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Barriers to providing palliative care for older people in acute hospitals

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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 8 focus groups and 4 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.

Background

Demographic trends coupled with a rise in long-term health conditions and chronic diseases means that the face of palliative care is ageing [1]. Many of the problems associated with life threatening illnesses must now be understood within the context of the lives of older people

and the provision of services to this population. This is a challenge to health services in general and palliative care in particular 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 needs has been identified as an international public health priority [2].

In 2008 in excess of a quarter million (56%) of all deaths in England and Wales occurred in NHS hospitals [3] and adults aged 75 to 84 years had the highest hospital death rates [4]. This age profile was reflected to some extent in an audit of hospital patients (n=3893) placed on the Liverpool Care Pathway for the Dying Patient whose median age was 81 [5].

The recently published 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 [6]. Whilst for many patients home is the preferred choice for end of life care and death [7], it should be acknowledged that 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 in this setting [8].

There are currently 314 hospital-based specialist palliative care (SPC) services in the UK, whose remit is to care for patients who require continuous or high levels of support [9]. 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 [10,11]. A census

of palliative care need in one UK hospital identified that only 3% of patients with identified palliative care needs (the majority of whom were older people) had been recommended for referral to SPC [12]. Whilst there is continuing evidence of inequalities in referral to and use of SPC services for older people, 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 [13,14]. Barriers to providing palliative care in acute hospitals are not well understood and whilst the End of Life Care Strategy for England advocates professional training to improve standards of generalist palliative care provision, evidence from the US indicates that this may not be sufficient to effect the culture change required [15]. This study contributes to the limited UK evidence base by exploring the perspectives of health professionals working within Geriatric Medicine, General Practice, and Specialist Palliative Medicine regarding barriers to optimal palliative care for older people in acute hospitals. The aim was not to evaluate specialist palliative care services, rather to explore palliative care as offered by all providers within acute hospitals. Both primary and secondary care professionals, and generalist and specialist palliative care providers were included in the study in order to capture perspectives from all professional groups involved in providing end of life care to older people.

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)¹ were held in acute hospitals and hospices in two UK cities selected to maximise socio-demographic diversity of patient

¹ Individual interviews were held in cases where participants were unable for practical reasons to attend a focus group; the same question guide was used for all focus groups and interviews.

populations (Sheffield and Lancaster). Participants from a range of disciplinary backgrounds and care settings were purposively 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. The study received ethical approval from the Sheffield Research Ethics Committee and all participants gave written informed consent.

[Table 1 to be inserted about here]

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 (CG, MG, CI) 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 CG. 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.

Registrar in geriatrics: *“surely we have some specialism in dying, in older people dying? We have a bit of experience of that? Again where do you fit that into your programme...to do it justice and do it properly” [focus group 4]*

Other participants, particularly those specialising in palliative care, believed that basic palliative care could, and should, be provided by all health professionals involved in caring for patients reaching the end of life, as an important component of routine care. In these circumstances generalist palliative care was seen as an important adjunct to the care provided by palliative care specialists.

Consultant in Palliative Medicine: *“palliative care is not only the business of specialist teams...everyone should be able to deliver the basic, generic palliative care... whether you like it or not in your career you will be facing death and dying whatever speciality you choose, so those skills have to be had by everyone and not just by the specialists” [focus group 8].*

However, significant barriers were identified to generalists providing palliative care and instigating referrals to specialist palliative care 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]

Consultant Geriatrician: *“If I’m being honest, and appreciating this is confidential, I think when you get people who are not old with an end of life or palliative diagnosis you can feel more sympathy towards them, more empathy, with them”.*[interview 1]

Participants confirmed that these beliefs, coupled with a perception that older people sometimes find it easier to come to terms with a terminal diagnosis, contributed to the lower levels of psychosocial support they felt older people with palliative care needs received.

