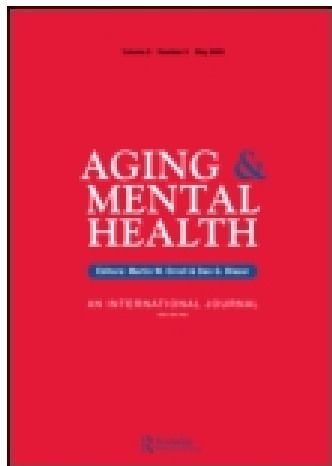


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Quality palliative care for cancer and dementia in five European countries: some common challenges

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Quality palliative care for cancer and dementia in five European countries: some common challenges

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Objectives: There is a growing consensus worldwide that palliative care needs to be both more inclusive of conditions other than cancer and to improve. This paper explores some common challenges currently faced by professionals providing palliative care for patients with either cancer or dementia across five countries.

Method: One focus group ($n = 7$) and 67 interviews were conducted in 2012 across five countries: England, Germany, Italy, the Netherlands and Norway, with professionals from dementia, cancer and palliative care settings.

Results: The interviews revealed five common challenges faced across the five countries: communication difficulties (between services; and between professionals, and patients and their families); the variable extent of structural/functional integration of services; the difficulties in funding of palliative care services; problematic processes of care (boundaries, definitions, knowledge, skills and inclusiveness) and, finally, time constraints.

Conclusion: These are not problems distinct to palliative care, but they may have different origins and explanations compared to other areas of health care. This paper explored deeper themes hidden behind a discourse about barriers and facilitators to improving care.

Keywords: palliative care; dementia; cancer; quality of health care; end of life care

Introduction

Europe's population is ageing and has been increasing steadily since World War II. Higher survival rates of people with life-threatening diseases result in a larger number of patients with multiple and complex health-threatening problems. The number of people in Europe with dementia, for example, is currently about 7.7 million and may double by 2050 (Radbruch & Payne, 2009), although the incidence may be falling and the prevalence in the older population may be closer to 6.5% than to the 8.3% sometimes quoted (Matthews et al., 2013). Cancer incidence is estimated at 3.2 million per year with a mortality rate of 1.7 million per year (Ferlay et al., 2007). Despite advances in cancer treatment, increases in incidence, mortality and morbidity are predicted as the population ages (Sternsward & Clark, 2004; World Health Organisation, 2006).

These changes mean more extensive palliative care services will be required. In 2003, the European Health Committee published its recommendations for palliative care in Europe, urging all countries to devise national plans for palliative care (Council of Europe, 2003). Palliative care is now at the forefront of many government initiatives worldwide (Payne, Leget, Peruselli, & Radbruch, 2012) such as England's National End of Life Care Strategy (Department of Health, 2008).

A review of progress in the development of palliative care across Europe has recently been published by the European Association for Palliative Care (EAPC) as the 'EAPC Atlas of Palliative care in Europe' (Centeno et al., 2013). The authors demonstrate that the greatest development of palliative care services has occurred in Belgium, Iceland and Ireland, followed closely by Austria, the Netherlands, Poland, Sweden and the UK. Encouragingly, it also demonstrates the increasing number of European countries which now recognise palliative medicine as a speciality or sub-specialty, with the EAPC defining a sub-speciality as 'a form of certification that requires special training following previous official certification as a specialist in a related field'. However, overlapping with the publication of progress made, an independent report has been published on the use of the Liverpool Care Pathway (LCP) in the UK, highlighting public concern over the quality of care provided at the end of life (Department of Health, 2013). This has resulted in the UK government's announcement to gradually phase out the use of the LCP.

Whilst palliative care for cancer has long been established, palliative care for people with dementia is only just beginning to develop and be accepted across Europe and beyond. Until recent publication of the EAPC White Paper on palliative care in dementia (van der Steen et al.,

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2013), there was relatively little guidance on the provision of palliative care for this patient group (van der Steen, 2010). In England, the National Dementia Strategy (Banerjee, 2009) and the National End of Life Care Strategy (Department of Health, 2008) have little overlap, which some believe reflect how dementia patients sometimes fall through the gaps in the health and social care systems (Sampson, 2010). However, the EAPC White Paper recommends paying special attention to eight areas of care including communication, person-centred care and optimal treatment of symptoms and providing comfort (van der Steen et al., 2013).

Many of the needs in end-stage dementia are similar to those with cancer, including shortness of breath, skin breakdown, infections and constipation (Mitchell et al., 2009), but in dementia these symptoms can be experienced for a prolonged period of time (McCarthy, Addington-Hall, & Altmann, 1997). Many practitioners use classification systems such as the functional assessment staging scale (FAST) 6d and above to define advanced or end-stage dementia, which captures symptoms ranging from urinary and faecal incontinence up to inability to hold the head up (Reisberg, 1987). However, these definitions and cut-off points are contested and there is debate within the palliative care and dementia communities about what is palliative care for someone with dementia and when it should begin, with many failing to recognise dementia as a terminal illness and when death is approaching (Sachs, Shega, & Cox-Hayley, 2004; Thuné-Boyle et al., 2010).

