seen as an encroachment. However, such a hostile approach to protecting professional jurisdictions may be a barrier to successful inter-professional working in end-of-life care. Negative encounters such as this will likely influence perceptions of services and impact on future interactions.

Feeling dismissed and downgraded by professional colleagues was particularly prevalent within the accounts of care home staff, who felt their professional status and expertise were afforded less value than that of other health care and social care professionals. Indeed, during the course of data collection care homes were repeatedly highlighted by other professional groups as a perceived weak link in end-of-life care, who inappropriately called on out-of-hours doctors and ambulance services against patient's wishes. High staff turnover and low levels of training within care homes were suggested as factors that may limit the ability of care homes to manage end-of-life patients effectively. In addition, as discussed regarding paramedics, fear of litigation was cited as a major barrier to care home staff's effective management of end-of-life patients.

> *the care homes are absolutely petrified of litigation. They will call us for any change. Then you think, "Well, you have called me. The healthcare plan says, 'Keep comfortable.'* […] *She is breathing heavily but she is quite comfortable. What do you want me to do?"*[…] *they will be incredibly risk*

> *averse or they will expect us to make the decisions, but we haven't got that information* (out-of-hours GP2)

It was suggested that this fear of litigation meant care home staff were paralyzed when dealing with patients at the end-of-life resulting in them abdicating the responsibility for decision making to other professional groups increasing the burden on other services who themselves may not necessarily be better placed to take on such responsibilities. The low view of care home staff, and their abilities, led to unsatisfactory encounters between the care home staff and other professionals:

> Nurse10(Care home): [we] *phoned the district nurses out* […] *because they* [carers] *felt he was in pain* […] *when they* [district nurse] *came, he wasn't showing any signs of pain and they* [district nurse] *refused to give him drugs* […] *I think it was a particularly unpleasant district nurse*, *who* ['s attitude] *was very much, 'I'm a district nurse, you're a carer', so therefore I can't give the drug* […]

> Carer1: *He was really agitated actually and crying … we are the staff that are looking after them, so we know… they* [district nurses] *had never met him before* […] *It was a shame they didn't, I think from our perspective,* [they need to] *listen perhaps more to the staff on the floor*

Understandably, care home staff were frustrated by the perceived dismissal of their expertise. It was also felt to be unwarranted, care home staff highlighted how they possessed a tacit knowledge of patients that was not necessarily afforded to other professionals. For example, they prided themselves on knowing residents as individual people, and sought to personalise their end-of-life experience as much as possible, by playing favourite pieces of music or engaging in tactile behaviours such as hair brushing, which the resident found soothing. Indeed, care home roles may facilitate the development of holistic knowledge of persons at the end-of-life that may be unavailable, or unachievable, to other professional groups. This holistic care, which goes beyond attending to physical needs and takes into account the importance of the 'little things' has been highlighted as a key component of high quality end-of-life care (Mistry et al., 2015). The dedication of care home staff to ensuring a positive end-of-life experience for residents was evident in the distress they expressed when recounting the few times that they had failed to achieve this aim, as the quote above demonstrates. Being unable to relieve the resident's pain was acutely upsetting. Similar frustrations have been noted amongst health care assistants who experience a lack of recognition of their knowledge, expertise, and ability to make valuable contributions to patients' care (Fryer et al., 2016).

EPaCCS as a potential facilitator of inter-disciplinary end-of-life care

Benefits of a shared electronic patient record for ACP

Effective end-of-life care is dependent upon high quality communication between the various professional groups involved. Yet, the aforementioned difficulties in accessing up-to-date information about a patient's condition and care preferences were reported as a considerable barrier to effective end-of-life care. Creation of a shared electronic record accessible to all health and social care services offers a potential solution to this problem, which could change professional boundaries, and facilitate a truly inter-professional approach to ACP and end-of-life care.

> *I would hope that that* [electronic record] *would, firstly, allow the services to give patients the care they want. Whether that be allowing them to die at home, peacefully, or admitting them for more active management* […] *It would presumably reduce the admission rate. I think more people would*

> *rather stay at home than end up being admitted, particularly to hospital.*
>
> (GP1)

Improved accessibility to patient information would facilitate delivery of care in-line with the individual's wishes. Access to documented patient preferences for end-of-life care would remove ambiguity and reduce the likelihood of the patient being admitted to hospital as a precaution. This would be particularly beneficial to typically "information-poor" services such as paramedics.

> *If we're able to go to that patient group and have full access to everything, it means we can make a better, more informed decision about their care, which will mean that we get the care right more of the time. It's going to be massively beneficial overall.* (Paramedic2)

Improved access to up-to-date patient information, and ACP documentation, en route or soon after arrival, could alleviate treatment uncertainty and facilitate informed decision-making (Pettifer and Bronnert, 2018). This could also empower paramedics to keep patients in their preferred place of care, reducing concerns about litigation, and instilling greater confidence in paramedics in terms of end-of-life management.

