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

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Executive Summary

Background: Palliative care can ease suffering across many areas of well-being for dying people and their families and loved ones. Older people, however, have been shown to miss out on palliative care.

Aim: We aimed to compare the experience of palliative and end-of-life care, both specialist and generalist, described by older people compared to younger people.

Method: We analysed four recent PhD research projects that accessed the personal accounts of people approaching the end of life with brain tumours, bowel cancer, liver failure or frailty in Scotland.

Findings: Older people had more unmet pain, less access to generalist and specialist palliative care and greater information needs than younger people with clearer illnesses. However, physicians were more likely to discuss the end of life with older people compared to younger people where there was a clear terminal diagnosis and death appeared imminent. There were clearly disparities in consideration of a palliative approach or specialist palliative services between those in the frail study and those diagnosed with clear terminal conditions. The issue would appear to relate to the diagnosing of a terminal illness and the lack of triggers for recognising the end-of-life in frailty compared to other conditions.

Poor symptom control was an issue described by some in the frail group and related to patients' experience of negative side effects, physicians' concerns about the potential exacerbation of other difficulties and normalisation of pain in older people leading to delays in recognising and addressing treatable problems.

GPs who had an established relationship were in a good position to support older people in transitioning to a palliative approach in the absence of a clear terminal diagnosis and to consider anticipatory care plans.

Conclusion: Older people generally have less clear early triggers for being identified for palliative care. This probably explains their lack of palliative care more than ageism. Lack of a clear diagnosis of "dying" and the association of palliative care with cancer hinder its introduction.

Clinical Implications: More efforts should be made to identify older persons for a palliative care approach in all settings. More attention to earlier triggers such as a hip fracture in a frail person, decreasing functional status or care home admission is indicated. This need not involve additional work being added to an already stretched service but rather that primary care staff are ideally suited to consider how last phase of life care could be shaped for older people.

Research Implications: More research is needed in liaison with geriatricians and with primary care staff to understand:

- How to identify older people for palliative care and to better understand how acceptable this might be to older people and their family and professional carers.

- How the palliative care approach might then best be operationalised in a suitable and patient centred way for older persons.

Background

The World Health Organisation has called for palliative care to be adopted in the care of older people stating that "older people suffer unnecessarily, owing to widespread under assessment and under treatment of their problems and lack of access to palliative care."(Davies and Higginson 2004: p6). A recent review titled '*Equity in the provision of palliative care in the UK: a review of the evidence' published by the London School of Economics"* (Dixon et al. 2015) reported that across all conditions people over 85 are much less likely to access palliative care than younger people. However evidence suggests that people over 85 have no less palliative care needs, and that they receive little hospice care although they have a high preference for it (Gomes and Higginson 2006). Furthermore, an international review noted that referrals for those over 65 years to palliative care were less than their younger counterparts (Dixon, King, Matosevic, Clark, & Knapp 2015).

However, access to services is a complex issue. Older people can be regarded by health care professionals as having less need by virtue of death being more expected (Gott et al. 2013;Gott et al. 2011) or unwilling to accept care services that may threaten their sense of independence (Kendall et al. 2015a;McKevitt et al. 2005). In terms of the experiences of receiving such care there is a mixed picture. Higginson & Gao suggested that compared to younger people, older people may receive less adequate pain relief in cancer (Higginson and Gao 2012). Other research suggested that the quality of care is equitable for those over 85 compared to younger age groups in the last months of life, but in the final days the older group received less emotional and spiritual support and were subjected to more unwanted treatment decisions (Hunt et al. 2014). Hunt et al. also found that the oldest old (those over 85) were less likely to have their preferences for place of death recorded or to die there.

More research is needed to understand this inequity and how the palliative care approach could be made more accessible or suitable for older persons.

Aims

1. To explore access to palliative care, pain and symptom control, quality and experience of care and actual and preferred place of death of older compared to younger people.
2. To consider how these issues may differ between older compared to younger people.