It is therefore timely to investigate the factors that affect the quality of palliative care and care of the dying, particularly but not exclusively for dementia syndrome. The study reported here is part of a larger European project (Implementation of Quality Indicators in Palliative Care Study), which aims to determine the common national factors that challenge the provision of high-quality palliative care for both cancer and dementia in five European countries (England, Germany, Italy, the Netherlands and Norway). These five countries were involved because in each there were close working relationships between researchers in dementia and in cancer palliative care. This paper will examine common challenges to providing high-quality palliative care for either dementia or cancer in the five European countries. It will discuss the deeper meanings behind these challenges, acknowledging that the language of 'barriers' can conceal deeper factors which impede provision of high-quality care (Checkland, Harrison, & Marshall, 2007).

Methods

Design

A qualitative design was adopted with open questions guided by a semi-structured interview schedule (Figure 1) developed by the authors from reviews of the literature (Raymond et al., 2013; Raymond et al., 2012). Semi-structured interviews were chosen because they offer deep understanding of individuals' experiences (Murphy,

Dingwall, Greatbatch, Parker, & Watson, 1998). The schedule explored which aspects of palliative care participants in each country felt their health service currently did well, and any areas for improvement. Questions were translated from English into other national languages, back translated and refined through discussion across the five research centres.

Participants

Participants were identified purposively, using a sampling framework (Figure 2), containing a matrix of micro-, meso- and macro-level organisations working across primary, secondary and tertiary care settings. This was supported by the use of snowballing methods (Murphy et al., 1998), where identification allowed for selection of national experts covering policy, service organisation, service delivery, patient groups and research in palliative care. Participants were personally invited to participate or nominate someone whom they felt would be more relevant to interview.

Procedure

The research received ethical approval from University College London ethics committee (ID: 3344/002) for the UK, and all other centres followed their own ethical review procedures. Verbal and/or written consent was received from all participants. Interviews took place in 2012, lasted 20–60 minutes and were mainly recorded or notes were made contemporaneously, with permission. Field notes were made by the interviewer(s). Face-to-face interviews were preferred; however, telephone interviews were conducted when requested. The interview schedule was adapted after the initial pilot interviews following discussions among the European team, to ensure consistency across all the five countries. Interviews were conducted by five researchers (ND, SI, JvRP, EM, BJ, RS).

Data analysis

All interviews, which were recorded, were transcribed verbatim in the national language. Interview notes and transcriptions were translated and summarised in English (when not conducted in English). All interview summaries were thematically analysed by three researchers (ND, SI, LM) from the English centre, using a coding strategy according to the principles of Corbin and Strauss (Aronson, 1994). Further translations into English were sought from national sites when their summaries appeared to touch on emerging themes. Themes were regularly discussed among the three researchers to enhance the credibility of the results, and rival explanations among the researchers were explored until consensus was achieved. Once the themes had been established they were discussed with the other four national sites (Germany, Italy, the Netherlands and Norway), and modified until agreement was achieved.

If you could recommend anything in your country that works well for people with dementia who are dying, what would that be?

If you can think of any area of care for people with dementia who are dying that needs to be improved the most, what would it be?

If you can think of something you wouldn't recommend to other countries in relation to palliative care for patients with dementia in your country, what would that be?

How well do you think professionals collaborate with each other in palliative care for patients with dementia?

If you could recommend anything in your country that works well for people with cancer who are dying, what would that be?

If you can think of any area of care for people with cancer who are dying that needs to be improved the most, what would it be?

If you can think of something you wouldn't recommend to other countries in relation to palliative care for patients with cancer in your country, what would that be?

How well do you think professionals collaborate with each other in palliative care for patients with cancer?

Figure 1. Semi-structured interview schedule.

Results

Participants

In total, 67 interviews were conducted: 16 interviews (3 interviews having 2 participants) from England, 10 interviews from Germany, 16 interviews from Italy, 11 interviews (1 interview having 2 participants) from the Netherlands and 14 interviews from Norway (Table 1).

One focus group of seven staff employed by a large private care home company based in England was held at the request of the participants. Recruitment of participants continued at each centre until the researchers felt that no new themes were being generated from the data. Frequent exchanges between researchers in each of the five countries, through face-to-face meetings, Skype discussions

Domain	Primary care		Secondary care	Tertiary care
Setting	Own home	Care home (including care home with nursing)	Hospital	Hospice****
Direct providers of care - Practitioners & professionals* (micro level)				
Other available services** (meso level)				
National policy context*** (macro level)				

* Those clinical practitioners who provide dedicated palliative care within the settings, their management and their sources of funding

** Other services available, including service management

*** Those developing and implementing high level guidelines and policies designed to support high quality palliative care

**** Some countries identified hospice as secondary care

Figure 2. Sampling frame for recruitment of participants.

and telephone conferences, and by email, gave the research teams confidence that they were discussing topics and themes that had credibility to others with experience of the topic and showed transferability to other settings (Guba & Lincoln, 1981), and that they had reached data saturation.