Challenges and changes to professional jurisdictions

Implementation of new technologies can have paradoxical effects, acting as both an agent and barrier for change (Star and Ruhleder, 1996). Although the EPaCCS proposed in this study would improve access to ACP documentation, different health and social care professional groups were to be afforded varying access and editing rights. Access, or lack of, to this new system could be seen as a reflection on the value of a profession, reinforcing professional boundaries and hierarchies. Having limited access to the system could further compound a sense of being a ‘periphery’, rather than core, service and lead to losses in professional jurisdiction.

> *I would feel quite strongly that if we’re to see ourselves in care homes as experienced people that can be in charge of 45 patients as one nurse, which quite often happens, but for some reason we don’t have that value to be able to contribute* [to shared patient records] [...] *I think that you’ve gone back to ‘we’re just a care home’* […] *You know at one time you thought you were a nurse in a care home and you were way down. I thought like that when I first qualified* […] *I thought if you went to work in a care home, you were obviously slightly second class.* (Nurse10-Care home)

Accounts of care home staff demonstrate concerns about the implications for a new system on their position in the hierarchy, that lack of administration rights would reinforce boundaries between themselves other professions. In contrast to Håland (2012), where access to the EPR enhanced the position of nursing staff by offering new rights and responsibilities, lack of access to the new system could mark a loss to the professional jurisdiction of care home staff, further downgrading their occupational knowledge and competence. Professional identities can comprise a valued aspect of our individual personal identity (Hudson, 2002), devaluation of one’s professional identity may have wider consequences for self-worth.

Ambiguity regarding ownership of the proposed EPaCCS was a major source of concern. In order for a shared record to be beneficial it must meet the needs of each professional group whilst maintaining meaning for all potential users. As professional groups will have differing informational requirements the potential of information overload was a key concern.

> *When we used to have SystmOne in my other practice, health visitors, physios, district nurses, OTs, it was a shared record, and it was like, ‘well,*

> *where's my information?' You were filtering, constantly trying to get back to just your*[s][...] *it was overwhelming. Also, the way that other people document. Nursing documentation seemed to be like massive paragraphs. It was almost you could be blinded by that. You wouldn't be able to spot the facts or the important bits.* (GP6)

Further, professional variances in documentation practices could be a source of conflict, with groups perceiving superiority of their own approach. Nurses recognised that their verbose reporting style could be a potential source of frustration for other professionals accessing the patient's record, but this information was necessary for their work.

Investment in people over computers

Scepticism about the need for another electronic system was evident, and many clinicians were resistant to the increasing bureaucratization of practice. GPs expressed a lack of enthusiasm about the proposed system, related to fears about workload implications.

> *If it increases our workload by any significant amount, it's just not going to be very easy to do because people are going to just not be bothered with it because it's going to be more work.* (GP6)

GPs' apparent apathy is noteworthy; as GPs are "information-rich" much of the information contained within the system would be populated from their records, however it would not significantly benefit them. Resultantly, GPs perceived they would experience limited benefit from increasing their professional jurisdiction to encompass this extra work. GPs' concerns about increased demands are not without merit, previous research has demonstrated that ICT systems can have a profound impact on organisation and workload (Heath et al., 2003).

Other concerns centred on investment in ICT over personnel. It was postulated that the money spent on developing new ICT systems, such as the EPaCCS, may be better invested in staff.

Increased staff numbers could reduce workload stresses, and potentially eliminate the need for a shared record to facilitate inter-professional communication.

> *I am a bit of a sceptic* [about the EPaCCS], *and I was sitting there thinking, 'Okay, so if we threw those millions into nurses and keep what we've got'… Potentially you wouldn't need out-of-hours doctors, because there would be more nurses on the ground to be more anticipatory*. (Nurse16)

Further, palliative care nurses themselves could potentially be viewed as boundary actors who facilitate patient management across different services, working to raise the profile of the end-of-life patient. Indeed, previous research indicates that nurses often fulfil these boundary spanning roles (Cramer et al., 2018, Allen, 2014).

A posited benefit of an EPaCCS was reduced burden on patients and their families, in terms of having to repeatedly explain their condition, prognosis, and care preferences as this information would all be available electronically. However, there were concerns that this would be at the expense of the relationship with the patient; the system may detract focus from the patient as an individual.

> *we don't want patients repeating their story time and time again. That's one of the benefits of this. Likewise, right until the very end of somebody's life, the majority of people that I've certainly looked after have got capacity very close to the end-of-life, and actually can still talk to you. I worry that in time we won't even try to talk to you and ask you, because it's all on the plan.* (Nurse19)

A balance must be achieved which avoids overburdening patients and their families, whilst maintaining the human connection with the patient, a valued aspect of the role for many health and social care professionals.