Consultant Geriatrician: *“there is some ageism there.....because you may get the drug that you want for the palliative approach but you may not get the psychological support, the*

counselling aspect. Things are much more when younger patients are treated in a palliative way.” [interview 4]

Limited social and family support were 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 specialist palliative care was seen as compounding the lack of psychosocial support available to older people, particularly those who live 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]

Lack of resources, particularly for people dying from conditions other than cancer

Both generalist and specialist palliative care provision within acute hospitals were identified as particularly deficient for the population of predominantly older people dying from conditions other than cancer. It was reported that patients with non-malignant disease were less likely to be referred to specialist palliative care services, in part due to the historical link between cancer and palliative care which continues to influence which patients are perceived to have palliative care needs.

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”.*

Practice nurse 1: *“I think you can now but normally they go on to the general wards don’t they”* [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 [acute 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 specialist palliative care, 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. Some doctors reported feeling as if they had ‘failed’ if they commenced palliative care, even if this was introduced alongside existing active care.

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 *you know, 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. A systematic review of specialist palliative care use in older people reported that older people are less likely to be referred to, or to use specialist palliative care [13]. Evidence from the UK Regional Study for Care of The Dying also reported an under-representation of older people within specialist palliative care settings [5]. Despite substantial evidence suggesting inequalities in access to specialist palliative care 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 [13, 16]. Indeed a recent study exploring equity of use of SPC in lung cancer clinic patients found that age was not associated with receipt of SPC services, and referral was based on need [14]. 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 can 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. While the findings reported by Burt et al. indicate that within specialist cancer services access to SPC is not affected by age, the majority of older people will remain outside the specialist cancer clinic setting, and may be subject to some of the inequity described in the current study.

Health professionals also recognised that the environment within which older people live, often socially and physically isolated, could contribute to poor access to care. In these situations, it is not the attitude of the health professional that influences access to care, but the lack of an advocate or a 'patient voice' demanding the level of care appropriate for an individual. This finding is consistent with previous research which has identified that access to SPC heavily depends on the availability of a carer, and their willingness to provide care [17]. In addition older carer age has been found to be negatively associated with palliative care access, and it has been suggested that younger carers are more effective at obtaining care, and may be more proactive in demanding care [18].

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. Whilst the British Geriatrics Society has recognised that end of life care for older people is often suboptimal [19], a clearer understanding of the inequalities relating to ageism in palliative care is now required in order that older people receive care that is appropriate to their needs and wishes.

Findings from this study also indicate a situation where specialist palliative services are still inextricably linked with cancer care, despite substantial evidence to suggest that patients with advanced non-malignant disease would benefit from this care [20]. Older people are proportionally more likely to die from conditions other than cancer, and hence are disadvantaged in access to SPC by diagnosis [21]. This is despite guidelines relating to age related conditions such as stroke and dementia recommending access to specialist palliative

care based on need [22,23]. Whilst research such as this highlights a need for further enquiry into equity in terms of access to specialist palliative care, specialist resources are unlikely to expand significantly. Therefore there is a pressing need to improve palliative and end of life care for patients in generalist care settings such as acute hospitals, where the majority of older people will be cared for [16].

A focus on interventionist care with curative intent was 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 [24]. The guidelines are intended to provide a decision making framework and 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, or referring to specialist palliative care services. Evidence has suggested that earlier integration of palliative care as part of a multidisciplinary team can facilitate optimum patient care [25]. 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 which contribute to poor access to palliative care for older people in acute hospital settings. 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. 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.

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Male	12 (20.7%)
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Mean age	46.3yrs (SD = 9.92)	
Age Range	28-69yrs	
Job Title	Consultant	4 (6.9%)
	Junior doctor	9 (15.5%)
	General Practitioner	6 (10.3%)
	Practice Nurse	4 (6.9%)
	Clinical Nurse Specialist	11 (19.0%)
	Other nurse	19 (32.7%)
	Allied Health Professional	5 (8.6%)
Place of work	Acute hospital	10 (17.2%)
	GP Practice	28 (48.3%)
	Hospice	15 (25.9%)
	Specialist palliative care unit	5 (8.6%)

Table 1: Descriptive information for focus group participants (n=58)