Themes

Five main themes were identified as common factors which challenge the quality of palliative care across the five countries included in this study:

- Communication difficulties between services, and between professionals and patients and their families
- The variable extent of structural/functional integration of services
- The difficulties in funding of palliative care services
- Problematic processes of care, including boundaries, definitions, knowledge, skills and inclusiveness
- Time constraints

Communication difficulties between services, and between professionals and patients and their families

Communication problems which negatively affected patients' palliative care were reported across all five countries.

Communication between professionals, services and settings.

Palliative care requires input from a range of different services, and professionals need to communicate with each other to ensure continuity of care. Participants observed that such communication is often poor. Patients are commonly transferred between different settings (for example, from hospital to care home), particularly at end of life, with inadequate information about treatment or care being passed to the new setting:

The handover from hospital to general practitioner and the handover from the general practitioner to out-of-hours general practitioner can be much better. [...] it is a bottleneck that the general practitioner sometimes doesn't know what is going on at the time the patient is being discharged and the out-of-hours general practitioner may not

Table 1. Participants characteristics.

National expert characteristics	England	Germany	Italy	The Netherlands	Norway
Male	6	5	9	5	3
Female	20	5	7	7	11
Nurse	5	1	2	–	3
Doctor	7	2	6	6	3
Researcher	2	1	1	2	4
Management/policy level	12	4	4	4	4
Other (i.e. psychologist)	–	2 (social workers)	3 (1 volunteer, 2 psychologists)	–	–

always have information [...]. (Professor in Palliative Oncological Care, The Netherlands)

Concern was expressed about the lack of bidirectional communication between specialist palliative care services and other services. Opportunities to share information and knowledge were missed as well as opportunities for mutual support. As a result, patients may not receive holistic care:

We try to follow up on these patients in our community, but there are a lot of them that slips our notice, since we don't know about them, for instance. If all patients that have stopped tumour treatment are referred to us, we will have gained a lot in that concern. (Oncologist in Palliative Care Unit, Norway)

In general, specialised palliative care personnel are consulted too late. (Palliative Care Physician 1, Germany)

[...] some of the Macmillan (specialist) nurses work too independently, they - I had a Macmillan nurse who will be prescribing stuff for patients without looking at what I was prescribing for a patient. (GP 3, England)

Communication between patients/family and professionals. Professionals in all countries expressed concern about communication with patients, in particular with people with dementia. At the end of life many people with dementia have less ability to communicate verbally. This has implications for the assessment of needs and subsequent care, with many dementia patients not receiving comprehensive pain assessment or pain management.

One of the biggest challenges in the care of palliative care patients is probably the direct communication with these patients. To be able to engage in the living world of these patients - there is a great need of training in communication for physicians and nurses. (Consultant/Advisor for Palliative Care, Germany)

[...] they don't warn either the person but more specifically the relatives and the carers that dementia is a disease that you're dying of. (GP 3, England)

There was recently a disputation (in Norway) about end-of-life decision making in nursing homes (in Norway). The thesis revealed that patients' wishes were not always taken into consideration when physicians and nurses discuss life-prolonging treatment with next of kin. [...] She also said that there are few procedures in place to ensure dialogue with patient and their families about end-of-life questions, despite the fact that most of the patients who are granted a place in a nursing home, die there. (Researcher 2, Norway)

This problem with communication was not limited to people with dementia. Many professionals were described as not taking opportunities to speak to their patients or being insensitive to patients' needs and emotions:

The communication has to be definitely improved and should be applied to the relationship, you know, yes definitely yes, to his terminality, to the patient's mood and anyway should ease his emotions, I mean, during the

dialogue, in the patients himself. Thus I see communication with a broad meaning and I expect that the communication on prognosis and diagnosis has been already done [before entering the hospice] so in this care phase when I talk about communication I mean another kind of communication that refers to the patient globally, you know, to his emotions, mood, all these aspects you know. (Hospice Nurse, Italy)

In some countries, such as Italy and England, participants spoke of professionals' fear of talking about death and dying. Medicine as a discipline helps to treat and cure patients, so death could be seen as a failure or an indication of poor quality care. Families as well were thought to find it difficult to discuss and accept death's approach:

But I think more and more these days relatives actually are more demanding and have higher expectations and see people dying as a failure. Doesn't matter the fact that they're 97 years of age and actually have come to the end of their life quite naturally, they still feel that everything must be done for them. (Senior Care Home Manager 2, England)

[...] Mediterranean Countries lack in communication, we do communicate in a bad way, or we do not communicate at all... this derives from a paternalism that belongs to us, you know. We are afraid to say, and this leads to a sort of farce, I call it the farce of lies, where everyone knows but nobody says. (Oncologist 1, Italy)

The German medical care system is technically and curative oriented: That's good how it is and there are a lot of progresses. But we still do not recognise that life is finite - despite all the progress. This is a wider societal issue. I mean the society as a whole should be more aware of death, dying and matters of end-of-life care. (Researcher, Germany)

