Barriers to providing palliative care for older people in acute hospitals

CLARE GARDINER1, MARK COBB3, MERRYN GOTT2, CHRISTINE INGLETON1

1University of Sheffield – School of Nursing & Midwifery, Sheffield, UK
2University of Auckland – School of Nursing, Auckland, New Zealand
3Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

Address correspondence to: C. Gardiner. Tel: (+44) 114 262 0174 ext 31. Email: c.gardiner@sheffield.ac.uk

Abstract

Background: the need for access to high-quality palliative care at the end of life is becoming of increasing public health concern. The majority of deaths in the UK occur in acute hospitals, and older people are particularly likely to die in this setting. However, little is known about the barriers to palliative care provision for older people within acute hospitals.

Objective: to explore the perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals.

Methods: fifty-eight health professionals participated in eight focus groups and four semi-structured interviews.

Results: participants identified various barriers to palliative care provision for older people, including attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources. Participants also reported differing understandings of whose responsibility it was to provide palliative care for older people, and uncertainty over the roles of specialist and generalist palliative care providers in acute hospitals.

Conclusions: numerous barriers exist to the provision of high-quality palliative care for older people within acute hospital settings. Additional research is now required to further explore age-related issues contributing to poor access to palliative care.

Keywords: palliative care, hospitals, older people, elderly

Background

Demographic trends coupled with a rise in long-term health conditions and chronic diseases mean that the core population of patients requiring palliative care is ageing [1]. This is a particular challenge for palliative care whose demographic profile has tended to be younger and whose historic disease focus has predominantly been cancer. Ensuring that palliative care becomes more accessible to older people and their particular complex and co-existing problems is therefore a priority.
needs has been identified as an international public health priority [2]. The care provided to people with advanced progressive and incurable illness is also increasingly the focus of debate regarding terminology [3]. In the UK, recent policy has seen a shift that has attempted to separate the term palliative care from dying [4]. Other countries including the USA and Australia have also moved away from associating palliative care with dying, particularly for older people [5]. These definitional issues add to the complexities of both researching and implementing good care for the growing numbers of older people with advanced progressive illness.

In 2008 in excess of a quarter million (56%) of all deaths in England and Wales occurred in NHS hospitals [6] and adults aged 75–84 years had the highest hospital death rates [4]. Palliative care provision in acute hospitals in the UK has been identified as an area of particular policy priority in light of a recent report identifying that a proportion of patients dying in hospitals, the majority of whom are older people, experience very poor care [7]. A survey of complaints within the NHS revealed that half of complaints made between 2004 and 2006 related to care given in acute hospitals, and of these 54% related in some way to end-of-life care [8].

The End of Life Care Strategy for England has highlighted the delivery of high-quality end-of-life care in acute hospitals as a particular area of priority [4], acknowledging that numbers of people dying in acute hospitals are increasing [9]. Whilst for many patients home is the preferred choice for end-of-life care and death [10], for some patients hospital is the preferred setting. Older people in particular have identified significant barriers to dying at home and often report preferences for care in hospital, feeling reassured by the presence of medical expertise and technologies [11]. There are currently 314 hospital-based specialist palliative care (SPC) services in the UK; these services comprise professionals with specialist training in palliative care whose remit is to care for patients who require continuous or high levels of support [12]. However, the majority of older patients dying in hospital will receive palliative care from ‘generalist’ providers, i.e. professionals working within specialties such as Geriatric Medicine who will not have undertaken specialist training in palliative care and who provide this care as a routine part of their ‘usual’ care [13, 14].

Whilst there is continuing evidence of inequalities in referral to and use of SPC services for older people [15], reasons for this are unclear and recent evidence has suggested that for patients within the specialist cancer care system, age is not associated with access to SPC [16, 17]. Barriers to providing palliative care in acute hospitals are not well understood and there is a paucity of published literature in this area, particularly in relation to older people. This study contributes to the limited UK evidence base by exploring the perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals.

