

Why do older people get less palliative care than younger people?

Anna Lloyd, Marilyn Kendall, Emma Carduff, Debbie Cavers, Barbara Kimbell and Scott A Murray have analysed data from four studies into the end-of-life experiences of people with glioma, bowel cancer, liver failure and frailty. They found that patients aged 70 and over received less palliative care. Why?

The WHO claims that older people suffer because of a lack of access to palliative care and has called for a palliative care approach to be adopted in their care.¹ Across all conditions, people over the age of 85 are less likely to access palliative care than people below the age of 85.² Evidence suggests that people over 85 have no less palliative care needs, and receive little hospice care despite this being a high preference.³ Older people can be considered to have less palliative care needs by virtue of death being more expected.^{4,5} They may be unwilling to accept care that they perceive might threaten their independence.^{6,7} Evidence suggests that there are a number of unmet needs in this patient group; for example, Higginson and Gao suggest that older people with cancer may receive less adequate pain relief.⁸ While the quality of care may be equitable in the last months of life, in the final days, older people may receive less emotional and spiritual support and be subjected to more unwanted treatment decisions.⁹ Hunt *et al* also found that those over 85 years of age were less likely

to have their preferences for place of death recorded, or to actually die there.⁹

We thus set out to explore access to palliative care, pain and symptom control, quality and experience of care, and actual and preferred place of death in older people compared with younger people.

Methods

We conducted a qualitative secondary analysis of Scottish data from four PhD studies that members of our research group had done to investigate the end-of-life experiences of people with four conditions: glioma,¹⁰ bowel cancer,¹¹ liver failure¹² and frailty.¹³ We used deductive and inductive analytical phases to facilitate access to a large data set and target specific age groups.¹⁴⁻²⁰

Although the demarcation between the 'younger old' and 'older old' is usually estimated to be somewhere between 75 and 80 years, we chose 70 as the cut-off age because of Scotland's lower life (and lower healthy life) expectancy relative to the UK.²¹ Table 1 details the number and age of participants and the number of interviews.

The analysis was conducted in three stages, described below.

- Stage 1: a deductive phase examining each PhD study separately. A subset of patients aged 70 or over was identified and a case summary was completed for each patient by the original researcher to provide context. A thematic analysis of the interviews was conducted to identify issues around access to palliative care, pain and symptom control, quality and experience of care, and actual and preferred place of death.
- Stage 2: an inductive phase looking outwards to the broad findings for the younger and

Key points

- A secondary analysis of data from four studies on the end-of-life experiences of people with glioma, bowel cancer, liver failure and frailty suggests that older patients (aged 70 and over) have more untreated pain, less access to generalist and specialist palliative care, and greater information needs than younger patients.
- In older people, there are less clear early signs indicating that they need, and triggering their referral to, palliative care. The lack of a clear diagnosis of dying and the association of palliative care with cancer also hinders older people's access to good end-of-life care.
- More efforts should be made to identify older patients who would benefit from a palliative care approach in all settings.

Table 1. Number and age of participants, and number of interviews conducted, in the four studies used for secondary qualitative analysis

	Bowel cancer	Glioma	Liver failure	Frailty	Total
Number of patients	16	21	15	13	65
Number of carers	8	19	11	13	51
Number of interviews	40	59	32	54	185
Mean age of participants	64 years	51 years	59 years	85 years	62 years
Number of participants aged 70 or over	4	1	4	13	22

older patients in each study. Each researcher considered the themes from Stage 1 for their older patients and reviewed these against the data for their younger patients. Each researcher then completed a chart showing where they perceived disparities and similarities between the two age groups.

- Stage 3: an inductive approach to the whole data set. All researchers discussed the data and themes during an analysis workshop. Similarities and differences between participants aged 70 or over and participants below the age of 70 across the studies were discussed for each patient group in turn. Salient points of similarity or difference within and across patient groups were noted. Researchers described how these may compare in older versus younger people.