Some countries (for example, the Netherlands) were often thought to be better at dealing with death, although one participant from the Netherlands felt that they simply dealt with it in different ways, including euthanasia, hiding behind the idea of controlling death and dying as opposed to being controlled by death and dying:

I think, [...] that euthanasia is sometimes too easily provided. There is, in this modern society of course not only in The Netherlands such inability to deal with death. It is a bit like you can order it [euthanasia]. (Regional Head of Palliative Care, The Netherlands)

The variable extent of structural/functional integration of services

'Integration of services' is multidimensional and often confusing as it refers not only to the integration of specialist palliative care with other services, but also to how services and systems should work together. Good organisation and service integration were perceived as lacking across all five countries in this study. A particular concern expressed about dementia was that being neither solely a medical nor social condition, it requires cooperation of both health and social care systems:

well, it is difficult for the healthcare system and the social system to set up palliative care projects together. . . everything is social or healthcare related, and working together is still difficult. (Geriatrician, Italy)

[. . .] it's [Dementia] so often being looked after by social services, you know, so it's been seen as a social disease. (Clinical Nurse Specialist, England)

Participants generally called for better and earlier integration of general and specialist palliative care services, with palliative care services being introduced earlier in the patient's journey at both an organisational and professional level:

Matter of early integration: in inpatient hospices and other settings, including outpatient services, patients are increasingly more advanced at admission than they used to be. (Hospice Manager, Germany)

I don't think the integration of palliative care is optimal yet. But I do see that a lot is happening. From the different levels, from the government for example, they really emphasize how palliative care should be provided. (Professor in Palliative Oncological Care, The Netherlands)

Some countries, however, were thought to lack an organised palliative care approach, which contributed to the lack of integration of services. While this was thought to be a problem for all conditions, it appeared to be multiplied in dementia:

Palliative care is not very well organised. You could say that there is no professional organisation of palliative care in the Netherlands. (Oncologist, The Netherlands)

But I haven't heard of anyone establishing any organizations or collaborating bodies across institutions, neither in primary care nor specialist care, when it comes to palliative care and dementia. (Researcher 1, Norway).

Participants expressed concern that when patients move through the care system, there is no structure to aid this and the information gets lost between services and settings, adding further complicating attempts at communication:

[I would improve] the integration with the settings who had cared the patients previously . . . well, usually it takes a lot for the patients before arriving in the advanced stage, sometimes years, sometimes not, and during this care pathway other settings care for them. (Oncologist 3, Italy)

I think the biggest problem is the transfer between institutions, that is, home care, nursing homes and hospitals. If we could manage a smoother transition, maybe by having the staff work across the different organizations, I think that would make things better. This applies to physicians and nurses as well as other professionals such as priests, physiotherapists and social workers. Because sometimes it seems a bit set in stone, "No, we can't do that, because we work here and we can't work out there". So being able to work across the institutions, at least during a transitional phase, I think this would have made it better. (Oncology Nurse, Norway).

The difficulties in funding of palliative care services

Funding within health and social care was a concern in many countries; some participants thought this affected the ability of services to provide good palliative care. Several subthemes emerged.

Eligibility and focus of funding. Participants compared the amounts of funding available to treat patients with cancer to those with other diagnoses (such as dementia) unfavourably. In their view, cancer was prioritised and other patients were 'left behind', particularly so when dementia was not recognised as a terminal condition or a disease requiring palliative care, but rather costly long-term care.

But it doesn't quite seem right that people with other life limiting terminal illnesses like dementia don't have access to the same level of care. It's a real dilemma actually. (Old Age Psychiatrist, England)

But all settings and actors in the field including health insurers and other funding bodies are that much focussed on cancer patients that it is really difficult. (Palliative Care Nurse, Germany)

The diagnosis of dementia isn't sufficient for the admission Criteria of inpatient hospices even if dementia is recognised as a terminal condition. Therefore patients with dementia in inpatient hospices mostly have also cancer or other terminal diseases. (Hospice Manager, Germany)

[in response to the question: 'what wouldn't you want to recommend to another country, of something that doesn't work in the Netherlands?'] "Narrowing down the concept of palliative care, that you make it clear that it is a concept applicable to all kind of diseases and that oncology is not the only patient group". (GP 1, The Netherlands)

Participants reported that many people with dementia see only generalists for palliative care, whilst people with cancer are much more likely to have contact with a palliative care specialist.

Lack of funding. Participants described not only current financial pressures on health systems but also a seeming reluctance to realign budgets to palliative care.