Discussion

This article draws on empirical research exploring how end-of-life care is currently managed and negotiated across professional boundaries and the potential utility of an EPaCCS to improve the sharing of patient information and delivery of end-of-life care. We have used the concept of boundary work to make sense of the activities and work which are carried out around end-of-life care, and frame our exploration of inter-professional working in this context. We have shown the work within end-of-life care is shaped by boundaries that are imposed organisationally due to the fragmented way health and social care are funded in the UK and those that professionals construct for themselves.

Our findings demonstrate that inter-professional working in end-of-life care operates within a hierarchical system, where unequal power dynamics, communication difficulties, and role confusion pose challenges. Professional boundaries and jurisdictions around end-of-life care are often unclear and overlap, in particular with regards to the responsibility for engaging patients in ACP, which may be a barrier to the delivery of effective care in line with patients' wishes. Uncertainty and ambiguity regarding the responsibility for engaging patients in ACP appears to be an ongoing problem (Robinson et al., 2013, O'Hara et al., 2015). Disparities were evident in the extent to which professionals perceive that ACP activities should fall within the boundaries of their role. At one end of the spectrum, care home staff were vehement that they should have a role in ACP and, due to their established relationships with residents, they were well placed to do so. However, at the other end of the spectrum paramedics perceived ACP to fall outside of their professional jurisdiction and they did not wish to expand the boundaries of their role to include it. The perspective of other professionals, such as out-of-hours GPs and hospital doctors working on A&E admissions, appeared to fall somewhere between these two extremes; whilst ACP was accepted as part of the job, it was not a task that they took on with particular relish, there was a sense that patients would be better served if ACP was delivered by services with a more established relationship with the patient.

This article explores the potential influence of the introduction of a new ICT innovation such as an EPaCCS on professional boundaries and jurisdictions. Concerns were expressed that the implementation of the tool would require boundaries to be renegotiated and redrawn to incorporate as has been found with previous ICT interventions (Håland, 2012, Huby et al., 2014, Fournier, 2000, Timmons and East, 2011). As argued by Wye et al. (2016), introduction of an EPaCCS alone will not be sufficient to solve the current challenges in end-of-life care if professionals continue to work in tribal silos. Our findings reflect previous research which has found that whilst provision of care may be a collective activity, providers may not instinctively know how to work in inter-disciplinary teams (O'Hare et al., 2016), power distribution between professional groups is unequal and some groups feel undervalued (Petrakaki et al., 2016, Fryer et al., 2016). Indeed, questions have been raised about whether health and social care can ever really be a collaborative endeavour (Nugus et al., 2010), as the roles of dominance and deference are part of the historical construction of nursing and healthcare (Mackintosh and Sandall, 2010). As this article demonstrates, some professional groups already feel that their expertise is undervalued and these groups were apprehensive that the EPaCCS would reinforce this further, and further reduce their professional standing. Whilst reconfiguration of services can be an opportunity for professionals to spread their wings and expand their professional roles (Pinder et al., 2005), it may also have the opposite effect resulting in a reduction of professional jurisdictions, reinforcing existing hierarchies, and potentially leading to occupational identity crises and discontent, risking these groups becoming increasingly disenfranchised. Consistent with previous literature (Powell and Davies, 2012), our interviewees demonstrated a desire to retain professional jurisdictions and resistance to a new system that would limit professional's ability to contribute to patients' ACP, losses to professional jurisdictions were seen as an insult to professional standings.

This article found concerns regarding the investment in ICT innovations over staff. EPaCCS are just one of many technological advancements in healthcare. Primary practice in particular, is being faced with increasing demands from ICT interventions (Iliffe, 2008, Steele Gray et al., 2018). Our interviewees' concerns about the EPaCCS reflected broader debates about the implication of increasing use of ICT and EPRs in healthcare and the influence of this on both the healthcare professional role and patient clinician relationship. Increasing utilisation of EPRs can be seen as promoting organisational professionalism, which is concerned with hierarchical structures of authority and standardization of working practices, over occupational professionalism which promotes discretionary decision-making, and trust between professional groups (Evetts, 2006, Håland, 2012). Moves towards organisational professionalism may not align with the priorities of professionals themselves. Introduction of new technologies may require redistribution of workload, which may contest professional boundaries (Grant and Guthrie, 2018). Resistance to expanding professional boundaries to encompass new tasks related to documentation was evident, as has been observed in previous research where moves towards increasing documentation have been suggested to reflect the erosion of boundaries between 'medical work' and 'secretarial work' (Håland, 2012). Tasks related to documentation appeared to be undesirable work and were an area of practice where professionals did not wish to expand their boundaries to encompass. Clinicians spending more time in front of a computer and less time with the patient, may give rise to concerns that these developments will be at the cost of human contact with patients (Håland, 2012), and fears that the role of the clinician is transitioning from that of healer to an impersonal technician (Lewinsohn, 1998). Increased use of EPRs has been linked to professional dissatisfaction and burnout (Ehrenfeld and Wanderer, 2018, Downing et al., 2018).