Methods: secondary analysis of qualitative data

We undertook a qualitative secondary analysis (QSA) study informed by Irwin and Winterton's process of deductive and inductive phases. (Hinds et al. 1997;Irwin et al. 2012;Irwin and Winterton 2011a;Irwin and Winterton 2011b;Irwin and Winterton 2011c;Irwin and Winterton 2012;Kendall et al. 2015b) This approach was considered appropriate because it offered a way of accessing a large data set in a targeted manner that could address the research aim of comparing the sub group of older people within and across studies then to the younger participants.

Data Sources

Data were gathered from four PhD studies investigating the experiences of people with advanced conditions and their informal carers. The conditions were glioma, bowel cancer, liver failure and frailty.

These four studies utilised the same methods, employing serial semi-structured interviews to gather prospective data over the course of the condition, and specifically asked about physical, psychological, social and existential well-being, support needs and experiences of care. All four gathered data from patients and their informal carers. Together, the PhDs investigated the experiences of 65 patients, 21 with glioma (Cavers 2010), 16 with bowel cancer (Carduff 2013), 15 with liver failure (Kimbell 2014) and 13 with frailty (Lloyd 2015).

Chronological definitions of 'old' vary, however the accepted definition of 'elderly' in developed countries is 65 years and older (World Health Organisation 2015). Population based estimates place transition to the fourth age, the demarcation between young old and old-old, at around 75-80 years and indeed 65% of deaths occur after the age of 75 (Office for National Statistics 2012). However as Scotland has both lower life expectancy and 4 years less healthy life expectancy than the UK as a whole (Office for National Statistics 2013) the age of 70 was chosen as the cut-off for old age in this study.

Table 1: Details of study participants and interviews conducted in the 4 studies

	Colorectal Cancer	Glioma	Liver Failure	Frailty	TOTAL
Patient	16	21	15	13	65
Carers	8	19	11	13	56
Interviews	40	74	32	54	213
Ave age	64	51	59	85	62
Over 70 yrs	3	1	4	13	21

Analytical approach

The author of each PhD worked with the researcher (AL) to identify the age cohort in each study, and conduct the analysis by age for each condition, guided by MK and SM, who were supervisors on each of the studies. We then compared the results by age across the conditions.

Analysis was conducted in three stages. Stage one was a deductive phase looking at each PhD. A subset of cases was identified according to a shared characteristic of being 70 years of age or over. A case summary was completed for each of these participants by the original researcher to provide an overview of what happened to the person over time and to provide familiarity with each participant for AL. Most of these had been completed at the time of the original research. Stage two was inductive, looking outwards to the broad findings for the younger and older patients in each study. Stage three looked across the data set as a whole.

Stage 1: Deductive approach to selected cases of participants over the age of 70

- Participants who were aged 70 and over were selected from each study
- Interview transcripts and case summaries for each selected participant were read, to provide familiarity and context.
- A thematic analysis was conducted, assisted by NVIVO, to identify issues relating to access to palliative care, pain and symptom control, quality and experience of care and actual and preferred place of death.
- Themes from the analysis were compiled according to the specific conditions. These were summarised and sent to the original PhD researchers.

Stage 2: Inductive approach to individual projects

- Each researcher reflected on their detailed knowledge of and insight about the participants in their studies aided by interview summaries, field notes, transcripts and analyses. The original researchers considered the themes described for the older participants as a framework for reviewing the data for the younger participants in their study. The researchers completed a chart showing where they perceived disparities and similarities between the older and younger patient groups.

Stage 3: Inductive approach to the whole data set

- All four original researchers discussed the data and themes at an analysis workshop. Similarities and differences between participants over and under 70 years of age across the four studies were discussed to evaluate if a consensus about any age disparities could be discerned. These were discussed by themes of access to or uptake of palliative care, pain and symptom control and place of death for each patient group in turn, annotating salient points of similarity or difference within and across patient groups under each theme. Other issues that emerged from the analysis were also discussed. This occurred in two rounds. First the information provided on the charts was outlined for each issue for each participant group. Each researcher offered reflections on the issue. Interpretation of the reflections was offered by all members of the group. The facilitator (AL) then provided a summary and description of points raised in each category. All researchers described how these may compare across the patient groups for older versus younger people. Following the consensus workshop results of the discussion were assimilated according to themes by AL and circulated to the full project group.