Findings

Pain and symptom control

In the cancer and liver failure patient groups, there were no obvious differences between older and younger patients regarding patient-reported pain and/or symptoms or patient-reported management thereof. In the frailty group, all patients were aged 70 or over; some of them experienced poorly managed pain as they struggled with the side effects of analgesic medications; one example was that of a man whose severe pain remained uncontrolled because increasing his analgesics would have increased his risk of falls; pain caused him great psychological and emotional distress. In frail older people, the underlying pathology can take a long time to be diagnosed, despite the complaints raised and pain experienced, as was the case here for a woman whose fractured vertebrae after a fall remained undiagnosed for some weeks.

Care experience

Patients of all ages and conditions found it hard to get information about their prognosis. There was some evidence that frail patients and the older cancer patients were more likely to report misunderstandings. Older patients with bowel cancer had been given information about their prognosis, but had not understood or engaged with it and remained unsure of their situation. This was despite the fact that cancer patients had access to a specialist nurse to answer their questions, offer guidance on available services and procedural and medical processes, and liaise with community palliative care. These services did not seem to exist for those living with frailty or liver failure. The information needs of frail older people concerned discharge planning and available services.

Cancer patients in both age groups gave mixed evaluations of hospital care and resisted hospitalisation, but were generally positive about healthcare staff. Liver failure patients were similarly positive about staff, but more accepting of hospitalisation, probably because of their familiarity with the liver ward. Frail older people became increasingly resistant to hospital admissions over time; some cited poor treatment or neglect, and spoke of witnessing such things in the care of other older people during inpatient stays; some revealed issues of personal agency: hospital stays could become protracted and patients often lacked the physical capacity to leave at their own behest, which led to a sense of imprisonment. This resonated with the experiences of the older glioma patients.

In the glioma group, the researcher noted that the youngest patients in the study (those who were under the age of 50) were more

likely to be offered supportive care through rehabilitation services than those aged 50 and over, despite both groups having similarly limited prognoses.

Two of the older liver failure patients had been offered a package of home care. One had reluctantly accepted it to help his wife, whereas the other had refused it. Professionals in the liver failure study commented that care packages offered to older patients were rarely considered for younger patients despite their potential benefit. Supportive care for the frail older people involved home care services but tended to remain task-oriented, although some older people managed to build supportive relationships with the regular care staff. Frail patients greatly valued access to rehabilitation therapy for giving them hope, and once such services had been stopped could feel abandoned and ‘written off’.

Advance care planning

Conversations about advance care planning were most common in glioma patients (although no such conversations took place for the one glioma patient aged 70 or over, as her prognosis had been withheld at the request of her family). In the bowel cancer group, little advance planning took place, whether in younger or older patients; one of the reasons for this may have been the lack of clarity that some of the older patients had about their prognosis. Advance care planning in the younger bowel cancer patients was also uncommon, but it may have occurred later in the disease trajectory. In the liver failure

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group, advance care planning discussions were more likely in older patients; none had occurred with the younger ones. No frail patient described having had any discussions about planning for a future deterioration or the end of life. Instead, they took a more reactive, ‘deal with it when it happens’ approach. Older frail patients generally wished to ‘carry on’ as they were and, despite understanding their mortality, death remained abstract for them.

Actual and preferred place of death

In the glioma study, discussions around place of death occurred as the illness progressed. The researcher noted that an explicit process of adaptation was more marked for the youngest patients (those under the age of 50).

The glioma patient aged 70 or over did not indicate a preferred place of death; she died in hospital after a protracted stay following surgery for a hip fracture.

In the bowel cancer study, one older and one younger patient (out of four and 12, respectively) expressed the wish to die at home. Both survived beyond the end of the study, so we do not know whether their preference was met.

No liver failure patient mentioned a preferred place of death, probably because of a poorer understanding of their condition and of its life-limiting nature. One older patient with primary liver cancer had community palliative care support in place and died at home; another died in hospital despite such services being in place; the other two older liver failure patients died in hospital.

In the frailty study, where all 13 patients were aged 70 or over, the only explicit wish regarding place of death resulted from a frank discussion between a patient and a family carer, who was also a healthcare professional. The patient wished to die at home but, because of complex needs, was unable to manage at home and died in hospital. This patient experienced severe emotional distress: specialist palliative care input – either a brief hospice stay or community support – might have been beneficial and would have possibly facilitated the desired home death. The other 12 frail patients expressed a wish to continue living in their own homes, although this did not necessarily mean they wished to die there. Two died at home, another died in hospital during an emergency admission and the last death occurred in a nursing home.

