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Understanding patterns of health and social care at the end of life

Research summary

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Care at the end of life is an important national priority in England. The national strategy (Department of Health, 2008) aims to help people have the care support they need beyond the gates of the acute hospital setting. Survey results show that many people with terminal illness would prefer to die with appropriate support at home rather than in hospital. This means developing a range of support services at the end of life, spanning both health and social care. Despite the importance of social care in supporting individuals at the end of their lives, there are remarkably few studies that look at how often these people receive social care services. This summary highlights the key findings from a report (Georghiou and others, 2012) commissioned by the National End of Life Care Intelligence Network. It builds on an earlier study (Bardsley and others, 2010) to create and analyse the largest linked health and social care dataset in England. Using this data we were able to describe the uptake of key health and social care services for people in the last 12 months of life.

Key Points

- In England social care is a significant part of care for people in the last 12 months of their life, with some form of local authority-funded social care being given to around 27.8% of people who died. On average, 14.9% of all people who died had some residential or nursing care service in the last year of life.
- There was considerable variation in the use of social care between local authorities. For example, there were twofold differences in the proportion of social care users in any given month prior to death – even when rates were standardised for age and sex differences between areas.
- Many more people used hospital care than social care in the last year of life (89.6% versus 27.8%), and total hospital costs in this period were approximately double those of social care services. However, for those people who did use a service, the average local authority social care costs exceeded hospital costs (£12,559 per social care user versus £7,415 per hospital user).
- Individuals in the last 12 months of their lives were significantly more likely to use a social care service than similar individuals in the general population (matched by age and sex).

- Social care needs were apparent well before the end of life. While hospital costs showed a sharp increase in the final few months, social care costs rose gradually up until death. The greatest increases in social care use were observed in care home use.
- Individuals with the highest social care costs had relatively low average hospital costs – this was broadly the case irrespective of age, and suggests that use of social care may prevent the need for hospital care. This is linked with a phenomenon observed elsewhere concerning people in residential care settings (Bardsley and others, 2012): that they tend to use less hospital care than people in intensive home care settings.
- There were significant differences in the use of social care between groups of individuals with certain long-term conditions: of the more commonly occurring conditions, usage levels were highest in people with dementia, falls and cerebrovascular disease, and were lower for people with cancer (even when adjusted for age and sex).
- The least socioeconomically deprived groups within the population tended to use less local authority-funded social care – which would be expected, given the role of means-testing for care. However, the relationship was not linear, and there was no discernible trend within the most deprived half of users. This suggests that means-testing only affected the provision of local authority-funded social care at the more affluent end of the spectrum, assuming that needs are constant.

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Background

Survey results consistently show that many people with terminal illness would prefer to die with appropriate support at home rather than in hospital (Gomes and others, 2011). The national direction of policy to enable them to do so was embodied in the end-of-life strategy (Department of Health, 2008). Yet people will need to access a range of support services at the end of life, spanning both health and social care (Department of Health, 2012a).

However, there are difficulties ahead. The National Health Service (NHS) currently has a parsimonious budget settlement that is likely to stretch into the next five to 10 years (Crawford and Emmerson, 2012), and recent cuts in social care budgets have raised significant challenges about how we care for certain vulnerable groups (Association of Directors of Adult Social Services, 2012). A recent review of palliative care funding proposed new ways of funding care services that recognise interactions across sectors (Hughes-Hallet and others, 2011). Currently this approach is being piloted, and may have significant implications for the organisation of end-of-life care. Therefore, it is more important than ever before to look very closely at the contribution of social care to the prevention of avoidable hospital care, particularly for the most vulnerable people: older people at the end of their lives.

It is important to look closely at the contribution of social care to the prevention of avoidable hospital care

Despite the importance of social care in supporting individuals at the end of their lives, there are remarkably few studies that look at how often people receive social care services, what types of care and when. The public funding of health and a good deal of social care means that there is huge potential to exploit routinely collected data to help understand the potential of social care to support people at the end of their lives, and understand the impact on needs for health care. Recent advances in the availability of data, its manipulation and methods of analysis, now make it feasible to analyse data across large populations and to identify patterns and trends as never before. This has the potential to help in understanding where best to invest public resources in health and social care, so that quality of care is highest for people, particularly in the end stages of life.