There is an overall attention to dementia, but it is anyway related to the available financial resources. . . we are living in a complex and difficult economic situation. (Nursing Home Coordinator 3, Italy)

The hesitant development of outpatient palliative care remains problematic, due to insufficient funding by the cost bearers. (Palliative Medicine Physician 2, Germany)

But I do think it's a real block, funding. (Commissioning Manager, England)

Despite examples of good care, concern was expressed over lack of resources. For example, in order to reduce costs organisations prefer to employ cheaper staff

despite them possibly lacking experience or qualifications, such as care assistants rather than nurses:

[...] I am afraid it costs money if you want to have more staff (in care homes) with a higher level of education [...]. (Researcher 1, The Netherlands)

Financial structure. There are differences in health and social care funding within European countries, particularly the level of involvement of insurance companies and market competition. Some participants suggested that the introduction of competition in some health and care systems means that many patients are not receiving optimal care and are having huge burdens placed upon them, such as accessing care and obtaining financial reimbursement:

What I think is important is that services cooperate with each other. But the Dutch system has prevented this from happening because of the market competition, as you have to compete with each other. That is not really stimulating the cooperation between services. (Head of Hospice, The Netherlands)

Sometimes there is a lack of networking between the different kinds of physicians, providers and palliative care teams. Thus networking could be improved. Generally it runs well – but sometimes there is competition of providers. Therefore the interfaces between different settings should be improved, too. (Researcher, Germany)

The system of remuneration should be changed. The most lucrative is to bill for many different treatments, but a home visit often counts only for one fee scale item [...] What comes to my mind is that we began to promote competition in the health sector. This may result in a competition focused on money/income of the providers. (Researcher, Germany)

Despite differing funding systems many of the countries seemed to experience similar problems arising from a complex system which is unclear and difficult to navigate. Indeed, navigation could be left to the dying patient and their family:

[...] the entire chaotic organisation, and all those financial arrangements [...] it is all so complicated. (Regional Head of Palliative Care, The Netherlands)

[...] huge funding issues. And I mean I know there has just been a funding review and all sorts of you know complexities around that but I think the way our services have grown up with mixture of voluntary and statutory provision is not necessarily where you want to be. (Researcher, England)

In most municipalities in Norway there are service booking offices [The Norwegian Labour and Welfare Service – NAV] that you contact and then someone there assesses what you are entitled to. And sometimes there can be great differences between what the specialist health care services recommend and what they [NAV] are willing to offer. [...] In some places, it [NAV] is a major obstacle to ensuring that people with dementia receive the help he or she needs. What they [NAV] are concerned with is following the law, i.e. what they are obliged to offer according to the law. (Researcher 3, Norway).

Problematic processes of care, including boundaries, definitions, knowledge, skills and inclusiveness

When to start and when to end treatment. Many participants were unclear about when palliative care should begin. In particular, in patients with cancer, understanding when curative treatment should cease was thought to be particularly problematic. Even when palliative care begins questions remain about when specialist palliative care should be introduced. As noted previously, many believed this needed to be implemented sooner in the trajectory:

[I wouldn't recommend] a strategy adopted by the oncologists in our, in my healthcare system, that doesn't understand when it is time to stop in terms of treatments. (Oncologist 4, Italy)

There are so many highly invasive treatment options for cancer that it seems to be more difficult to opt for the palliative care pathway for cancer patients than for dementia patients. (Researcher, Germany)

[...] sometimes particularly in people with dementia, it's difficult to know when they're actually, when do you define that they're palliative or end of life, you know? At what point do you recognise that? (Care Home Director 1, England)

Boundaries and definitions. The remit of palliative care and its patient group is still not understood. There was reportedly much confusion, not only among the public but also among professionals, about what differentiates the terms 'palliative care', 'basic palliative care', 'specialist palliative care' and 'end-of-life care'.

I'd love to either import or export some definitions so that when we talk about palliative care or supportive care or end of life care, you know, that's something a little bit more robust. (GP 2, England)

The term palliative care remains a difficult one since it is never used in daily life. (Researcher 2, The Netherlands)

There is neither a clear definition nor funding of basic palliative care; furthermore it is unclear who should provide basic palliative care and for how long. (Palliative Medicine Physician 2, Germany)

Many participants spoke of the misperception that palliative care is only for people with cancer and how this coincides with general misunderstandings about dementia. As a consequence, there was limited acknowledgment that dementia is a life-limiting condition, and a failure to recognise that people with dementia can and do experience pain:

[...] if you've got a cancer then you're termed as palliative and everybody knows the input that you're going to get. But if you're coming to the end of life phase with complex conditions, then you don't come under the palliative care labels and you don't get the same level of care. (Senior Care Home Manager 1, England)

I believe that dementia is not seen – by most physicians – as a disease that will lead to death, and hospices are not properly prepared for the approach that it belongs into that category. (Hospice Manager, Germany)

Knowledge and skills. Participants thought that misunderstandings about dementia had ramifications for the skills of professionals, who were thought to lack experience but did not have any opportunity to undertake dementia care training:

I think the need is greatest when it comes to knowledge, skills and competence. An improvement in these areas will automatically improve the organization of the [nursing home] units as well as the nursing homes and the municipalities in general. I think that people know too little about what it entails to be dying with or from dementia. (Geriatrician 2, Norway)

With dementia, you've mostly got, in residential homes, untrained carers, and even in nursing homes you've got nurses who aren't trained [...]. (GP 3, England)