**Methods**

Given the exploratory nature of the enquiry and the limited existing evidence base, a qualitative study design was adopted. Four focus groups were held at general practices (n = 28), and four focus groups (n = 26) and four interviews (n = 4) were held in two acute hospitals and two hospices in UK cities selected to maximise socio-demographic diversity of patient populations (Sheffield and Lancaster). The acute hospitals were large city hospitals both providing geriatric medicine services (one of the hospitals housed an SPC inpatient unit, the other had no inpatient SPC provision but had access to outreach services). Participants from a range of disciplinary backgrounds and care settings were selected in order to achieve the maximum possible variation of experience and opinion (Table 1). The focus group and interview guide was developed following a review of the literature and relevant policy (Table 2). Focus groups and interviews were conducted and led by CG. The study received ethical approval from the Sheffield Research Ethics Committee and all participants gave written informed consent.

**Analysis**

Focus group and interview transcripts were recorded and transcribed verbatim, field notes were included where appropriate. To address issues of rigour and trustworthiness, transcripts were read by three of the authors (C.G., M.G., C.I.) and core themes were identified. A coding framework was developed by consensus and was grounded in the data rather than decided a priori. Sub-themes were then identified with the assistance of the data analysis programme NVivo 8. The themes and sub-themes discussed in this article were then further analysed by C.G. Direct quotations have been selected to illustrate the issues raised by participants and they are indicative both of typical responses and of the diversity of views obtained.

**Findings**

Whilst participants agreed that high numbers of predominantly older inpatients in acute hospital settings have palliative care needs, understandings regarding whose responsibility it was to address those palliative care needs differed. Participants reported that amongst some health professionals, palliative care was seen as a service to be delivered by specialists and was not seen to be in the remit of those providing acute care in hospitals.

**Clinical nurse specialist:** ‘I think there’s some real attitudes within medical teams or surgical teams as well,'
that it’s not really their business to deal with that… to deal with palliative care.’ [focus group 5]

The prevailing view amongst geriatricians was that the nature of their speciality gave them some experience in the care of dying patients. However, they were uncertain as to whether or not to claim expertise in this area and did not view palliative care as a core part of their role, there was also a tendency to not to claim expertise in this area and did not view palliative care as a core part of their role, however, they were uncertain as to whether or not their speciality gave them some experience in the care of dying patients. However, they were uncertain as to whether or not just by the specialists’ [focus group 8].

However, significant barriers were identified to generalists providing palliative care and instigating referrals to SPC teams. Whilst some were common to patients of all ages, the majority had particular resonance for older patients.

### Barriers to ensuring appropriate palliative care provision for older patients

Several participants acknowledged that an older patient with palliative care needs elicited a different response from them than a younger patient with comparable needs, and that this had implications for clinical practice. For example, a terminal diagnosis in an older person was seen as less ‘shocking’ and more expected than in a younger person.

**Consultant Geriatrician:** ‘I think it’s possibly the case that… it’s more acceptable in older people… it’s the good innings argument… you know they’ve had their innings, they’re old so they’ve perhaps got less to live for’ [interview 3]

Limited social and family support was also identified as contributing to a lack of palliative care provision for older people. Younger people were seen to have more comprehensive support networks, as well as often having an advocate who could demand best quality care on their behalf. The role that family and support networks could play in facilitating access to services such as SPC was seen as compounding the lack of psychosocial support available to older people, particularly those who have been alone.

**Hospice Nurse:** ‘There’s often a lot more support for younger people as far as families and people go. With younger people nearly always family members, friends, neighbours will rally round. Often with old people there’s no one.’ [focus group 8]"
services, in part due to the historical link between cancer and palliative care.

Practice nurse 1: “They don’t admit them to the palliative care unit do they... the COPD and heart failure?”

Practice nurse 2: “They go on to the general ward” [focus group 3]

Generalist palliative care provision within acute hospitals was seen as being particularly susceptible to resource restrictions. It was acknowledged that inadequate staffing levels and increased time pressures on generalists impacted on the ability of staff to provide good palliative care. Psychosocial palliative care in particular was rarely prioritised under these circumstances.