This analysis was based on a group of more than 73,000 people who died across seven local authority areas. In this first study of the datasets the use of hospital care (inpatient, outpatient and Accident and Emergency (A&E) department visits) was tracked in the final 12 months of life. At the same time it was possible to link data at a person level to identify the local authority-funded social care services that individuals may have been receiving during this period.

The analysis shows that social care and NHS records at person level can be linked to identify the use and associated costs of NHS and social care services by individuals in the last months of their lives. The techniques used in the analysis could fill important gaps in national and local understanding of the range and quality of services delivered. This type of analysis should be an essential part of local planning and commissioning of services for patients.

Method

This study used information from seven different local authority areas from across England, with a pooled population of more than three million people. The study was able to extract summary health and local authority social care records for all the people who died in these areas over a one- to three-year period. Before the datasets were transferred to the research team, all sensitive personal information was removed and key linkage fields (NHS numbers or other) were pseudonymised by analysts in the health or local authorities, using dedicated software tools.

The core datasets for these analyses were electronic data routinely collected on operational administrative systems by the NHS or local authority social services departments. The datasets included:

- NHS Secondary Users Services (SUS) data (information on inpatient admissions, outpatient attendances and A&E visits)
- general practitioner (GP) register information (on all people registered with a general practice at any given time), including information on deaths
- information about the local authority-funded social care services received.

By using data linkage techniques this meant that the study was able to see, for individual (anonymised) people, the type of hospital services and local authority-funded social care services that were used in the months leading up to death. In addition, costs were attached to these services, so it was possible to estimate the overall resources linked to care in this period.

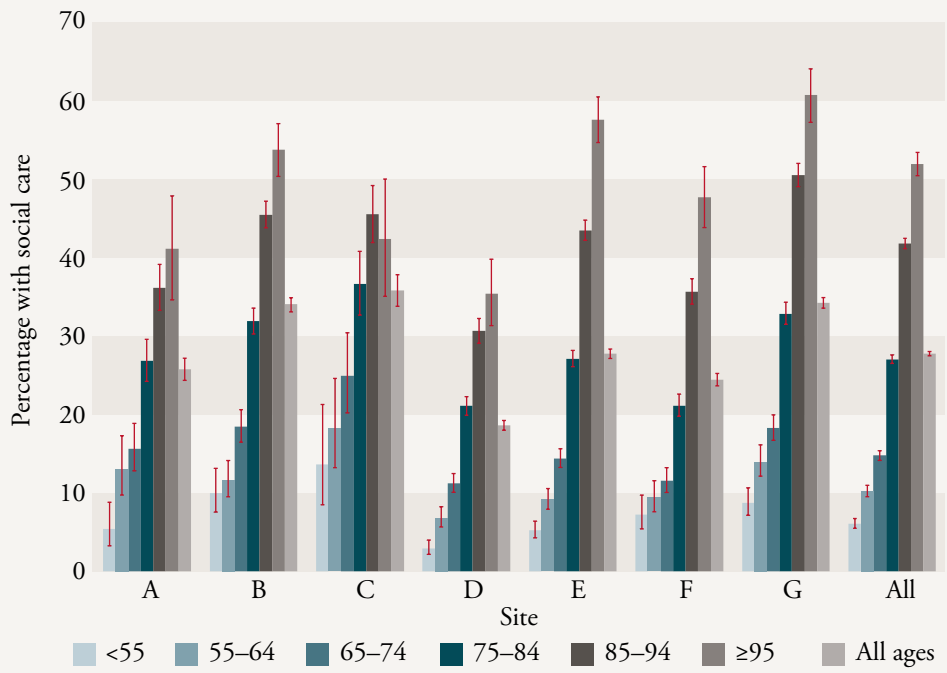
Selected findings

Figure 1 summarises for each site, the proportion of people accessing local authority-funded care in the last 12 months of life. This shows that social care is a significant part of care, with some form of local authority-funded social care being given to around 27.8% of people who died, with higher values for older people.