Findings

The findings across the four patient groups revealed the following initial themes: events, future, health care professionals, legitimacy, response to diagnosis or prognosis, support and treatment, symptoms and understanding, and information. These were grouped into higher order categories relating to palliative care of pain and symptom control, care experience, advance planning, access to palliative care, and existential issues. Comparisons with the younger participants in these areas were as follows:

Pain and symptom control

Within the cancer and organ failure groups, older and younger people reported no clear difference in pain or symptoms or in their management. Some of the people in the frailty group (average age of 85) had poorly managed pain. They had tried analgesic medications that had been unsuitable due to side effects, especially involving instability or confusion. There were instances within the frail group where underlying pathology - an arthritic hip in one and a fractured vertebrae in another - took a long time to diagnose despite the complaints raised and pain experienced. A further incident involved a frail older man whose severe pain was left untreated as it was felt that increased analgesic medication would exacerbate mobility problems and increase the risk of falling. The ongoing pain caused great emotional and psychological distress right up to the end of life for the older person concerned.

Care experience

Information needs and communication were sources of difficulty and distress for all of the participant groups. Information about prognosis was hard to get for all conditions and ages, though there is some evidence to suggest greater confusion in the frail group and the older cancer patients. For those in the colorectal cancer group older participants were unsure of their diagnosis or prognosis yet the researcher involved in this study highlighted that information had been given but not understood or engaged with. They appeared to have had more difficulty than younger participants in gaining or processing information. The information needs for frail older people surrounded planning for discharge and available services as they told of their struggles of who or where to turn to. Those in the cancer groups had potential access to a specialist nurse to answer questions, to offer guidance on services available, and on procedural and medical processes and to liaise with community palliative care services. There was no such service described for those with liver failure or for frail older people - the closest was a social worker who gave information to one frail older person and their carer. However, poor communication between health care settings was a frequently voiced complaint across all groups and ages.

Experiences of care in hospital again differed by condition. Liver failure patients across all ages felt well supported clinically. Those with glioma and bowel cancer offered mixed evaluations that did not differ by age group. They were generally positive about health care staff while resisting hospitalisation. The frail older people became increasingly resistant to hospital admissions over time. Some cited poor treatment or neglect and of witnessing this in the care of other older people while in hospital. However, for some the issue was about personal agency. Hospital stays often became protracted and the older person would certainly have differed from a younger person as they often lacked the physical capacity to leave at their own behest, leading to a sense of imprisonment. This resonated with the experience of the older glioma patient and was a source of distress.

In terms of supportive care it seemed that within the glioma study that patients aged under 50 were offered more rehabilitation (physio/OT etc.) to support them for a period of time. Those in the 50 – 70 age group did not seem to be given the same access as younger patients. This was despite their limited prognosis, though treatment itself was increasingly assessed according to function rather than on age alone. Of the older liver failure patients one had reluctantly accepted a package of care to help his wife manage his personal care at home, one refused and it was not clear if others had been offered this or not. Such services had the potential to benefit younger patients but was not always offered to the younger patients and was an issue raised by many of the professionals involved with the liver failure study.

Supportive care for the frail older people involved home care services and was task orientated, due to time constraints, although some older people managed to build supportive relationships with individual staff when they were regular. Physiotherapy and occupational therapy was accessed by the frail older people and found to be valuable for conveying a sense of hope, as once withdrawn from such services the frail older people could feel abandoned and 'written off'.

Advance planning

Conversations about advance planning were most common in glioma patients. The older glioma patient's family had requested that her terminal diagnosis be withheld from her, making any possible advance planning discussions difficult and accordingly not discussed. In bowel cancer one out of four of the older patients and one of the 12 younger patients had discussed future plans in terms of preferred place of death. As previously mentioned it was unclear if some of the older people had any knowledge, understanding or acceptance of their prognosis which would have impacted on any discussions surrounding end of life planning. In liver failure advance planning discussions were more likely in older people: none took place with the younger patients.