Hospice Social Worker: “The staffing levels there [hospital] are often so poor that it isn’t a question of not wanting to do it, it’s not being able to do it. They’re not even able to satisfy the basic requirements, much less go in and listen to people in the way that they’d like to.” [focus group 5]

A focus on acute or interventionist care

Participants reported that both generalist palliative care, and timely referral to SPC, could be compromised by an inappropriate focus on interventionist care with a curative intent. This was described in some instances as a reluctance of ‘doctors to let patients die’. The widespread public expectation that hospital is a place ‘where ill people go to get better’ was cited as a further justification for the focus on acute care, with physicians not wanting to seem as if they had ‘given up’ on patients.

Consultant Geriatrician: “I think some doctors find it difficult to let go, some doctors find it uncomfortable to admit that the patient is going to die, they feel that they should carry on, doing all they can for them in terms of investigations and treatment” [interview 3]

Discussion

This qualitative study confirms that significant barriers exist to the provision of optimum palliative care for older people within acute hospital settings. The finding that older age can act as a barrier to accessing SPC resonates with previous research findings [16]. Despite substantial evidence suggesting inequalities in access to SPC for older patients, there is little consensus as to why this should be the case, and in addition whether inequality in access to care necessarily implies inequity in care [16, 18]. Indeed, a recent study exploring equity of use of SPC in lung cancer clinic patients found that age was not associated with the receipt of SPC services, and referral was based on the need [17]. However, health professionals in our study reported that they often believed older people to be less requiring of palliative care than younger people, as a consequence of death being more expected in an older person, and the perception that older people find it easier to come to terms with a terminal diagnosis. It seems that, for a proportion of health professionals, the belief that older people have fewer requirements for SPC may be a factor affecting referral patterns and leading to reduced utilisation of specialist care.

 Provision of good palliative care for older people is also crucially mediated by a situation where the role of the first line of health professionals for older people, specifically geriatricians, is ill-defined in terms of responsibility for providing palliative care [19]. A further debate surrounds the definitional and conceptual issues relating to palliative care for older people. The findings show that, for generalists in particular, palliative care is often equated with dying. This conceptual issue may present a further barrier to optimum care, particularly for patients with non-malignant disease where ‘dying’ may not be diagnosed until close to death. At both practice and policy levels, there is a tendency to compartmentalise chronic disease management and end-of-life care. This complicates the implementation of ‘continuous palliation’ for older people, as advocated within Geriatric Medicine [20]. Ensuring both the early introduction of palliative care and continuous palliation is central to achieving improvements in the end-of-life experiences of older people. Indeed, overall, there is an urgent need to clarify the terminology used within palliative care in order to ensure consistency in clinical practice.

Findings from this study indicate a situation where specialist palliative care services are still inextricably linked with cancer, despite substantial evidence to suggest that patients with advanced non-malignant disease would benefit from this care [21]. Older people are proportionally more likely to die from conditions other than cancer, and hence are disadvantaged in access to SPC by diagnosis [22]. A focus on interventionist care with curative intent was also identified as contributing to a delay in the implementation of appropriate palliative care within acute hospitals. This finding has particular resonance in the context of recent UK guidelines produced by the General Medical Council regarding Treatment and Care Towards the End of Life [23]. The guidelines acknowledge that the most challenging decisions in this area are generally regarding withdrawing or not starting a treatment when it has the potential to prolong a patient’s life. Findings from this study confirm the difficulties faced by health professionals when making decisions about adopting a palliative care approach. Evidence has suggested that earlier integration of palliative care as part of a multidisciplinary team can facilitate optimum patient care [24]. However, recognition is required, particularly by generalist palliative care providers within acute hospitals, that a focus on interventionist care may not always be appropriate for patients with life-limiting conditions.

Additional research is now required to further explore the issues identified in this paper. At policy level, there is much to support palliative care for older people, but there are clearly challenges in translating this into practice. Part of the challenge arises because of the traditional palliative care model and its institutional and cancer focus. Further
challenges result from the definitional and conceptual issues surrounding palliative care, and its relevance for older people. An ageing population with chronic conditions, co-morbidities and complex social circumstances may be better served by a more dispersed model of palliative care with case management across the pathway. Evidence suggests that comprehensive case management can be effective in the management of chronic long-term conditions [25]. Further research should seek to explore the appropriateness of the expansion of these services to incorporate palliative care, and facilitate the implementation of continuous palliation. In addition, culture change is required in order that ageist attitudes are replaced with optimal palliative care regardless of age. As evidence suggests that education alone may be insufficient to effect a significant culture change [26], further research should seek to explore practical and policy-driven initiatives that more effectively moderate attitudes and behaviour.