On average 14.9% of all people who died had some residential or nursing care service in the last year of life, and the average number of days that these individuals spent in a residential or nursing home was 229.

There was considerable variation in the use of social care between local authorities. For example, there were twofold differences in the proportion of social care users in any given month prior to death – even when rates were standardised for age and sex differences between areas. Individuals in the last 12 months of their lives used significantly more social care services than similar individuals in the general population (matched by age and sex).

Figure 1. Use of social care services in final year of life by age band, by site



Note: 95% confidence intervals; N = 73,243

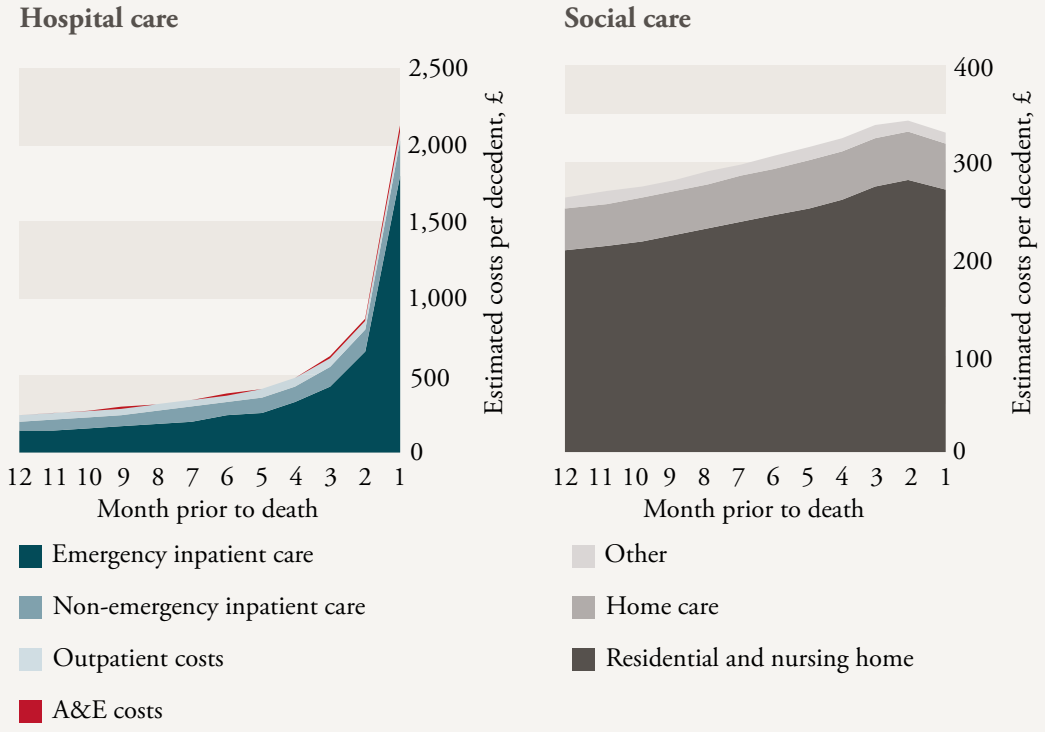
Many more people used hospital care than social care in the last year of life (89.6% versus 27.8%), and total hospital costs in this period were approximately double those of social care services (making up 65.6% of the combined £742 million costs). However, for those people who did use a service, the average local authority social care costs exceeded hospital costs (£12,559 social care costs per social care user versus £7,415 hospital care costs per hospital user).

It was possible for the study to track the way in which service use and costs changed during the last 12 months of life. Figure 2 contrasts changes in the main cost elements in both health and social care. While hospital costs showed a sharp increase in the final few months, especially in emergency care, social care costs rose gradually up until death. The greatest increases in social care use were observed in care homes.

The marginal costs of increases in local authority-funded social care in the last few months of life appear to be relatively modest, which should allay fears over any costs associated with an entitlement to free social care at the end of life, as suggested by the palliative care review (Hughes-Hallet and others, 2011).