No frail older person described having had any discussions about planning for the end of life. Planning for future deterioration was similarly not described. Instead they took a more reactive and 'deal with it when it happens' approach to the future. They generally wished to 'carry on' as they were. It should be noted, however, that this did not mean that they had come to conclusions about dying or had even considered death. Furthermore death remained abstract and was not expected or considered in a concrete way.

Actual and preferred place of death

Within the glioma study, timely discussions around place of death occurred as their illness progressed and they became more cognisant and accepting of dying as it approached. This was more marked in the people under the age of 50 in the study, while those between the age of 50 and 70 appeared more reluctant. The older glioma patient did not express a preferred place of death, but died in hospital after a protracted stay, following emergency admission with a hip fracture and subsequent surgery. Her husband reported that he could not manage to care for her at home, despite a strong sense of duty to look after his wife. In bowel cancer one out of four older patients and one of the 12 younger patients expressed a preferred place of death as home although it is not clear if their preferences were met as they both survived beyond the end of the study. Only one of the older bowel cancer participants mentioned wishing to die at home, however when directly asked about the hospice as an option one replied that he would stay at home but if his wife couldn't cope he would go to the hospital. The other older bowel cancer patients described concerns about being a burden on their families. Actual advance planning in the younger bowel cancer patients was also not common yet may have occurred later in the disease trajectory.

Of the liver patients none offered a preferred place of death in the interview. One of the four older liver patients, a man with liver cancer, had community palliative care in place and died at home. A second had community palliative care in place yet died in hospital. The remaining two older liver patients died in hospital. However the lack of discussion about a preferred place of death did not differ by age group in liver failure probably due to patients' generally poor understanding of their condition and its life-limiting nature.

The only explicit wish for place of death for a frail participant resulted from a frank discussion with their family carer who happened to be a health care professional. However due to the complexity of her needs at the end of life she was unable to manage at home and died in hospital. This participant suffered from very severe emotional distress and had very poor mobility. Specialist palliative care input either in terms of a brief hospice referral or community input had the potential to benefit both the patient and her carer and could possibly have facilitated a home death. The other frail participants described their wish to continue living in their own homes although this does not necessarily mean they wished to die there. Two died at home, one being found on the floor another died during an emergency hospital admission and a final death occurred in a nursing home.

Palliative care services

Thirteen out of 18 of the younger Glioma patients were referred to palliative care services. The remaining six younger glioma patients were lost to follow up so it is not clear if such services did become involved. The older Glioma patient was not referred for palliative care services while increased palliative care input could have altered the end-of-life experience for her and her husband. However this patient's family had explicitly withheld the patient's diagnosis and prognosis from her preventing consideration of palliative services. Two out of 12 of the younger bowel patients had input from a palliative care specialist nurse. One of the older bowel patients had input from a palliative care specialist nurse. Another had not come to terms with the terminal nature of his condition and so would not consider palliative services. In bowel cancer and Glioma problems with access to palliative care could relate to ongoing hospital care or lack of appreciation of the conditions as terminal however this was not specific to older people in the bowel study. Two of the four older liver patients were referred to community palliative care services although one initially rejected Marie Curie input precisely because of the link to cancer. His ongoing palliative care support in the community was then hampered by his frequent re-admissions to hospital. A third liver patient's GP had considered palliative care for his patient on several occasions, but had not gone ahead as he was uncertain of his judgement of the patient's level of deterioration given his limited condition-specific knowledge. In liver failure it appears that the older people, however, were more likely to be referred for palliative care than younger people.