Twofold concerns were expressed about knowledge and skills for palliative care. One regarded the lack of expertise of professionals who are not palliative care specialists but work with patients needing palliative care. The other related to the fact that the majority of day-to-day basic palliative care is provided by people who are often low paid and under qualified:

I'm just thinking back to how it was when I qualified, which is kind of how it is now actually, it's distressingly the same. And the idea was that we were not all that good at working out how to do palliation and it was done slightly here and slightly there. And as a result of that in fact it could be good but in fact it often wasn't good because doctors and nurses didn't actually have the skill base and the response base and the structures to enable them to be good. (Old Age Psychiatrist, England)

What I think is most important is that the expertise of the people who provide palliative care should be further developed, while I see that, especially in home care organisations, increasingly lower levels of skills are used for these types of patients. (Hospice Director, The Netherlands)

There is a need for a lot more palliative care beds in the nursing homes and that the health personnel there have palliative care expertise. There is also a need to strengthen the palliative expertise of general practitioners (GPs) who visit the nursing homes and are medically responsible for them. (Oncologist, Norway)

Time constraints

Professionals' time is often limited and this was seen as preventing them from performing tasks that were lower down on their list of priorities or were felt as less important:

[...] I think they (hospital staff) are fantastically busy and I think that they have, really I just think they've just lost

sight of what they, I think people just get burnt out [...]. (Research Nurse, England)

The area that needs to be improved the most is the way in which it [palliative care] is prioritized in [health care] institutions. There is increased focus on it, but it is still not part of the daily clinical life in the medical wards. Talking with patients, spending time with the patients, caring for the patients, all this is rationalized away in our system. Clinicians working in palliative care do an important job in trying to get this on the agenda. On the other hand, I think there is a lot of knowledge about this out there [among clinicians], but there just isn't time to prioritize it. (Researcher 4, Norway)

home care services and GPs work under enormous time pressure [...], there is little time for home visits. This runs counter to the principles of palliative and hospice care. (Researcher, Germany)

Discussion

This qualitative study suggests that subject-matter experts from different countries, care settings and positions share concerns about the difficulties of communication within palliative care, the variable integration of services, the problems of securing sustained funding in different reimbursement systems, the complexities of care itself and the time constraints on providing good quality care. These are substantial problems, but they are not new and have all been described previously (Lynch et al., 2010). We agree with Checkland and colleagues (Checkland et al., 2007) that the discourse about 'barriers' to good quality care conceals issues which are much deeper, and we suggest that these perceived barriers may be less important than the context and underlying social relations that have given rise to them.

Communication

Concerns about poor communication between patients and professionals, and between professionals, illustrate this well. Staff providing and patients receiving palliative care face the dilemma of maintaining warm human contact that expresses the reality of death, whilst maintaining sufficient distance to avoid being emotionally overwhelmed (Ramsay, 2000). It is easier to avoid emotionally charged conversations about death and concentrate instead on the more comfortable, familiar task-oriented approach to managing diseases (Ballatt & Campling, 2012). The lack of recognition by family carers and professionals of dementia as a terminal illness then comes as no surprise (Baldereschi et al., 1999). This is not an effective defence against reality. The risks for those working in palliative care is that they then adopt a stance of 'chronic niceness', as nice people who care for nice dying people who will have a nice death in a nice place. The incongruousness of this stance with actual experience creates stresses for palliative care staff, as does any attempt to live up to the nice ideal (Speck, 1999).

Integration

The desire for structural or virtual integration of services into a coherent and effective mechanism may also reflect the disparate nature of the subject of dying. McNamara tries to capture this by describing the time before dying as both a period when ill people negotiate the circumstances of their dying with their family and their professional carers, but also as a drama enacted on a medical stage (MacNamara, 2001). She also adds that palliative care services, however, well embedded in hospitals or other service settings, are a symbolic critique of those other services. And she points out that the dominant culture's focus on the dying individual's autonomy shifts the locus of responsibility for decisions to them, without understanding that the westernised, medicocentric conceptualisation of the self and responsibility is not necessarily shared by patients and their families.

Funding

Many of the funding difficulties seemed related to problems of complicated systems. We do not suggest that this is any different to any other areas of health care, but there are different reasons for difficulties. The needs at the end of life that people with dementia and/or cancer have create confusion and conflict as to who bears the responsibility of funding their care and support. Particular challenges were voiced about funding care for people with non-malignant conditions such as dementia, as it is often not categorised as a terminal condition and people may lack a clear prognosis, leading to complications with insurance payments in countries like Germany and the Netherlands. The USA has long had a problem within its health care system of requiring a 6-month prognosis as a precondition for hospice care, which creates difficulties for people with conditions such as dementia (see below). This accurately depicts people with dementia as the disadvantaged dying.