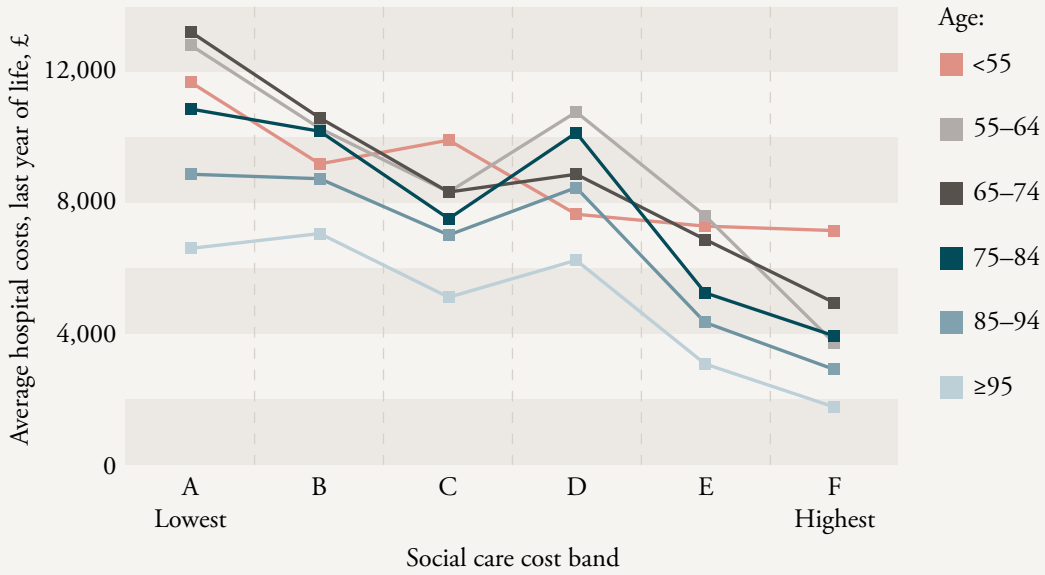
The study was able to compare the level of hospital use according to the social care inputs that a person received at the end of life (Figure 3). Individuals with the highest social care costs had relatively low average hospital costs: this was broadly the case irrespective of age, and suggests that use of social care may prevent the need for hospital care. This is linked with a phenomenon observed elsewhere concerning people in residential care settings (Bardsley and others, 2012): that they tend to use less hospital care than people receiving intensive home care.

Figure 2. Estimated average costs of care services in each of last 12 months of life, by type of service, hospital care and social care



Note: N = 73,243

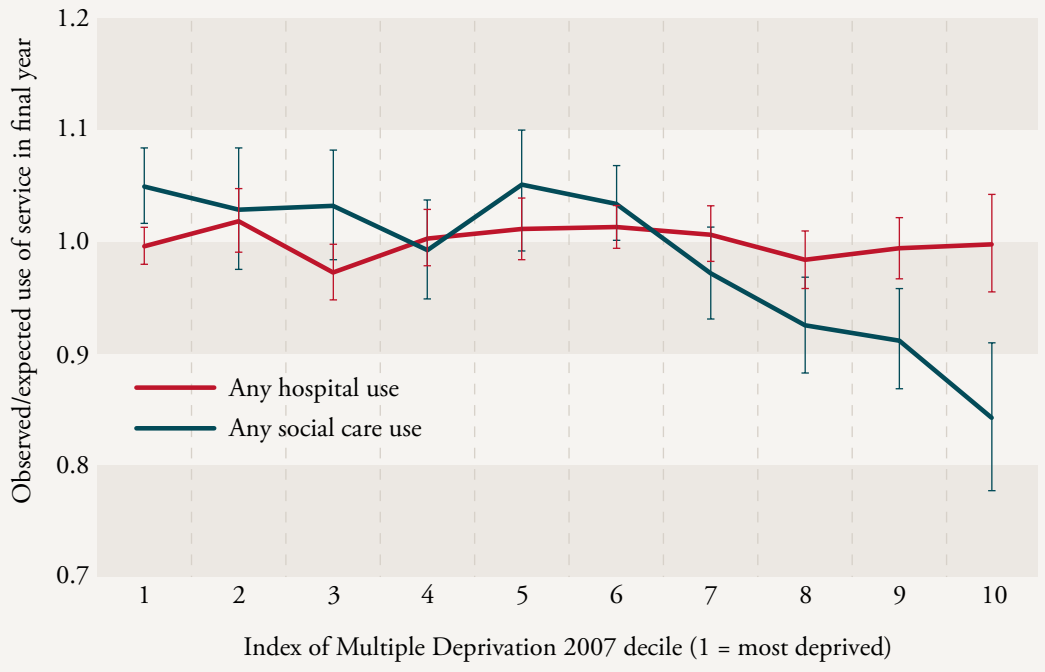
Figure 3. Average costs of hospital care in the final year of life, by social care cost group and age band