No frail older person reported being offered any level of palliative care service. One carer who was a palliative care professional described her relative's GP as explicitly rejecting her request for a palliative care approach believing her mother was not yet at the appropriate stage. There were, however, clear indications where consideration of a palliative approach or specialist input could have eased suffering for a frail older person. Specifically, a frail older man with severe pain had complex needs that may have warranted referral to a hospice. Although his GP talked about admission to hospital or temporarily to a care/nursing home, a hospice was not considered. A further example was a frail older lady, described above. However, two participants were moving to a more palliative approach to their care with the support of a GP who knew the patients, their families and their circumstances well. These participants were then able to evaluate what they were and were not willing to consider in terms of investigations or treatment according to the likely impact on their lives in general and their wishes for the future.

Existential concerns

Coping with a terminal prognosis varied by individual. Across all the different conditions and age groups some people were stoical, some less so, while others did not accept it at all. Older people in the cancer and liver failure groups were more accepting of the terminal nature of their condition citing such rationalisations as having had a decent length of life and having seen their grandchildren grow up. However, not all patients understood that they were dying, even when this information had been communicated to them. The older cancer patients were less likely than their younger counterparts to have fully understood that they were dying. Glioma patients over 60 were more likely than those under 60 to draw on spiritual support, including the local church community, and to engage in existential reflection.

For frail older people an issue that emerged near the end of life was a disconnection between their bodily experience and their understanding of it. Without a clear trigger to suggest that death may be soon it was frequently only recognised in retrospect for the frail people. Accordingly it seems that they knew they were deteriorating but did not fully understand why. They began to search for a reason but experienced an ‘undiagnosed death’. Existential, and psychological, issues were a source of distress for some of the frail older people as they became less able to adapt to ever increasing physical deterioration and dependence and losses to self-determination. These older people began to express feelings of frustration, hopelessness, shame and social alienation. This may have precipitated the existential ‘giving up’ that could occur before eventual death in frailty. This existential giving up also appeared to have been the case for the older Glioma patient who had not been told of her terminal diagnosis. She was described as having stopped communicating with her family for two weeks in hospital prior to her death.

Discussion

This analysis suggests that older people have more unmet pain, less access to generalist and specialist palliative care and greater information needs. Pain control was more often described as a problem in the frail group that related to patients’ experience of negative side effects and physicians concerns about the potential exacerbation of other difficulties. Furthermore it may be that pain was considered in a more normalised frame, given the advanced age of the older people. Pain may thus have been underestimated or not recognised as potentially treatable leading to delays in investigating or addressing its cause. Previous conflicting findings about age disparities in pain control are based on retrospective estimations of pain by bereaved relatives and may well be subject to the same difficulties (Higginson & Gao 2012;Hunt, Shlomo, & Addington-Hall 2014;Office for National Statistics 2013).

Participants that were in the frail group were not referred to palliative care even when such input would have been indicated. This may be due to their advanced old age but a more likely reason is that they did not have a terminal diagnosis or clear trigger to signal a terminal phase that would lead a health care professional to consider that a palliative approach may be warranted. This may also be true of other conditions with erratic and unpredictable trajectories and is suggested by the situation for those with liver failure. Health care professionals were less likely to consider death as an outcome in their younger liver failure patients with older patients being more likely to be referred to palliative services. Perhaps liver failure is not commonly considered as potentially or imminently terminal in younger people. Alternatively it is possible that the older liver failure patients, through many years of attending diabetic clinics, had established a relationship with their GP who was then able to recognise a point of decline that would trigger consideration of dying.

Recognising death is also complicated for those reaching the end of life on a frail trajectory. Frail older people do not generally die with a defined terminal illness and transition into the dying stage is often not recognisable (Seymour and Gott 2011). Death may only be recognised at a very late stage in non-cancer groups (Harrison et al. 2012) and a palliative care approach is most likely to be considered for those with cancer (Mason et al. 2013). Discussing the end of life in the absence of a definable prognosis is certainly challenging and likely to make end-of-life discussions less likely. Identifying patients for palliative care is more problematic during the earlier phase of an illness than at a later more terminal stage (Beernaert et al. 2014;Boyd and Murray 2010;Rhee et al. 2008) and most likely to take place just prior to death or not at all in organ failure (Beernaert et al. 2013). This is supported by this research as palliative care services were absent, for the period of the study, for most of those with bowel cancer who had a more prolonged prognosis while in the short prognosis of glioma all the younger participants had been referred for palliative care.