Palliative care services

Thirteen younger glioma patients were referred to palliative care services. The remaining ones were lost to follow-up, so we do not know whether such services became involved. The older glioma patient died without palliative care input, probably because of her family’s decision to withhold her prognosis.

Two of the younger and one of the older bowel cancer patients received care from a palliative care specialist nurse. Another older bowel cancer patient had not come to terms with the terminal nature of his condition, so would not consider palliative care input.

In the bowel cancer and glioma groups, problems with access to palliative care might

have been related to a focus on ongoing hospital care or a lack of recognition that patients had reached the terminal stage.

In liver failure, the older patients were more likely to have been referred for palliative care than the younger ones. Two of the four older patients had been referred to community palliative care services, although one of them had initially rejected this because of a perceived link to cancer. However, implementation of this palliative care support was hampered by frequent readmissions to hospital. In a third older liver failure patient, the patient's GP described having limited knowledge of the condition and feeling unsure of his patient's level of deterioration, so had not made a referral.

No frail older patient reported being offered any level of palliative care support, despite the fact that there were clear instances where a palliative approach or specialist input could have eased patients' suffering. A frail man with severe pain had complex needs that may have warranted referral to a hospice; his GP talked about admission to hospital or to a care/nursing home, but a hospice referral was not considered. One carer, who was herself a palliative care professional, described her mother's GP as explicitly rejecting her request for a palliative care approach, believing the patient was not yet at the appropriate stage.

However, two frail patients were moving to a more palliative approach to their care. With the support of a GP who knew them, their families and their circumstances well, these patients evaluated what investigations or treatments they were willing to consider, according to the likely impact on their lives in general and their wishes for the future.

Existential concerns

Older people in the cancer and liver failure groups were more accepting of the terminal nature of their condition, although older cancer patients were less likely than their younger counterparts to have fully acknowledged that they were dying.

An issue that emerged for frail patients was a disconnection between their bodily experience and their understanding of what was happening. Without a clear sign indicating that death was near, death was frequently only recognised in retrospect by the families. Many

frail patients thus experienced an 'undiagnosed death'. It seems that frail patients knew they were deteriorating but, because they did not have an explanatory diagnosis, began to question why. They started expressing feelings of frustration, hopelessness, shame and social alienation, which may have precipitated the existential 'giving up' that can occur before death. Such giving up also appeared to happen in the older glioma patient who had not been told her terminal diagnosis: she stopped communicating with her family for some weeks in hospital before dying.

Untreated pain appears to be related to the absence of a diagnosis or prognosis

Discussion

Our analysis suggests that older people have more untreated pain, less access to generalist and specialist palliative care, and greater information needs than younger people.

Untreated pain

Reports of unmet pain were more evident in the frail older people than in the older people with other conditions, and related to negative side effects and physicians' concerns about the potential exacerbation of other difficulties. Pain in frail people could also have been considered more normal given their advanced age, and may thus have been underestimated or unrecognised as potentially treatable, leading to delays in investigating and addressing its causes. Such factors may explain that our findings conflict with previous findings about age disparities in pain control, as the latter were based on retrospective estimations of pain by bereaved relatives.^{8,9,21} The issue of untreated pain appears to be related to the absence of a diagnosis or prognosis rather than to age, as it was not present in any other older people apart from those with frailty.