Processes of care

A recent UK audit showed that 71% of people on their general practitioners (GPs) end-of-life register had a diagnosis of cancer, but only 28% of deaths had a primary diagnosis of cancer (Cole, 2012). The needs of older people who are dying are not prioritised to the same extent as they are in younger people (Seymour et al., 2005). People with other life-limiting conditions are not being included in structured palliative care programmes, for a variety of reasons. For example, it is difficult to reach an accurate prognosis for people dying with or from dementia (van der Steen et al., 2013). All the complexities of communication and service integration discussed above are intensified by the lack of autonomy of the dying individual. Decline in the ability to communicate in dementia is prompting some to try and bring the negotiation forward in the disease trajectory, to the point before communication capabilities are lost (Hughes, Robinson, & Volicer, 2005).

Time

No one has enough time. A tragic, because inevitable, contradiction of modern, scientific medicine is that its application so often depends on the timescale of disease, whilst its efficacy lies in the timescale of illness (Frankenberg, 1992). Doctors and nurses work within one time frame, patients and family carers live within another. To analyse and treat disease, doctors and other professionals must step back from the patient's subjective world and place them on the conveyor belt of diagnosis, assessment and treatment, which moves at its own pace and which creates brief encounters between professionals and patients. However, to really help a person with a life-limiting disease, professionals need to meet them in their own time, within their individual experience of illness. Our interviews suggested that palliative care practitioners move between the two tasks, sometimes with discomfort and difficulty.

Time and power are disconnected. The most powerful people in dementia care are 10 minute people, the medical professionals who interpret test results and make decisions. The next most powerful are nurses or social workers, who may be 2 hour people (at least sometimes). Family members, friends and staff who do the bulk of the caring are 12–24 hour people, but they often have the least formal control over what happens, and frequently their time is not their own. Pritchard describes the deliberate attempt to understand the patient's appreciation of time as 'time empathy' (Pritchard, 1992). There are suggestions that 12–24 hour people should be given time to tell their side of the story, and that 10 minute people could learn to take time out to explain themselves. Our interviews perhaps served some of these purposes.

Strengths and limitations of the study

In-depth interviews with a small range of professionals working at slightly different levels in five health systems produced a rich, if partial, picture of the problems of palliative care in Europe, all of which can be addressed. The relatively small numbers of interviewees may mean that some opinions or perspectives were missed, although the consistency of our findings with other reports suggests that we have captured the essential problems. Regional variations may not have been highlighted enough, particularly in countries with decentralised health care systems (Italy, Germany).

Implications for policy, practice and research

The findings presented in this paper may help governments, commissioners and professionals, by contributing to the growing evidence-based highlighting problems and aspects of palliative care. We have provided examples of problems that span different countries, suggesting that solutions may lie outside the confines of nation states and traditional models of policy and practice reform. These are not unique problems to European countries, for example,

it is well reported there are funding difficulties within the USA for people with dementia, due to the difficulties in making an accurate prognosis (van der Steen, 2010; van der Steen et al., 2013).

Conclusion

Despite differences among the participating countries with regard to their health care systems, culture and funding mechanisms, this study has identified similar themes arising from interviews with national experts. Participants from all five countries confirmed that the quality of palliative care for cancer patients was much better and better organised than for people with dementia. The problems identified by participants were relatively simple, but behind clear descriptions may lay deeper issues that are more difficult to express. We consider that delving below the face value of participants' accounts may help to explain the pervasiveness of problems with palliative care, and the variations within it for people with different diseases.