It may be that even when death is expected that referrals to palliative care are not considered. Physicians have been found to be less likely to refer people over the age of 85 dying from terminal conditions for palliative care than those under the age of 65 (Beernaert et al. 2015). The explanation for non-referral cited by physicians is more likely to be that they consider that a patient's needs are being adequately met the older the patient is. This may suggest underestimation of the palliative care needs in older people as found previously (Hearn and Higginson 1998;Higginson & Gao 2012) or a physician's belief that are adequately able to meet any needs (Beernaert, Deliens, Pardon, Van den Block, Devroey, Chambaere, & Cohen 2015). In the frail study a GP who was well known to a frail older person, and who has 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 (Jerant et al. 2004), in a manner consistent with a palliative care approach. This sort of advocate would be advantageous, and need not be a GP, as frail older people lack a 'specialist person' who can negotiate services.

Finally, even when community palliative care referrals are made, implementation can be difficult. The cause of this finding is not clear. There may be a disparity when services are limited for palliative teams to prioritise younger people, or because of communication difficulties between care settings. Furthermore, frequent planned and unplanned hospital admissions, as is common in organ failure, may hamper access to these patients in the community and was the case here for one of the older liver failure patients. It is also worth considering how a patient approaches palliative care services themselves. Older people may reject palliative services due to the link with cancer or because of the lack of understanding as was evident in an older bowel cancer patient who revealed a lack of understanding about what a hospice was for. Alternatively older people, due to the greater likelihood of having had more hospital visits for comorbidities and acute events, may be more inclined to turn to hospital services when facing a crisis. Younger people, may conversely be more likely to turn to community palliative support teams.

Although there was only one older participant in the glioma study she did not receive palliative care or have any advance planning discussions when all the younger glioma patients we studied did. Although the motivations for withholding a diagnosis from an older person may be well-meaning it is perhaps telling that this was not something that happened in any younger glioma patient and suggests a degree of diminished personhood (Hockey and James 1993) with an older person being attributed a protected and childlike status. That people over the age of 85 have been reported to be less likely to know that they are dying and as less likely to have recorded any preferences about place of death (Hunt, Shlomo, & Addington-Hall 2014) is supported by this research. None of the frail participants described explicit discussions about how they may die or having had anticipatory care discussions. An open awareness of death was only evident very close to the end of life. As noted in previous research (Carrese et al. 2002;Lloyd-Williams et al. 2007) frail older people spoke of dying in terms of the aftermath of death such as making wills. They also discussed dreads rather than preferences as they described their fears of developing dementia or entering a nursing home.

Although unmet information needs were highlighted across all age groups this was a particular difficulty in the older people. The older bowel cancer patients may highlight this point, remaining unclear about their diagnosis, prognosis and treatment despite being given information. Participants certainly spoke of over-medicalised language leaving them confused and none the wiser as to their status. Older people can have poor eyesight and hearing, and may not be able to access information that is given to them in quick consultations or when the speed of and amount of information exceeds their capacity to process.

Limitations

The numbers of older people in the cancer and liver studies was small. The average age of participant in the liver failure study reflected the average age of dying with the condition, however in the colorectal cancer study it was 64, yet more than half of all bowel cancer deaths occur in those over the age of 75 (Bowel Cancer UK 2015). Similarly the median age of diagnosis with glioma is 55 (American association of neurological surgeons) with death common within months: the average age of participants in the glioma study was 51. A number of glioma patients in the older age group were not given surgical or oncological treatment which, while offering life extension of only a matter of months, was considered too invasive in already vulnerable and functionally impaired older people. People over the age of 70 were frequently missed from the study as a result. Small numbers of older participants in the cancer and liver failure groups make it difficult to make comparisons and highlights the need for further study focussing on age-related palliative care experiences. There may also be a degree of gatekeeping where the oldest participants are not put forward for research by health care professionals. Certainly gaining ethical approval for the study of frailty was not straightforward. Some on the review committee believed that it was not ethically acceptable to recruit very old frail people for what they considered to be intrusive research. It is finally worth considering that the GPs of all the participants in the studies would have received notification that their patient had been recruited into a study with the description of the research or the palliative care research group potentially acting as a prompt to consider their patients within a palliative framework.