Note: Social care costs > £1,000; N = 17,992

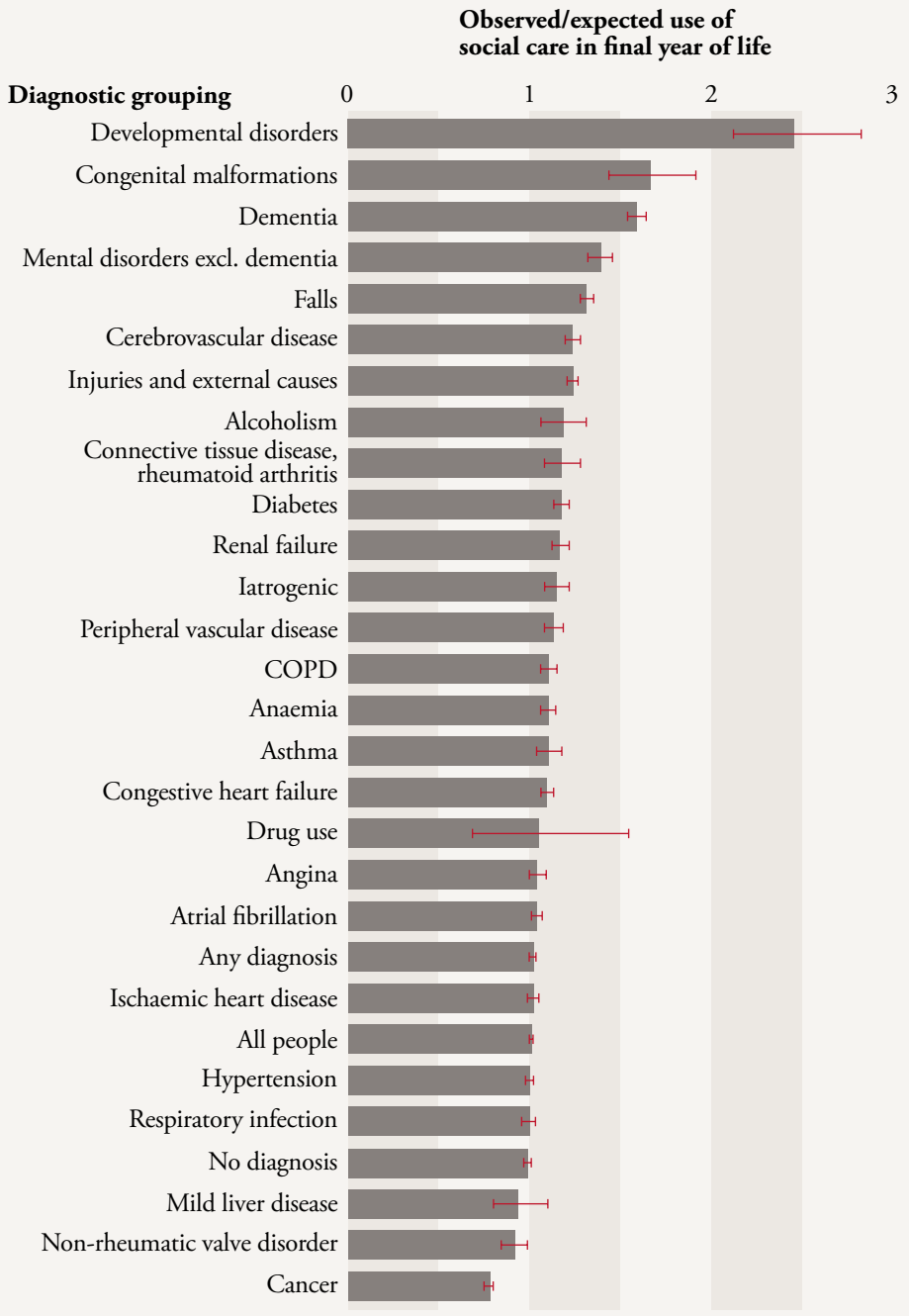
The study looked at how the use of social care varied according to the deprivation levels of the area in which a person lived (Figure 4). The least socioeconomically deprived groups within the population tended to use less local authority-funded social care – which would be expected, given the role of means-testing for care. However, the relationship with regard to deprivation was not linear, and there was no discernible trend within the most deprived half of users. This suggests that means-testing only affected the provision of local authority-funded social care at the more affluent end of the spectrum, assuming that needs are constant.