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References

- Aronson, J. (1994). *A pragmatic view of thematic analysis: The qualitative report 1*. Retrieved from <http://www.nova.edu/ssss/QR/BackIssues/QR2-1/aronson.html>
- Baldereschi, M., Di Carlo, A., Maggi, S., Grigoletto, F., Scarlato, G., Amaducci, L., & Inzitari, D. (1999). Dementia is a major predictor of death among the Italian elderly. ILSA Working Group. Italian Longitudinal Study on Aging. *Neurology*, 52(4), 709–713.
- Ballatt, J., & Campling, P. (2012). *Intelligent kindness: Reforming the culture of health care*. London: Royal College of Psychiatrists.
- Banerjee, S. (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.
- Centeno, C., José Pons, J., Lynch, T., Donea, O., Rocafort, J., & Clark, D. (2013). *EAPC atlas of palliative care in Europe 2013 – cartographic edition*. Milan: E. Press.
- Checkland, K., Harrison, S., & Marshall, M. (2007). Is the metaphor of 'barriers to change' useful in understanding implementation? Evidence from general medical practice. *Journal of Health Services Research & Policy*, 12(2), 95–100.
- Cole, A. (2012). Hospital deaths are on decline, but change is slow, says new report. *British Medical Journal*, 344, e3307.
- Council of Europe. (2003). Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organization of palliative care. Retrieved from <https://wcd.coe.int/ViewDoc.jsp?id=85719>
- Department of Health. (2008). *End of life care strategy: Promoting high quality care for all adults at the end of life*. London: Author.
- Department of Health. (2013). *More care, less pathway: A review of the Liverpool care pathway*. Retrieved from gov.uk: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- Ferlay, J., Autier, P., Boniol, M., Heanue, M., Colombet, M., & Boyle, P. (2007). Estimates of the cancer incidence and mortality in Europe in 2006. *Annals of Oncology*, 18(3), 581–592.
- Frankenberg, R. (1992). 'Your time or mine?': Temporal contradictions of biomedical practice. In R. Frankenberg (Ed.), *Time, health and medicine* (pp. 1–30). London: Sage.
- Guba, E., & Lincoln, Y. (1981). *Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches*. San Francisco, CA: Jossey-Bass.
- Hughes, J.C., Robinson, L., & Volicer, L. (2005). Specialist palliative care in dementia. *British Medical Journal*, 330(7482), 57–58.
- Lynch, T., Clark, D., Centeno, C., Rocafort, J., De Lima, L., Filbet, M., ... Wright, M. (2010). Barriers to the development of palliative care in Western Europe. *Palliative Medicine*, 24(8), 812–819.
- MacNamara, B. (2001). A good enough death. In M. Purdy & D. Banks (Eds.), *The sociology and politics of health* (pp. 244–257). London: Routledge.
- Matthews, F.E., Arthur, A., Barnes, L.E., Bond, J., Jagger, C., Robinson, L., & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the cognitive function and ageing study I and II. *Lancet*. Advance online publication. doi:10.1016/S0140-6736(13)61570-6
- McCarthy, M., Addington-Hall, J., & Altmann, D. (1997). The experience of dying with dementia: A retrospective study. *International Journal of Geriatric Psychiatry*, 12(3), 404–409.
- Mitchell, S.L., Teno, J.M., Kiely, D.K., Shaffer, M.L., Jones, R. N., Prigerson, H.G., ... Hamel, M.B. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, 361(16), 1529–1538. doi: 10.1056/NEJMoa0902234
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998). Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment*, 2(16), 1–274.
- Neuberger, J. (2013). *More care, less pathway: A review of the Liverpool Care Pathway*. London.
- Payne, S., Leget, C., Peruselli, C., & Radbruch, L. (2012). Quality indicators for palliative care: Debates and dilemmas. *Palliative Medicine*, 26(5), 679–680.
- Pritchard, P. (1992). Doctors, patients and time. In R. Frankenberg (Ed.), *Time, health and medicine* (pp. 75–93). London: Sage.
- Radbruch, L., & Payne, S. (2009). White paper on standards and norms for hospice and palliative care in Europe: Part 1. *European Journal of Palliative Care*, 16, 278–289.
- Ramsay, N. (2000). Sitting close to death: A palliative care unit. In R.D. Hinshelwood & W. Skogstad (Eds.), *Observing organisations: Anxiety, defence and culture in health care* (pp. 142–151). London: Routledge.
- Raymond, M., Warner, A., Davies, N., Baishnab, E., Manthorpe, J., & Iliffe, S. (2013). Evaluating educational initiatives to improve palliative care for people with dementia: A narrative review. *Dementia: The International Journal of Social Research and Practice*. Advance online publication. doi:10.1177/1471301212474140
- Raymond, M., Warner, A., Davies, N., Manthorpe, J., Ahmedzai, S., & Iliffe, S. (2012). Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia: The International Journal of Social Research and Practice*. Advance online publication. doi:10.1177/1471301212450538
- Reisberg, B. (1987). Functional assessment staging (FAST). *Psychopharmacology Bulletin*, 24(4), 653–659.

- Sachs, G.A., Shega, J.W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, 19(10), 1057–1063. doi:10.1111/j.1525-1497.2004.30329.x
- Sampson, E.L. (2010). Palliative care for people with dementia. *British Medical Bulletin*, 96(1), 159–174.
- Seymour, J.E., Witherspoon, R., Gott, M., Ross, H., Payne, S., & Owen, T. (2005). *End of life care: Promoting comfort, choice and wellbeing among older people facing death*. Bristol: Policy Press.
- Speck, P. (1999). Working with dying people: On being good enough. In A. Obholzer & V.Z. Roberts (Eds.), *The unconscious at work: Individual and organisation stress in the human services* (pp. 94–100). London: Routledge.
- Sternsward, J., & Clark, D. (2004). Palliative medicine – a global perspective. In D. Doyle, G. Hanks, N. Cherny, & K. Calman (Eds.), *Oxford textbook of palliative medicine* (pp. 1119–1224). Oxford: Oxford University Press.
- Thuné-Boyle, I.C.V., Sampson, E.L., Jones, L., King, M., Lee, D. R., & Blanchard, M.R. (2010). Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia*, 9(2), 259–284. doi: 10.1177/1471301209354026
- van der Steen, J. (2010). Dying with dementia: What we know after more than a decade of research. *Journal of Alzheimers Diseases*, 22(1), 37–55. doi:10.3233/JAD-2010-100744
- van der Steen, J., Radbruch, L., Hertogh, C.M., de Boer, M.E., Hughes, J.C., Larkin, P., . . . on behalf of the European Association for Palliative Care. (2013). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European association for palliative care. *Palliative Medicine. Advance online publication*. doi:10.1177/0269216313493685
- World Health Organisation. (2006). *Quality of care: A process for making strategic choices in health systems*. Geneva: Author.