Conclusions

This study highlights potential areas that may give rise to the inequalities in end-of-life care. Older persons generally have less clear early triggers for being identified for palliative care. This probably explains their lack of palliative care more than ageism. Lack of a clear diagnosis of 'dying' and the association of palliative care with cancer and dying imminently hinder its introduction. This study highlights potential areas that may give rise to the inequities in end-of-life care.

Clinical Implications

More efforts should be made to identify older people for a palliative care approach in all settings.

Research Implications

Research is needed in liaison with geriatricians and primary care professionals to establish how best to identify those that would benefit from palliative care and to understand how acceptable this might be to older people and their family and professional carers. There is also a need to understand how the palliative care approach might then best be applied in a suitable way for older persons.

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References

Beernaert, K., Cohen, J., Deliens, L., Devroey, D., Vanthomme, K., Pardon, K., & Van den Block, L. 2013. Referral to palliative care in COPD and other chronic diseases: A population-based study. *Respiratory medicine*, 107, (11) 1731-1739

Beernaert, K., Deliens, L., De Vleminck, A., Devroey, D., Pardon, K., Van den Block, L., & Cohen, J. 2014. Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients. *Palliative medicine*, 28, (6) 480-490

Beernaert, K., Deliens, L., Pardon, K., Van den Block, L., Devroey, D., Chambaere, K., & Cohen, J. 2015. What Are Physicians' Reasons for Not Referring People with Life-Limiting Illnesses to Specialist Palliative Care Services? A Nationwide Survey. *PloS one*, 10, (9) e0137251

Bowel Cancer UK. Bowel Cancer Statistics. 2015.
http://www.bowelcanceruk.org.uk/information-resources/bowel-cancer-facts-figures/

Boyd, K. & Murray, S.A. 2010. Recognising and managing key transitions in end of life care. *Bmj*, 341,

Carduff, E. 2013. *Realising the potential: Developing qualitative longitudinal methods for understanding the experience of metastatic colorectal cancer.* University of Edinburgh.

Carrese, J.A., Mullaney, J.L., Faden, R.R., & Finucane, T.E. 2002. Planning for death but not serious future illness: qualitative study of housebound elderly patients. *BMJ.325(7356):125,*

Cavers, D. 2010. *Understanding the supportive care needs of glioma patients and their relatives: a qualitative longitudinal study.* University of Edinburgh.

Davies, E. & Higginson, I.J. 2004. Better palliative care for older people.

Dixon, J., King, D., Matosevic, T., Clark, M., & Knapp, M. 2015. Equity in the provision of palliative care in the UK: review of evidence.

Gomes, B. & Higginson, I.J. 2006. Factors influencing death at home in terminally ill patients with cancer: systematic review. *Bmj*, 332, (7540) 515-521

Gott, M., Ingleton, C., Gardiner, C., Richards, N., Cobb, M., Ryan, T., Noble, B., Bennett, M., Seymour, J., & Ward, S. 2013. Transitions to palliative care for older people in acute hospitals: a mixed-methods study.

Gott, M., Ingleton, C., Bennett, M.I., & Gardiner, C. 2011. Transitions to palliative care in acute hospitals in England: qualitative study. *Bmj*, 342,

Harrison, N., Cavers, D., Campbell, C., & Murray, S.A. 2012. Are UK primary care teams formally identifying patients for palliative care before they die? *British Journal of General Practice*, 62, (598) e344-e352

Hearn, J. & Higginson, I.J. 1998. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative medicine*, 12, (5) 317-332

Higginson, I.J. & Gao, W. 2012. Opioid prescribing for cancer pain during the last 3 months of life: associated factors and 9-year trends in a nationwide United Kingdom cohort study. *Journal of Clinical Oncology* JCO-2012

Hinds, P.S., Vogel, R.J., & Clarke-Steffen, L. 1997. The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research*, 7, (3) 408-424

Hockey, J.L. & James, A. 1993. *Growing up and growing old: Ageing and dependency in the life course* Sage London.