Less access to palliative care

We identified several issues regarding older people's access to palliative care. First, referrals to palliative care services did not happen for frail older people, even when palliative care input would have been indicated. This may be because of their advanced age, or because they lacked a terminal diagnosis, or because there was nothing that would have signalled the terminal phase and triggered the healthcare

professional to consider a palliative approach. In the liver failure group, there were more referrals of older patients than younger ones, healthcare professionals being less likely to consider imminent death as an outcome in the latter. This indicates a difficulty in recognising the end of life and thus identifying patients likely to benefit from palliative care. Palliative care input was absent, for the period of the study, for most bowel cancer patients, but was in place for all the younger glioma patients. This supports previous research showing that identifying patients for palliative care is more problematic during the earlier phase of an illness than at a later, more terminal stage,²²⁻²⁴ and is most likely to occur just before death – or not at all in those with organ failure.²⁵ However, although dying may only be identified at a very late stage in non-cancer groups,²⁶ this is even more complicated in frailty. Frail older people often lack a defined terminal illness and transition into the dying stage is, as a result, frequently difficult to recognise.²⁷

Second, even when death is expected, referrals to palliative care did not seem to be considered for frail older people. In previous research, physicians were found to be less likely to refer people over the age of 85 who were dying from terminal conditions than those under the age of 65.²⁸ Physicians were more likely to believe that needs were being met the older the patient was. This may show underestimation of palliative care needs in older people,^{8,29} or overestimation by physicians of their own capacity to ensure that needs are met.²⁸ In the frailty study, a GP who was well known to the older person and had a good relationship with them was able to work with the patient to provide care involving symptom management and investigations, alongside negotiating goals of care,³⁰ in a manner consistent with a palliative care approach. This sort of advocate, who need not be a GP, would be advantageous for frail older people, who currently lack a ‘specialist person’ who can negotiate services.

Third, even when community palliative care referrals were made, implementation could be difficult, perhaps because, when services are limited, palliative care teams give priority to younger people, or because of communication difficulties between settings.

Discussing the end of life is challenging in the absence of a definable prognosis

Furthermore, frequent hospital admissions, common in organ failure, may hinder access to patients in the community. It is also worth considering how patients themselves react to the idea of getting support from palliative care services. Older people may reject palliative services due to a perceived link with cancer or because of a lack of understanding of who and what these services are designed for. In a crisis, older people may also be more inclined to turn to hospital services, because they are more likely to have been admitted to hospital more often, whether for co-morbidities or acute events. Conversely, younger people may be more likely to turn to community palliative support teams.

There was only one older participant in the glioma study, and she did not receive palliative care or have any advance planning discussions, whereas many of the younger glioma patients did. Withholding the prognosis did not happen with any of the younger glioma patients. This suggests that older patients can have, to some degree, a protected childlike status.³¹ Our

research supports the fact that people over the age of 85 are less likely to know that they are dying and less likely to have their preferences for place of death recorded.⁹ None of the frail patients described anticipatory care discussions or explicit discussions about how they may die. An open awareness of death was only evident very close to the end of life, reflecting previous accounts of older people speaking of death and dying in terms of the aftermath, such as making wills.^{32,33} Discussing the end of life is challenging in the absence of a definable prognosis.

Greater information needs

A final issue is that of unmet information needs. Although the lack of information was highlighted across all ages and conditions, it was a particular difficulty for older patients. Many participants spoke of over-medicalised language that left them confused and none the wiser as to their status. It is worth considering issues such as poor eyesight and hearing difficulties, which may impair older people’s ability to absorb information during time-limited consultations. They may also be experiencing agism from health- and social care professionals or overprotectiveness from the family in the consultation process.

Strengths and limitations

The original researchers who had collected and analysed the primary data were able to bring their in-depth understanding of the data to the secondary analysis, which is considered a strength in qualitative analysis.³⁴ The small number of older participants in the cancer and liver failure groups limits our capacity to extrapolate the findings, and highlights the need for further research on age-related palliative care experiences.

Conclusions

This study highlights potential areas of inequality in end-of-life care. In older persons generally, there are less clear early signs indicating that they need, and triggering their referral to, palliative care; this is likely to be one of the reasons why they do not receive as much palliative care as younger people. The lack of a clear diagnosis of dying and the association of palliative care with cancer and imminent death also hinder older people's access to good end-of-life care. More efforts should be made to identify older patients who would benefit from a palliative care approach in all settings. This overview of age disparities in palliative care provision sets an important research agenda. We need to understand more fully the nature of age-related inequalities in order to build an evidence base informing the provision of good-quality, timely palliative care across all age groups and conditions.

Declaration of interest

The authors declare that there is no conflict of interest.

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