Key points

- This study confirms that numerous barriers exist to the provision of optimum palliative care for older people in acute hospitals.
- There is some evidence of ageism in relation to equitable access to palliative care in hospitals.
- Differing understandings were reported regarding the role of specialist and generalist palliative care for older people.

Conflicts of interest

None declared.

Funding

This study was funded by the National Institute for Health Research (NIHR), under the Service Delivery and Organisation (SDO) stream. The views and opinions expressed herein are those of the authors and do not necessarily reflect those of the Department of Health.

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Received 3 June 2010; accepted in revised form 10 November 2010

Angiotensin-converting enzyme gene and plasma protein level in Alzheimer’s disease in Taiwanese

YUAN-HAN YANG1,2,3, CHIOU-LIAN LAI1,3, YU-CHANG TYAN4,5, MEI-CHUAN CHOU3, LING-CHUN WANG6, MING-HUI YANG7, CHING-KUAN LIU1,2,8

1Department of and Master’s Program in Neurology, Faculty of Medicine, Kaohsiung Medical University, Kaohsiung City, Taiwan (R.O.C.)
2Graduate Institute of Medicine, College of Medicine, Kaohsiung Medical University, Kaohsiung City, Taiwan (R.O.C.)
3Department of Neurology, Kaohsiung Medical University Hospital, Kaohsiung City, Taiwan (R.O.C.)
4National Sun Yat-Sen University-Kaohsiung Medical University Joint Research Center, Kaohsiung City, Taiwan (R.O.C.)
5Department of Medical Imaging and Radiological Sciences, Kaohsiung Medical University, Kaohsiung City, Taiwan (R.O.C.)
6Department of Biological Sciences and Technology, National University of Tainan, Tainan City, Taiwan (R.O.C.)
7Department of Chemistry, National Sun Yat-Sen University, Kaohsiung City, Taiwan (R.O.C.)
8Department of Neurology, Kaohsiung Municipal Hsiao Kang Hospital, Kaohsiung City, Taiwan (R.O.C.)

Address correspondence to: C.-K. Liu. Tel: (+886) 73121101 6760; Fax: (+886) 73162158. Email: ckliu@kmu.edu.tw

Abstract

Background: angiotensin-converting enzyme (ACE) gene insertion/deletion (indel) polymorphism is considered a biomarker for Alzheimer’s disease (AD). However, the associations of ACE gene and protein level to AD are undetermined among Taiwanese.

Methods: this study investigated 257 Taiwanese cases with AD and 137 ethnically matched controls using ACE gene indel genotype association methods with logistic regression adjusted for other variables. Besides, 65 out of 257 AD patients, 11 with D/D genotype, 28 with I/I genotype and 26 with I/D genotype were recruited. Their plasma ACE protein levels were measured by enzyme-linked immuno-sorbent assay and compared for their corresponding ACE gene indel polymorphism.

Results: patients with ACE-I/I homozygote were less likely to be associated with AD, compared with both I/D and D/D (OR: 0.601; 95% CI: 0.372–0.969; P = 0.037), or only I/D genotype (OR: 0.584; 95% CI: 0.349–0.976; P = 0.040). There were significantly different plasma ACE protein levels among these three different genotype groups (P = 0.023). The I/I genotype group had significantly lower ACE plasma levels [114.79 ± 31.32 ng/ml (mean ± SD)], compared with D/D (164.07 ± 86.36 ng/ml; P = 0.010), but not I/D (141.45 ± 51.50 ng/ml; P = 0.064).

Conclusion: ACE-I/I homozygote corresponds to lower plasma ACE protein level and it is independently but less likely to be associated with AD. These findings signal the importance of ACE indel polymorphisms to their corresponding protein levels and to AD.

Keywords: angiotensin-converting enzyme, Alzheimer’s disease, Taiwanese, elderly