Hunt, K.J., Shlomo, N., & Addington-Hall, J. 2014. End-of-life care and preferences for place of death among the oldest old: results of a population-based survey using VOICES short form. *Journal of palliative medicine*, 17, (2) 176-182

Irwin, S., Bornat, J., & Winterton, M. 2012. Timescapes secondary analysis: Comparison, context and working across data sets. *Qualitative Research*, 12, (1) 66-80

Irwin, S. & Winterton, M. 2011a. Debates in qualitative secondary analysis: Critical reflections. *Timescapes: An ESRC qualitative longitudinal study.UK Data Archive: University of Leeds, London South Bank University, Cardiff University, The University of Edinburgh, The Open University*

Irwin, S. & Winterton, M. 2011b, *Qualitative secondary analysis in practice: An extended guide*, Timescapes Working Paper Series.

Irwin, S. & Winterton, M. 2011c, *Timescapes data and secondary analyses: Working across the projects*, Timescapes Working Paper.

Irwin, S. & Winterton, M. 2012. Qualitative secondary analysis and social explanation. *Sociological Research Online*, 17, (2) 4

Jerant, A.F., Azari, R.S., Nesbitt, T.S., & Meyers, F.J. 2004. The TLC model of palliative care in the elderly: preliminary application in the assisted living setting. *The Annals of Family Medicine*, 2, (1) 54-60

Kendall, M., Buckingham, S., Ferguson, S., MacNee, W., Sheikh, A., White, P., Worth, A., Boyd, K., Murray, S.A., & Pinnock, H. 2015a. Exploring the concept of need in people with very severe chronic obstructive pulmonary disease: a qualitative study. *BMJ supportive & palliative care* bmjspcare-2015

Kendall, M., Carduff, E., Lloyd, A., Kimbell, B., Cavers, D., Buckingham, S., Boyd, K., Grant, L., Worth, A., & Pinnock, H. 2015b. Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews with Patients with Cancer, Organ Failure, or Frailty and Their Family and Professional Carers. *Journal of Pain and Symptom Management*

Kimbell, B. 2014. *Living, dying and caring in advanced liver disease: the challenge of uncertainty.* University of Edinburgh.

Lloyd, A. 2015. *Exploring the changing multidimensional experiences of frail older people towards the end of life: a narrative study.* University of Edinburgh.

Lloyd-Williams, M., Kennedy, V., Sixsmith, A., & Sixsmith, J. 2007. The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *Journal of Pain & Symptom Management.34(1):60-6,*

Mason, B., Epiphaniou, E., Nanton, V., Donaldson, A., Shipman, C., Daveson, B.A., Harding, R., Higginson, I., Munday, D., & Barclay, S. 2013. Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study. *British Journal of General Practice*, 63, (613) e580-e588

McKevitt, C., Baldock, J., Hadlow, J., Moriarty, J., Butt, J., & Walker, A. 2005. Identity, meaning and social support. *Understanding Quality of Life in Old Age* 131-145

Office for National Statistics. Mortality in the United Kingdom 2010. 2012. http://www.ons.gov.uk/ons/rel/mortality-ageing/mortality-in-the-united-kingdom/mortality-in-the-united-kingdom--2010/mortality-in-the-uk-2010.html

Office for National Statistics 2013, *National survey of bereaved people*.

Rhee, J.J.-O., Zwar, N., Vagholkar, S., Dennis, S., Broadbent, A.M., & Mitchell, G. 2008. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *Journal of palliative medicine*, 11, (7) 980-985

Seymour, J. & Gott, M. 2011. The challenges of health technology for ageing and dying. *Living with Ageing and Dying.Palliative and End of Life Care for Older People* 42-51

World Health Organisation 2015, *Definition of an older or elderly person*.