Figure 4. Use of services in final year of life by deprivation decile (standardised by age, sex and site)



Note: 95% confidence intervals shown; N = 73,243

Figure 5. Standardised ratio: use of any social care service in final year of life, by diagnostic group



Note: 95% confidence intervals shown; N = 73,243

As with our earlier study, the present study found significant differences in the use of social care between groups of individuals with certain long-term conditions: of the more commonly occurring conditions, usage levels were highest in people with dementia, falls and cerebrovascular disease, and lower for people with cancer (even when adjusted for age) – see Figure 5. We assume that the relatively low rate among people with cancer was linked to the greater use of hospices.

Conclusion

We believe that the present study is the largest so far to look at the cost and use of services across sectors for people who are near to death in England. While the sample of individuals may not be representative of the whole country, the individuals lived in a mix of areas: urban and rural, north and south.

There are many avenues for future research that could be developed to improve on this analysis:

- understanding how social care (particularly nursing and residential care) support may be preventing the need for hospitalisation
- investigating other forms of care – particularly in community settings and the voluntary sector, including hospice care
- the role played by self-payer-funded care (including family top-ups to local authority-funded care) and NHS continuing health care-funded social care at the end of life, and how this use relates to hospital use
- direct information on the choices and experiences of service users and their carers and relatives.

This analysis has shown how important the interaction between health and social care can be for many people at the end of life. The findings show that there is an interplay between health and social care costs – this will be especially important for areas considering pooled budgets and integrated care services. Those devising policies and making local decisions on care provision should understand all the potential consequences as far as possible, such as unintended shifts in care from one area to another. For example, if funding for social care is cut back, costs may increase in the NHS (Goodwin and others, 2012).

The findings show that there is an interplay between health and social care costs

These approaches to understanding patient pathways across care services will be important for future funding options: for example, the recent palliative care funding review proposed a new approach to funding care based on set tariffs linked to a patient-level classification, which is being piloted in seven areas (Department of Health, 2012b). One recommendation of the review was that social care costs are included within the tariff. We note that the funding review advocated the removal of means-testing for social care at the end of life. In addition, we observe that the order of costs for social care at the end of the life are reasonably predictable, based on earlier care patterns. The absence of a sharp increase in social care costs perhaps indicates that the economic risk to the Exchequer of funding social care at the end of life is not great, if the patterns observed in this study were observed elsewhere.

The type of analysis described in this report can inform a number of key policy areas. This includes exploring ways to better evaluate the impacts of new services, especially community-based care strategies designed to improve quality and satisfaction for patients, and to avoid expensive hospital or institutional care. Given the short- to medium-term financial climate, this type of analysis is critical now more than ever, if greater value is to be extracted from public funds.

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