Practice implications and recommendations

Our findings indicate potential benefits for an innovation, such as an EPaCCS, which would improve access to ACP documentation. Such a system appeared likely to be of particular benefit to responsive services, such as paramedics, who are traditionally quite information poor. Out-of-date, ambiguous, or unavailable ACP documentation was a source of uncertainty which left paramedics feeling unsure of the best course of action when attending patients at the end-of-life, potentially resulting in unwanted transfers to hospital. Improved access to ACP documentation could increase confidence in this area of practice, in particular helping paramedics feel confident in keeping end-of-life patients in their home without the fear of legal repercussions or damage to their career.

As touched on above in relation to concerns about focusing on ICT over investments in personnel. An EPaCCS only offers a solution to the sharing of information between professional groups. The usefulness of improved access to ACP documentation will be limited by the quality of the information that is recorded. If the information contained within the documentation is insufficient or of poor quality, access to it will do little to unsure practice is aligned with patient's wishes. Moreover, an EPaCCS may not be the best or only solution to the current challenges in inter-disciplinary end-of-life care, which may be better served by increased investment in professionals, such as nurses, in boundary spanning roles. If these boundary actors are accepted across health and social care, and able to move between professional groups transferring patient information, and facilitating inter-professional collaboration they may potentially eliminate the need for a shared electronic record. There have been calls to give greater credence to the inter-personal aspects of end-of-life care. Hopkins et al. (2020) have recently suggested that the true value of ACP, lies not in the production of ACP documents, but in the process of engaging patients in conversations about their preferences and wishes and that we should give greater focus to the importance of these interactions rather than purely focusing on the production of care plans.

Finally, this article reinforces the need to respect contributions from all professional groups and avoid discounting the knowledge of those in subordinate positions (Nugus et al., 2010, Silbey, 2009). Attempts to reconfigure services, and/or introduction of technological innovations must be mindful not to reproduce the hierarchy and reinforce professional boundaries. Stakeholders from all professional groups need to be included in the development and trialling of an EPaCCS tool in order to ensure that there is investment in the system and that it does not reconfigure workload in a way that is damaging to professional jurisdictions.

Strengths and limitations

Qualitative studies exploring EPaCCS are limited (Wye et al., 2016, Hall et al., 2019, Whole Systems Partnership, 2016, Finucane et al., 2019), to our knowledge this is the first to explore the potential implications of an EPaCCS within the lens of boundary work and to discuss the implications on professional hierarchies. This article draws on the perspectives of a wide range of health and social care professionals providing an in-depth understanding of some of the key issues concerning professional jurisdictions and boundaries at work within end-of-life care. Whilst efforts were made, through a range of recruitment methods, to include a diverse sample of health and social care professionals there were variances in our success with recruitment for different professional groups. For example, whilst we were able to recruit GPs from 6 different medical practices, care home staff proved a challenge, despite email invitations being sent to each care home within the trial region, and attendance of the research team at local commissioning meetings we were only able to recruit staff from one care home. Though these participants provided an insight into their care home, we cannot infer that their experiences are relevant to, or representative of, all care homes. Indeed, the level of engagement with ACP demonstrated by both care home carers and nurses sampled in this study was likely to be unrepresentative of care homes in general. Further focus on the experience and perceptions of care home staff would be beneficial.

In this article interviewees are reflecting on a hypothetical system rather than something they were actively incorporating into their practice, follow up work is required to explore the impacts of the system once it has been implemented into practice.

Conclusions

This article explored how professional boundaries shape and constrain inter-professional collaboration and delivery of end-of-life care. We found a need for greater clarity regarding the professional responsibility for end-of-life care, particularly ACP where uncertainty may be a barrier to the delivery of care which is aligned with patients' wishes. Disparities were evident in the extent to which professionals wanted to encompass end-of-life care within the boundary of their work. This article also explored the potential role for an EPaCCS in facilitating inter-professional communication between health and social care professionals in the management of end-of-life care. Whilst we identified potential benefits from an EPaCCS, particularly for those services who are typically 'information poor' we emphasise the need to consider the implications of such a tool on professional boundaries and hierarchies. Inter-professional working occurs within established professional hierarchies unless the development and access of tools is carefully considered, they may serve to reinforce rather than reduce existing hierarchies.

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